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The Lived Experiences of African American Women with Breast Cancer: Implications for Counselors

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The Lived Experiences of African American Women with Breast Cancer:
Implications for Counselors

A Dissertation

Submitted to the Graduate Faculty of the
University of New Orleans
in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy
in
Counselor Education

by

LaTasha K. Clay

B.A., Dillard University of New Orleans, 1998
M.A., Xavier University of Louisiana, 2001

May 2013

Copyright page

DEDICATION

I dedicate this dissertation to my mother, Dianne Johnson, for her love, encouragement, and support throughout my doctoral journey. My mother's experience with breast cancer inspired me to focus on this as my dissertation topic. She was diagnosed with Stage III breast cancer and has been cancer free for four years now. Mama, you have shown me that with faith, anything is possible. There are no words to express the amount of love and gratitude that I have for you. You are truly my best friend and my hero. I will always admire your strength and appreciate all that you have given me in my life. Thank you for simply being you. I love you.

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ABSTRACT

Qualitative phenomenological methodology was used to explore the lived experiences of African American women diagnosed with breast cancer. Phenomenology focuses on the meaning of the lived experiences of individuals experiencing a concept, structure, or phenomenon (Creswell, 2007). The purpose of phenomenological research is to identify phenomena as perceived by the individual. Utilizing an existential perspective, the focus of this study was to uncover meaning which defined the essence of the participants' experiences. Seven African American women diagnosed with breast cancer participated in this study. The participants' ages ranged from 33-63 years. A semi-structured interview process with open-ended questions was utilized to gain an understanding of the participants' personal experiences related to the phenomenon. Data was analyzed using Interpretative Phenomenological Analysis (Smith, 2004) to ascertain emergent themes and to interpret the meaning of the participants' breast cancer experience.

Seven common themes emerged from the cases. Those themes included: spirituality; support systems; self-care; resiliency; existential meaning; education; and perception of counseling. These seven themes will help to provide insight into how counselors can help to facilitate emotional wellness within this particular population. Implications and recommendations for counselor educators, counselors, and counselors-in-training with this population are also addressed.

Key words: African American, women, breast cancer, spirituality, existentialism

CHAPTER ONE

INTRODUCTION

In this chapter, background information is presented on the effects of breast cancer on African American women. The problem is defined and the purpose of this qualitative study of the lived experiences of African American women with breast cancer is stated. The significance of the study is explained. The conceptual framework and the overview of methodology are explored, the research questions are presented, and the limitations and delimitations of this study are discussed. A definition of terms is also provided in this chapter.

Background

Breast cancer is the most prevalent form of non-skin cancer diagnosed and the second leading cause of cancer deaths among American women (Underwood, Richards, Bradley, & Robertson, 2008). Breast cancer can affect women of all racial/ethnic groups, cultural backgrounds, socio-economic statuses, and religious affiliations. However, some evidence suggests that survival rates differ by race. According to the American Cancer Society (2011), the five-year survival rate for breast cancer among African American women is 77%, as compared to 90% among Caucasian women.

Many factors are associated with developing breast cancer. According to Underwood et al. (2008), the most common risk factors may include family history, age, racial or ethnic background, genetic changes, and reproductive history. Suspected risk factors include alcohol intake, obesity, and lack of exercise.

African American women face many challenges related to breast cancer treatment and prevention. According to the American Cancer Society Facts and Figures (2011), factors such as

low socioeconomic (SES), lack of access to health care/insurance, and co-morbidity rates may contribute to the differences in survival among breast cancer patients in general. For example, women with higher SES levels may have better access to medical services and preventive care, which may decrease their chances of being diagnosed later in life with a more advanced stage of breast cancer, as compared to women with lower SES levels. African American women are far more likely to die from breast cancer when compared to Caucasian women. In addition, African American women have the highest death rate from breast cancer of any ethnic group (Jones & Chilton, 2002).

Statement of the Problem

The literature is scant on the topic of African American women and their experiences with breast cancer. An extensive body of literature has focused on preventive methods, diagnosis, and treatment available for women who have been diagnosed with this illness. There is also a small, but substantial body of qualitative studies on African American women diagnosed with breast cancer. However, a literature search did not discover any research conducted using a qualitative, phenomenological method from an existential perspective on the lived experiences of African American women who are breast cancer survivors.

African American women are far more likely to die from breast cancer than are Caucasian women (Davidson & Mahanna, 2010). Breast cancer can have a negative impact on the emotional and psychological health of African American women as they experience the effects of this illness. Despite the alarming statistics and higher risk of death in this population, research based on the experiences of African American women with this disease is scant.

A lack of knowledge about the experiences of African American women with breast cancer can have serious implications for counselors attempting to facilitate emotional wellness among this particular population. Family support and spirituality are important components to transcend the emotional and psychological effects of this illness. Counselors should seek to understand the essence of lived experiences to inform the development of culturally sensitive interventions that can assist African American women and their families as they experience this potentially life-changing phenomenon.

Purpose Statement

The purpose of this phenomenological study was to explore the lived experiences of African American women diagnosed with breast cancer. Specifically, the aim of the study was to understand and describe the breast cancer experiences of African American women, focusing on their perceptions and the meaning behind their lived experiences. Utilizing an existential perspective, the focus of this study was to uncover meaning which defined the essence of the participants' experiences.

Significance of the Study

According to the American Cancer Society (2011), African American women have a higher incidence rate before 40 years of age and are more likely to die from breast cancer at every age. In addition, incidence and death rates for breast cancer are lower among women of other racial and ethnic groups than among non-Hispanic-White and African American women. Despite the alarming statistics and higher risk of death in this population, research based on the experiences of African American women with this disease is scant. A lack of knowledge about

the experiences of African American women with breast cancer can have serious implications for counselors attempting to facilitate emotional wellness among this particular population.

Counselors have skills that can improve the well-being of women diagnosed with breast cancer, or women who are worried about getting breast cancer due to risk factors such as family history, age, and obesity. Without specialized knowledge about the disease and its treatment, or knowledge about the experiences of African American women who have been diagnosed with such a serious illness, counselors are less likely to be effective when counseling this population. Counselors who are familiar with the history, treatment, screening, and experiences of African American women with breast cancer can be stronger advocates for their clients and more effective in treating their individual needs.

Conceptual Framework

According to Glesne (2011), the intent of introducing theory into qualitative investigation is to advance the understanding of the personal experiences of the research participants instead of relying on generalizations. A conceptual framework serves as the theoretical lens to shape the context of the research questions and methods used (Glesne, 2011). Existential theory is the most salient theory for conceptualizing the life experiences of African American women diagnosed with breast cancer because this theory is based on how a person makes meaning of her existence and how she perceives life and/or her personal experiences of life. Existential theory centers on the belief that inner conflict within an individual stems from that individual's confrontation with the givens of existence. According to Yalom (1980), these givens include the inevitability of death, freedom, isolation, and meaninglessness. Having been diagnosed with a potentially life-threatening illness can have a major impact on thought processes, perceptions of

life, and also the meaning and purpose of life itself (Henderson, Gore, Davis, & Condon, 2003). Existential counseling theory is based a philosophical movement, which can be closely associated with the literary works of Kierkegaard, Camus, Sartre, and Heidegger. During the 19th century, existentialism was constructed out of a social reaction, which was primarily cultivated from the philosophical community, to the scientific, industrial, psychiatric, and political communities (Fall, Holder, & Marquis, 2004). The foundational work of these philosophers has provided existentialists with fundamental tools applicable to counseling and psychotherapy theories and approaches. Existentialism became a trendy concept in the post-World War years as a way to strengthen the importance of human individuality and freedom (Fall, Holder, & Marquis, 2004).

Existentialists believe that death awareness and anxiety play a major role in human motivation (Fall, Holder, & Marquis, 2004). Death is the ultimate threat to human existence. Once we are born, the potential for physical death occurs (Yalom, 1989). Our awareness of death begins early in life. The potential for psychological death also becomes a part of our existence as the self begins to develop (Yalom, 1989). Most people tend to avoid the topic completely, but the reality is that death does, in fact, exist. Our attempts to overlook it or create myths to comfort ourselves only feed the dysfunction that conceals the reality of death. Existentialism seeks to identify and reassess these defenses in order to create the acceptance of the finality of death as a part of our existence (Yalom, 1989).

Yalom (1989) stated that anxiety occurs within our existence when we realize the responsibility of actually having freedom. When people realize that they do have the freedom to make choices in their lives, the realization may lead them to deny this responsibility. Although

existential therapy theorists acknowledge that people's choices or decisions in life are restricted by outside influences, the existentialist rejects the idea that people's actions are determined (Engler, 1991). Many choices are available to people on a daily basis and, consequently, individuals are free to make those choices and are responsible for the actions that are created by those choices. Existentialists believe that individuals must create and live with their own individual freedom (Engler, 1991). Freedom necessitates an individual's ability to take ownership of his or her own growth and development. Freedom is fundamental to existentialism as it induces a person's capacity to choose. People have the freedom to make decisions based on choices and alternatives available to them. Therefore, people play a major role in creating their own destinies. Freedom and responsibility involve being accountable for both the path and direction of one's life (Engler, 1991). Freedom and responsibility are parallel concepts as they relate to meaning of existentialism.

According to Engler (1991), existential anxiety is a critical part of life. As individuals become more aware of the choices available to them, they are also more aware of the consequences of those choices. Anxiety is inevitable as individuals deal with day-to-day existence. Existential counselors differentiate between normal and neurotic anxiety and view anxiety as a potential source of growth (Engler, 1991). Normal anxiety is an appropriate response to an event or circumstance taking place. Neurotic anxiety is an out of control response to an event or circumstance taking place (Engler, 1991). Existentialists believe that it is healthy to survive with some anxiety; it would not be therapeutic to completely eliminate normal anxiety.

According to Engler (1991), an important component of existentialism is increasing one's self-awareness. Increasing one's self-awareness can aid in fostering a meaningful life that

emphasizes the importance of choice and responsibility. Courage is necessary to enhance one's self-awareness as it is an essential component of discovering one's purpose and meaning in life. Through this self-discovery and life-enhancing awareness, individuals can choose their actions and, as a result, create their own destiny. Existentialism seeks to help people to accept responsibility for their freedom and empower them to make better choices (Engler, 1991).

People also have a tendency to spend a great deal of time avoiding the pain of being alone. Many people are so afraid of being alone that they fail at connecting with other people on a personal level. Anxiety and grief can be produced by the fear of being alone which can sabotage the potential for close, personal relationships. Existential therapy seeks to identify these self-defeating behaviors to help create a space to foster healthy, significant relationships (Yalom, 1989).

According to Josselson (1992), despite the constant presence of others, each person is ultimately alone. People are basically responsible for the decisions they make in life. Each person is different and unique and experiences life in his or her own personal way. No one will ever have the exact same life experiences and no one will ever be completely understood by someone else. Even if an individual is surrounded by loved ones for support while in a suffering state, that person is ultimately suffering alone and has to endure that pain alone. Existentialists believe that this awareness of isolation may, in fact, produce anxiety of being alone.

Existential issues often arise when diagnosed with a terminal illness such as breast cancer (Landmark & Wahl, 2002). In a study of breast cancer survivors conducted by Sadler-Gerhardt et al. (2010), one of the existential issues that emerged was the fear of recurrence. African American women have a higher death rate when compared to any other ethnic group (Davidson

& Mahanna 2010; Jones & Chilton, 2002). Consequently, they are at increased risk of a premature death. As people experience obstacles in life, they try to make sense of or understand what has happened. Many people diagnosed with potentially life-threatening illnesses such as breast cancer may struggle with attributing significance to the illness or making meaning out of a difficult situation (Sadler-Gerhardt et al., 2010). An existential approach to counseling can help individuals to find meaning in their lives when experiencing the vicissitudes of life. The possibility of an untimely death can create feelings of loneliness, meaninglessness, and anxiety. Existential therapy seeks to help individuals cope with accepting the tenuousness of their existence and the finality of death.

Overview of Methodology

The purpose of this phenomenological study was to explore the lived experiences of African American women diagnosed with breast cancer. A phenomenological approach was used to explore the essence of the participants' experience of this phenomenon. Semi-structured interviews were conducted to gain a deeper understanding of those experiences. Interpretative Phenomenological Analysis (IPA; Smith, 2004) served as the methodology for this study by providing a structure for gathering detailed descriptions on how African American women experience breast cancer and how they perceive this experience.

Research Questions

This phenomenological study began with exploring the central question, "What are the lived experiences of African American women diagnosed with breast cancer?" This broad question led to another question that sought to understand, "What does it mean to be diagnosed with breast cancer as an African American woman?"

Limitations and Delimitations

Due to the nature of this study, it was delimited to seven participants. A second delimitation was that the participants were African American women diagnosed with breast cancer and lived in the New Orleans area. Although it is not the purpose of qualitative research to generalize findings, a limitation is that the results of this study may be difficult to generalize.

Definition of Terms

The following terms are relevant to this research study. The definitions are presented to assist the reader in fully understanding the meaning of the terms within the context of this study.

African American

Of or relating to Americans of African ancestry. An American of African ancestry. (Webster's II New College Dictionary, 1995).

Breast Cancer

Breast cancer (malignant breast neoplasm) is cancer originating from breast tissue, most commonly from the inner lining of milk ducts or the lobules that supply the ducts with milk. Cancers originating from ducts are known as ductal carcinomas; those originating from lobules are known as lobular carcinomas. Breast cancer is a disease of humans and other mammals; while the overwhelming majority of cases in humans are women, men can also develop breast cancer (American Cancer Society, 2007).

Cancer Stages

The stage of cancer is based on the extent to which the cancer has spread at the time of diagnosis. According to the American Cancer Society (2007), "a cancer's stage is based on the primary tumor's size and location and whether it has spread to other areas of the body"

(p. 3). Staging is based on three factors: 1) the size of the primary tumor; 2) absence or presence of regional lymph node involvement; and 3) absence or presence of disease in other organs of the body (American Cancer Society). Once these factors are determined, a disease stage of I, II, III, or IV is assigned for diagnostic purposes, with Stage I representing early stage of disease and Stage IV signifying advanced disease.

Chemotherapy

Chemotherapy is a treatment for cancer using drugs designed to kill cancer cells or stop them from multiplying (Rosenbaum & Rosenbaum, 2005). Statistics show that most people who are treated for cancer receive chemotherapy at some point during their treatment regimen (Eyre, Lange, & Morris, 2002).

Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) was first introduced by Smith (1998) in the mid-1990s as a phenomenological approach to qualitative research in health psychology. Theoretically, IPA seeks to “explore in detail participants’ personal lived experience and how participants make sense of that personal experience” (Smith, 2004, p. 40). IPA recognizes the central role of the researcher in the analytical and interpretive processes.

Phenomenology

Phenomenology is considered a philosophy, approach, and research method that is both inductive and descriptive. Phenomenology allows the investigator to gain access into a person’s world and understand the meaning of that person’s experiences (Wilson & Washington, 2006). Phenomenology refers to “knowledge as it appears to consciousness, the science

of describing what one perceives, senses, and knows in one's immediate awareness and experience" (Moustakas, 1994, p. 26).

Radiation Therapy

At least half of all people who undergo treatment for cancer receive radiation therapy (Eyre et al., 2002). Also known as radiotherapy, x-ray therapy, and irradiation, radiation therapy involves the use of x-ray waves or a stream of energy particles to destroy cancer cells or damage them in such a way that they can no longer multiply.

Spirituality in African American women

Newlin, Melkus, Knafl, and Newlin (2002) suggested following definition for African American women's spirituality:

"Faith in an omnipotent, transcendent force; experienced internally and/or externally as caring interconnectedness with others, God, or a higher power; manifested as empowering transformation of and liberating consolation for life's adversities; and thereby inspiring fortified belief in and reliance on the benevolent source of unlimited potential" (p. 68).

Support Group

A group of people, sometimes led by a therapist, who provide each other moral support, information, and advice on problems relating to some shared characteristic or experience (Webster's II New College Dictionary, 1995).

CHAPTER TWO

LITERATURE REVIEW

The purpose of this chapter is to examine the extant literature and research related to African American women and breast cancer. This literature review is organized into six main sections that will develop the context from which to examine the lived experiences of African American women who have been diagnosed with breast cancer. In the first section, an overview of breast cancer is presented. The second section explains psychological and emotional effects of breast cancer. Coping with a breast cancer diagnosis is discussed in the third section. Counseling and support groups for breast cancer survivors are the focus of section four. Qualitative research with breast cancer survivors, and specifically with African American women who are breast cancer survivors, is explored in the fifth section. Finally, the last section summarizes the information presented in this literature review.

Overview of Breast Cancer

Although there is not a universal definition of breast cancer, the American Cancer Society (2011) described cancer as “a group of diseases that cause cells in the body to change and grow out of control” (p. 3). Eventually, most types of cancer cells will form a lump or tumor. The tumor is named after the part of the body where the tumor is formed. Breast tissue is made up of glands or lobules to produce milk, and ducts which connect the lobules to the nipple. Other parts of the breast include fatty, connective, and lymphatic tissue (American Cancer Society, 2011).

All women are at risk for breast cancer. Breast cancer is the most prevalent cancer among women (Keitel & Kopala, 2000). American women have the highest rates of breast cancer in the

world, and it is the second leading cause of death in women in the United States overall. Breast cancer can affect women of all racial/ethnic groups, cultural backgrounds, socio-economic statuses, and religious affiliations. However, some evidence suggests that survival rates differ by race. Although the disease is most common in Caucasian women, it occurs more frequently in African American women. In addition, African American women are more likely to die from breast cancer (Keitel & Kopala, 2000). According to the American Cancer Society (2011), the five-year survival rate for breast cancer among African American women is 77%, as compared to 90% among Caucasian women.

Many factors are associated with developing breast cancer. According to the American Cancer Society (2011), the most common risk factors may include family history, age, racial or ethnic background, genetic changes, and reproductive history. Suspected risk factors include alcohol intake, obesity, and lack of exercise.

Breast cancer, when diagnosed in African American women, frequently is aggressive and in late stage with a high morbidity rate and a poor prognosis (Jones & Chilton, 2002; Underwood et al., 2008). African American women between the ages of 25 and 39 have the highest incidence of breast cancer among all ethnic groups in the United States (American Cancer Society, 2011). Younger African American women are diagnosed with more aggressive cases of breast cancer and have an increased rate of recurrence and poorer prognosis than older African American women (Jones & Chilton, 2002).

Signs and Symptoms of Breast Cancer

There are typically no symptoms of breast cancer when the tumor is small and most treatable. One of the most common physical signs of breast cancer is a painless lump. Less

common signs and symptoms swelling; warmth, redness, or darkening; change in the size of shape of the breast; dimpling or puckering of the skin; itchy, scaly sore or rash on the nipple; pulling in of the nipple or other parts; nipple discharge that starts suddenly; or new pain in one spot that does not go away (American Cancer Society, 2011). The American Cancer Society recommends that any persistent change or abnormality in the breast should be evaluated by a doctor as soon as possible. In addition, it is extremely important for women to follow recommended screening guidelines before symptoms develop and get worse (American Cancer Society, 2011).

Breast Cancer Screening

According to the Centers for Disease Control and Prevention (2003), mammography, breast self-examination (BSE), and clinical breast examinations (CBE) by a medical practitioner frequently are identified as the three primary ways to screen for breast cancer. The American Cancer Society recommends yearly mammograms starting at age 40 and continuing as long as a woman is in good health. For women in their 20s and 30s, clinical breast examinations are recommended every three years. According to the American Cancer Society (2011), women in their 20s should be educated on the benefits and limitations of BSE and should be aware of how their breasts feel normally and immediately report any concerns and/or changes to their health care provider.

According to the American Cancer Society (2011), breast cancer incidence rates are higher in non-Hispanic White women than in African American women for most age groups. However, African American women have a higher incidence rate before 40 years of age and are more likely to die from breast cancer at every age. Despite gains in reducing screening

disparities, the mortality rate from breast cancer continues to be higher among African American women (Gullatte, 2006). African American women are 25% more likely than Caucasian women to have late-stage breast cancer at the time of diagnosis (Jemal, Murray, Ward, Samuels, Tiwari, Ghafoor, et al., 2005). African American women have a 20% higher mortality rate (Jemal, et al., 2005). According to the literature, one of the factors contributing to late-stage diagnosis in African American women is delay in breast cancer screening, which can result in increased breast cancer mortality (Bradley, Neumark, Bednarek, & Schenk, 2005). Delay is defined as “the time from self-detection of breast changes and first encounter with a medical provider regarding the breast change” (Gullatte, 2006 p. 89). Factors such as cultural beliefs, lack of access to health care, lower socioeconomic status, prior negative experiences, and distrust of the medical profession affect breast cancer screening behaviors of African American women (Phillips & Underwood, 2009). Additional barriers include the high cost of mammograms, doctors’ failure to discuss mammography with women, misconceptions about preventive methods, lack of health insurance, and cancer fatalism (Phillips & Underwood, 2009).

