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Lived Experiences of Pre-menopausal African American Women with Advanced Breast Cancer

Carmelita Whitfield
Walden University

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Walden University
2017

Abstract

Lived Experiences of Premenopausal African American Women with
Advanced Breast Cancer

by

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MA, University of Phoenix, 2008

BS, Alabama A&M University, 1986

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

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May 2017

Abstract

This qualitative study examined the phenomenology of advanced breast cancer (ABC) among 7 female participants between the ages of 20 and 45. Oral data were collected to extract participants' interpretations of their spiritual and psychosocial experiences of living with ABC. Findings suggest that these women experienced a dichotomous relationship with regard to their bodies and their relationships with others; this served as a means of making sense of their experiences and as a coping mechanism. Positive psychology and the theory of reasoned action and planned behavior provided the theoretical framework for examining the role of social reinforcements, beliefs, and attitudes and intentions on the health behavior of premenopausal African American women with ABC in Northern and Southern Delaware. Additionally, the theoretical framework provided answers to the overarching questions of how pre-menopausal African American women with advanced breast cancer applied meaning-making and spirituality to find purpose in their diagnosis. Inductive analysis of their narrative data suggested a set of themes: the body as a medical object, the body as a feminine object, honesty in relationships, missed opportunities from healthcare professionals, from wounded to mended, and the joy of purposeful living. The participants reported that an intimate relationship with God helped them feel supported in a way that family and friends could not. The findings in this study support potential spiritual and meaning-making interventions as well as promote a more positive quality of life for premenopausal women living with advanced breast cancer.

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Chapter 1: Introduction to the Study

Introduction

In the United States, African American women have a disproportionate breast cancer burden. They have the highest death rate and the lowest rate of survival of any ethnic or racial group (DeSantis, Naishadham, & Jemal, 2013). The American Cancer Society (ACS, 2013) estimated that 82,080 African American women were diagnosed with breast cancer. The evidence shows that 1 in 11 African American women are diagnosed with invasive breast cancer every year in the United States (Ashing-Giwa, Kim, & Tejero, 2008). This statistic will continue overwhelming the United States until equality occurs in healthcare. Adding to these numbers, African American women are less likely to use mammograms; if they do receive the test, they are less likely to attend any follow ups, which increases their risk of developing serious complications if they have breast cancer. To worsen matters, at the time of diagnosis, African American women usually present with more aggressive tumors and have poorer prognoses (DeSantis et al., 2013).

The ACS (2013) posited that the 5-year survival rate equated to 77% for African American women compared to 90% for White women with breast cancer. Based on these statistics, researchers placed emphasis on the prevention of breast cancer, detection of early warning signs, and detection and importance of mammograms for African American women (Bourjolly & Hirschman, 2001; Komen, 2017). Supporting the necessity of preventative care and medical interventions, evidence shows (Bourjolly &

Hirschman, 2001; Komen, 2017) that, over the past several decades, breast cancer diagnoses have significantly decreased.

Based on the types of interventions the use of mammograms, and education about early warning signs are the typical interventions; however, minimal research was found on integrating spirituality (i.e., meaning and faith) as an intervention to help support and emotionally heal breast cancer patients (Breitbart, 2002; Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2013). In the ethics code, the American Psychological Association (2010) noted that one should understand and respect spirituality and religion as an individual's identity and life journey during intervention therapy. Despite this ethical notation, many mental health and healthcare professionals minimized or neglected (Breitbart, 2002; Thuné-Boyle et al., 2013).

W. Breitbart (personal communication, September 2, 2014) developed a meaning-making program designed to determine whether a positive correlation occurred between engaging individuals with cancer in the meaning-making process. This occurrence would increase their self-efficacy, personal growth, and satisfaction (W. Breitbart, personal communication, September 2, 2014). The meaning-making program could help young African American women diagnosed with ABC (i.e., Stage III cancer) take control of their cancer diagnosis with the hope of finding meaning, thereby discovering a reason to live. W. Breitbart's (personal communication, September 2, 2014) research was the thematic backdrop for this study, which included research into (a) situational sources of meaning, (b) relationships and meaning, (c) attitude and meaning, (d) hopes for the future. Meaning-making is not a new concept, in fact meaning-making strategies in

psychology have been around for more than a quarter century and can be used to understand and make sense of unexpected life changing events and the conclusions human beings develop within their new reality or perception.

Frankl (1984), a Viennese neuropsychiatrist, Holocaust survivor, and founder of logotherapy, stated, “Striving to find purpose or meaning in one’s life is the most powerful and driving force in humans” (p. 20). Other scholars have provided insight into meaning by defining the concept as re-evaluating an event, such as breast cancer, as positive or the ability to re-assess the situation or circumstance (Park & Folkman, 1997). This reevaluation might help ABC patients find answers to any hopelessness they might experience (Park & Folkman, 1997).

Background to the Problem

Although research showed a positive relationship between meaning-making and optimism in patients with breast cancer, some health care professionals may find discussing holistic approaches more difficult compared to discussing allopathic approaches (Bourjolly & Hirschman, 2001; Taylor, 1993). According to Meraviglia (2006), less psychosocial distress is reported among cancer patients who have a greater spiritual awareness. In addition, Bryant-Davis et al. (2015) stated that a woman’s decisions, thoughts, and feelings about life, including her experiences, relationships, and future possibilities, are predicated on the notion of her spirituality and belief system. The spirituality and belief system can provide the framework for meaning-making and how women can cope with their breast cancer challenges.

Although great strides have been made in creating breast cancer intervention and prevention programs to assist with early detection and screenings in the African American community, spirituality and meaning are rarely a focal point for intervention (Bourjolly & Hirschman, 2001). Meraviglia (2006) confirmed that the characteristics of spirituality, such as meaning making and prayer, lessened the biopsychosocial impact of breast cancer. Fairley (2006) purported that oncology nurses were in a unique position to address spirituality. However, these nurses must feel comfortable with the topic, think the patient is receptive, and choose the right timing. According to Ashing-Giwa et al. (2008) and Meraviglia (2006), women diagnosed with breast cancer can be more optimistic and less fatalistic in their approach to their disease. Healthcare professionals, who do not recognize or minimize the spiritual history of some African American women newly diagnosed with breast cancer, miss an opportunity for a more purposeful doctor/patient relationship (Fairley, 2006; Turner et al., 2007).

Religiosity and/or faith and spirituality and/or meaning are important and often interchangeable in African American culture (Ashing-Giwa & Lim, 2011). Religion and spirituality are usually a primary source of strength in times of crisis and need (Lewis, Sheng, Rhodes, Eubanks-Jackson, & Shover, 2012). In addition, spirituality and meaning-making are closely associated with positivity, self-transcendence, and well-being (Peterson & Seligman, 2007; Seligman & Csikszentmihalyi, 2000). For instance, Frankl (1984) described self-transcendence as an inherent distinction of humans to connect with that which was greater than their personal concerns and needs. Hence, incorporating spirituality and meaning-making into treatment practices may help young

African American advance breast cancer survivors—whose bodies are scarred and altered by treatment—find empowerment.

Problem Statement

African American women experience lower survival rates for breast cancer than other ethnicities (Centers for Disease Control and Prevention [CDC], 2013). According to the CDC (2013), although breast cancer is less common among African American women than any other racial or ethnic group, for many African American women, at the time of their diagnosis, the cancer is more advanced. In addition, they have a poorer prognosis than other ethnicities (Bourjolly & Hirschman, 2001). Possible contributing factors for this public health crisis of advanced cancer diagnoses (and other health disparities) include socioeconomic conditions, limited access to quality healthcare, and a lack of education (Ashing-Giwa, Tejero, Kim, Padilla, & Hellemann, 2007).

The ACS (2014) reported 232,670 new cases of invasive breast cancer were diagnosed in women in the United States in 2014. The CDC (2013) affirmed that African American women have a 70% less chance of survival compared to White women. One reason for this disparity and decrease is closely related to the cancer's stage at the time of diagnosis (CDC, 2013; Underwood & Teresi, 2002). Another reason the morbidity/mortality rate is higher within this younger demographic is that malignant tumors are more aggressive at this stage and likely to be *triple negative*. This means that the tumors do not respond to hormonal therapies and the growth of the cancer is not supported by the hormones of estrogen, progesterone, or the presence of HER2 (human epidermal growth factor receptor2). The HER2 gene makes HER2 protein that, when

normal, helps control how the breast cells grow, divide, and repair (Breastcancer.org, 2014; CDC, 2013), representing a more aggressive and malignant tumor compared to other cancerous tumors (Breastcancer.org, 2014; CDC, 2013; Komen, 2017).

One potential barrier for early diagnosis is distrust among the African American community and healthcare advocates. The lack of trust, medical and socioeconomic discrimination, and minimum knowledge and understanding of their disease are what keep some African Americans from proactively participating in their healthcare (Ashing-Giwa et al., 2007). These barriers are salient and have deep roots that are historically racial and exploitative (Kinney, Emery, Dudley, & Croyle, 2002; Wolf, Ly, Hobart, & Kernic, 2003). Examples of exploitations leading to generational mistrust can be found throughout the United States; however, the most well-known is the Tuskegee Study of Untreated Syphilis in the Negro Male (i.e., the Tuskegee Experiment), which lasted from 1932 to 1972 (CDC, 2013). The duration of the North Carolina Eugenics Project was even longer, from 1929 to 1974, which represented another example of where African American men and women were sterilized without consent because someone deemed them unworthy to procreate (Severson, 2011).