Stages of Breast Cancer

According to the American Cancer Society (2011), most masses or lumps are benign, which means they are not cancerous, have not spread uncontrollably, and are not life-threatening. However, the seriousness of invasive breast cancer is strongly influenced by stage of the disease or the extent to which the disease has spread when initially diagnosed. Stages of the disease are described below.

Stage 0 is used to describe non-invasive breast cancers, such as DCIS (ductal carcinoma in situ). In stage 0, there is no evidence of cancer cells or non-cancerous abnormal cells breaking

out of the part of the breast in which they started, or getting through to or invading neighboring normal tissue (American Cancer Society, 2011).

Stage I describes invasive breast cancer (cancer cells are breaking through to or invading normal surrounding breast tissue) in which the tumor measures up to 2 cm and no lymph nodes are involved. Microscopic invasion is possible in stage I breast cancer. In microscopic invasion, the cancer cells have just started to invade the tissue outside the lining of the duct or lobule, but the invading cancer cells cannot measure more than 1 mm (American Cancer Society, 2011).

Stage II is divided into subcategories known as IIA and IIB. Stage IIA describes invasive breast cancer in which no tumor can be found in the breast, but cancer cells are found in the lymph nodes under the arm (axillary) or the tumor measures 2 cm or smaller and has spread to the axillary lymph nodes or the tumor is larger than 2 cm but not larger than 5 cm and has not spread to the axillary lymph nodes (American Cancer Society, 2011).

Stage IIB describes invasive breast cancer in which the tumor is larger than 2 cm but no larger than 5 cm and has spread to the axillary lymph nodes or the tumor is larger than 5 cm but has not spread to the axillary lymph nodes (American Cancer Society, 2011).

Stage III is divided into subcategories known as IIIA, IIIB, and IIIC. Stage IIIA describes invasive breast cancer in which either (a) no tumor is found, but cancer is found in axillary lymph nodes, which are clumped together or sticking to other structures, or (b) cancer may have spread to lymph nodes near the breastbone or the cancer is any size and has spread to axillary lymph nodes, which are clumped together or sticking to other structures (American Cancer Society, 2011).

Stage IIIB describes invasive breast cancer in which the cancer may be any size and has spread to the chest wall and/or skin of the breast and may have spread to axillary lymph nodes, which are clumped together or sticking to other structures, or cancer may have spread to lymph nodes near the breastbone. Inflammatory breast cancer is considered at least stage IIIB. Typical features of inflammatory breast cancer include: reddening of a large portion of the breast skin, the breast feels warm and may be swollen, and cancer cells have spread to the lymph nodes and may be found in the skin (American Cancer Society, 2011).

Stage IIIC describes invasive breast cancer in which: there may be no sign of cancer in the breast or, if there is a tumor, it may be any size and may have spread to the chest wall and/or the skin of the breast and the cancer has spread to lymph nodes above or below the collarbone or the cancer may have spread to axillary lymph nodes or to lymph nodes near the breastbone (American Cancer Society, 2011).

Stage IV describes invasive breast cancer that has spread beyond the breast and nearby lymph nodes to other organs of the body such as the lungs, distant lymph nodes, skin, bones, liver, or brain. Words such as “advanced” and “metastatic” are used to describe stage IV breast cancer. Cancer may be stage IV at first diagnosis or it can be a recurrence of a previous breast cancer that has spread to other parts of the body (American Cancer Society, 2011).

Treatment Options

The size, stage, rate of growth, and other characteristics of the tumor determine the kinds of treatment (Rosenbaum & Rosenbaum, 2005). Treatment may include surgery, drugs (hormonal therapy and chemotherapy), radiation, and/or immunotherapy. Surgical removal of the tumor provides the single largest benefit, with surgery alone being capable of producing a cure in

many cases. To somewhat increase the likelihood of long-term disease-free survival, several chemotherapy regimens commonly are included in addition to surgery. Most forms of chemotherapy kill cells that are dividing rapidly anywhere in the body, and as a result cause temporary hair loss and digestive disturbances (Rosenbaum & Rosenbaum, 2005). Radiation may be added to kill any cancer cells in the breast that were missed by the surgery. Radiation usually extends survival somewhat, although radiation exposure to the heart may cause heart failure in the future (Eyre et al., 2002). Some breast cancers are sensitive to hormones such as estrogen and/or progesterone, which make it possible to treat them by blocking the effects of these hormones (Eyre et al., 2002).

Psychological and Emotional Effects of Breast Cancer Diagnosis

Breast cancer can have a negative impact on the emotional and psychological health of women as they experience the effects of this illness. According to Aapro and Cull (1999), emotional effects of breast cancer patients often go unrecognized and unnoticed. The prevalence of depression among cancer patients is reported to be in the 20-25% range, increasing with higher levels of physical disability, pain, and advanced stages of the illness (Sellick & Crooks, 1999). Sellick and Crooks (1999) further explained that depressed patients are more likely to commit suicide or ask for physician-assisted suicide.

According to Aapro and Cull (1999), depression accompanying a chronic physical illness is associated with a higher death rate, longer time in hospital, and greater overall disability. People who are diagnosed with a chronic physical illness and depression have a poorer quality of life when compared to those diagnosed with a chronic illness alone (Aapro & Cull, 1999). Major depression also can affect compliance with breast cancer treatment. Recognition of depression is

imperative because of the effect of mood in the outcome of breast cancer patients. Researchers have found that patients who react to the initial diagnosis of breast cancer with a “fighting spirit” have a higher disease-free survival rate than those who react with a feeling of helplessness and/or hopelessness (Aapro & Cull, 1999).

According to Del Mastro et al. (2002), breast cancer patients often report psychological distress or anxiety at the time of diagnosis and during treatment. Patient distress is also related to the frequency of side effects from treatment such as chemotherapy and radiation (Leventhal, Easterling, Coons, & Luchterhand, 1986). Researchers have found that 50% of women report feelings of anxiety and depression for as long as three years post-treatment (Redd, Montgomery, & DuHamel, 2001). The results of other studies have indicated that subclinical levels of distress and/or anxiety continue five years or more after a diagnosis of breast cancer (Saleeba, Weitzner, & Meyers, 1996). In addition, 50% of patients believed that they were more at risk of becoming depressed than they were before they were diagnosed with breast cancer (Halttunen, Hietranen, Jallinoja, & Lonnqvist, 1992).

Coping with a Breast Cancer Diagnosis

Coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing and that exceed the resources of the person” (Lazarus & Folkman, 1984, p. 141). According to Hilton (1996), coping with breast cancer can be both emotionally and physically challenging for women and their families. Coping strategies can play a vital role in how African American women adapt to their diagnosis of breast cancer. Reynolds et al. (2000) found that African American women suppressed their feelings, used “wishful” thinking, and practiced positive reappraisal strategies to

cope with breast cancer. These findings suggest that African American women may be less likely than Caucasian women to seek counseling as a resource for emotional support in coping with a breast cancer diagnosis. Reynolds et al. (2000) found that women who chose not to express themselves or seek emotional support were more likely to have poorer survival from breast cancer than those who chose to express their emotions and sought out emotional support.

Further evidence of the reluctance of African American women to seek treatment for mental health issues has been provided by Brown and Keith (2003), who noted that African American women tend to minimize the seriousness of their problems. Many believe their symptoms are “just the blues” and eventually will disappear. Thus, they are not proactive in changing their condition (Brown & Keith, 2003). African American women seek mental health care less often than Caucasian women; and when they do seek it, they do so later in life and at later stages of their mental illness (Myers, 1991). This could be attributed to poor service received from mental health professionals who, historically, have consistently under-diagnosed disorders like depression and over-diagnosed disorders like schizophrenia in the African American community (Myers, 1991). In addition, because of socioeconomic factors African American women have limited access to health care compared to Caucasians and are more likely to discontinue mental health services than Caucasians and other ethnic groups (Brown & Keith, 2003).

Additionally, a number of barriers may contribute to the under-utilization of mental health services by African American women. Researchers suggest that age, marital status, education, race, and diagnoses are the best predictors of who will use mental health services (Howard, Cornille, Vessey, Leuger, & Saunders, 1996). Particularly, educated women, married

women, Caucasian women, younger women, and women diagnosed with major depression are more apt to utilize mental health services. Practical barriers such as lack of information, lack of transportation, and denial that there is a problem may contribute to the decision not to seek out professional mental health services (Gibbs & Fuery, 1994; Howard et al., 1996).

Culturally, mental health problems in the African American community tend to be stigmatized and viewed as a sign of personal weakness, not as an illness. African American women tend to rely on supports other than mental health services. They have a strong reliance on community, the support of family, and the religious community during periods of emotional distress (Mays, Caldwell, & Jackson, 1996). According to Gibson and Hendricks (2006), spirituality can be a significant factor in coping in general and while coping with a chronic illness.

Spirituality

Tanyi (2002) described spirituality as being both subjective and intangible as it relates to a personal search for meaning of one's existence in the universe. Spirituality can play an integral part in the process of coping with illness by mediating the relationship between life events and outcomes (Reynolds et al., 2000). Breast cancer is an example of a life event for which the outcome appears to be mediated by spirituality in African American women. In a concept analysis of spirituality in African American women, African American women's spirituality was defined as "faith in an omnipotent, transcendent force; experienced internally and/or externally as caring interconnectedness with others, God, or a higher power; manifested as empowering transformation of and liberating consolation for life's adversities; and thereby inspiring fortified belief in and reliance on the benevolent source of unlimited potential" (Newlin, Melkus, Knafl,

& Newlin, 2002, p. 68). Findings of a study conducted by Ashing-Giwa et al. (2004) revealed that minority women expressed that spirituality is an important coping mechanism used to overcome many different challenges.

Spirituality functions in a variety of ways for many African American women, and may be used to help cope with a major life event or stressor such as breast cancer. Gibson (2003) noted that, historically, African American women have demonstrated the ability to cope successfully with major life stressors or events. This ability can be attributed to ex-slave and spiritual narratives that revealed a sense of strength and fortitude of giving thanks to God and having hope for a better day (Gibson, 2003).

According to Mattis and Jagers (2001), spirituality can operate through a wide range of affect, cognition, and behaviors, which in due course serve to enhance a better understanding of self and meaningful relationships. The spirituality of African American women is a dynamic process that leads to self-reflection, self-awareness, inner strength, and a sense of calmness (Mattis, 2000). Mattis implied that once the African American woman immerses herself in her own self-awareness and becomes engaged with her spiritual self, she then can improve her understanding of self and relationships with others which may, in fact, assist her along her breast cancer journey by providing a source of strength, identity, comfort, and peace.

Simon, Crowther, and Higgerson (2007) conducted a study with 18 African American Christian women focusing on the role of spirituality throughout their breast cancer experiences. The results indicated that, for most of the survivors, spirituality and faith assisted them throughout their breast cancer experience. The researchers focused on various spiritual resources used by the participants at different levels of their journey, and they explained the need for health

care providers to understand the importance of those spiritual resources to help African American women better cope with this illness. The results of other studies support this finding that spirituality is key in the lives of women coping with breast cancer (Gibson & Hendricks, 2006; Henderson et al., 2003)

Henderson et al (2003) conducted an exploratory study to determine how African American women cope with breast cancer. The participants included 66 African American women diagnosed with breast cancer in southeastern United States. Focus group interviews were conducted. A semi-structured interview protocol was used. Findings indicated that coping strategies such as prayer, avoiding negative people, developing a positive attitude, having a will to live, and receiving support from family, friends, and support groups were important factors in adapting to the diagnosis of breast cancer. In addition, spirituality played a major role in the lives of these African American women coping with breast cancer.

Gibson and Hendricks (2006) conducted an integrative review of spirituality in African American breast cancer survivors over 18 years of age, including published and unpublished data-based research studies between 1994 and 2004. The following indexes were used: Medline, Cumulated Index of Nursing and Allied Health Literature, Psychology Abstracts, Sociology Abstracts, and the Religion and Philosophy index. Key themes found included: caring; belief, faith, and healing; coping; and support. The researchers found that the spirituality of African American women helps to facilitate their ability to cope with major life stressors and illnesses such as breast cancer. Gibson and Hendricks discussed the importance of coping as it includes a key spiritual dimension.

In summary, reliance upon spirituality as a coping strategy among African American women has been well documented. Breast cancer is a life event for which the outcome appears to be mediated by spirituality in African American women.

Prayer

As mentioned previously, Henderson et al. (2003) conducted an exploratory study to evaluate coping styles and breast cancer survival among 66 African American women. They found that prayer was the most frequently used coping mechanism among the participants. Many participants reported that prayer in combination with their spirituality helped them to cope better with each phase of breast cancer—from discovery of a lump to recovery. Many of the women in this study reported that their relationship with God grew stronger through prayer. Some participants believed that prayer helped to keep them grounded and faithful throughout their breast cancer experience. Counselors and other mental health professionals should recognize that prayer is an important coping strategy for African American women as this can help to facilitate a culturally sensitive journey to wellness.

Family and Support Networks

Many African American women tend to rely on family members, church members, friends, and pastors/ministers for help in coping with breast cancer (Henderson et al, 2003). Gibbs and Fuery (1994) found that utilization rates of formal mental health services by African American women were low due to use of alternative resources to cope with emotional and psychological issues. One main alternative resource is the Black church. Many churches have developed outreach programs to assist African American women with emotional, economic, and social support. Henderson et al. (2003) found that participants more readily sought out faith-

based cancer support groups that were designed specifically for African American women with breast cancer due to cultural sensitivity and the inclusion of prayer and support of women who looked like them. Although churches provide great resources for African American women and families, ministers and pastors lack adequate training to facilitate wellness and deal with serious mental health issues (Taylor, Chatters, Levin, & Lincoln, 2000).

Breast cancer survivors may rely on friends and family members for support, but these people may not always be supportive (Wilmoth & Sanders, 2001). In a study conducted by Wilmoth and Sanders (2001), participants reported that friends and family could sometimes be unsupportive and overbearing when compared to friends and family of Caucasian women, and that patterns of family communication may also change due to the diagnosis of breast cancer. The African American women who participated in the study conducted by Henderson et al. (2003) reported that being around negative people brought down their spirits and made them feel hopeless about their current situation. Many of the women stated that they purposely distanced themselves from negative family members, friends, and co-workers due to negative attitudes or conversations about their breast cancer experience or about the negative experience of someone they knew. Some participants stated that this type of negative dialogue or unsupportive words contributed to their physical or mental decline which made them realize the importance of surrounding themselves with positive family members and friends (Henderson et al., 2003).

Having a Positive Attitude and Will to Live

Gates, Lackey, and Brown (2001) found that African American women were able to move forward with breast cancer treatment because they were either receiving care from others or giving care to others, especially to family members. According to Henderson et al. (2003),

having the will or determination to live by helping others is another important coping strategy for African American women. The “Will to Live” emerged as a central theme in two studies that explored existential meaning in the lives of breast cancer survivors (Landmark & Strandmark, 2001; Landmark & Wahl, 2002). Landmark and Wahl (2002) found that a tenacious fight for life arose as an important aspect of living with newly diagnosed breast cancer. Maintaining a fighting spirit and possessing a continual sense of hope to cope with the illness trajectory is essential to survival among women diagnosed with breast cancer (Landmark & Strandmark, 2001). For many of these women, family members are dependent on them, which contributes to their motivation to get better and stay focused on survival. In addition, helping others may help to increase a positive attitude and frame of mind. Several women reported that having a positive attitude and being around positive family and friends helped them to cope better with their breast cancer diagnosis (Henderson et al., 2003).

Counseling and Breast Cancer Support Groups

Many women diagnosed with breast cancer experience a range of emotions. They may experience severe emotional distress, major depression, post-traumatic stress disorder, and generalized anxiety disorder (American Cancer Society, 2011). Effective mental health treatments for individuals diagnosed with breast cancer include individual counseling, existential counseling, and breast cancer support groups. These types of treatments may provide emotional and social support, coping strategies, financial and informational resources, and treatment options for women who are newly diagnosed, or for those who have been diagnosed for years.

Counselors as Consultants and Educators

Mental health professionals can play an important role in assisting medical personnel to provide more responsive services to these patients. They can serve as advocates and can train doctors, nurses, and other medical professionals in active listening skills. Additionally, they can educate them about psychological issues that women with breast cancer may confront throughout their breast cancer experience (Keitel & Kopala, 2000).

Mental health professionals can consult with medical professionals to help them understand the cultural and social needs of this population, as well as the types of support that their patients may need. Medical professionals also need to be aware of the varying coping styles of breast cancer patients so that they may individualize patient treatment more effectively. Understanding the phases and time frame for psychological morbidity can help medical professionals to develop better treatment plans and refer those whose emotional distress may require professional mental health services (Keitel & Kopala, 2000).

Individual Counseling

Individual counseling can be used for anyone working to cope with life's challenges. For breast cancer patients, trying to work through this process alone can be emotionally draining and devastating. Because breast cancer is not a singular event, but an ever-changing process that involves many challenges, counselors can help during all phases of the disease (early, middle, and terminal).

Women who are initially diagnosed with breast cancer may experience high levels of anxiety and depression. Denial of the symptoms or diagnosis of breast cancer can result in physical and psychological consequences and make it more difficult for the client to adjust

(Keitel & Kopala, 2000). Counselors can be extremely helpful in the early phase by assisting clients to break through their denial and establish effective communication with their families and health care practitioners.

Adapting to the various stages of cancer can also be a stressful time. Counselors need to be aware of issues that occur during the middle phase of breast cancer so that they do not begin to act in the same way as some health care professionals, family, or friends (Keitel & Kopala, 2000). For example, many women in this stage feel lonely and abandoned. They may feel mistreated and think that no one understands or cares. Women in this stage may have had surgery, such as a lumpectomy, and may complain that other people may not perceive them as being ill or take them seriously. Clients may also be going through various treatments and taking different types of medication. Counselors working with clients in this stage will need to be extremely supportive and understanding as these clients may not be getting support and understanding from friends or family. In addition, empathic counselors can help clients learn to manage their fears, doubts, and disappointments (Keitel & Kopala, 2000). Stress management and coping skills training may also be effective tools to help reduce levels of stress in this stage of the illness.

During the terminal phase, counselors can help clients process the psychological conflicts and anxieties they may be experiencing as they confront the inevitable (Keitel & Kopala, 2000). Counselors working with clients during this phase should empathize with them, listen to them, and give them permission to discuss, express, or confront any issues they wish. Counselors can also help clients to prioritize their struggles and allow them to identify their deepest, anxiety-provoking concerns as they face existential issues (Keitel & Kopala, 2000). Counselors can help

clients explore feelings, examine their own isolation, explore meaning, and provide insight into their own personal feelings, as people who are dying may be experiencing increased conflict with their closest loved ones. Counselors can help women address “unfinished business” and find meaning in their death so that they can continue to grow in their final phase of existence (Keitel & Kopala, 2000).

Existential Counseling

As was suggested by Keitel and Kopala (2000), discussed above, culturally competent counselors working with clients diagnosed with potentially life-threatening illnesses can utilize the basic concepts of existentialism to foster growth along their clients’ personal journeys of wellness. Part of the meaning-making of any life-threatening illness involves confronting the possibility of dying. For many people, facing death is a difficult task. Regardless of spirituality or religious ideologies, the awareness of not being or not living in the physical body can take an emotional toll and can be difficult for anyone to accept.

A study conducted by Landmark and Strandmark (2001) revealed the importance of existential awareness in the lives of 10 women diagnosed with breast cancer. A central theme of “The Will to Live” emerged. According to Landmark and Strandmark (2001), health care professionals should increase their awareness of existential aspects connected to “The Will to Live” in order to better assist women diagnosed with breast cancer and their families with effective coping strategies. For many women with children, the idea of dying may be especially difficult as they may begin to think of how their children will adjust without them being there or of not being around to see them graduate high school or get married.

Existential change such as a deepening spiritual faith or spirituality, making sense of what happened, or a searching for a renewed purpose or meaning in life may become significant aspects to consider in counseling. Existential issues such as the potential recurrence of breast cancer and the possibility of an untimely death can create anxiety and feelings of isolation and loneliness for many survivors of this illness.

Breast Cancer Support Groups

Breast cancer support groups can provide an opportunity for women to share their experiences, exchange information, interact with others, and learn to self-advocate (Keitel & Kopala, 2000). Newly diagnosed women may benefit from support groups by interacting in a social environment with their peers, by asking questions, and by resolving issues surrounding a new diagnosis (Coward & Kahn, 2005). Other issues that may emerge for newly diagnosed women include relationships with professionals, family issues, and other social supports or networks. Coward and Kahn (2005) indicated that support groups can positively affect the healing process as women gain knowledge and opportunities for emotional expression in a safe environment.

According to Barg and Gullatte (2001), cancer patients who are members of minority groups are less likely to attend cancer support groups than those who belong to a majority group. Wilmoth and Sanders (2001) found that few African American women attended cancer support groups, and they perceived the need for a support group designed specifically for African American women. They concluded that African American women tend to keep their diagnosis private and do not seek information and support. However, they tend to actively participate in

breast cancer outreach activities and breast cancer awareness in their own communities when compared to Caucasian women.