As evidenced from literature, when faced with a life-altering disease, both religion (external) and spirituality (internal) are identified as greater sources of strength with distinct approaches to coping (Holt et al., 2009; Levine, Yoo, Aviv, Ewing, & Au, 2007). Although religion and spirituality may be fundamentally rooted in many young African American women diagnosed with breast cancer, these young women still manifest poorer psychological adjustments compared to White women when transitioning

from *normal* to having a diagnosis of breast cancer. This transition can lead to increased incidence of depression and anger (Butow et al., 2004; Corcarelli et al., 1993; Meyerowitz, Leedham, & Hart, 1998; Northouse et al., 1999; Taha, Matheson, Paquet, Verma, & Anisman, 2011). Newly diagnosed African American women not only experience increased incidence of depression, but they are also more likely to take a fatalistic approach to their diagnosis, especially those on the lower end of the socioeconomic continuum (Levine et al., 2007; Levine, Aviv, Yoo, Ewing, & Au, 2009; Northouse et al., 1999; Taha et al., 2011). The fear and anxiety remains longer in women with breast cancer who are lower in socioeconomic status and lack access to quality healthcare, compared to women who are more informed and have access to medical care (Thuné-Boyle et al., 2013).

The lack of participation by African American women in research studies leaves a knowledge gap that can be examined to see whether breast cancer survival rates are predicated on a positive outlook, spirituality, and/or the ability to find meaning in their situation despite ABC and socioeconomic barriers (Bourjolly & Hirschman, 2001; Meraviglia, 2006). I explored the significance of spirituality and meaning-making in the lived experiences of young African American women diagnosed with ABC. Research in mental health shows that, in the face of major life stressors, classism, sexism, and racism, many African Americans can successfully cope with their circumstances (Gibson, 2003). I sought to determine whether those coping mechanisms can be applied or attributed to increasing the survival of young African American women diagnosed with ABC.

Purpose of the Study

In this phenomenological study, I explored the lived experiences of premenopausal African American women, between the ages of 20 and 45, who were diagnosed with advanced breast cancer, and I identified the inner resources, specifically, the role of sense of coherence, self-transcendence, and meaning as a source of comfort and healing. The purpose of this study was to examine the lived experiences of premenopausal African American women in Delaware who were diagnosed with ABC. Furthermore, by engaging these women in a meaning-making/meaning-centered coping process early in their diagnosis, research suggested an increase in self-efficacy, personal growth, and life satisfaction while minimizing depression, anger and stress (W. Breitbart, personal communication, September 2, 2014). According to Levine et al. (2007), meaning (i.e., faith or spirituality) provides an “emotional blanket of support for a person that may feel alone, as well as the idea that God is always there and in control” (p. 57).

For young African American women diagnosed with ABC, taking control through logotherapy—freedom of will, will to meaning, and the meaning of life (Frankl, 1984)—or finding the will of meaning provided the optimism through spirituality and a connectedness with both strong support and social networks while coping with their diagnosis (Bourjolly & Hirschman, 2001). Spirituality and meaning-centered coping had a significant role in the healing process. Moreover, African American women with strong support systems and a spiritual foundation were less fatalistic in their approach to coping with their breast cancer than those without support (Bourjolly & Hirschman, 2001). According to Sarenmalm, Browall, Persson, Fall-Dickson, and Gaston-Johansson (2013),

when women are faced with breast cancer, they cope with multiple stresses, including treatment, side-effects, reoccurrence, and mortality.

When women were brought to a life-changing crossroad and began to examine their mortality, the decision became whether to hold on to pain, anger, and regret, or choose to heal and find meaning (Kübler-Ross, 1997). According to Van Ness, Kasl, and Jones (2003), spirituality and religion are often used interchangeably. The identified religion of the diagnosed represented a significant and intimate connection with a higher power that gave them purpose and meaning, which gave them the ability to self-love and find meaning. Similarly, Ashing-Giwa and Ganz (1997) and Levine et al. (2007) showed that spirituality, rather than religiosity, was essential to finding meaning in the healing process. According to Miller and Thoreson (2003), hope and spiritual well-being were positive indicators in people with chronic illness. There is credibility in helping women tap into their spirituality and inner resources while finding meaning in their disease, which can improve both their immediate condition and the rate of recovery).

Research Questions

The research questions guided this study by focusing on the following inquiries:

RQ1. To what degree do premenopausal African American women diagnosed with ABC find utility in incorporating spirituality and meaning?

RQ2. How do premenopausal African American women diagnosed with ABC find utility in incorporating spirituality and meaning?

RQ3. When do premenopausal African American women diagnosed with ABC find utility in incorporating spirituality and meaning?

Theoretical Framework

The two theoretical frameworks that shaped this study included Seligman's (2008) concept of positive psychology, and Ajzen and Fishbein's (1980) theory of reasoned action (TRA) and the theory of planned behavior (TPB). According to Seligman (2008), when we face life's challenges with a positive outlook, that outlook can significantly change the outcome. When Seligman (2008) introduced positive psychology as the year's theme of the American Psychological Association, a growing interest in this phenomenon occurred. Moreover, Seligman and Csikszentmihalyi (2000) stated that positive psychology defined an individual's well-being as happiness, enthusiasm, love, uniqueness, and purposeful living. This theoretical framework implies that people with this outlook will experience positive health, which includes living longer, strong mental acuity, and improved prognosis when diagnosed with a life-threatening disease (Seligman, 2008; Underwood & Teresi, 2002).

Complimentary to Seligman's (2008) positive psychology is Ajzen and Fishbein's (1980) TRA and the TPB. These theories are an assessment of human behavior and the relationship between beliefs, attitudes, intentions, and behavior. This historical perspective of the TRA and the TPB has utility in examining the role of social reinforcements, beliefs, attitudes, and intentions on the health behavior (Ashing-Giwa, 1999, p. 60). Furthermore, current research shows that using the TRA and TPB often equates behavioral intentions with actual behavior (Montano & Kasprzyk, 2015).

Nature of Study

The interpretive phenomenological analysis (IPA) approach was used to examine the lived experiences of young African American women diagnosed with ABC. The foundations of IPA include phenomenology (the focus on the lived experience) and the focus on the particular experience of a similar population (Smith, 2011). In other words, IPA is interested in the unique experience of the participant while understanding that the information gathered from the participant is influenced by the relationship between the researcher, the participant, and the data collected. Additionally, researchers using IPA are interested in examining the data from a small sample size that is similar in many aspects (Smith, 2011). Hence, using IPA to capture rich data could reveal the experiences of being a premenopausal woman living with advanced breast cancer.

To generate the written and oral narratives of young women living with ABC, I used a modified Life Story Interview (McAdams & Bowman, 2001) and semi-structured interview questions (see Appendix A). In phenomenology, it is assumed that the similar lived experience and the individual stories, sharing the same phenomenon, may capture the experiences of people of color, women, and other groups of people whose stories have been marginalized or ignored (McAdams, Josselson, & Lieblich, 2001; Wong, 2010). IPA provides the researcher a means to access the essence, personality, and identity of the storyteller (Lieblich, Tuval-Mashiach, & Zilber, 1998; Wong, 2010). This has positive implications for Black women who feel isolated and alone as a result of being diagnosed with and living with ABC (Spiegel & Cassen, 2000). I was curious about the role of social constructs in life stories and in the creation of meaning from the

experiences of young African American women diagnosed with ABC. Likewise, I was curious about how social norms (as disclosed in the stories) influence how a woman saw her body and viewed her relationships when living with breast cancer.

Another reason for choosing life story inquiry was that it held inherent healing properties (Josselson, 1996) and could have a significant catalytic effect on healing (McAdams, Josselson, & Lieblich, 2006). According to McAdams et al. (2001), “Personal stories contribute to our identities, help us cope with challenges and stress, shape how we see the future, and help to determine the nature of our interpersonal relationships and our unique positioning in the social and cultural world” (p. xv). Meaning-making appears at the heart of life changes (McAdams et al., 2001).

Definitions

ABC: ABC, also known as Stage III, means that the cancer has spread to the lymph nodes or other tissue within the breast (ACS, 2013).

African American women: There are so many terms that describe but do not quite define African American women. The closest definition is an ethnic group of citizens or residents of the United States with total or partial ancestry in the sub-Saharan Africa, Afro-Caribbean, Haitian, and Jamaican (Rastogi, Johnson, Hoeffel, & Drewery, 2010).

Health disparities: A health disparity refers to a health difference closely related to socioeconomic and/or environmental disadvantages (HealthyPeople2020, 2012).

Inner resources: Inner resources consist of the inner aspects of a person that are used to cope with a stressor such as breast cancer (Gibson, 2003).

Interpretative Phenomenological Analysis (IPA): Smith (2011) introduced IPA as a phenomenological approach to qualitative research in health psychology. Theoretically, IPA seeks to “explore in detail participants’ personal lived experiences and how participants make sense of that personal experience” (Smith, 2011, p. 40). IPA recognizes the central role of the researcher in the analytical and interpretative processes.

Logotherapy: This concept is based on three pillars: the freedom of will, the will to meaning, and the meaning of life (Frankl, 1984).

Meaning (Meaning-making): Meaning is unique to the human experience and the precursor for mental and physical well-being (Frankl, 1984). Klinger (1998) added that meaning gives one purpose to serve something greater than one’s self.

Phenomenology: Phenomenology is considered a philosophy, approach, and research method that is both inductive and descriptive. Phenomenology allows the investigator to gain access into the person’s world and understand the meaning of the person’s experiences (Moustakas, 2004). Phenomenology refers to “knowledge as it appears to consciousness, the science of describing what one perceives, senses, and knows in one immediate awareness and experience” (Moustakas, 2004, p. 26).

Religiosity: Religiosity refers to the organized system of beliefs, practices to rituals, and symbols associated with god or gods, and is one manifestation of an individual’s spiritual life. It is also defined as an important part of the social and cultural fabric (Holt, Lukwago, & Kreuter, 2003; Holt et al., 2009).

Self-transcendence: Self-transcendence refers to an experience of expanded self-boundaries and an orientation toward broadened life perspectives and activities.