Cultural Considerations in Counseling African American Women with Breast Cancer

According to Corey (1996), culture is defined as the values and beliefs shared by a group. Culture also includes ethnic and racial heritage and background, along with age, gender, religion, lifestyle, socioeconomic status, and physical and mental abilities. Although counselors typically are trained to focus on psychological dynamics and emotional concerns, they should also focus on social influences, especially the impact of culture on how women view themselves.

Culture influences how we view medical and mental health professionals as well as our decisions on seeking treatment (Keitel & Kopala, 2000). In addition, culture defines the roles we take on as men and women in society. For example, women in our society are socialized to be sexually appealing to men. Young girls and women are flooded with images of the ideal woman in magazines, television, and over the internet. Many of these images are male-defined standards of beauty that include large breasts and small waists. Many women work hard to meet this standard even if doing so can negatively affect their own health. Counselors should strive to understand cultural beliefs and gender role socialization to work effectively with women diagnosed with breast cancer (Keitel & Kopala, 2000).

An important component in counseling African American women living with breast cancer is to be a culturally competent counselor. Culturally sensitive interventions, educational programs, and informational literature are all important and necessary to reach African American women and positively impact their compliance with breast cancer screening guidelines (Phillips & Underwood, 2009). A lack of knowledge can have serious implications for counselors

attempting to facilitate emotional wellness among this particular population, especially when considering the higher mortality rate. To gain a deeper understanding of the client's perceptions and life experiences, counselors should first understand the dynamics of race and its influence on experiences. Counselors should be aware of the potential risks of counseling clients without achieving an understanding of possible racial issues that may emerge throughout the client-counselor relationship. Potential risks might include miscommunication, misunderstanding, and misinterpretation, which could create a barrier that prevents the client from continuing counseling or seeking counseling services in the future.

Researchers have found that the majority of master's level counselors are of European descent (Arredondo, 1998). Although it is likely that an African American woman would seek counseling from a Caucasian counselor, it is important to note that understanding both the client's and counselor's identity development status is crucial for the development of an effective therapeutic relationship. In addition, counselors should understand that there are greater differences among people within a particular cultural group than between cultural groups. If a counselor overemphasizes cultural differences, this can negatively impact the relationship and may result in improper treatment (Keitel & Kopala, 2000). For example, if a counselor believes that all African American women know a great deal about breast cancer, she may not provide much information about breast cancer to the client. This could be potentially harmful to the client and could affect the outcome of mental health services. Also, a client's level of acculturation, religious beliefs, and health locus of control are important to understand when providing mental health services. Many African American women have strong religious values that may affect their perceptions of mental health professionals and the therapeutic relationship (Keitel &

Kopala, 2000). For example, they may believe that God or prayer will heal them. Some would rather seek support from the pastor or other church members due to the stigma attached to seeing a “therapist.”

Qualitative Research with African American Breast Cancer Survivors

The literature is scant on the topic of African American women and their experiences with breast cancer. A small, but substantial number of qualitative studies have been conducted specifically focusing on African American women, who may differ in some significant ways from White women as they experience breast cancer (Ashing-Giwa, et al. 2004; Ashing-Giwa, 1999; Ashing-Giwa & Gantz, 1997; Underwood et al., 2008).

Underwood et al. (2008) focused on the breast cancer experiences of African American women with a family history of breast cancer. Sixteen African American women with a familial predisposition for developing breast cancer participated in the study. The results of this study indicated that, although the women were knowledgeable about breast cancer and the potential risks, the extent to which they discussed their concerns with their healthcare providers and engaged in preventative methods varied. However, concerns about the health of family members and perceptions of immediate versus future risk of developing breast cancer did significantly impact screening practices of women who participated in the study.

Ashing-Giwa et al. (2004) focused on understanding the breast cancer experience of women. The researchers used a qualitative approach to study the experience of African American, Asian American, Latina, and Caucasian breast cancer survivors. A total of 102 breast cancer survivors participated in focus group interviews. The purpose of this study was to increase understanding of the psychosocial pathology of breast cancer among minority women

and to increase knowledge about specific cultural influences that may affect survivors and healthcare professionals. The researchers found that concerns for all women included overall health, physical concerns, cancer recurrence, worrying about children and burdening the family, body image, and sexual health. Other challenges focused on costs, insurance, knowledge about breast cancer, cultural sensitivity of healthcare providers, language barriers, and cultural beliefs and values.

Ashing-Giwa (1999) conducted a descriptive study on the quality of life and psychosocial concerns of 117 African-American women who were long-term survivors of breast cancer. Questionnaires were completed by the participants. The questionnaires focused on the following: quality of life, socioecological context, and new items generated by earlier qualitative research. The questionnaire also included sections on demographic characteristics, breast cancer and other medical conditions, perceived quality of health care, health beliefs, social support, life stress, living situation, health perceptions, partner support; dating, body image, spirituality; and physical, psychological, sexual, and marital functioning. Results indicated that spiritual faith and family support were used as coping mechanisms to assist these women through their breast cancer experience. The participants also reported having difficulty talking about breast cancer and a lack of emotional and financial support.

Ashing-Giwa and Gantz (1997) conducted a study focused on understanding the psychosocial needs of African American women diagnosed with breast cancer. Three forms of qualitative interviews (key-informant interviews, focus-group interviews, and in-depth interviews) were conducted. Twelve informants (physicians, nurses, and administrators) who had worked in the area of cancer prevention or management for 5–25 years participated in the key-

informant interviews. Twenty-three women ages 38-74 years participated in the focus group interviews. Eight women ages 38–65 years participated in the in-depth interviews. The researchers found that many participants did not receive adequate information and support to guide them through the initial diagnosis and treatment phases of the breast cancer experience. They also found that the participants with less education and lower incomes experienced a lack of coordinated and effective medical care, were either uninsured or underinsured, and experienced a poor patient-doctor relationship. Spiritual beliefs were also found to be a primary source of support and coping for these women.

Three studies (Albaugh, 2003; Lackey, Gates, & Brown, 2001; Luoma & Hakamies-Blomqvist, 2004) have been conducted using a phenomenological method to explore the lived experiences of women diagnosed with breast cancer. However, only one of these studies (Lackey, Gates, & Brown, 2001) focused on African American women specifically. Luoma and Hakamies-Blomqvist (2004) investigated the meaning of advanced breast cancer patients' quality of life. A semi-structured interview format was used to collect the data and the researchers utilized a phenomenological approach to analyze the data. The researchers found that limitations in patients' physical functioning increased their dependency on other people, which lead to a decrease in the patients' autonomy. This study was not specific to African American women.

Albaugh (2003) used a phenomenological method to examine the lived experiences of individuals when confronted with a life-threatening disease. The participants included five women and two men ages 44-74. Only the participants' gender and ages were provided. This study was conducted with patients with a variety of diagnoses who lived in the Midwest. Although the study was not specific to breast cancer, diagnoses of the participants included

breast cancer as well as colorectal cancer, prostate cancer, pulmonary fibrosis, and myocardial infarction. Findings indicated that spirituality provided comfort through the participants' journey in facing potentially life-threatening illnesses and trust in a higher power to see them through their individual journeys.

In a study that is perhaps the most similar to my study, Lackey, Gates, and Brown (2001) conducted a phenomenological study which focused on the experiences of African American women following breast cancer diagnosis and initial treatment. Thirteen African American women in the mid-South were purposefully chosen to participate in the study. The methods used to collect the data included interviews and field notes. Three major themes were found: experience trajectory, femininity, and spirituality. Subthemes were also found under each major theme. Experience trajectory included subthemes of finding the lump, being diagnosed, and undergoing treatment or surgery. Subthemes of femininity included sexual unattractiveness and loss of breasts and hair. A subtheme of spirituality was identified as connectedness with God. The researchers concluded that understanding the women's stories may help with assessing feelings and emotions as well as fears following diagnosis and initial treatment. Implications for nursing practice were also discussed. My study differed from this phenomenological study as I utilized an existential perspective to uncover meaning and to understand the lived experiences of African American women diagnosed with breast cancer. It is my hope that the findings of this study will promote a greater understanding among counselors to inform the development of culturally sensitive interventions.

Only two studies were found that specifically explored existential themes among breast cancer survivors (Landmark, & Wahl, 2002; Landmark & Strandmark, 2001). A qualitative study

conducted by Landmark and Wahl (2002) focused on describing the experiences of 10 women newly diagnosed with breast cancer ages 39-69 years. A grounded theory design was used. The researchers conducted open-ended interviews to collect information. The researchers found that many existential issues surfaced as a critical component of living. “The Will to Live” emerged as a central theme. The researchers revealed other aspects of the women’s awareness of living with breast cancer such as physical changes, emotional/psychological factors, social functioning, and meaningful day-to-day activities.

Landmark and Strandmark (2001) described the experiences of 10 Norwegian women diagnosed with breast cancer. The researchers focused on the meaning of existential issues and used open-ended, in-depth interviews in a grounded theory design. The data revealed the importance of existential awareness in the lives of these women. As was found by Landmark and Wahl (2002), a central theme of “The Will to Live” emerged, which included existential aspects of life expectations, the fight against death, life related to the future, religious beliefs and doubts, and increased awareness of values in life. My study differed from these two existential studies as I used a phenomenological approach and IPA analysis. The participants in this study were exclusively African American women. Some of the same existential themes emerged in this current study, which will add support to this small base of existing literature. Additional themes were also generated in this study, which will also help counselors to better understand the breast cancer experience of African American women specifically.

No research studies were found that used a qualitative, phenomenological method and an existential perspective to understand the lived experiences of African American women who are breast cancer survivors. Most studies on African American women diagnosed with breast cancer

have aimed to contribute to nursing and/or medical literature. For example, Underwood (2006) conducted a study focusing on breast cancer in African American women, with the purpose of increasing the knowledge of the nursing profession. The author provided a thorough overview of facts and figures for African American women and a review of breast cancer risks, treatment, diagnosis and staging, and she also gave a brief review of nursing research focused on breast cancer in African American women.

Only one study was found related to counseling. Heppner et al. (2009) conducted a qualitative study of 10 breast cancer survivors coping with lymphedema. The purpose of the study was to promote a greater understanding among counselors and other helping professionals regarding the stressors associated with lymphedema, how women cope with the stressors, and the role of social support. All of Heppner et al.'s participants were White and lived in Missouri. The focus was specifically on lymphedema and how counselors who work with cancer survivors who experience lymphedema can better assist them with their psychological difficulties.

A review of the literature illuminated the limited amount of research on the experiences of African American women diagnosed with breast cancer. Although researchers have discussed certain aspects of the breast cancer experience of women, they have not focused specifically on the meaning behind the experiences of African American women with breast cancer. According to the American Cancer Society (2011), African American women have a higher incidence rate before 40 years of age and are more likely to die from breast cancer at every age. Despite the alarming statistics and higher risk of death in this population, research based on the experiences of African American women with this disease is scant. Existential issues often arise when diagnosed with a terminal illness such as breast cancer (Landmark & Wahl, 2002). Only two of

the studies discussed above specifically explored existential themes (Landmark, & Wahl, 2002; Landmark & Strandmark, 2001). These two studies were not specific to African American women diagnosed with breast cancer. My conceptual framework focuses on existentialism as existential theory is the most salient theory for conceptualizing the life experiences of African American women diagnosed with breast cancer because this theory is based on how a person makes meaning of her existence and how she perceives life and/or her personal experiences of life.

A unique aspect of this study was the use of Interpretive Phenomenological Analysis (IPA), along with the incorporation of an existential perspective to uncover the essence of the participants' experiences. Three studies mentioned above have been conducted using a phenomenological method to explore the lived experiences of women diagnosed with breast cancer (Albaugh, 2003; Lackey, Gates, & Brown, 2001; Luoma & Hakamies-Blomqvist, 2004). However, only one of these studies (Lackey, Gates, & Brown, 2001) focused on African American women specifically. There were no studies found that used a qualitative, phenomenological method and an existential perspective to explore the lived experiences of African American women with breast cancer.

I anticipate that these findings will contribute to the counseling literature, as counselors will benefit from understanding the essence of lived experiences to inform the development of culturally sensitive interventions that can assist African American women and their families as they experience this disease. A lack of knowledge about the experiences of African American women with breast cancer can have serious implications for counselors attempting to facilitate emotional wellness among this particular population.

Chapter Summary

Breast cancer is a potential issue for all women. Counselors have the ability to be strong advocates and life-enhancing practitioners if they are knowledgeable about breast cancer and the breast cancer experience of women, particularly African American women. Although research has indicated that coping strategies exist for African American women with breast cancer, research is lacking that explores the essence of the African American woman's experience surrounding this phenomenon. The exact cause of this disease is unknown and for many reasons breast cancer may remain undetected and untreated. Counselors should seek to understand the essence of survivors' lived experiences to inform the development of culturally sensitive interventions that can assist African American women and their families as they experience this potentially life-changing phenomenon.

Most research studies of African American women with breast cancer have contributed to the medical literature as a tool to foster better relationships among doctors, nurses, and breast cancer patients. I hope that these findings will help to facilitate change in the counseling profession and contribute to the existing literature by uncovering meaning of the breast cancer experience of African American. In addition, I hope that these findings will help counselors to better understand the breast cancer experience, to be more culturally aware, and to provide more effective services in meeting the needs of this population.

CHAPTER THREE

METHODOLOGY

In this chapter, the methodology for this research study is described. Specifically, the chapter is organized in subsections that state the purpose; research questions; the nature of the inquiry; role of the researcher; and researcher bias. The procedures and participants are discussed. Additionally, data collection methods and data analysis are described in detail. Last, trackable variance and credibility are addressed. The chapter ends with a summary.

Purpose of the Study

The purpose of this phenomenological study was to explore the lived experiences of African American women diagnosed with breast cancer. Specifically, the aim of the study was to understand and describe the breast cancer experiences of African American women, focusing on their perceptions and the meaning behind their lived experiences. Utilizing an existential perspective, the focus of this study was to uncover meaning which defined the essence of the participants' experiences.

Research Questions

This phenomenological study began with exploring the central question, "What are the lived experiences of African American women diagnosed with breast cancer?" This broad question led to another question that sought to understand, "What does it mean to be diagnosed with breast cancer as an African American woman?"

Nature of Inquiry

Qualitative phenomenological methodology was used to explore the lived experiences of African American women diagnosed with breast cancer. Phenomenology focuses on the meaning

of the lived experiences of individuals experiencing a concept, structure, or phenomenon (Creswell, 2007). The purpose of phenomenological research is to identify phenomena as perceived by the individual. Phenomenologists study the conscious experience and seek to find answers to the essence of personal experiences from the subjective viewpoint. Those experiences include meanings of sensory qualities as well as the meanings of significant things, individuals, and/or objects in a person's life. According to Creswell (2007), phenomenologists believe that truth and understanding of life can emerge from people's life experiences or by experiencing a common phenomenon. The focus of phenomenology is to describe what is given to us in an immediate experience. An essential characteristic of phenomenology is that of intuiting the universal essence or the meaning of those individual experiences.

Interpretative Phenomenological Analysis (IPA; Smith, 2004) served as the specific methodology for this study by providing a structure for gathering detailed descriptions on how African American women experience breast cancer and how they perceive this experience. Smith (2004) described IPA as inductive, idiographic, and interrogative. IPA is inductive because of its flexible and emergent data collection and analysis. In addition, IPA begins with broad research questions to explore specific phenomena under investigation as opposed to confirming detailed hypotheses.

IPA is idiographic as its focus is on the particular rather than the general analysis or investigation of each case. Each individual case is explored first, before the researcher analyzes the next case, until all cases in the study are explored. Cross-analysis can then be conducted to discover common themes among all cases in the study. Smith, Flower, and Larkin (2009) stated, "In a good IPA study, it should be possible to parse the account for both shared themes, and for

the distinctive voices and variations of those themes” (p. 38). Hence, a small sample size is recommended. Additionally, individual accounts are revealed as well as those shared across all cases.

IPA is interrogative as it entails in-depth analysis of a phenomenon and the findings contribute to existing literature. Additionally, the most commonly used method for IPA is the semi-structured interview, which is what I used for data collection, along with a personal characteristics questionnaire. Semi-structured interviews are both flexible and well-organized, which is why semi-structured interviews are ideal for obtaining rich data (Smith, Flower, & Larkin, 2009).

According to Smith and Osborn (2003), “IPA is a suitable approach when one is trying to find out how individuals are perceiving the particular situations they are facing” (p. 53). IPA has been used in the examination of individuals with physical illnesses. For example, in a study conducted by Wallace, Harcourt, Rumsey, and Food (2007), IPA was used to analyze the impact of physical changes on adolescents who were diagnosed with cancer. I also found IPA to be the most appropriate qualitative methodological approach for this study because it allowed me to conduct an in-depth analysis of the participants’ meaning behind their breast cancer experiences. In addition, it allowed me to gain new insight into each participant’s world.

Role of the Researcher

Researchers are the primary instruments in qualitative research. The main role of a researcher in qualitative research is to achieve a holistic view of the phenomena being studied (Miles & Huberman, 1994). According to Creswell (2007), researchers collect data by interviewing participants, reviewing documents, or by observing participant behavior. In this

study, semi-structured interviews were used to understand the essence of the breast cancer experience of African American women as reported by the participants. Appropriate steps were taken to ensure the confidentiality of all participants in the study: (a) all information was stored in a computer program that is password protected in a locked office; (b) all participants were given pseudonyms to protect their identity; (c) all written information was secured in a locked filing cabinet in a locked office; and (d) tape recordings were kept on a digital recorder secured in the same locked office.

Another important role of the researcher is to establish rapport and make the participants feel comfortable throughout the interview process (Glesne, 2011). Rapport building helps to facilitate an atmosphere of trust, which will in most cases allow for participant self-expression throughout the interview process. To establish rapport, I provided participants with the opportunity to review the questions before the scheduled interview session, I began the interviews by thanking the participants for participating in the study, I explained the purpose and nature of the study to the participants, I emphasized confidentiality, and I informed the participants that if at any time they did not feel comfortable with answering a question, they were not obligated to do so.

Given the sensitive and potentially emotional nature of the subject matter that was addressed in this study, appropriate steps were taken to protect and support all participants by providing counseling resources to participants who might request assistance with emotional issues. Counseling was made available from a licensed counselor at no cost to the participants. This offer of free supportive counseling was disclosed in the informed consent document, which was reviewed and signed by each participant.

Another important role of the researcher is to be self-aware of his or her own personal biases and experiences. This study followed an IPA model in which the researcher plays an active role in the collection of data throughout the interview process with the participants. Because of the active role of the researcher throughout the data collection and analysis portion of the study, the potential for researcher bias must be acknowledged.

Researcher Bias

Many factors contribute to bias in terms of data collection, interpretation, and analysis. Creswell (2009) stated that clarifying the bias that researchers may bring to the study can help to create an open and honest narrative for the readers. Therefore, my biases are explicitly stated below.

I began to think about my topic while taking my first qualitative research course as a doctoral student. A few months prior to the beginning of the course, my mother was diagnosed with stage III breast cancer --Invasive Ductal Carcinoma (IDC). At the time, I was a licensed master's level counselor working at an outpatient facility with chronically mentally ill clients. Due to the nature of this work, I had to stay focused, yet I was completely devastated as we had no family history of the disease. It was difficult as my family and I had to face the possibility of my mom dying. My mother was always there for me and seeing her struggle with the effects of this illness made me realize the importance of life. I had never cried so hard in my life when I first learned of my mom's condition. I was now challenged with the task of facing my own anxiety and fear of death. I coped with this anxiety by talking to my family and friends about my feelings. I prayed and found peace in my faith and spiritual foundation. Most importantly, my mom and I had in-depth conversations about her life and her needs if the inevitable showed its

ugly head. My mom's diagnosis of breast cancer was definitely a turning point in my life. I learned to appreciate the little things in life. I have also learned to become more aware of my own health. I have become more proactive and I am taking preventative measures to decrease my risk of developing breast cancer.

Although it was only my mother's left breast that was affected, she made the decision to have a double mastectomy for fear the cancer would return. During the semester, she was also completing weekly chemotherapy treatments. She was physically and emotionally exhausted. She could not work and my sister and I were providing for her both emotionally and financially. During this time, I often wondered how people, especially African American women, get through these times without support from family, friends, or other people. My mom would often pray about her situation and put on a happy face, despite the grim statistics. Her resiliency throughout this process impressed me and inspired me to focus on my dissertation topic.

To limit researcher bias in this study, I utilized bracketing, consulted with my dissertation chair, and used peer debriefing. Moustakas (1994) described one of Husserl's concepts called *epoche*, or bracketing, which refers to researchers setting aside their own personal experiences to gain a fresh perspective on the phenomenon under investigation (Creswell, 2007). Bracketing allowed me to become aware of any feelings or experiences that may have come to mind throughout the interview process. Prior to conducting the interviews, I met with my dissertation chair and disclosed any and all information related to personal issues associated with my mother's breast cancer experience. I also discussed with my dissertation chair and two of my peers any issues, feelings, values, and perceptions related to my own experiences coping with the phenomenon as a way to remain unbiased.