Advancing age and life-threatening illness, such as cancer, can be stimuli for expansion of one's previous concepts of self-boundaries that can lead to changes in personal life purpose and meaning (Breitbart, 2002).

Sense of coherence: Gibson (2003) stated this sense of coherence is

A global approach to life or an underlying personality characteristic that expresses the extent to which a person has a pervasive, dynamic feeling of confidence that (a) stressors are predictable, orderly, and understandable (comprehensibility); (b) the person has adequate resources to manage stressors (manageability); (c) the person feels that life has meaning because the majority of its problems represent challenges to face and overcome rather than burden (meaningfulness). (p. 20)

Social support: The ACS (2012) defined social support as friends, family, organizations available to provide emotional support and comfort while an individual was going through a crisis.

Spiritual perspective: Spiritual perspective is an individualized awareness of one's inner self and a sense of connection to a higher being (Reed, 1987).

Spirituality: Spirituality refers to one's transcendental relationship to some form of "higher power" (Miller & Thoresen, 2003, p. 415).

Triple negative breast cancer: Triple negative breast cancer is when breast cancer cells test negative for estrogen receptors (ER-), progesterone receptors (PR-), and HER2. HER2 means the tumor is triple negative and does not respond to hormonal or HER2 therapies that target those receptors (Breastcancer.org, 2014; Komen, 2017).

Assumptions

The assumptions underlying this study included but were not limited to the mind and body as two integrated, communicating entities possessed by humans. Humans are motivated toward self-healing. I also assumed that spirituality was a state of mind. In addition, I assumed that a sense of meaning in life was a basic, fundamental human need. Lastly, I assumed that the morbidity and mortality rate among young African American women with breast cancer would continue unabated if not addressed.

Scope and Delimitations

The delimitations for this study were African American women, diagnosed with ABC, who were between the ages of 20 to 5 at time of diagnosis with survivorship based on the time since diagnosis to the time of participation in the study. There were brief comparative examples between ethnicities; otherwise, this qualitative study focused solely on premenopausal African American women. The research participants were located throughout the regions of New Castle, Kent and Sussex Counties within the state of Delaware. Since the focus of the study was with African American women and breast cancer, the results were limited and cannot be generalized to other ethnicities or other cancers.

Limitations

This qualitative research was open to a minimum of seven participants who were African American women between the ages of 20 to 45 diagnosed with ABC with survivorship based on the time of diagnosis to the time of participation in the study. The small sample size represented a limitation; however, researchers stated that such a small

sample could provide sufficient opportunity to identify and classify themes (Creswell, 2013). Although other software programs were available specific to qualitative analysis, such as NVivo 9, MAXQDA, and HyperRESEARCH, ease of use and familiarity with Atlas ti 8 made this the software program of choice for assisting identify and sorting themes for the research data. This qualitative study would not yield the same results if reproduced.

The only other limitation that might be of some concern was the differences in personality the participants exhibited. If the study was conducted in exactly the same manner with the same parameters, methodology, and research design, but with different participants with new personalities, the outcome might slightly change. However, seeing that this was a phenomenological study one could never obtain an absolute outcome. For that reason, the results of this study could not be statistically measured.

Summary

This chapter provided the introduction and overview of the problem philosophies, research methods, and concepts that contributed to the significance of this study. This included defining and examples of inner resources, spirituality, and meaning and the implications positivity has on the healing process and the social implications of the study. Examined through this research are the voices through stories told of women diagnosed with ABC and their lived experiences thoughts, feelings, beliefs, values and assumptive worlds. It was the intent of the researcher to illuminate how spirituality, in particular through IPA, positive psychology, and spirituality, influenced the cognitive and emotional processes (meaning-making) of African American women as they transition

from normalcy to being diagnosed with ABC. I was especially interested in the role spirituality and meaning-making had in empowering women living with ABC. Moreover, within this study, steps were made to identify specific ways medical providers and health care providers could better cultivate, initiate, and propel individuals living with chronic and terminal conditions toward the personal growth and adjustment afforded by the meaning making processes.

In Chapter 2 an in-depth examination occurs of the research and strategies that support the concepts from Chapter 1. Chapter 3 contains a review of methodology used, including participant information, data analysis, and data collection. Chapter 4 contains the results of the study, while Chapter 5 contains the findings from these results in relation to the literature and social change.

Chapter 2: Literature Review

Introduction

Friedrich Nietzsche (as cited by Frankl, 1984) reminded, “To live is to suffer, but to survive is to find some meaning in the suffering” (p.74). The purpose of this study was to examine the lived experiences of premenopausal African American women in Delaware who were diagnosed with ABC. Increasingly, spirituality and meaning and the effect on quality of life of women after a diagnosis of breast cancer are being studied (Breitbart et al., 2015; Meyerowitz et al., 1998). All women experience psychological distress shortly after a breast cancer diagnosis; however, African American women experience more fatalism and longer periods of depression even though they may have a spiritual foundation (Meyerowitz et al., 1998).