Procedures

Setting

Initial interviews were audio taped in the homes of six of the participants. One of the participants stated that she felt more comfortable meeting at my home because she had house guests. As a result, we met at my house and audio taped the interview there. All participants gave verbal and written consent to be audio taped prior to conducting the interview.

Approval for the study

Prior to data collection, approval was obtained through the University of New Orleans Institutional Review Board (IRB). The IRB application was approved on July 2, 2012. Interviews began on July 25, 2012. Informed consent was also obtained from each participant prior to the interview (Appendix B).

Participants

Typically, IPA studies utilize small sample sizes (Smith & Osborn, 2003). Seven African American women diagnosed with breast cancer agreed to participate in this study. The participants lived in the New Orleans area. Access to the participants was provided by a gatekeeper who was identified prior to conducting the interviews. The gatekeeper is the leader of a support group specifically for African American women who have been diagnosed with breast cancer. The gatekeeper agreed to be the first interviewee. Some of the women who participated in the study were members of a local support group for African American women diagnosed with breast cancer. A snowball approach was used in recruiting other women. Once the participants were identified, telephone calls were made to schedule a meeting to discuss research plans and to schedule a time to conduct the interviews.

Participant Profiles

Betty

Betty is a 63-year-old retired school teacher who was diagnosed with Stage I breast cancer at the age of 51. Betty attended college and went on to receive a graduate degree. She reported being divorced but in a relationship at the time of diagnosis. Betty reported having three children, two of whom are deceased. Betty explained that her tumor was the size of a green pea and therefore she had to undergo a lumpectomy to remove the tumor. After removal of the tumor, Betty received radiation and four rounds of chemotherapy. Betty's father is a minister and she expressed that her religion and faith kept her optimistic during her time of treatment and recovery. Betty is also an active member of a local support group specifically for African American women diagnosed with breast cancer. She has also been an advocate for breast cancer since her diagnosis almost 12 years ago.

Korinne

Korinne is a 60-year-old retired stylist/manicurist who was diagnosed with Stage III breast cancer at the age of 57. Korinne is married and has one son. Korinne graduated from high school and was self-employed for many years. She had a lumpectomy and afterwards received several treatments of chemotherapy and radiation. Korinne stated that her husband and family were very supportive throughout her treatment. She is also a member of a local support group for African American women with breast cancer.

Dionne

Dionne is a 71-year-old retired teacher who was diagnosed with Stage I breast cancer one year ago. Dionne decided to have a unilateral mastectomy and has a family history of breast

cancer. She is married with two children and earned a graduate degree in education. Dionne's brother is a minister and has helped her cope through this process. Dionne related that her faith has been a major part of her existence and has kept her positive throughout this experience.

Fiona

Fiona is a 35-year-old woman who was diagnosed with Stage I breast cancer at the age of 32. Fiona had a lumpectomy to remove the tumor from her breast and had to undergo seven months of chemotherapy and radiation. Fiona is a college graduate and is currently working as a teacher in the local public school system. Fiona is divorced and has one daughter. Fiona has no family history of breast cancer. Fiona has attended support groups for breast cancer survivors in the past.

Crystal

Crystal is a 32-year-old woman who was diagnosed with Stage II breast cancer eight years ago. In 2009, Crystal experienced a recurrence of breast cancer. Crystal received several rounds of chemotherapy and radiation for a second time. She is currently a graduate student at a local university and is employed full-time. Crystal is married and has no children but expresses the desire to start a family soon. Crystal expressed that she is now an advocate for breast cancer awareness and has a strong faith that has empowered her to help other women along their journeys.

Paula

Paula is a 56-year-old woman who was diagnosed with Stage I breast cancer four years ago. Paula has a family history of breast cancer and received 36 treatments of radiation. Paula is married and is the mother of three children, one of whom is deceased. She earned a graduate

degree and is currently working full-time in the mental health field. Paula is also an ordained minister and has a strong Christian faith.

Jordyn

Jordyn is a 33-year-old woman who was diagnosed with Stage II breast cancer two years ago. Jordyn is a single mother of three children. Jordyn decided to have a double mastectomy and several rounds of chemotherapy and radiation as part of her treatment. Jordyn is currently unable to work and has a high school diploma. Jordyn also expressed the importance of faith and how it allowed her to be strong throughout this entire process.

Table 3.1 Personal Characteristics Demographics

Participants	Age	Stage of Cancer	Marital Status	Educational Level	Employment
Betty	63	I	Divorced	Graduate Degree	Retired
Korinne	60	III	Married	High School Diploma	Retired
Dionne	72	I	Married	Graduate Degree	Retired
Fiona	35	I	Divorced	College Degree	Employed
Crystal	32	II	Married	Graduate Degree	Employed
Paula	56	I	Married	Graduate Degree	Employed
Jordyn	33	II	Single	High School Diploma	Unemployed

Data Collection Methods

To obtain the desired information, each participant was individually interviewed, face-to-face, using a semi-structured interview. All participants gave verbal and written consent to be audio taped prior to the interview. The interview questions were developed by the researcher (Appendix A). I answered all of the questions by discussing them with my dissertation chair to eliminate any bias as I have disclosed personal experiences related to the phenomenon. The interview questions were based on the participants' experiences related to breast cancer. The initial interviews were no more than one hour in length. Participants were provided the opportunity to review the questions before the scheduled interview session. A face-to-face, follow-up interview, lasting approximately 30 minutes, was conducted with each participant for purposes of verification and clarification. Preliminary findings were shared with the participants during the follow-up interview to ensure agreement with themes and to give the participants the opportunity to correct any misrepresented ideas or interpretations. Follow-up interviews were not recorded.

Written informed consent was obtained from each participant (Appendix B). The informed consent was summarized verbally for each participant to ensure that she understood her involvement in this process. Prior to each interview, the participant was asked to complete the personal characteristics questionnaire attached to the informed consent. The personal characteristics questionnaire consisted of items pertaining to the participants' age, stage of breast cancer when diagnosed, marital status, educational level, and employment status.

I began each interview by thanking the participant for participating in the study. I explained that this study will help to increase awareness of breast cancer and how it emotionally

affects women of African American descent. In addition, it may help others gain a deeper understanding of the coping mechanisms used by African American women, and therefore may serve as a tool to assist others along their journey with breast cancer. I also explained that the information gained from this study will help counselors to develop culturally sensitive interventions that can assist African American women and their families as they experience this potentially life-changing phenomenon. The participants were informed that if at any time they did not feel comfortable with answering a question, they were not obligated to do so. They were also informed that each participant would be given a pseudonym to protect her identity.

I began each interview by asking the participant, “How long have you been diagnosed with breast cancer?” Beginning the interview with this question assisted in establishing rapport and trust with the participants. For the most part, the interview protocol was followed closely. However, there were some instances where I asked additional questions as they arose to gain more insight into the phenomenon under investigation. The participants were able to express themselves freely without interruptions. Clarification was requested when needed. The interview protocol was reviewed at the end to make certain that all the information was covered.

Data Analysis Methods

According to Smith and Osborn (2003), the aim of interpretive phenomenological analysis is to understand the meaning of the participants’ personal and social world, specifically how participants make sense of their world. The central focus is on meaning and understanding the content and complexity of those meanings. It is through the exhaustive examination of in-depth interviews that the researcher is likely to find the meaning or essence of the participants’ experiences, which is the fundamental nature of IPA research.

I transcribed and analyzed the tapes using the IPA approach. Each individual case was explored first, before analyzing the next case, until all cases in the study were explored. A six-step analytical process established by Smith, Jarman, and Osborn (1999) was followed to conduct a thorough analysis and to develop themes.

Preliminary step: I transcribed the data.

Step one: Looking for themes. I read the first transcript several times for significant statements and responses. The transcripts were written in a two-column format to keep a record of interpretive comments and reflections of each interview. This helped to limit researcher bias and to maintain integrity of the participants' unique experiences with this phenomenon. As I read the transcript, new insights were recorded and noted into the column on the transcription. After all notes were written, emerging themes were established from the notes and documented in the column. Key words were used to describe the essence of the text. According to Smith and Osborn (2003), the entire transcript is to be treated as potential data and no attempts should be made to destroy, omit, or change any information within the document.

Step two: Connecting themes. According to Smith et al. (1999), the purpose of this step is to create some sort of order from the themes that were developed from the participant's responses. To do this, I created a list of emerging themes and made a connection among them. As themes were organized into clusters, the results were compared with the actual transcription to see if there was a connection (Smith & Osborn, 2003).

Step three: Creating a table of themes. The third step of IPA focused on organizing themes into a table. The clustering process that occurred in step two produced groupings that were given names and represented major themes. In developing a table, some themes were

omitted if there was no connection to the emerging structure or if they were not confirmed by data collected in the transcripts (Smith & Osborn, 2003).

Step four: Continuing the analysis with other cases. An analysis was conducted of the interviews with the other participants utilizing the previous steps to produce a list of themes.

Step five: A master list of themes for the cases. Step five involved creating a master list of themes once the list of themes from all the cases was created. I was able to determine which themes belonged on the master list of themes. Themes on the master list were selected based on the importance of the text that supported the theme.

Step six: Writing up the findings. This step involved transferring the master theme list into a write-up. In-depth description of what the participants have experienced (textual description) and descriptions of how they experienced breast cancer (structural experiences) were provided.

Trackable Variance and Credibility

Trackable variance

In qualitative research, trackable variance is used in place of reliability (King & Horrocks, 2010). Gibbs (2007) suggested a few procedures which were used in my study. The first procedure involved checking transcripts to make sure that there were no mistakes in the transcriptions. The second procedure involved checking for flawed coding by constantly comparing data and using a codebook. The third procedure involved double checking each transcription and coding to allow for reliable findings. These procedures helped to ensure that the approach would be consistent across different researchers or multiple coders.

Credibility

King and Horrocks (2010) referred to credibility as “the extent to which the researcher’s interpretation is endorsed by those with whom the research was conducted” (p.160). Creswell (2009) suggested strategies to check the accuracy of the findings. To increase credibility, I clarified personal biases, completed member checks, and used triangulation. As a qualitative researcher, making biases known is an important aspect of clarifying those biases.

As previously mentioned, I bracketed my experiences with the phenomenon, consulted with my dissertation chair, and used peer debriefing, with two colleagues to help uncover any personal biases or assumptions with the phenomenon under investigation. Secondly, member checks were conducted as the preliminary findings were discussed with the participants during a face-to-face follow-up interview to ensure accurate information and to eliminate misinterpretation. This provided the participants an opportunity to comment on the preliminary findings and to make any changes. No changes were necessary in any of the participants’ cases. Thirdly, triangulation was used to justify themes. Triangulation is a qualitative approach used as a way to validate data by relying on multiple methods or data sources (Glesne, 2011). Data sources used included participant interviews, literature, and field notes. During the follow-up interviews, participants verified preliminary findings, which enhanced the credibility of the findings.

Chapter Summary

The purpose of this phenomenological study was to explore the lived experiences of African American women diagnosed with breast cancer. A phenomenological approach from an existential perspective was used to explore the essence of the participants’ experience of this

phenomenon. Semi-structured interviews were used to gain a deeper understanding of those experiences. Interpretative Phenomenological Analysis (IPA; Smith, 2004) served as the methodology for this study by providing a structure for gathering detailed descriptions on how African American women experienced breast cancer and how they perceived their experience. IPA was an appropriate methodology for this study due to its distinctive features that allowed for in-depth analysis of the participants' breast cancer experience.

CHAPTER FOUR

RESULTS

The purpose of this phenomenological study was to explore the lived experiences of African American women diagnosed with breast cancer. A phenomenological approach from an existential perspective was used to explore the essence of the participants' experience of this phenomenon. Semi-structured interviews were conducted to gain a deeper understanding of those experiences. Interpretative Phenomenological Analysis (IPA; Smith, 2004) served as the methodology for this study by providing a structure for gathering detailed descriptions on how African American women experienced breast cancer and how they perceived their experience.

This chapter is divided into four sections. First, existential theory is revisited to provide the reader with a foundation for the findings. Second, a summary of the case study analysis process is provided. Thirdly, a case study analysis of each of the seven research participants is presented. The experiences of the study's participants and the results of the data analysis are reported. Presented in the last section is the summary of the case findings.

Existential Theory

Existential theory was the most salient theory for conceptualizing the life experiences of the participants in this study because this theory is based on how a person makes meaning of her existence and how she perceives life and/or her personal experiences of life. Existential theory centers on the belief that inner conflict within an individual stems from that individual's confrontation with the givens of existence. According to Yalom (1980), these givens include the inevitability of death, freedom, isolation, and meaninglessness. Having been diagnosed with a

potentially life-threatening illness can have a major impact on thought processes, perceptions of life, and also the meaning and purpose of life itself (Henderson, Gore, Davis, & Condon, 2003).

Summary of Case Study Analysis

An in-depth analysis of the interview transcript for each participant was conducted. To protect participant confidentiality, pseudonyms were given and identifying information was altered. The case studies, beginning with Betty and ending with Jordyn, are discussed in the same sequence as the interviews were conducted. In adherence to the first three steps of Interpretative Phenomenological Analysis, a case by case approach was conducted to analyze the data collected from interviews with each participant. Specifically, the transcripts of the interviews were read several times. As I read each transcript, new insights were recorded and noted into the column on the transcription. After all notes were written, emergent themes from each participant were identified and key words were used to describe the essence of the text. Connections were made among the list of emerging themes and then organized into clusters. The results were then compared with the actual transcription. Quotes from the participants' transcripts were included as support for the findings in answering the research questions of this study. Quotations have been edited for readability.

Themes that were not related or relevant were deleted from the list. Descriptive titles were given to the groups to indicate major themes that emerged from the data. These major themes were compared to the actual transcribed words of the participant to validate the existence of a connection. As a third step, a list of main themes was developed for each participant. Each main theme provided insight into the participant's essence and experience with the phenomenon under investigation. The same three-step interpretative process was followed for all seven

participants in this study. Follow-up interviews were conducted for clarification purposes and to verify all themes from the transcripts.

Betty

Betty was the first participant I interviewed. She is a 63-year-old woman who was diagnosed with Stage I breast cancer 12 years ago. Betty was very forthcoming and honest as she discussed with me very candidly her experience as an African American woman with breast cancer. I remember the day I interviewed her like it was yesterday. It began to rain as I pulled into her driveway. Soon after I knocked on her door, it began to storm and all I heard was a loud thunder. She greeted me with a huge, warm smile and a big hug. Although it was a rainy July afternoon, the energy she exuded created a warm, pleasant, and soothing environment. She offered me a drink and we sat on her sofa to begin the interview. I explained to Betty details of the consent to participate and asked if she had any questions. She politely said “no” and signed the form. She then filled out the personal characteristics questionnaire and we began the one-hour interview.

The initial analysis of the transcript revealed 43 emergent themes listed in Table 4.1. I grouped those themes into 14 major categories. Connections among emergent themes were apparent. Each category represented a major theme that I interpreted from Betty’s audio and transcribed interview. Each major theme was assigned a descriptive title that depicted the essence of the theme’s meaning. Table 4.2 lists the major themes supported by emergent themes.

Table 4.1 List of Emergent Themes from the Case of Betty

<ul style="list-style-type: none"> • Having a supportive family • Having supportive friends • Using prayer and faith as a coping mechanism • Fighting for life • Living each day as if it were your last • Ability to take off work • Having a spiritual foundation • Attending support groups • Importance of African American women Support Groups • Being knowledgeable about African American women and breast cancer • Eating well and getting rest • New perspective on cancer • New meaning of life • Not giving up • Accepting the possibility of recurrence • Accepting the responsibility of treatment • Encouraging other women to be proactive with their health • Coping with depression • Coping with anxiety • Coping with fear • Difficulty with finances • Cancer not being a death sentence 	<ul style="list-style-type: none"> • Questioning medical procedures • Getting the cancer out • Emotional and physical changes during treatment • Understanding treatment options • Fatigue of treatment • Lack of overall energy • Having a positive outlook on life • Living life to the fullest • Not taking life for granted • Treating people right • Educating other women • Advocating for self and others • Not letting fear of cancer overcome you • Make decisions that work for you • The importance of having adequate resources • Acceptance of physical transformation • Loss of hair • Counseling as an option • Counseling from an African American Woman • Unresolved grief • Loss of two children
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Connecting the Themes

Table 4.2 List of Cluster of Themes from the Case of Betty

Major theme #1 – Coping with Feelings

- Coping with depression
- Coping with anxiety
- Coping with fear
- Not letting fear of cancer overcome you

Major Theme #2- Support Systems

- Having a supportive family
- Having supportive friends
- Attending support groups
- Importance of African American women Support Group

Major Theme #3 – Involvement with Treatment

- Accepting the possibility of recurrence
- Getting the cancer out
- Questioning medical procedures
- Emotional and physical changes during treatment
- Understanding treatment options
- Fatigue of treatment
- Accepting the responsibility of treatment

- Make decisions that work for you
- The importance of having adequate resources

Major Theme #4 – Spirituality as Coping

- Using prayer and faith as a coping mechanism
- Having a spiritual foundation

Major Theme #5 – Will to Live

- Fighting for life
- Living each day as if it were your last
- Not giving up

Major Theme #6 – Existential Meaning of Life

- New perspective on cancer
- New meaning of life
- Having a positive outlook on life
- Living life to the fullest
- Not taking life for granted

Major Theme #7 – Accepting God's Will

- Cancer not being a death sentence

Major Theme #8 – Advocating/Educating Others

- Being knowledgeable about African American women and breast cancer
- Encouraging other women to be proactive with their health
- Educating other women
- Advocating for self and others

Major Theme #9 – Meaning of Personal Relationships

- Treating people right

Major Theme #10 – Self-Care

- Eating well and getting rest

Major Theme #11 – Grief

- Unresolved grief
- Loss of two children

Major Theme #12 – Job-related concerns

- Ability to take off work
- Difficulty with finances

Major Theme #13 – Physical/Emotional changes

- Acceptance of physical transformation
- Loss of hair
- Lack of overall energy

Major Theme #14 – Counseling as a Resource

- Counseling as an option
- Counseling from an African American woman

The major themes listed above were supported by Betty's statements from the interview transcripts. I have included Betty's verbatim statements from the transcripts not only to support the themes, but also to convey a better understanding of the meaning behind Betty's experience as an African American woman diagnosed with breast cancer. Table 4.3 lists the connections between the major themes and transcribed statements from Betty's interview.

Table 4.3 Connection between Themes and Transcribed Statements from Betty

Major theme #1 – Coping with Feelings

“I was shocked. I was in disbelief. I really had a lot of feelings of anxiety.”

Major Theme #2- Support Systems

“I am so glad that I knew God and I had him in my life at the time this happened and I had a wonderful support group of people...”

Major Theme #3 – Involvement with Treatment

“ It was a relief having the surgery because I felt like once the cancer was out, I was going to be all right and I felt the longer it stayed in there, the more chance of it spreading.”

“I had a lumpectomy, which is when they only remove the tumor and surrounding tissue affected.”

“Back in the day before there were other options to offer women, they would automatically do a mastectomy no matter what size the tumor was.”

“They told me they don’t do radical procedures like that anymore unless it is absolutely necessary.”

Major Theme #4 – Spirituality as Coping

“I knew I was going to need prayer, strength, and encouragement at the time and I wanted him to pray with me to give me the strength and courage to be able to tell my daughter, my mother, and my close friends. So, I called my daddy first and we prayed about it and I cried and then I was able to kind of like compose myself.”

“I’ve always had that spiritual connection in my life. I’ve always not just gone to church and stuff like that, but I’ve always tried to live the golden rule. Do unto others as you would have them do unto you.”

Major Theme #5 – Will to Live

“It makes me want to live life to the fullest.”

Major Theme #6 – Existential Meaning of Life

“The difference between a good day and a bad day is your attitude and I don’t have any bad days anymore. So, when I am not at my best, I still look at all the good things that God has done for me and it just, it goes. I don’t even think twice about it.”

“We all wake up with a slow day and if it is a slow day for me, I still thank Him for it. The prayer of serenity is where I am in life and, with that, I respect every day for what it brings. Every day for me is a new beginning.”

Major Theme #7 – Accepting God’s Will

“I really didn’t think it was a death sentence for me. You know, I just thought it was one of these things that I will get through in time.”

“If it comes back, I’m still okay with it because that’s just God’s will.”

Major Theme #8 – Advocating/Educating Others

“I came out on the other side like a brand new person with even more joy, hope, and good things to tell women and to encourage other women.”

“I was going to try to help as many women with my story as I possibly could and support them in any way that I could.”

Major Theme #9 – Meaning of Personal Relationships

“Take nothing or no one for granted and really, I try not to ever take anything or anyone for granted.”

Major Theme #10 – Self-Care

“It is essential that we take care and follow up if something doesn’t feel right or you start to feel a certain way and it lasts too long, check it out. That’s the best thing we can do for ourselves.”

“As African American women, we take care of everybody else and we rarely take good care of ourselves.”

Major Theme #11 – Grief

“The pain from the loss of a child—I can’t even give nobody a description for that and I don’t even want somebody that has had a loss to try to describe it to me because it’s beyond words...That’s why I say God has been in my life.”

Major Theme #12 – Flexibility w/job

“I was able to take off work a whole year from my job...”

“They donated sick leave to afford me to be able to draw my pay, pay my insurance and everything to go on for a whole year. So, I’m truly blessed.”

Major Theme #13 – Physical/Emotional changes

“Every time I got treatments for a week, I would be down. I mean I would be sick, sick, sick.”

“I lost all my hair...I was fatigued, a little, tired, and sluggish.”

Major Theme #14 – Counseling as a Resource

“I didn’t feel a need for it [counseling] because I had the support group and we met every month.”

“If I sought counseling, I would like to have an African American female counselor...I just don’t feel that I could get the support that I need from somebody other than somebody that looks like myself. I prefer that person to be a little bit more mature...”

In the last step of data analysis in the case of Betty, I created a main list of themes that represent the essence of Betty’s meaning about the phenomenon under investigation. During the follow-up interview Betty verified all themes and no changes were necessary. Table 4.4 illustrates the main themes from the case of Betty.

Table 4.4 Main List of Themes from the Case of Betty

Spirituality as Coping

- Strong faith
- Spiritual foundation
- Prayer

Support Systems

- Importance of family and friends
- Support from co-workers
- Support from friends

- Attending support groups

Self-Care

- Eating health
- Sleeping well
- Taking medications
- Keeping doctor appointments

Involvement with Treatment

- Asking questions
- Discussing options w/doctors

Will to Live

- Fighting spirit
- Resilient behavior
- Positive attitude

Existential Meaning of Life

- Inevitability of death
- Connection to God
- Meaning of breast cancer

Importance of Educating Others

- Participating in health fairs w/support group
- Speaking in public

- Telling her story

Perception of Counseling

- Open to counseling
- Prefers African American female Counselor
- Prefers middle-aged counselor

Summary of the Case of Betty

Eight main themes provided insight into Betty's experience of the phenomenon under investigation. For Betty, spirituality and family were the most important ways she was able to cope with the diagnosis of breast cancer. Betty expressed in her interview that her father, daughter, and church members provided her with support. Betty explained that one of the first people she contacted after learning her diagnosis was her father, who is a minister. Betty also emphasized the importance of treatment and how she and her doctors were able to openly talk about her options prior to surgery, which made her more comfortable throughout the process. Betty expressed her openness to counseling, but stated she didn't seek counseling for breast cancer as she didn't think she needed it because she attended once a month a support group for African American women. Betty further explained that if she sought counseling, she would prefer a middle-aged African American female counselor. Betty also reflected on the importance of self-care and educating other women about breast cancer. Betty's experience allowed her to look at life differently as she acknowledged the importance of accepting responsibility for one's own behavior, attitude, and outlook on life.

Korinne

Korinne is a 60-year-old woman who was diagnosed with Stage III breast cancer three years ago. As I pulled up to meet Korinne for the first time in person, she was waiting outside in her driveway on a sunny July afternoon. As Korinne showed me her beautiful flower garden, she slowly walked me inside her home. She offered me a drink and we made small talk for a few minutes before starting the interview. I explained the consent to participate, and then we proceeded with the interview process.

The initial analysis of Korinne's interview transcript revealed 25 emergent themes illustrated in Table 4.5. The themes were grouped into 9 major categories based on evident connections among them. Each category represented a major theme that I interpreted from Korinne's case. In addition, each major theme was given a title depicting the essence of the meaning. Table 4.6 lists the major themes supported by emergent themes.

Table 4.5 List of Emergent Themes from the Case of Korinne

<ul style="list-style-type: none"> • Importance of self-care • Importance of advocacy • Acceptance of breast cancer diagnosis • Being a “strong” woman • Having a good medical team • Spiritual connection/prayer • Attending support groups • Having a supportive family • Feeling tired and weak • Being optimistic • Importance of self breast exams • Accepting treatment • Other medical issues 	<ul style="list-style-type: none"> • Loss of hair • Family history of cancer • Taking care of family • Seeing crying as a weakness • Staying focused on health • Helping other women with breast cancer • Not taking life for granted • Having good friends • Open to counseling • Importance of family • Volunteering • Choosing the right doctors
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Connecting the Themes

Table 4.6 List of Cluster of Themes from the Case of Korinne

Major Theme #1 – Support Systems

- Attending support groups
- Having a supportive family
- Importance of family
- Having good friends

Major Theme #2 – Spirituality as Coping

- Spiritual connection/prayer

Major Theme #3 – Physical changes

- Feeling tired and weak
- Loss of hair

Major Theme #4 – Self-Care

- Importance of self-care
- Importance of self breast exams
- Staying focused on health
- Family history of cancer
- Other medical issues

Major Theme #5 – Involvement with Treatment

- Accepting treatment
- Choosing the right doctors
- Acceptance of breast cancer diagnosis

Major Theme #6 – Advocacy/Educating Other Women

- Importance of advocacy
- Helping other women diagnosed with breast cancer
- Volunteering

Major Theme #7 – Counseling as a Potential Resource

- Open to counseling as an option

Major Theme #8 – Existential Meaning of Life

- Taking care of family
- Not taking life for granted

Major Theme #9 – Having a positive attitude

- Being a “strong” woman
- Being optimistic
- Seeing crying as a weakness

In adherence to IPA data analysis, the major themes were supported with the participant’s significant statements from the transcribed interviews. The significant statements both complemented the interpreted themes as well as conveyed the essence of Korinne’s meaning of the phenomenon under investigation. The significant statements are listed in Table 4.7

Table 4.7 Connection between Themes and Transcribed Statements from Korinne

Major Theme #1- Support Systems

“My son and my husband were there for me when I needed them”.

“The support was my counseling [support group] and everything. They were right there for me.”

Major Theme #2 - Spirituality as Coping

“God helped me through it. I prayed all the time.”

Major Theme #3 – Physical Changes

“It [hair] will come back, but it will come back a different color, a different texture. I can handle that. What’s next?”

“I was tired and weak. A weak spell would come over me.”

Major Theme #4 – Self-Care

“We women are always last on the totem pole. I took care of everybody else but me. Young women should take care of their bodies.”

Major Theme #5 – Involvement with Treatment

“I found the lump myself and it had been hurting me. We asked to put me on fast track and they got it out. I wanted it out.”

“I accepted it all. I had a lumpectomy and then chemotherapy and radiation.”

Major Theme #6 – Advocating/Educating Other Women

“I love to volunteer...wherever they [support group] would send me or ask me to do, I did it. I never said, no.”

Major Theme #7 – Counseling as a Potential Resource

“If I felt I needed to be there [counseling], trust me, I would be there...”

“I would want the counselor to just be positive and be real.”

Major Theme #8 – Existential Meaning of Life

“You have to be strong and put everything else on the back burner. You and your family are the focus.”

“Sometimes we take things for granted. So, I have learned how to take nothing for granted...nothing.”

Major Theme #9 – Having a positive attitude

“My son and I never cried and we never broke down. We said, what’s next?”

“I can handle that!”

“I accepted it right away. I just took it by the hand and I said come on. We’re going to walk together.”

The last step of data analysis in Korinne’s case involved creating a main list of themes that represented the essence of Korinne’s meaning about her breast cancer experience. During the follow-up interview, Korinne verified all themes and no changes were needed. Table 4.8 lists the main themes from Korinne’s case.

Table 4.8 Main List of Themes from the Case of Korinne

Family Support

- Importance of family support
- Have friends
- The value of support groups

Having good doctors and medical support

- Being involved in treatment
- Ability to ask the right questions
- Importance of medical resources

Perception of Counseling

- Willingness to seek counseling if needed
- No preference regarding counselor ethnic background or gender
- Would like counselor to be open, honest, and genuine

Self-Care

- Importance of conducting self breast exams

- Going to the doctor for annual visits
- Listening to one's body
- Educating other women to be proactive

Spiritual faith

- Prayer as a coping strategy
- Putting God first

Existential Meaning

- Not taking life for granted
- Having a positive attitude toward life
- Accepting responsibility, not blaming others

Summary of the Case of Korinne

Six main themes represented the essence of Korinne's experience with breast cancer. These themes provided insight into the meaning behind her perceptions and experience with the phenomenon under investigation. Korinne emphasized the importance of family and friends throughout her treatment and recovery. She also has a strong spiritual foundation that encouraged her to stay positive and focused on getting well. Korinne acknowledged the importance of giving back to her community by volunteering and participating in health fairs and conferences in support of breast cancer awareness and research. She also highlighted the need for women to take better care of themselves and their bodies. In addition, she also reported a positive perception of counseling if she ever needed to seek out services. Lastly, Korinne expressed that it

was more important for her to have a genuine and open counselor who would not be afraid to challenge her at any given moment.

Dionne

Dionne is a 72-year-old woman who was diagnosed with Stage I breast cancer one year ago. We met at her home and talked about her experiences at her dining room table. Dionne was very open and animated while discussing her experiences. She also has a family history of breast cancer. After signing the consent and filling out the characteristics questionnaire, we proceeded with the interview. The initial analysis of Dionne's transcript revealed 24 emergent themes illustrated in Table 4.9. The emergent themes were grouped into 9 categories based on the connections among them. Each category represented major themes that were interpreted from the interview transcripts. In addition, each major theme was given a title that depicted the essence of the meaning of the phenomenon. Table 4.10 lists the major themes supported by emergent themes.

Table 4.9 List of Emergent Themes from the Case of Dionne

<ul style="list-style-type: none"> • Fear of cancer • Family history of breast cancer • Faith in God • Family Support • Being a survivor • Living above the cancer • Importance of getting mammograms • Educating women about breast cancer • Proactive screening • Accepting the possibility of death • Fear of Recurrence • Prayer as Coping Mechanism 	<ul style="list-style-type: none"> • Supportive Friends • Take life day by day • Not taking people/life for granted • Appreciate living • Open to counseling • Prefers an African American female counselor • Frustration with treatment choices • Coping with anxiety • Coping with fear • Understanding options • Getting information/resources • Importance of taking medicine
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Connecting the Themes

Table 4.10 List of Cluster of Themes from the Case of Dionne

Major Theme #1 – Support Systems

- Family Support
- Supportive Friends

Major Theme #2 – Educating Women

- Importance of getting mammograms
- Educating women about breast cancer

Major Theme #3 – Coping with Fear

- Fear of cancer
- Fear of recurrence
- Coping with anxiety
- Coping with fear

Major Theme #4 – Resiliency

- Being a survivor
- Living above the cancer

Major Theme #5 – Involvement with Treatment

- Understanding options
- Family history of breast cancer
- Getting information/resources
- Frustration with treatment choices

Major Theme #6 – Counseling as an option

- Open to counseling
- Prefers and African American female counselor

Major Theme #7 – Existential Meaning

- Accepting the possibility of death
- Take life day by day
- Not taking people/life for granted
- Appreciate living

Major Theme #8- Self-Care

- Proactive screening
- Importance of taking meds

Major Theme #9 – Spiritual Connection w/God

- Faith in God
- Prayer as a coping mechanism

Adhering to IPA, each major category was supported by significant statements extracted from Dionne’s interview transcripts. The significant statements are included to help strengthen and convey the essence of Dionne’s meaning and to support the interpreted themes. The significant statements are listed in Table 4.11

Table 4.11 Connection between Themes and Transcribed Statements from Dionne

Major Theme #1 – Support Systems

“I had girlfriends. I had two girlfriends that were very supportive.”

“My husband and two daughters were there with me. My daughter said, I’m with you mom.”

Major Theme #2 – Educating women

“I feel that God blessed me to survive that procedure and go through that experience so that I can help other Black women to let them know how important it is to get a mammogram.”

“I have to tell all women.”

Major Theme #3 – Coping with Fear

“At first I was frightened. I had a mixture, combination of feelings. I was afraid because I was always afraid of the word cancer. I had a sister who died at 47-years-old from breast cancer. So, when I got the news, it was amazing.”

Major Theme #4 – Resiliency

“I was protected – I was above that cancer. I say I’m above it. God has me in between Heaven and the clouds and cancer is below that.”

Major Theme #5 – Involvement with Treatment

“I had to deal with the surgery, the healing process...it was fine.”

“The only thing I wish the doctor had offered me was the reconstruction when I had the surgery.”

Major Theme #6 – Counseling as an Option

“I would feel more comfortable talking to someone of my race because they would understand my plight and my problems. Chances are they have experienced some of the same things I’m experiencing. They would have to seem genuine and believe in God—have a spiritual relationship with God.”

Major Theme #7 – Existential Meaning

“Don’t take anyone for granted.”

“Live life everyday like it’s your last day because it may be.”

“I try not to put things off that I would like to do.”

Major Theme #8 – Self-Care

“It is important that you get your health screening. It’s the only thing I can say; be proactive about your health.”

Major Theme #9 – Spiritual Connection with God

““God is able to do all things. I am giving it all to You.”

“I was not afraid anymore. I was calm...It’s in God’s hands.”

“I had put it in God’s hands. And if you worry, you don’t give it to God. If you’re going to worry, you don’t give it to Him. If you give it to Him, you don’t worry.”

The last step of data analysis involved creating a main list of themes that represented the essence of Dionne’s meaning about her breast cancer experience. During the follow-up interview, Dionne verified all themes and no changes were needed. Table 4.12 lists the main themes from the case of Dionne.

Table 4.12 Main List of Themes from the Case of Dionne

Spiritual Connection

- Having faith in God
- Prayer as a coping mechanism
- Giving it all to God

Existential Meaning

- Inevitability of death
- Resiliency
- Not taking life for granted
- Living each day as if it were the last
- Not putting off what can be done today

Self-Care

- Scheduling wellness visits
- Importance of self-breast exams
- Taking medication

- Knowing one's body

Support Systems

- Support of family
- Support of friends
- Support of children

Educating other women

- Encouraging other women to take care of their health
- Providing information to others

Being involved in treatment

- Asking questions
- Being aware and knowledgeable of options
- Access to information and resources

Perception of counseling

- Open to counseling if needed
- Prefers African American female counselor
- Importance of trust in the therapeutic relationship
- Counselor has to be genuine, honest, and have a spiritual relationship with God.

Summary of the Case of Dionne

Seven main themes revealed insight into Dionne's perceptions and experience with the phenomenon under investigation. Dionne has a strong, spiritual base which has allowed her to transcend the emotional and physical distress caused by breast cancer. Dionne explained that her brother is a minister and, as a result, she has a deep-rooted faith in God. Dionne explained that she did not have to have radiation or chemotherapy because of the size of the tumor, which was less than 1 cm. Consequently, she has to take Tamoxifen for the next five years. Dionne explained that her doctors were very open to hearing her opinions and to answering her questions. However, she expressed frustration about not being able to have a double mastectomy due to insurance limitations. Dionne also mentioned throughout the interview that her husband and two daughters were supportive during her experience. She stated, *"I didn't feel like I needed counseling. I went to the best counselor I knew. I went to God with it."* Dionne also explained that if she would ever seek counseling, she would prefer an African American female counselor as she would feel more comfortable talking to someone who understood her plight. Moreover, Dionne also emphasized the importance of self-breast exams and how important it is to educate other women about breast cancer, particularly African American women, to increase awareness.

Fiona

Fiona is a 35-year-old woman who was diagnosed with Stage I breast cancer three years ago. She was diagnosed with a triple negative—one of the most aggressive types of breast cancers. I met Fiona at her home. Upon arriving at her home, we chatted for a few minutes at her kitchen table. Before beginning the interview, I reviewed the consent to participate; she signed the form and filled out the characteristics questionnaire. The initial analysis of Fiona's transcript

revealed 29 emergent themes illustrated in Table 4.13. I grouped the emergent themes into 9 major categories. Each category was given a title depicting the essence of the meaning. Table 4.14 lists the major themes supported by emergent themes.

Table 4.13 List of Emergent Themes from the Case of Fiona

<ul style="list-style-type: none"> • Financial hardship • Childbearing concerns • Sex life • Losing hair • Memory loss • Attending support groups • Supportive family • Supportive friends • Supportive coworkers • Apprehension about having a White, male counselor • Open to counseling • Anger • Shock • Going back to work 	<ul style="list-style-type: none"> • Coping by drinking • Withdrawal • Coping with depression • Fatigue • Dealing with infections • Facing the possibility of death • Ignoring symptoms • Blessings from God • Taking care of self • Self-breast exams • Importance of community outreach • Life is short • Being honest with others about illness • Fear • Weight gain
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Connecting the Themes

Table 4.14 List of Cluster of Themes from the Case of Fiona

Major Theme #1 – Support Systems

- Supportive family

- Supportive friends
- Supportive coworkers
- Attending support groups

Major Theme #2 – Sexuality

- Sex life
- Childbearing concerns

Major Theme #3 - Counseling as a resource

- Apprehension about having a White, male counselor
- Open to counseling

Major Theme #4 – Educating others

- Importance of community outreach
- Being honest with others about illness

Major Theme #5 – Physical/Emotional changes

- Losing hair
- Weight gain
- Memory loss
- Fatigue
- Coping with depression
- Fear
- Shock
- Anger

- Withdrawal
- Dealing with infections

Major Theme #6 – Self- Care

- Taking care of self
- Self-breast exams
- Ignoring symptoms

Major Theme #7 – Existential Meaning

- Facing the possibility of death
- Life is short

Major Theme #8 – Spiritual Connection

- Blessings from God

Major Theme #9 – Finances

- Financial Hardship
- Going back to work

In adherence to IPA, I was able to discern major themes through Fiona's significant statements from the interview transcripts. The significant statements provided insight into Fiona's experiences and provided understanding and support of the interpretative process. The significant statements are listed in Table 4.15.

Table 4.15 Connection between Themes and Transcribed Statements from Fiona

Major Theme #1 – Support Systems

“I started initially with the hospital. And my radiologist suggested I go to the young survivors group – she thought it would be more appropriate and it was. I got a lot from them. And even from there, at the Young Survivor’s convention I met up with the Sisters Network and then I went to their conventions. So I’ve been to several support groups. I’ll go a little while, and they’re helpful. They’re really helpful, but I’ve always got so much going on and it’s just never convenient to go.”

“My friends, my family, everybody was really supportive—my coworkers, my daughter.”

Major Theme #2 - Sexuality

“Going to groups that were for women with breast cancer was difficult because all of them were older; they had grandchildren; they weren’t thinking about their sex lives; and they didn’t have children to raise.”

Major Theme #3 – Counseling as a resource

“Someone [a counselor] who has helped someone through grieving; death, the possibility of death. Medical ailments; drastic life, you know – where your physical drastically changes all aspects of your life, friendships, employment.”

“I think, in our community, in the African-American community, especially in urban areas, it is important for it to be a woman, and it is important for them to be African-American, because they’re not going to talk to anyone else.

Major Theme #4 – Educating others

“It is important to be aware of your body. So, I just want women, in general, people to know your bodies. Go for checkups, annuals, pay attention to what’s supposed to be done at what age. You know, if you’re 40, you need a mammogram; if you’re a man, you need to check your prostate. Just pay attention, especially if you’re an African American woman.”

Major Theme #5 – Physical/Emotional Changes

“Initially, I felt shock, fear, and maybe anger. I remember shock and I remember fear I’m sure, but I don’t remember much after that.”

“My chemotherapy was horrible! I was sick all the time...I was tired. I was lethargic, my body got infections. The only thing I knew about chemotherapy was that your hair falls out. I didn’t know about other side effects—you get infections, chemo brain—memory loss.”

“I gained a lot of weight from the steroids. I had steroids so that the medicine would take.”

Major Theme #6 – Self-Care

“I think the biggest thing is to be aware of your body. I ignored my symptoms for months. I ignored it for maybe eight or nine months before I even took the time to go to the doctor. It actually had to bother me first. So, I just want women to know their bodies.”

Major Theme #7 – Existential Meaning

“Life is short. Life is short. Actually, I’m a much happier person since being diagnosed. I don’t take myself as serious as I used to. Life to me is not as complicated as it used to be. Either I can do it or I can’t. I try to make my life more meaningful. Sometimes I think about what my legacy might be – what will people remember and so I try to live the best life. It’s made me a better

person. It's made me aware of what I do physically to my body or how I live my life or how it may impact my body physically."

Major Theme #8 – Spiritual Connection

"I ignored my symptoms for months. It was just a blessing from God that I had a lump that hurt because according to what I've read and what the doctors told me, it rarely hurts."

Major Theme #9 – Finances

"The ones [women in the support group] that were younger women had financial support systems where they could take off for a year and do whatever it is they wanted to do. I didn't have time to do all of that because I had to go right back to work."

The final step of data analysis in the case study of Fiona involved developing a main list of themes that represented the essence of Fiona's meaning about her breast cancer experience as an African American woman. During the follow-up interview, Fiona verified major and main themes and no changes were needed. Table 4.16 lists the main themes extracted from the major theme in the case of Fiona.