Young African American women diagnosed with breast cancer were chosen for this study primarily to examine their inner resources using sense of coherence (SOC), spirituality, and meaning. Though faced with the challenges of classism, sexism, and racism, many African Americans exhibit successful coping skills and appear to have a more spiritual perspective on their circumstance than other ethnicities (Bourjolly, 1998; Gibson, 2003). Sadler-Gerhardt, Reynolds, Britton, and Kruse (2010) showed that spirituality could empower young women to seek meaning during a life-changing event such as breast cancer. This self-transcendence allows them to see past their circumstance to live fuller, meaningful lives (Breitbart, 2002). The process of meaning-making can provide participants the safe space and opportunity to identify, create, and envision their unique life (and death) visions, as they describe this process as empowering. Kübler-Ross

(2007) wrote of empowerment: “People are like stained-glass windows. They sparkle and shine when the sun is out, but when the darkness sets in; their true beauty is revealed only if there is a light from within” (p. 120). In this chapter, I have compiled an interdisciplinary exploration into meaning, spirituality, African American culture, and an explanation of ABC, which is the focus of the study.

Search Strategy

For this review the main topics researched are quality of life and African American women, breast cancer, psychosocial needs, spirituality, meaning, coping mechanisms, ethnicity and breast cancer, barriers, SOC, and prayer. First, several interdisciplinary searches were explored for clarification of meaning and meaning-making. For this phase of the review, I examined definitions from artists, philosophers, social scientists, and authors. In addition, an examination of multiple peer-reviewed journals from various disciplines was included. The following search engines were used: Academic Search Premier, CINAHL Plus with full text, PsycArticles, PUBMED, Google Scholar, and Lyrics on Demand. The following keywords were used: *young African American & breast cancer, breast cancer, quality of life, BCS in young African American Women, Spirituality, Meaning, Ethnic differences, African American beliefs and breast cancer, African Americans and the Black church, BCS, ABC, Lifestyle and cancer, Breast cancer and sexuality, Sexuality and the Black church, Blacks and breast cancer diagnosis, African Americans, healthcare, and mistrust.*

Second, after receiving the search results, the articles were divided into sections based on the study design and the following terms were also included: *perception,*

reflection, interview, narrative inquiry, and storytelling. The reviewed articles indicated that spirituality and meaning were important coping tools for women diagnosed with breast cancer. However, while the articles were specific to African American women, the majority covered the age range of 40 and 65, which barely overlapped with this study's age range of 20 to 45 years.

Third, additional terms were searched, including *loneliness, body image, mastectomy, death and dying, spiritual laws, habits of highly effective people, cancer, survivorship, healing, and health promotion.* Snowballing or obtaining references from articles through a primary reference search offered an overabundance of reference materials, including books and studies using quantitative and mixed methodologies and interviews. My research garnered information on fatalism, depression, and advanced progression of tumors in young African American women with breast cancer, yet very little literature was found dealing with spirituality and meaning of young African American women between the ages of 20 to 45 diagnosed and living with breast cancer.

Theoretical Foundation

Seligman's (2008) concept of positive psychology was implemented in this study. Seligman posited that, when faced with life's challenges, a positive outlook could significantly change the outcome. When Seligman introduced positive psychology as the years' theme of the American Psychological Association, there has been a growing interest in this phenomenon. In addition, Seligman and Csikszentmihalyi (2000) stated that positive psychology defined an individual's well-being as happiness, enthusiasm, love, uniqueness, and purposeful living. This theoretical framework implies people will

experience positive health, which includes living longer, strong mental acuity, and improved prognosis when diagnosed with a life-threatening disease (Seligman, 2008; Underwood & Teresi, 2002).

The complementary framework that has utility for this study included the TRA and the TPB. These theories were developed for younger, more educated college population and proposed that behavioral goals were persuaded by attitudes toward the behavior and beliefs about the circumstantial and social appropriateness of the behavior (Ashing-Giwa & Ganz, 1997). The strength of the TRA and TPB included the association between beliefs, attitudes, and behavioral intentions (Montano & Kasprzyk, 2015). The literature also found an area of weakness using the TRA and TPB in the fact that behavioral intentions were often connected with actual behavior (Ashing-Giwa & Ganz, 1997; Montano & Kasprzyk, 2015).

Breast Cancer

The leading organizations in community research and education on breast cancer are the ACS (2017), National Breast Cancer Foundation (2016), and Komen (2017). As cited by these organizations, the most common cancer among women in the United States is breast cancer. Breast cancer is generally discussed as a single disease; however, there are many types and disease families of breast cancer (Komen, 2017). The commonality for all types of breast cancer is that the malignant tumor starts in the breast and, if not caught in time, can metastasize and infect other parts of the body (ACS, 2013, 2014). Every area of the breast can be infected, from the lymph nodes or blood vessels to the milk ducts. The most common of breast cancer is ductal or in situ carcinoma (Komen,

2017). These noninvasive types of breast cancer are most commonly found in the ducts, and are either ductal carcinoma *in situ* (DCIS) or lobular carcinoma *in situ* (LCIS; DeSantis et al., 2013). Although approximately 2,450 men are also diagnosed each year with breast cancer (ACS, 2012), women diagnosed with noninvasive types of cancer have a 70% to 80% favorable survival rate (ACS, 2012; DeSantis et al., 2013). However, individuals diagnosed with Stage IV or metastatic breast cancers have a 5-year survival rate of about 22% (ACS, 2012).