Table 4.16 Main List of Themes from the Case of Fiona

Support System

- Having family and friends
- Support of her daughter
- Support of coworkers

Openness to Counseling

- Importance of having an African American female counselor
- Importance of coping with fear, anxiety, and depression

- Benefits of support groups

Meaning of Life

- Accepting challenges of life
- Not taking life for granted
- Enjoying life and doing what makes you happy
- Inevitability of death

Spiritual Foundation

- Believing in God
- Seeing challenges as blessings from God

Self-Care

- Going to doctor's visits
- Importance of self-breasts exams

Sexuality

- Childbearing concerns
- Acceptance of physical changes/scars
- Having healthy relationships

Summary of the Case of Fiona

Six main themes revealed insight into Fiona's perceptions and experience with the phenomenon under investigation. Fiona expressed that her support system, which included her family, friends, and coworkers helped her to overcome a lot of the fear and shock she felt when

she was diagnosed. In addition, Fiona articulated her new-found meaning toward life and relationships. Fiona also expressed that although she had a White, male counselor, she was able to benefit as counseling helped her to better process her feelings throughout her journey. However, she also expressed the importance of having an African American female counselor as many women may not be willing to speak to someone of a different race or gender. As a young woman, another main theme included sexuality. Fiona is still in her childbearing years and would like to have more children. Naturally, she expressed concern about the ability to have more children in the future and maintaining healthy sexual relationships. Fiona also reported the need to conduct self-breast exams and the importance of having yearly check-ups. Additionally, Fiona perceives this experience as blessing from God as she now realizes that “*Life is short.*”

Crystal

Crystal is a 32-year-old woman who was diagnosed with Stage II breast cancer eight years ago. Crystal has a family history of breast cancer. We met one afternoon at Crystal’s office. Crystal seemed to be very comfortable with discussing her breast cancer experiences. After reviewing the consent to participate and filling out the characteristics questionnaire, we proceeded with the interview. The initial analysis of Crystal’s transcript revealed 32 emergent themes presented in Table 4.17. Emergent themes were then grouped into ten categories based on connections among them. Each category represented major themes that were interpreted from the interview. A title was given to each major theme to depict the essence of the meaning.

Table 4.17 List of Emergent Themes from the Case of Crystal

<ul style="list-style-type: none"> • Fertility concerns • Other medical conditions • Financial hardship • Academic concerns/grades • Poor relationship with health care professionals • Supportive family • Relationship concerns • Sexual attractiveness • Hair loss • Fatigue • Weight gain • Attending faith-based programs • Supportive friends • Internalizing feelings • Fear of dying • Going to the doctor 	<ul style="list-style-type: none"> • Attending support groups • Open to counseling • Fear of recurrence • Christian faith • Knowing family history • Insurance limitations • Coping with depression • Self-advocating • Stomach problems • Taking charge of health • Conducting self-breast exams • Access to resources • Going to church • Dating • Prayer as a coping strategy • New perspective on life
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Connecting the Themes

Table 4.18 List of Cluster of Themes from the Case of Crystal

Major Theme #1 – Support Systems

- Supportive family
- Attending support groups
- Supportive friends

Major Theme #2 – Health Care Concerns

- Financial hardship
- Poor relationship with health care professionals
- Access to resources
- Insurance limitations
- Taking charge of health
- Self-advocating

Major Theme #3 – Spiritual Foundation

- Attending faith-based programs
- Going to church
- Prayer as a coping strategy
- Christian faith

Major Theme #4 – Physical/Emotional Changes

- Hair loss
- Fatigue
- Weight gain
- Fear of recurrence
- Coping with depression

Major Theme #5 – Academic Hardship

- Academic concerns/grades

Major Theme #6 – Medical Issues

- Other medical conditions
- Fertility concerns
- Stomach problems

Major Theme #7 – Sexuality

- Relationship concerns
- Sexual attractiveness
- Dating

Major Theme #8 – Counseling as an Option

- Open to counseling
- Internalizing feelings

Major Theme #9 – Existential Meaning

- New perspective on life
- Fear of dying

Major Theme #10 – Self-Care

- Knowing family history
- Conducting self-breast exams
- Going to the doctor

All major categories were reinforced by Crystal's significant statements extracted from the interview transcripts. The statements were included to highlight the essence of the meaning

of Crystal's experience and to support the interpreted themes. The significant statements are listed in Table 4.19

Table 4.19 Connection between Themes and Transcribed Statements from the Case of Crystal

Major Theme #1 – Support Systems

“I actually called my aunt first. She is a registered nurse and she also worked on a unit that had worked primarily with that. So, I talked to her a lot about it...The first person I told following my aunt was my mom.”

“I attended a support group for eight sessions, but there was another group that I tried out for like one session. I observed it, but there was no structure.”

Major Theme #2 – Health Care Concerns

“He [doctor] was very cold to me—the way he explained it [cancer] to me...”

“He spoke to me as if I had no medical knowledge...it was the delivery, no bedside manner whatsoever.”

“I had a pre-existing condition and was not covered under that plan. I wound up having to come up with a lot of money out of pocket.”

“I had to rob Peter to pay Paul.”

Major Theme #3 – Spiritual Foundation

“I have a strong Christian faith. I have been raised Baptist for a while. I attend prayer meetings, go to church faithfully...”

Major Theme #4 – Physical/Emotional Changes

“I felt disbelief, uncertainty, and emotional distress.”

“I was depressed and internalized a lot of stuff.”

“I just didn’t want to do anything.”

“I had a significant amount of weight gain...I lost a significant amount of hair. I went from having long hair to all of a sudden, short hair...I never was a big proponent of fake hair before this...”

Major Theme #5 – Academic Hardship

“I was focused on my studies and had to take a “W” that semester...I was like, how come this is happening to me?”

Major Theme #6 – Medical Issues

“I became very somatic. I wound up getting acid reflux and stomach issues. I suffered from migraine headaches and blurred vision.”

“I also had issues with childbearing.”

Major Theme #7 – Sexuality

“I wound up having a very small portion of the breast removed and they had to reattach the area. I had to get my nipple tattooed, which is another story. When you are dating, explaining prosthetics and wearing gel bras can be weird.”

Major Theme #8 – Counseling as an Option

“I would like someone that’s warm. Someone that’s gentle. Someone that’s understanding. Someone else that may be aware of multi-cultural issues that are specific to African American females...being able to allow them to have a voice. For them to be able to talk about their experiences, not just based on what they’ve read in the textbook that oh, okay I’m working with a Black woman so this is what Black women experience. Not taking the universal look, but like

allowing them to say this is how I want us to approach this relationship. This is how I want us to work together.”

Major Theme #9 – Existential Meaning

“When I was first diagnosed, I felt like I was going to die...like this is a death sentence...this is going to kill me...”

“I learned how to seize the moment and not allow anything to be taken for granted. Enjoy the moments and to make sure I stay on top of this [cancer]. I learned more about what I want spiritually...”

Major Theme #10 – Self-Care

“It’s never too early to get detected, even if it’s a well woman’s exam or checking yourself. Do it! Don’t wait!”

“I learned to take charge of my health and not wait for some doctor to help me out. I learned about patient advocacy. I learned more or less about how to advocate for my needs.”

The final step of data analysis in Crystal’s case involved the development of a main list of themes that represented the essence of Crystal’s meaning of the phenomenon under investigation. Crystal verified the themes during the follow-up interview. No changes were needed. Table 4.2 lists the main themes from Crystal’s case.

Table 4.20 Main List of Themes from the Case of Crystal

Support Systems

- Having a supportive family
- Having supportive friends

Spirituality as coping

- Prayer
- Going to church
- Participating in faith-based activities

Perception of Counseling

- Positive perception of counseling
- Counselor's knowledge and ethnicity is important
- Preference for a female counselor

Access to Resources

- Positive relationship with health care professionals
- Access to information
- Importance of talking about options/treatment

Existential Meaning

- Seizing the moment
- Not taking life for granted
- Taking responsibility for life

Self-Care

- Importance of going to the doctor
- Conducting self exams to prevent recurrence

Family Planning/Sexual Relationships

- Would like to start a family
- Having a healthy relationship with husband
- Concerns about physical changes

Summary of the Case of Crystal

Seven main themes provided insight into Crystal's inner world with regard to the topic under investigation. Crystal emphasized the importance of having a supportive family during her initial diagnosis. She also explained that she had a recurrence in 2009 and decided to have treatment for a second time. Crystal discussed the importance of women having a good relationship with their doctors. In addition, she expressed frustration about not having a personal connection with her doctor, which limited her comfort level in discussing the options available to her. Crystal's strong faith in God has given her the strength to overcome her fears of recurrence and to focus on the positive things in life. In her words, she is learning to "*seize the moment*". Crystal also highlighted the importance of conducting self-breast exams. She encourages many young women to go to the doctor and to complete their own self exams. Crystal also believes in the benefit of counseling and attending support groups, which has helped her to move forward in her own journey as she is planning to start a family of her own very soon.

Paula

Paula is a 56-year-old woman who was diagnosed with Stage I breast cancer four years ago. She is an ordained minister and mother of three children. Paula has a family history of breast cancer. Paula asked if she could meet at my house because she would feel more comfortable as she had house guests at the time. So, we met at my house and sat at my kitchen

table. Paula was very sincere and straightforward regarding her breast cancer experiences. After reviewing the consent to participate and filling out the characteristics questionnaire, we began the interview process. Initial analysis of the transcript revealed 25 emergent themes illustrated in Table 4.21. According to IPA procedure, I grouped emergent themes into seven major categories. Each category represented major themes which were interpreted from the interview transcript. A title was assigned to each major theme that conveyed the essence of the emergent themes. Table 4.22 lists the major themes supported by emergent themes.

Table 4.21 List of Emergent Themes from the Case of Paula

<ul style="list-style-type: none"> • Importance of self-care • Having a supportive husband • Knowing your family history • Having faith in God • Accepting physical changes • Empowering yourself • Overcoming fear • Prayer as coping • Spiritual foundation • Having a good team of doctors • Asking the right questions • Getting yearly checkups • Reading scriptures for comfort • Being a survivor 	<ul style="list-style-type: none"> • Dealing with grief • Having a good relationship with doctors • Taking medications • Educating oneself • Not taking life for granted • Having a positive attitude • Life is a gift from God • Talking openly about illness • Cancer is not a death sentence • Open to counseling • Prefers a female counselor
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Connecting the Themes

Table 4.22 List of Cluster of Themes from the Case of Paula

Major Theme #1 – Self-Care

- Importance of self-care
- Getting yearly checkups
- Taking medications

Major Theme #2 – Support Systems

- Having a good team of doctors
- Supportive husband
- Having a good relationship with doctors

Major Theme #3 – Education

- Knowing your family history
- Asking the right questions
- Educating oneself

Major Theme #4 – Spirituality

- Having faith in God
- Prayer as coping
- Spiritual foundation
- Reading scriptures for comfort

Major Theme #5 – Existential Meaning

- Not taking life for granted

- Life is a gift from God
- Cancer is not a death sentence

Major Theme #6 – Resilience

- Accepting physical changes
- Empowering yourself
- Overcoming fear
- Being a survivor
- Dealing with grief
- Talking openly about illness
- Having a positive attitude

Major Theme #7 – Perception of Counseling

- Open to counseling
- Prefers a female counselor

As in accordance with IPA, I found each major category to be supported by Paula's significant statements that were extracted from the transcripts. The statements provided insight into Paula's inner world and perceptions related to her experience with breast cancer. These statements were necessary for understanding the interpretative process and to signify the essence and meaning of Paula's experience. The significant statements are listed in Table 4.23

Table 4.23 Connection between Themes and Transcribed Statements from the Case of Paula

Major Theme #1 – Self-Care

“I’m still currently going to the doctor. I do mammograms every six months. It’s the preventative action that you take. I started taking mammograms when I was about 35. So that was a yearly routine for me. So when they did catch it, it was at the beginning stages.”

Major Theme #2 – Support Systems

“My fiancé was very supportive. I didn’t feel like I needed counseling. I decided not to tell my family. My faith played a major role—prayer from my heart and I prayed constantly. And so there was just nothing another person could tell me because I was at peace with what I was going through.”

“It is important to find a team of doctors that you trust and that you know you’re comfortable with; and then be willing to work with them for your recovery. It’s not all about them recovering me - you have to do your part in it. You’re going to have to be able to trust them to make decisions, to sit down with you and explain to you what the choices are and the possible outcomes.”

“And then faith; faith was ultimate. I can say that because every doctor that I had had a measure of faith—and when I say a measure of faith, they believe in God. So, that was a plus for me also.”

Major Theme #3- Education

“As an African American woman, the key is to be educated on breast cancer. If you’re not sure, ask plenty of questions. If you’re uncertain, don’t leave with any doubts.”

Major Theme #4 – Spirituality

“First of all, if you have your faith, you have faith in God, then you have to have faith in yourself – knowing that I can do this; you know, I can do this.”

“You know my faith played a major role—prayer from my heart and I prayed constantly.”

“The Word of God says I am the God of healing people. So I would say all the time that God, you said you were the God of healing people and so I kept repeating that.”

Major Theme #5 – Existential Meaning

“I think my life is supposed to be lived in accordance to God’s will.”

“The Bible says that life and death is in the power of the tongue. I’m in control of this situation.”

“Oh, because most people hear cancer, the first thing they think of is I got a death sentence and oh, I’m about to die. Well no, you’re not about to die. You’re about to live if you want to live.”

“I know that life is precious. I know that life is something you don’t take for granted. I believe that we’re supposed to live life to the fullest.”

Major Theme #6 – Resilience

“What it [breast cancer] did was more or less empowered me because I knew that it was a situation that I had to deal with. Of all the choices, I’m in control of how it’s going to affect my life and so I became very proactive about it.”

Major Theme #7 – Perception of Counseling

“I think that first I would look for a female and that’s because she would be able to identify what I was going through. Second, I think I would look for – she wouldn’t necessarily need to be African-American – she would have to have some knowledge on breast cancer and breast cancer survivors and their families. And then I would like her to be someone who is genuine. Someone

that would, you know, would be able to empathize with what I'm going through. A good listener – because sometimes people don't need anybody to talk to them, sometimes you just want someone to listen. And then someone that would be able to give me feedback on what I'm saying; you know, sometimes you need feedback and that would be it. Someone that I knew, someone that was genuinely concerned. Someone that I could establish a relationship and know that relationship was genuine. You know, she wouldn't be judgmental –She wouldn't have to have faith as I have, but she would have to be open to my spirituality and my faith.

The final step of data analysis in the case of Paula involved the development of a main list of themes that represented the essence of Paula's meaning behind the phenomenon under investigation. During the follow-up interview, Paula verified both the major themes and main themes. No changes were needed. Table 4.24 lists the main themes from Paula's case.

Table 4.24 Main List of Themes from the Case of Paula

Spiritual Foundation

- Having faith
- Prayer as coping
- Believing that God will heal

Support System

- Importance of having husband as a support
- Having a good team of doctors

Existential Meaning

- Having a positive outlook on life
- Not taking life for granted

- Living life to the fullest

Self-Care

- Getting yearly mammograms
- Talking to your doctors
- Being proactive with health
- Being educated about personal family history

Perception of Counseling

- Open to counseling if needed
- Preferably a female counselor
- Prefers a counselor who believes in God and has some knowledge about breast cancer

Summary of the Case of Paula

The main five themes centered on Paula's spiritual beliefs as she has a strong faith in God. The themes conveyed the essence of Paula's perceptions and experience with the topic under investigation. Although Paula has a strong relationship with her family, God, her husband, and her team of doctors were the main supports for her throughout this process. Paula also emphasized the importance of knowing one's family history with breast cancer as her sister was also diagnosed with breast cancer. Paula highlighted the importance of self-care and getting yearly checkups as she believes that being proactive can prevent being diagnosed at a later stage. Paula also expressed the need to have a positive attitude toward life and not to take life for granted. Lastly, Paula stated that she considered God to be counselor, but was open to the idea of

seeking counseling services with a Christian counselor if needed at some point throughout her journey.

Jordyn

Jordyn is a 33-year-old woman who was diagnosed with Stage II breast cancer two years ago. Jordyn has a family history of breast cancer and she is a mother of three young children. I met Jordyn at her home one afternoon. Jordyn was very pleasant and humorous. She was very easy to talk with and honest about her breast cancer experiences. I reviewed with Jordyn the consent to participate; she signed the form and filled out the characteristic questionnaire. Shortly thereafter, we proceeded with the interview process. Initial analysis of the transcript revealed 32 emergent themes presented in Table 4.25. Further analysis involved grouping emergent themes into major categories based on evident connections among them. Each category was assigned a title that depicted the essence of the meaning among the themes. The review of emergent themes was comprehensive and resulted in nine major themes. Table 4.26 illustrates the list of major themes supported by emergent themes.

Table 4.25 List of Emergent Themes from the Case of Jordyn

<ul style="list-style-type: none"> • Importance of learning about breast cancer • Ability to toughen up • Having faith in God • Fear of death • Fear of not being here for children • Prayer as a coping mechanism • Being a strong believer • Knowing your family history • Understanding treatment options • Losing hair • Fighting the battle • Importance of self-breast exams • Inability to work • Excited about physical transformation • Staying positive • Importance of telling her story 	<ul style="list-style-type: none"> • Importance of second opinions • Challenging doctors • Supportive family • Paying attention to one’s body • Physical illness • Fatigue • Unable to be active with children • Determination to meet goals • Documenting journey to find meaning • Importance of early detection • Financial stress • Being a survivor • Ability to overcome obstacles • Importance of getting checkups • Receptive to counseling • No preference with respect to counselor background
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Connecting the Themes

Table 4.26 List of Cluster of Themes from the Case of Jordyn

Major Theme #1 – Resiliency

- Ability to toughen up
- Fighting the battle
- Staying positive

- Determination to meet goals
- Being a survivor
- Ability to overcome obstacles

Major Theme #2 – Education/Awareness

- Importance of learning about breast cancer
- Knowing your family history
- Importance of second opinions
- Challenging doctors
- Understanding treatment options

Major Theme #3 – Spirituality

- Having faith in God
- Prayer as a coping mechanism
- Being a strong believer

Major Theme #4 – Self-Care

- Importance of self-breast exams
- Importance of early detection
- Importance of getting checkups
- Paying attention to one's body

Major Theme #5 – Physical Changes

- Losing hair
- Physical illness

- Fatigue
- Excited about physical transformation
- Unable to be active with children

Major Theme #6 – Existential Meaning

- Fear of death
- Fear of not being here for children
- Importance of telling her story
- Documenting journey to find meaning

Major Theme #7 – Support Systems

- Family support system (mom, cousin, children)

Major Theme #8 – Financial Concerns

- Financial stress
- Inability to work

Major Theme #9 – Perception of Counseling

- Receptive to Counseling
- No preference regarding counselor background

The next step in IPA analysis involved identification of the participant's significant statements in relation to each major category. The statements were extracted from the interview transcription for the purpose of reinforcing major themes and better conveying the essence of

Jordyn's meaning about the investigated phenomenon. The significant statements are listed in Table 4.27.

Table 4.27 Connection between Themes and Transcribed Statements from the Case of Jordyn

Major Theme #1 – Resiliency

“When I found out, all I could think about was my kids. I have three children and I was scared of not being here for them. I know they need their mama and no one is going to raise them like I am. I was willing to fight the battle and get over it.”

“I weigh in more on the positive things than the negative. I have more to be thankful for and more to look forward to.”

Major Theme #2 – Education/Awareness

“We as Black women need to be educated and aware of breast cancer.”

“Once I finish with all of my treatment, I'm definitely going to get out and talk about it and educate more African American women on this disease so I could teach them to be more aware of their bodies...”

Major Theme #3 – Spirituality

“My faith helped me overcome my emotions. I am a strong believer and I feel that with God in your life any and everything is possible.”

“I have strong faith, so I have to pray and let it go.”

Major Theme #4 – Self-Care

“Most people don't do self breast exams and pay attention to the little things, you know, and that's helpful because that helps with early detection.”

“I knew my breasts from doing self-breast exams. So, I knew what was supposed to be there and what wasn’t supposed to be there. I knew that [lump] was something that wasn’t always there.”

Major Theme #5 – Physical Changes

“I have my bad days like a day or two days after my chemo. I may be nauseated, but after that I’m pretty much back to myself...”

“I did ask myself why did I have to go through pain after surgery and feeling the sickness after the chemo, but that was in the beginning when I found out about the cancer. After I got past all of that I was fine and everything.”

Major Theme #6 – Existential Meaning

“I really was devastated. From time to time, I would worry, but I always kept my faith and kept praying. Being human, I always would worry from time to time, but I was more scared than anything because basically when you hear the word cancer, all you think about is death. So, when they said breast cancer, the first thing that came to my head was that I was going to die.”

“I was scared of not being here for them [children]. I want to be here to see them grow as young adults...I just don’t want to leave my kids here and have no one else step in and do my part. So, when I say fear, I was more scared not for my sake, but for my kids’ sake.”

Major Theme #7 – Support Systems

“My mom and my cousin are my support system. My cousin lives here with me and she’s twenty-two. My mom’s been here with me back and forth. My mom and my cousin basically take care of me and help me with the kids. If I’m having a bad day, they’ll step in and get the kids ready for school and drop them off. If everything’s fine, I’ll step in and do my part, but when I’m feeling

bad they step in and take care of me. They make sure I eat, cook, they clean for me and everything. So, my mom and my cousin have really been here for me and I'm thankful for them."

Major Theme #8 – Financial Concerns

"Because I don't qualify for disability, I have to penny pinch and put things together financially to make sure that my bills are straight and we have food to eat and my kids have clothes to put on."

Major Theme #9 – Perception of Counseling

"I didn't go to a counselor or a support group because I had my mom and cousin to help me. God is keeping me afloat...But if I needed counseling, it wouldn't matter what color the person was. I would just like them to know about breast cancer."

The final step in IPA analysis involved the development of a main list of themes that reflected the essence of Jordyn's meaning about the investigated topic. During the follow-up interview, Jordyn verified all themes. No changes were needed. Jordyn concurred that the themes represented her experience related to breast cancer. Table 4.28 lists the main themes from the case of Jordyn.

Table 4.28 Main List of Themes from the Case of Jordyn

Family Support

- Mother as a major support system
- Cousin as support system
- Children as a support

Spirituality

- Faith in God

- Prayer to cope
- Having a strong spiritual foundation

Self-Care

- Conducting self-breast exams
- Attending doctor's visits
- Importance of listening to your body
- Having a second opinion

Education/Awareness

- Knowing family history
- Asking questions
- Educating oneself about breast cancer
- Talking to others about breast cancer

Resiliency

- Staying positive
- Overcoming obstacles

Perception of Counseling

- Receptive to counseling
- Would seek services if necessary
- Looks to family first for support

Existential Meaning

- Focus on family
- Leaving a legacy for children
- Fear of dying
- Acceptance of dying
- Not taking life for granted

Summary of the Case of Jordyn

Seven main themes evolved from the interview with Jordyn. Spirituality was one of the main themes that surfaced throughout the interview with Jordyn. Jordyn expressed that her faith in God has given her the strength she needs to move forward in her life. Jordyn stated that she perceives this experience as a blessing from God. Prayer is one of the coping strategies she uses to uplift her spirits and faith empowers to make good decisions for her and her family. Jordyn also emphasized the importance of educating other African American women about breast cancer. Because Jordyn has a family history of breast cancer, she has a passion for increasing awareness in her community. She expressed the need to give back to others by encouraging women to get their checkups and mammograms every year. She also encourages self-breast exams as this was how she realized that something abnormal was going on in her body. Family was also an extremely important theme in Jordyn's life. Jordyn explained the importance of having family support, especially when experiencing a disabling condition. Furthermore, due to her strong family support, Jordyn explained that she chose not to seek counseling or a support group. However, she also mentioned that if she ever decided to seek counseling, she would like

the person to have some knowledge about breast cancer, specifically with African American women.

Cross-Case Analysis

After completing the individual analysis of all seven cases, I cross analyzed the cases to find shared themes among all of the participants. A comprehensive review of main and major themes across each case provided a list of common themes of all of the participants. Table 4.29 illustrates the themes shared by all seven cases.

Table 4.29 Main List of Shared Themes from All Cases

- Spirituality: prayer, trusting in God, having faith in God, God heals
- Support Systems: importance of family support, having a good team of doctors, going to support groups
- Self care: going to doctor's visits, conducting self-breast exams, getting mammograms done, paying attention to one's own body, taking medication
- Resiliency: overcoming obstacles, challenges, seeing breast cancer diagnosis as a blessing or lesson to help others, fighting the battle, survivorship
- Existential meaning: not taking life or people for granted, living each day to the fullest, will to live, enjoying every moment, facing fear, fear of recurrence, accepting death, making meaning out of life
- Education: importance of educating oneself about breast cancer, knowing family history, asking questions, understanding treatment options, knowing side effects of medication
- Perception of counseling: willingness to seek counseling if needed, counselor's multicultural competence, spirituality, and knowledge of breast cancer are important

Summary of the Findings

The main list of shared themes is comprised of seven common themes that emerged from all of the participant's cases. Those themes include spirituality; support systems; self-care; resiliency; existential meaning; education; and perception of counseling. The primary research question in this study focused on the lived experiences of African American women with breast cancer and the meaning behind those experiences. In addition, each participant's perception of counseling was also addressed. The main list of shared themes provides insight into the essence of the participants' experience with breast cancer and conveys the meaning with the phenomenon under investigation.

All of the participants mentioned that their faith in God allowed them to get through this process. Faith seems to play a major role in all of these women's lives. Some stated that being diagnosed with breast cancer has actually increased their relationship with God. These women believe that God brings a person through things for a reason. All the participants stated that they can help others by telling their story about how God has brought them through this process. They expressed that spirituality, prayer, and going to church have given them the strength they need to make it through their various surgeries and treatments. They expressed that God has given them the strength when family and friends may have been unable to help them.

As the participants discussed spirituality and prayer, existential themes emerged. The thought of death surfaced for many of the women, but it was not looked upon as a negative concept. As I reflect on the interviews, the concept of death was an initial thought as expressed by the participants. I think because of their unwavering faith in God, these women began to grow a thicker skin as a means of coping and, consequently, dying became less of a concern. I think

because of their faith, life became more important than death. These women wanted to make sure that they began to live a life full of meaning as opposed to living a life full of defeat.

Family support was also another theme that emerged in each of the interviews. The women expressed that their families were a major support while going through this process. Each of the participants discussed how much their children meant to them and/or how much their companions and other extended family helped them out when they needed them most. Three of the women were of childbearing age. One woman, in particular, had not had any children yet and explained that she would like to start a family. They related that family was able to make sure that they ate properly and took their medicines on time. They expressed the importance of having someone there to help them after they had their surgeries or to take care of the kids when they didn't have the strength to do so. One of the women even explained that she decided to marry her fiancé based on his actions during her illness. Some of the women stated that their families helped financially as it was difficult to work full-time throughout their treatment.

Having a good team of doctors and understanding treatment options were important aspects as well. Most of them had to undergo both chemotherapy and radiation and subsequently endured physical and emotional changes throughout that process. One of the women did not have to undergo chemotherapy, but she did have to go through radiation. She and one of the other women stated that the radiation caused burns on their breasts and under their arms. Each of the women stated that radiation and/or chemotherapy made them fatigued and nauseated. One of the women decided to have a bilateral mastectomy. One woman expressed feeling excited about her upcoming surgery as she is preparing to have implants and is looking forward to her new hair. Even after undergoing all of those exhausting treatments, the women stated that it was important

for them to continue their daily routine as this provided them with a sense of normalcy for themselves and for their families.

In terms of emotions, the women talked about having a positive outlook on life. The importance of their personal relationships and being around positive people made a difference in how they reacted to being diagnosed with this illness. They related different reactions when told by their physicians about their diagnosis. After accepting the diagnosis, they all were able to raise themselves up and focus on the positive aspects of their lives. Having a positive attitude and new meaning of life seem to have made a difference in the lives of these women by giving them a sense of hope and self-worth.

Another theme that emerged included the importance of early detection and education. The freedom to educate others and self-advocate was extremely important in the lives of these women. They all expressed that being aware of family history is also an important aspect of early detection. Four of the seven women had a family history of breast cancer. Three of the women found out about their cancer in the first stage. The other women found out at stages two and three. None of the women in this study were diagnosed at Stage IV or V. The participants talked about the importance of conducting self-breast exams and/or getting mammograms done every year. They expressed the need to know one's own body and the importance of not being afraid of going to the doctor. In addition, I think it is also important to note that most of these women related that, although they may not have sought counseling during their breast cancer treatment and/or recovery, they would prefer to have a female African American counselor who is knowledgeable about breast cancer if they ever need counseling services.

I was amazed by the stories of these women. I couldn't believe the strength and motivation that each of them exhibited. Each of them is resilient in her own unique way. They all seemed to have a positive attitude despite the pain and obstacles they endured. Each of them has had struggles unrelated to their breast cancer and still remains focused and happy. Their unyielding faith and supportive families have truly impacted their lives along this journey.

CHAPTER FIVE

DISCUSSION

In this chapter, the research findings are discussed. Findings are presented and discussed in relation to the existing literature. The chapter is divided into seven sections. The purpose of the study; significance of the study; summary of procedures; discussion of findings; implications and recommendations; and the limitations of the study are included in this chapter. The chapter ends with a summary, and my personal reflections.

Purpose of the Study

The purpose of this phenomenological study was to explore the lived experiences of African American women diagnosed with breast cancer. Specifically, the aim of the study was to understand and describe the breast cancer experiences of African American women, focusing on their perceptions and the meaning behind their lived experiences. Utilizing an existential perspective, the focus of this study was to uncover meaning which defined the essence of the participants' experiences.

Significance of the Study

A review of the literature illuminated the limited amount of research on the experiences of African American women diagnosed with breast cancer. Although researchers have discussed certain aspects of the breast cancer experience of women, they have not focused specifically on the meaning behind the experiences of African American women with breast cancer. According to the American Cancer Society (2011), African American women have a higher incidence rate before 40 years of age and are more likely to die from breast cancer at every age. Despite the alarming statistics and higher risk of death in this population, research based on the experiences

of African American women with this disease is scant. Existential issues often arise when diagnosed with a terminal illness such as breast cancer (Landmark & Wahl, 2002). Only two studies specifically explored existential themes (Landmark, & Wahl, 2002; Landmark & Strandmark, 2001). These two studies were not specific to African American women diagnosed with breast cancer.

My conceptual framework focused on existentialism as existential theory is the most salient theory for conceptualizing the life experiences of African American women diagnosed with breast cancer because this theory is based on how a person makes meaning of her existence and how she perceives life and/or her personal experiences of life. Three studies have been conducted using a phenomenological method to explore the lived experiences of women diagnosed with breast cancer (Albaugh, 2003; Lackey, Gates, & Brown, 2001; Luoma & Hakamies-Blomqvist, 2004). However, only one of these studies (Lackey, Gates, & Brown, 2001) focused on African American women specifically.

Summary of Procedures

Seven African American women diagnosed with breast cancer agreed to participate in this study. The participants lived in the New Orleans area. Some of the women who participated in the study were members of a local support group for African American women diagnosed with breast cancer. A snowball approach was used in recruiting other women. Once the participants were identified, telephone calls were made to schedule a meeting to discuss research plans and to schedule a time to conduct the interviews.

To obtain the desired information, each participant was individually interviewed, face-to-face, using a semi-structured interview. All participants gave verbal and written consent to be

audio taped prior to the interview. The initial interviews were no more than one hour in length. Participants were provided the opportunity to review the questions before the scheduled interview session. A face-to-face, follow-up interview, lasting approximately 30 minutes, was conducted with each participant for purposes of verification and clarification. Preliminary findings were shared with the participants during the follow-up interview to ensure agreement with themes and to give the participants the opportunity to correct any misrepresented ideas or interpretations. Follow-up interviews were not recorded.

I began each interview by asking participants, “How long have you been diagnosed with breast cancer?” Beginning the interview with this question assisted in establishing rapport and trust with the participants. The participants were able to express themselves freely without interruptions. Clarification was requested when needed. The interview protocol was reviewed at the end to make certain that all the information was covered.

I transcribed and analyzed the tapes using the IPA approach. Each interview was transcribed verbatim. A six-step analytical process established by Smith, Jarman, and Osborn (1999) was followed to conduct a thorough analysis and to develop themes. Those steps involved: (1) looking for themes, (2) connecting the themes, (3) creating a table of themes, (4) continuing the analysis with other cases, (5) creating a master list of themes for the cases, and (6) writing up the findings.

Discussion of the Findings

In my analysis, seven common themes emerged from all of the participant’s cases. Those themes included spirituality, support systems, self-care, resiliency, existential meaning, education, and perception of counseling. The primary research question in this study focused on

the lived experiences of African American women with breast cancer and the meaning of those experiences. In addition, each participant's perception of counseling was addressed. The shared themes provided insight into the essence of the participants' experience with breast cancer and conveyed the meaning of the phenomenon under investigation.

Spirituality

One of the main and most unique themes that emerged from all the cases in this study was the importance of spirituality and its role in coping with the diagnosis of breast cancer. Spirituality emerged as an overarching theme in all seven of the common themes. Simon, Crowther, and Higginson (2007) conducted a study with 18 African American Christian women focusing on the role of spirituality throughout their breast cancer experiences. The results indicated that, for most of the survivors, spirituality and faith assisted them throughout their breast cancer experience. The results of other studies support this finding that spirituality is key in the lives of African American women coping with breast cancer (Gibson & Hendricks, 2006; Henderson et al., 2003).

Henderson et al (2003) conducted an exploratory study to determine how African American women cope with breast cancer. Prayer was found to be an important factor in adapting to the diagnosis of breast cancer. Gibson and Hendricks (2006) conducted an integrative review of spirituality in African American breast cancer survivors over 18 years of age. The researchers found that the spirituality of African American women helped to facilitate their ability to cope with major life stressors and illnesses such as breast cancer.

All of the participants in this study reported that faith and prayer have given them the strength to overcome their fear and other challenges in their lives. Previous researchers have

found similar themes. Ashing-Giwa et al. (2004) found that spirituality is an important coping mechanism for minority women, used to overcome many different challenges. Gibson (2003) noted that, historically, African American women have demonstrated the ability to cope successfully with major life stressors or events. A quote by Paula illustrates the significance of spirituality in her life: *“First of all, if you have your faith, you have faith in God, then you have to have faith in yourself – knowing that I can do this; you know, I can do this...You know my faith played a major role—prayer from my heart and I prayed constantly...The Word of God says I am the God of healing people...So I would say all the time that God, you said you were the God of healing people and so I kept repeating that.”*

Support Systems

Family support, having a good team of doctors, and attending monthly support groups for African American women specifically were important components in the lives of the participants, who were women diagnosed with breast cancer. All of the participants attributed their positive outcomes to having a good support system, including church, family, and friends. Jordyn explained the importance of family support as she recovered from treatment. *“My mom and my cousin are my support system. My cousin lives here with me and she’s twenty-two. My mom’s been here with me back and forth. My mom and my cousin basically take care of me and help me with the kids. If I’m having a bad day, they’ll step in and get the kids ready for school and drop them off. If everything’s fine, I’ll step in and do my part, but when I’m feeling bad they step in and take care of me. They make sure I eat, cook, they clean for me and everything. So, my mom and my cousin have really been here for me and I’m thankful for them.”*

Henderson et al. (2003) found that many African American women relied on family members, church members, friends, and pastors/ministers for help in coping with the diagnosis of breast cancer. Henderson et al. (2003) also found that participants in their study more readily sought out faith-based cancer support groups that were designed specifically for African American women with breast cancer due to cultural sensitivity and the inclusion of prayer and support of women who looked like them. Korinne stated, *“The support was my counseling [support group] and everything. They were right there for me.”*

Self-Care

Another theme that emerged in all the participants’ narratives was the importance of self-care. Some of the women found their lumps by completing their own self-breast exams. The participants emphasized the importance of getting checkups and yearly mammograms. Many believed that if they had not gone to the doctor when they did, they might not be alive today. Below are participant quotes that illustrate the importance of self-care:

Paula: *“I’m still currently going to the doctor. I do mammograms every six months. It’s the preventative action that you take. I started taking mammograms when I was about 35. So that was a yearly routine for me. So when they did catch it, it was at the beginning stages.”*

Jordyn: *“Most people don’t do self breast exams and pay attention to the little things, you know, and that’s helpful because that helps with early detection.”*

Dionne: *“It is important that you get your health screening. It’s the only thing I can say; be proactive about your health.”*

Betty: *“It is essential that we take care and follow up if something doesn’t feel right or you start to feel a certain way and it lasts too long, check it out. That’s the best thing we can do for*

ourselves...As African American women, we take care of everybody else and we rarely take good care of ourselves.”

Korinne: *“We women are always last on the totem pole. I took care of everybody else but me. Young women should take care of their bodies.”*

According to the literature, one of the factors contributing to late-stage diagnosis in African American women is delay in breast cancer screening, which can result in increased breast cancer mortality (Bradley, Neumark, Bednarek, & Schenk, 2005). Fiona alluded to this as she discussed during the interview that *“I think the biggest thing is to be aware of your body. I ignored my symptoms for months. I ignored it for maybe eight or nine months before I even took the time to go to the doctor. It actually had to bother me first. So, I just want women to know their bodies...I ignored my symptoms for months. It was just a blessing from God that I had a lump that hurt because according to what I’ve read and what the doctors told me, it rarely hurts.”*

Previous researchers have found that factors such as cultural beliefs, lack of access to health care, lower socioeconomic status, prior negative experiences, and distrust of the medical profession affect breast cancer screening behaviors of African American women (Phillips & Underwood, 2009). Additional barriers include the high cost of mammograms, doctors’ failure to discuss mammography with women, misconceptions about preventive methods, lack of health insurance, and cancer fatalism (Phillips & Underwood, 2009). Crystal emphasized the importance of women having a good relationship with their doctors. She also expressed frustration about not having a personal connection with her doctor, which limited her comfort level in discussing the options available to her. She stated, *“It’s never too early to get detected,*

even if it's a well woman's exam or checking yourself. Do it! Don't wait! I learned to take charge of my health and not wait for some doctor to help me out. I learned about patient advocacy. I learned more or less about how to advocate for my needs."

Resiliency

In this study, all of the participants discussed the importance of overcoming obstacles and challenges, having a positive attitude, helping others, fighting the battle, and being a survivor. Many of the participants emphasized the importance of keeping their routines and helping friends, family members, or other women diagnosed with breast cancer to uplift their spirits and keep their minds focused on the positive. Each participant was able to transcend her experience of breast cancer in a unique way. It seems worth noting that, no matter how each participant conquered her illness, she was able to prevail even with the odds against her. Previous researchers have concurred with this phenomenon, as is discussed below.

Gates, Lackey, and Brown (2001) found that African American women were able to move forward with breast cancer treatment because they were either receiving care from others or giving care to others, especially to family members. According to Henderson et al. (2003), having the will or determination to live by helping others is another important coping strategy for African American women. In addition, helping others may help to increase a positive attitude and frame of mind. Several women reported that having a positive attitude and being around positive family and friends helped them to cope better with their breast cancer diagnosis. Betty referenced this in the following quote: *"The difference between a good day and a bad day is your attitude and I don't have any bad days anymore. So, when I am not at my best, I still look at all the good things that God has done for me and it just, it goes. I don't even think twice about*

it... We all wake up with a slow day and if it is a slow day for me, I still thank Him for it. The prayer of serenity is where I am in life and, with that, I respect every day for what it brings. Every day for me is a new beginning.”

Existential Meaning

Previous researchers have found that having been diagnosed with a potentially life-threatening illness can have a major impact on thought processes, perceptions of life, and also the meaning and purpose of life itself (Henderson, Gore, Davis, & Condon, 2003).

All seven participants in this study expressed the importance of creating meaning in their lives after being diagnosed with breast cancer. According to Landmark and Wahl (2002), existential issues often arise when diagnosed with a terminal illness such as breast cancer.

Some participants mentioned that the fear of death and recurrence had crossed their minds, but it also made them more aware of the importance of life and the significance of their loved ones. Many of them stated that life is too short and emphasized the importance of not taking life or people for granted. One particular quote by Dionne, *“Live life everyday like it’s your last day because it may be,”* resonated with me.

In a study of breast cancer survivors conducted by Sadler-Gerhardt et al. (2010), one of the existential issues that emerged was the fear of recurrence. African American women have a higher death rate when compared to any other ethnic group (Davidson & Mahanna, 2010; Jones & Chilton, 2002). Consequently, they are at increased risk of a premature death. As people experience obstacles in life, they try to make sense of or understand what has happened. Many people diagnosed with potentially life-threatening illnesses such as breast cancer may struggle

with attributing significance to the illness or making meaning out of a difficult situation (Sadler-Gerhardt et al., 2010).

The “Will to Live” emerged as a central theme in two studies that explored existential meaning in the lives of breast cancer survivors (Landmark & Strandmark, 2001; Landmark & Wahl, 2002). Landmark and Wahl (2002) found that a tenacious fight for life arose as an important aspect of living with newly diagnosed breast cancer. Maintaining a fighting spirit and possessing a continual sense of hope to cope with the illness trajectory is essential to survival among women diagnosed with breast cancer (Landmark & Strandmark, 2001). Fiona spoke to this new self-awareness when she stated: *“Life is short. Life is short. Actually, I’m a much happier person since being diagnosed. I don’t take myself as serious as I used to. Life to me is not as complicated as it used to be. Either I can do it or I can’t. I try to make my life more meaningful. Sometimes I think about what my legacy might be – what will people remember and so I try to live the best life. It’s made me a better person. It’s made me aware of what I do physically to my body or how I live my life or how it may impact my body physically.”*

Education

Being educated about breast cancer, especially regarding statistics related to African American women, was a major theme in all of the cases in this study. A study conducted by Underwood et al. (2008) focused on the breast cancer experiences of African American women with a family history of breast cancer. Sixteen African American women with a familial predisposition for developing breast cancer participated in the study. The results of this study indicated that, although the women were knowledgeable about breast cancer and the potential

risks, the extent to which they discussed their concerns with their healthcare providers and engaged in preventative methods varied.