Research from the National Breast Cancer Foundation (2016) showed that women diagnosed with invasive breast cancers have a 70% to 80% poorer survival rate upon diagnosis compared to women whose breast cancer has not metastasized. Invasive means the cancer has spread; although the cancer remains localized in the breast, it has attacked other parts of the breast (Komen, 2017; National Cancer Institute [NCI], 2013), while regional breast cancer indicates the cancer is in the breast region. However, once diagnosed with distal breast cancer this simply means the cancer has traveled outside of the breast and has infected other areas of the body (NCI, 2013). Overall, women diagnosed with invasive breast cancer have a poorer survival rate than women diagnosed with noninvasive breast cancer. One type of invasive breast cancer is inflammatory breast cancer (IBC), which is known to pit or dimple the breasts. Other signs of IBC are the nipple becoming inverted and what looks like a rash on the breast, which can be warm to the touch. Although this type of cancer affects about 2% of the diagnosed, this form is highly malignant with an unfavorable prognosis (ACS, 2014).

In the United States, an estimated 232,670 women were diagnosed with breast cancer in 2014 (ACS, 2014, p. 3). The ACS (2013) reported that of the 232,670 newly diagnosed, approximately 82,080 should have been African American women. Continuing to flesh out the numbers, 62,570 were diagnosed with DCIS or LCIS (ACS, 2013). Although breast cancer is more common in White women, Black women tend to be diagnosed with advanced stages of cancer and have a lower survival rate (Bourjolly & Hirschman, 2001; DeSantis et al., 2013). In addition, statistics showed that African American women under the age of 45 have a greater chance of being diagnosed with breast cancer as compared to White women, and those under 30 have a 52% higher risk with a 5-year survival rate than White (Dunn, Campbell, Penn, Dwyer, & Chambers, 2009).

Treating cancer requires identifying certain protein receptors in the cancer in order to know which prophylaxis is needed. When diagnosed, many young African American women under 30 have a significantly shorter lifespan because oncologists are dealing with more aggressive tumors, which are likely to be triple negative (i.e., no positive protein receptors; ACS, 2013). Treating cancer successfully requires both an allopathic and holistically tapping into the mind and spirit (DeSantis et al., 2013). According to Holt (2007), neglecting to address spiritual or psychosocial support may impede healing and recovery. For example, one participant in that study stated that “having breast cancer gave [her] purpose” (Holt, 2007, p. 20).

Relationship of Literature to the Problem

Historical and in-depth literature can be found linking spirituality and meaning to the experience of chronic illness, especially breast cancer. Researchers considered meaning-making and spirituality as both a phenomenon and a transformative experience (Carter, 1990; Lin, 2008; Wong, 2010). This transformative experience, according to Taylor (1993), provided greater insight into finding purpose, while Killoran, Schlitz, and Lewis (2002) classified this transformational experience as a time of entering a journey, including one of clarification and wholeness. Killoran et al. (2002) observed the narratives of 17 long-term survivors of Stage IV breast cancer and found a thematic generalization from the participants: “One can have control over health and even resist a recurrence of cancer” (p. 208). Within the analysis, three themes included (a) the diagnosis as insignificant; (b) disbelieving the diagnosis; (c) faith, allopathic treatment, and individual resolve explain the survival of the terminal diagnosis. Killoran et al. (2002) concluded that a belief in North American culture implied faith and true resolve could have significant impact on healing. The researchers demonstrated this conclusion through providing life stories about the relationship between first personal story telling, the adverse situations, and what society offers (Killoran et al., 2002).

Meaning

During World War II, as a prisoner in Auschwitz, Frankl (1984) introduced the concept of meaning to psychological research. Frankl’s own experience in the concentration camp provided him the foundation for the theory of meaning. Logotherapy and existential analysis are built on the foundational works of Freud’s (1977)

psychoanalysis and Adler's (1964) individual psychology. Logotherapy is an original approach based on three philosophical and psychological concepts: freedom of will, will to meaning, and meaning of life (Frankl, 1984). This quest for meaning led him to the belief that meaning was unique to the human experience and was the precursor for mental and physical well-being. Klinger (1998) added that meaning provided one with the purpose to serve something greater than one's self.