During the interviews, the women stressed the need to educate other women about the importance of early detection, knowing one's family history, understanding treatment options, and how to conduct self-breast examinations as a preventative method. Jordyn stated, "*We as black women need to be educated and aware of breast cancer...once I finish with all of my treatment, I'm definitely going to get out and talk about it and educate more African American women on this disease so I could teach them to be more aware of their bodies...*" The women in this study also emphasized the need to ask questions and to discuss concerns with health care professionals so that there is no misunderstanding or miscommunication between the patient and doctor. Paula stated, "*As an African American woman, the key is to be educated on breast cancer. If you're not sure, ask plenty of questions. If you're uncertain, don't leave with any doubts.*"

Perception of Counseling

Previous researchers have found that cancer patients who are members of minority groups are less likely to attend cancer support groups or counseling services than those who belong to a majority group (Barg & Gullatte, 2001). Wilmoth and Sanders (2001) found that few African American women attended cancer support groups, and they perceived the need for a support group designed specifically for African American women. They concluded that African American women tend to keep their diagnosis private and do not seek information and support. However, they tend to actively participate in breast cancer outreach activities and breast cancer awareness in their own communities when compared to Caucasian women.

At the end of each interview, each participant was asked about her counseling experience to provide insight related to the phenomenon under investigation. Two questions in the Interview Protocol (Appendix A) focused on the participants' experience with counseling and their perception of the counseling process. The questions were:

- 1) Did you seek counseling when you learned your diagnosis or while you were receiving treatment? If not, did you consider seeking counseling? What led you to decide against it? If so, what about the counseling process was helpful to you? What was hindering?
- 2) What characteristics might you look for in a counselor?

All of the participants in this study were receptive to the idea of counseling. However, not all of them sought counseling during their breast cancer experience. Two of the seven participants who sought counseling during their treatment took advantage of the counseling services provided as a part of this study. Many of them expressed that if there was a need to seek counseling, they would prefer an African American female counselor who has some knowledge about breast cancer. Some of them chose not to seek counseling because their needs were being met by a support group, church, or their family members and/or friends. For example, Betty stated, *"I didn't feel a need for it [counseling] because I had the support group and we met every month...If I sought counseling, I would like to have an African American female counselor...I just don't feel that I could get the support that I need from somebody other than somebody that looks like myself. I prefer that person to be a little bit more mature..."*

Other related themes

Other related themes in this study included physical changes such as hair loss, loss of breast, scars, financial hardships, sex lives, and starting a family. Many of these themes emerged in the stories of the younger women diagnosed with breast cancer in this study.

Fiona stated, *“Going to groups that were for women with breast cancer was difficult because all of them were older; they had grandchildren; they weren’t thinking about their sex lives; and they didn’t have children to raise.”* Fiona discussed the importance of physical appearance as it relates to dating. Fiona expressed that she is a single mom with one child and would like to feel comfortable in her skin as a breast cancer survivor. Crystal is married now and has no children yet. She is also in her thirties and expressed concern about physical appearance as it related to her breast cancer experience while in her twenties. Crystal stated, *“I wound up having a very small portion of the breast removed and they had to reattach the area. I had to get my nipple tattooed, which is another story. When you are dating, explaining prosthetics and wearing gel bras can be weird...I also had issues with childbearing.”* Jordyn, who is in her thirties and also a single mom of three, expressed looking forward to her “new body.” She also highlighted the importance of having family to help her financially as she is unable to work while going through treatment. Jordyn stated, *“Because I don’t qualify for disability, I have to penny pinch and put things together financially to make sure that my bills are straight and we have food to eat and my kids have clothes to put on.”*

Implications and Recommendations

The findings from this study offer a basis for future research for counselors and other mental health professionals, researchers, and counselor educators. Although previous researchers

have explored the breast cancer experience of African American women, there were no studies found that used a qualitative, phenomenological method and an existential perspective to explore the lived experiences of African American women with breast cancer.

Implications for Counselors and Other Mental Health Professionals

Counselors and mental health professionals are vital in helping medical health care professionals provide quality services to their patients. Counselors and mental health professionals can serve as both advocates and educators by training medical professionals on how to utilize active listening skills and by educating them on psychological issues that may surface during their patients' breast cancer experience (Keitel & Kopala, 2000).

Counselors and other mental health professionals can help those in the medical field better understand the critical role of culture and societal norms and how important those may be in terms of the patient's outcome. Counselors can also educate medical professionals on the importance of various coping strategies used by breast cancer patients who are African American. This knowledge can help them to individualize treatment more effectively and to develop treatment plans accordingly. In addition, understanding the phases of psychological morbidity can help medical professionals know when to refer those who may be experiencing extreme emotional distress (Keitel & Kopala, 2000).

The participants in this study expressed their openness to counseling services. In addition, they emphasized the need for counselors to have some knowledge of breast cancer in African American women. Counselors have skills that can improve the well-being of women diagnosed with breast cancer, or women who are worried about getting breast cancer due to risk factors such as family history, age, and obesity. Counselors who are familiar with the history, treatment,

screening, and experiences of African American women with breast cancer can be stronger advocates for their clients and more effective in treating their individual needs.

The findings of this study may help to facilitate change in the counseling profession and contribute to the existing literature by elucidating the meaning of the breast cancer experience of African American women from an existential perspective. Furthermore, the findings may help counselors better understand the breast cancer experience, be more culturally aware, and provide more effective services in meeting the needs of this population. Two participants stated they had no preference for gender or ethnic background. The other five participants emphasized the importance of having an African American female counselor. All of the participants stated that they would prefer counselors to have some knowledge of breast cancer specifically as it relates to African American women. The participants also stressed the need for counselors to be spiritually grounded or to be open to understanding their spirituality and how it impacts their life.

Paula highlighted the need for counselors to be culturally aware and to understand the significance that spirituality plays in a survivor's life. Paula's story illustrates the need for counselors to embrace culture and spirituality, and to provide an authentic experience while exploring the client's personal journey. She stated, *"I think that first I would look for a female and that's because she would be able to identify what I was going through. Second, I think I would look for – she wouldn't necessarily need to be African-American – she would have to have some knowledge on breast cancer and breast cancer survivors and their families. And then I would like her to be someone who is genuine. Someone that would, you know, would be able to empathize with what I'm going through. A good listener – because sometimes people don't need anybody to talk to them, sometimes you just want someone to listen. And then someone that*

would be able to give me feedback on what I'm saying; you know, sometimes you need feedback and that would be it. Someone that I knew, someone that was genuinely concerned. Someone that I could establish a relationship and know that relationship was genuine. You know, she wouldn't be judgmental –She wouldn't have to have faith as I have, but she would have to be open to my spirituality and my faith.”

Crystal emphasized the importance of counselors being genuine and authentic. She stated, *“I would like someone that's warm. Someone that's gentle. Someone that's understanding. Someone else that may be aware of multi-cultural issues that are specific to African American females...being able to allow them to have a voice. For them to be able to talk about their experiences, not just based on what they've read in the textbook that oh, okay I'm working with a Black woman so this is what Black women experience. Not taking the universal look, but like allowing them to say this is how I want us to approach this relationship. This is how I want us to work together.”*

Implications for Researchers

Research based on the experiences of African American women with breast cancer is scant. More research needs to be done in the area of mental health and how mental health professionals can better facilitate change in this population. The existential aspect of this study provides counselors with insight in terms of meaning behind the women's existence once diagnosed with a life-threatening illness such as breast cancer. Most studies on African American women diagnosed with breast cancer have aimed to contribute to nursing and/or medical literature, and to provide tools to foster better relationships among doctors, nurses, and breast cancer patients.

Future research studies could address the limitations of this study. The sample in my study was limited to African American women diagnosed with breast cancer living in New Orleans. Findings could be different if the geographical location was different. For example, replication of this study could be done with African American women living in the mid-western or northern states. There may be a difference in available counseling or support groups in those areas, or there may be differences in utilization of counseling by African American women diagnosed with breast cancer who live in those areas. Cultural dynamics may also be a factor when compared to southern states. Additionally future studies could also focus on differences between breast cancer survivors who live in urban/suburban vs. rural areas.

Future qualitative research could also be done focusing specifically on the experiences of African American women who fall within a specific age group or stage of breast cancer. Findings in this study indicated that younger women diagnosed with breast cancer were more concerned than older women about child-bearing, sexual relationships, physical changes, and financial hardships. It would be interesting to find out more about the experiences of younger African American women diagnosed with breast cancer. In addition, the stage of breast cancer diagnosis for African American women may make a difference in terms of their experience.

Quantitative research could focus on variables that contribute to negative outcomes between breast cancer patients and their medical care professionals. Some of the participants in this study mentioned having a negative experience with their doctors and medical care providers. Crystal stated, *“He [doctor] was very cold to me—the way he explained it [cancer] to me...He spoke to me as if I had no medical knowledge...it was the delivery, no bedside manner*

whatsoever.” Findings from such studies could be used to help improve relationships between medical professionals and breast cancer patients who are African American women.

Implications for Counselor Educators

Counselor educators are responsible for educating counseling students about theories, interventions, and approaches. In addition, counselor educators are responsible for enhancing the skill set of counseling students. Findings from this study might increase counselor educators’ understanding and awareness of how existentialism can be used as a theoretical approach to facilitate meaning of a client’s personal experiences. Keitel and Kopala (2000) suggested that culturally competent counselors working with clients diagnosed with potentially life-threatening illnesses can utilize the basic concepts of existentialism to foster growth along their clients’ personal journeys of wellness. Part of the meaning-making of any life-threatening illness involves confronting the possibility of dying. Counselor educators can help students understand that existential change such as a deepening spiritual faith or spirituality, making sense of what happened, or a searching for a renewed purpose or meaning in life may become significant aspects to consider in counseling. Existential issues such as the potential recurrence of breast cancer and the possibility of an untimely death can create anxiety and feelings of isolation and loneliness for many survivors of this illness. Counselors should seek to understand those feelings as a way to facilitate wellness and to develop culturally sensitive interventions. In addition, existentialism could be used to help students who are enrolled in counselor education programs confront their own anxiety and fears of cancer while they are still in training. Students might then graduate with a greater self-awareness and be more prepared to work with this population.

Counselor education programs may also benefit from recruiting and retaining more African American female students who might go on to counsel this population. As indicated in the findings, African American women diagnosed with breast cancer prefer to have a counselor who is both female and African American. In addition, more internship sites need to be established where students could gain supervised experience in counseling this population. These sites may include hospital settings, non-profit agencies, outpatient facilities, and cancer treatment centers. All of the participants in this study reported the need for counselors to have some knowledge base on breast cancer, specifically as it pertains to African American women.

Limitations

Possible limitations to this study included the fact that I was personally connected to the topic under investigation, my interpretations of the interview, and the participants' interpretations of their own experience. To eliminate bias, I attempted to remain transparent and to ensure that throughout the discussions of the personal stories, the participants were in control of the interpretation of life events. I was also able to separate my role as a counselor and to remain mentally aware of my role and the purpose of this research study by utilizing bracketing, consulting with my dissertation chair, and peer debriefing. I disclosed all information related to personal issues associated with my mother's breast cancer experience to my dissertation chair. I discussed with my dissertation chair any issues, feelings, values, and perceptions related to my own experiences in coping with the phenomenon as a way to remain unbiased.

Chapter Summary

The breast cancer experiences of seven African American women were explored in this study. Seven common themes emerged from the cases. Those themes included: spirituality, support systems, self-care, resiliency, existential meaning, education, and perception of counseling. These seven themes will help to provide insight into how counselors can help to facilitate emotional wellness within this particular population. Findings indicated that many African American women diagnosed with breast cancer may prefer to have an African American female counselor who is knowledgeable about breast cancer. It is my hope that the findings will help to facilitate reflection on current counselor education practices and lead to changes that enhance service provision to this population. I also hope that the findings will help to create more skilled counselors and better training for counselor education programs across the country. In addition, incorporation of spirituality within therapeutic conversations seems to be important when working with this population. I anticipate that counselor educators and counselors-in-training will consider the revealed areas pertinent for meeting the needs of this client base. I hope that counselors-in-training will utilize these findings in their work with African American women diagnosed with breast cancer or any other life-threatening illnesses. Furthermore, I hope that counselor educators will consider the findings useful when teaching multicultural competency courses.

Personal Reflections

This journey is one I will never forget. My mother's breast cancer experience inspired me to focus on this dissertation topic. It has been four years since my mom's diagnosis of breast cancer. I am happy to report she is doing fairly well and is my hero and best friend. It has been

amazing being a part of this experience. I have to admit, when I began writing, I didn't know exactly how this study would impact my life. All I could do at the time was prepare for it and do what I was trained to do. I had to face my own anxiety and fears about the possibility of my mom's death, which was a difficult and scary task.

As I interviewed the participants, I found peace in their stories. I was able to connect with them in such a way because of my mother's experience. Their stories, their words, their tears, their sighs, their smiles, and their laughter inspired me to look deep within and reflect on my own life both personally and professionally. I have so much respect for these women. Their strength speaks volumes and their narratives possess a richness that transcends all. They have given me so much more than they know. I will forever cherish my time with them and I cannot thank them enough for their words of wisdom and for allowing me to be a part of their lives for such a short time. I am eternally grateful to have been granted this opportunity and I pray that God will continue to give each and every one of them the many blessings life has to offer. To honor the journeys of my participants, I will close with this final quote:

“Dance like there's nobody watching,
Love like you'll never be hurt,
Sing like there's nobody listening,
And live like it's heaven on earth.”

--William W. Purkey

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Appendix A
Interview Protocol

Appendix A

Interview Protocol

1. How long have you been diagnosed with breast cancer?
2. What feelings did you experience when you received the news?
3. How did you tell your family?
4. Has anyone else in your family been diagnosed with breast cancer? If so, who?
5. How did you cope with the process?
6. What type of treatments or surgeries did you undergo? How did those affect you both physically and emotionally?
7. What or who did you use as your support system?
8. How has the diagnosis of breast cancer impacted your life as an African American woman?
9. What meaning did you gain from this experience?
10. What would you like others to know about your experience?
11. Have you ever attended support groups?
12. Did you seek counseling when you learned your diagnosis or while you were receiving treatment? If not, did you consider seeking counseling? What led you to decide against it? If so, what about the counseling process was helpful to you? What was hindering?
13. What characteristics might you look for in a counselor?

Personal Characteristics Questionnaire

Please complete this questionnaire by checking the appropriate answer that applies to you. The information you provide will remain confidential and not be disclosed to any person not involved in the research study.

Personal Characteristics

Age (yrs.): _____

Educational Level:

Age at Diagnosis: _____

Did not complete high school: _____

Stage of Breast Cancer at Diagnosis:

High School Diploma or GED: _____

Stage I _____

College Graduate: _____

Stage II _____

Graduate Degree: _____

Stage III _____

Stage IV _____

Marital status:

Employment:

Never married/single _____

Married _____

Divorced/separated _____

Employed/currently working _____

Employed/currently on disability _____

Widowed _____

Unemployed/unable to work _____

Appendix B
Consent to Participate

Appendix B

Consent to Participate

Research Project: *The Lived Experiences of African American Women with Breast Cancer: Implications for Counselors*

Please carefully read the following information prior to signing this form.

1. LaTasha K. Clay, M. A. (504-256-5180; lkclay@uno.edu) a doctoral student in the Counselor Education program, under the direct supervision of Dr. Barbara Herlihy (504-280-6662 or bherlihy@uno.edu), a faculty member at the University of New Orleans, is requesting your participation in a research study entitled, *The Lived Experiences of African American Women with Breast Cancer: Implications for Counselors*. The purpose of this study is to explore the lived experiences of African American women diagnosed with breast cancer. I hope to learn more about how your experiences have affected all aspects of your life. I hope to gain a better understanding of your perceptions and the meaning related to your experiences with breast cancer. Your participation will involve being interviewed face-to-face for approximately 60 minutes at which time you will be asked open-ended questions. A second interview may be required for clarification purposes. You will be audio-taped during the interview process. Once the study is complete, the tapes will be discarded. Your real name will not be revealed in the study. Anything you say can be used in the study.
2. One risk associated with this study is that you will be asked to share personal information regarding your experience. You do not have to answer any question that you do not wish to answer. Due to the length of the interview (approximately 60 minutes), you may become tired or fatigued. Should that happen, you may take a break or choose to discontinue this interview. Due to the sensitive nature of this topic, a licensed counselor will be available to provide services at no cost to you if needed.
3. The benefits of participating in this study for you personally are minimal; however, you will be contributing to the scholarly research about the experiences of African American women with breast cancer as it pertains to the counseling profession.
4. You do not have to participate and are free to stop the interview at any time without consequence. Additionally, you are free to withdraw from this study at any point.
5. The results of this study will be used for my dissertation, publication, and conferences; however, your name and identity will not be revealed. You will be assigned a pseudonym and it will be used in any reporting of your comments. The researcher will only know your name and any transcriptions of this interview will be kept in a locked file cabinet accessible only to the researcher.
6. Your participation in this research study is voluntary and you will not be compensated. Refusal to participate will involve no penalty. You may withdraw from participation in this research study at any time.
7. If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, please contact Dr. Ann O'Hanlon, Institutional Review Board, at the University of New Orleans at 504-280-6501.

By signing the Consent to Participate form, you acknowledge having read this document and understand the conditions of participation in the research study.

Participant:

Researcher:

_____ Date _____ LaTasha K. Clay _____ Date

Appendix C

Oral Script for Recruiting Participants

Appendix C

Oral Script for Recruiting Participants

My name is LaTasha Clay and I am conducting research on the experiences of African American women diagnosed with breast cancer. I am a doctoral candidate in counselor education at the University of New Orleans. The study that you are being asked to participate in involves my dissertation research.

The purpose of this study is to explore the lived experiences of African American women diagnosed with breast cancer. I hope to gain a better understanding of the breast cancer experiences of African American women and the meaning behind their lived experiences. I hope that the results of the study will help counselors to better understand the breast cancer experience, to be more culturally aware, and to provide more effective services in meeting the needs of this population.

I am hoping to complete my dissertation research between the months of July 2012 and October 2012. Upon verbal agreement from you, we can set up the face-to-face interview based on your convenience.

After reading and signing the consent form, you will be asked to fill out a short questionnaire describing personal characteristics. You will then be asked to agree to be interviewed, possibly on two separate occasions to expand on your answers and to clarify information gathered and interpreted by the researcher. The research will require the following time commitment from you:

- 1) Estimated time to complete the short questionnaire – 1-2 minutes (administered on one occasion)
- 2) Estimated time to conduct the interview – approximately 60 minutes (may be conducted on two occasions as mentioned previously for clarification purposes).

Your total time commitment for this research study is estimated to be between 1 ½ and 2 hours. You will be audio taped during each interview.

Before you can participate in this research study, you must first agree in writing by signing a consent form to use your information in the study. Prior to signing the consent form, I will read it with you so you clearly understand the conditions of participation in this study. If you choose to participate, your information will be held confidential and you will be assigned a pseudonym to protect your identity. You are encouraged to ask questions if any of the information is unclear. Do you have any questions or concerns at this time about the research study?

Thank you for your time and consideration.

Appendix D
IRB Approval Letter

Appendix D

IRB Approval Letter

University Committee for the Protection of Human Subjects in Research University of New Orleans

Campus Correspondence

Principal Investigator: Barbara Herlihy

Co-Investigator: LaTasha K. Clay

Date: July 10, 2012

Protocol Title: "The Lived Experiences of African American women with Breast Cancer: Implications for Counselors"

IRB#: 02Jul12

The IRB has deemed that the research and procedures described in this protocol application are exempt from federal regulations under 45 CFR 46.101 category 2, due to the fact that any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation. Please correct Dr. O'Hanlon's number to 504-280-3990 in your informed consent.

Exempt protocols do not have an expiration date; however, if there are any changes made to this protocol that may cause it to be no longer exempt from CFR 46, the IRB requires another standard application from the investigator(s) which should provide the same information that is in this application with changes that may have changed the exempt status.

If an adverse, unforeseen event occurs (e.g., physical, social, or emotional harm), you are required to inform the IRB as soon as possible after the event.

Best wishes on your project.

Sincerely,

Robert D. Laird, Ph.D., Chair
UNO Committee for the Protection of Human Subjects in Research

VITA

LaTasha Clay was born in New Orleans, Louisiana. In 1998, she graduated from Dillard University of New Orleans with a bachelor's degree in psychology. In 2001, she earned a master's degree from Xavier University of Louisiana in mental health counseling. In 2003, LaTasha obtained a certification in marriage and family therapy from Our Lady of Holy Cross College in New Orleans. In the spring of 2009, LaTasha began pursuing her doctoral studies at the University of New Orleans to earn a Ph.D. in Counselor Education. LaTasha is a Licensed Professional Counselor, Licensed Marriage and Family Therapist, National Certified Counselor, and a Licensed Professional Counselor Supervisor.