Bellin (2009) and Maddi (1998) defined existential psychology as one's personal sense of meaning and the main determination of a person's thoughts and behavior. Moreover, it is in this existential space that research examines how family, culture, and social norms intersect to influence personal meaning and the personal daily choices one makes (Ryff & Keyes, 1995). Bellin (2009) and Maddi (1998) also reflected how people might transcend influential extra-personal norms to create a more personal meaning. Frankl (1984) suggested that similar to the story of Job in the Bible, people could be stripped of all other aspects of life (health, wealth, and family), but they have the choice to decide how they perceived the situation. It is in this ability to choose that can be transcendent and liberate an individual from past experiences (i.e., willfulness) and propel one into future possibilities (i.e., willingness; Bellin, 2009; Maddi, 1998). Maddi (1998) suggested that cynicism and criticism could be derived by individuals choosing the past and remaining stuck, whereas to choose a positive future and overcome adversity a person could experience "vitality of physical and mental functioning" (p. 6). However, one may question how young women living with ABC form a positive view of the future. Another question may include finding what possibilities are afforded to premenopausal

women who live with the knowledge that they are dying or at a minimum need to re-evaluate their outlook on life.

Research on Meaning

Inconsistencies in meaning were found while looking at general health and well-being (Park, Edmondson, Fenster, & Blank, 2008). The quest for meaning has been viewed as adaptive and appears to add to one's sense of self-worth and well-being (Bellin, 2009; Breitbart, 2005; Frankl, 1984; Park & Folkman, 1997). Further exploration found that distress might give rise to meaning making, confounding distress and efforts to make meaning (Park et al., 2008). For example, being young, and then being confronted to make sense of an ABC diagnosis, may certainly create distress in a young woman's life. However, this diagnosis may present an opportunity to challenge prior beliefs, evolve relationships, and change circumstances that may lead to a deeper more meaningful lived experience (Park et al., 2008).

Meaning as a Concept of Reality

Individuals may actively construct the meaning in their lives (Baumeister, 1991). Meaning is acquired socially and influenced by languages, communications, media, symbols, institutions, and cultural norms (Baumeister, 1991). Therefore, an individual's meaning derives from selecting among cultural offerings in the areas of societal norms, roles and expectations (Baumeister, 1991). There exist interesting implications when one examines the cultural offerings available to women living in the United States and, in particular, African American women with ABC. For example, the commonality of young African American women being treated for breast cancer and other ethnicities is that all

women are likely to gain weight, lose their hair, and potentially suffer significant breast disfigurement (Helms, O’Hea, & Corso, 2008). These commonalities often end there with little to no attention given to the perceptions African American women’s social norm, body images, and dark skin from prophylaxis, and hair loss (Watson, Livingston, Cliette, & Eaton, 2015). Thompson (2009) described the *distress* some African Americans already feel about their “too black, kinky, unruly, willful, or ugly” (p. 831) hair; hence, the possibility of going and remaining bald might keep some women from actively participating in treatment. Within the African American culture, black hair at any moment can be a sense of pride, identity, shame, or a political statement (Thompson, 2009). The loss of hair during breast cancer treatment combined with skin discoloration can therefore cause additional distress on the mind, body, and spirit (Thompson, 2009).

According to Helms et al. (2008), those living in a society that values thin, young women with perky breasts, and long hair find these changes (e.g., weight gain, hair loss and breast disfigurement), though cosmetic in nature, the most influential in a woman’s sense of well-being and adjustment to life after cancer. The unfortunate truth is that before examining content of character, African American women remain judged by their weight, body image, and color of their skin both within their culture and then by other ethnicities (West, 1993). Further, while meaning serves to aid in the discernment of patterns in the environment (prediction) and control of oneself (decision-making, guide actions, and regulate emotions), culture provides ideologies that aid in the construction of how people ought to behave, who they should be and what they should do (Baumeister, 1991, p. 8).

Emotions determined by goals. Most emotions and thoughts are determined by the goals one sets for one's self (Emmons, 2003). According to Klinger (1998), goals are considered the "linchpin of psychological organization" (p. 44). Emmons (2003) posited, "Without goals, life would lack structure, purpose" (p. 106) and meaning. The "psychic life of [a person] (as suggested by Adler, cited in Sweeney, 1998) is determined by [her] goals" (Emmons, 2003, p. 91). This positive relationship between goals, meaning, and life satisfaction is a recurrent theme in Wong and Fry's (1998) empirical research, and meaning combined with resilience has been demonstrated as associated with life satisfaction and vitality (Emmons, 2003). Further, a lack of meaning has been associated with depression and maladaptive behaviors (Emmons, 2003). According to Lewis et al. (2012), anxiety and the fear of dying, which caused severe depression, existed in 61% of their research participants. This is important when examining life satisfaction in women who live with ABC and the construction and reconstruction of life goals.

Work, intimacy, spirituality, and transcendence. Work, intimacy, spirituality, and transcendence (WIST) are the Big 4 that Emmons (2003) suggested as the possibility of personal meaning research. This classification of personal meaning is similar to that of the personality classification of the Big 5: openness, conscientiousness, extraversion, agreeableness, and neuroticism (Trapnell & Wiggins, 1990). Emmons (2003) presented three summarized research studies from the various research methodologies that categorized and studied the sources of meaning (Emmons, 2005; Wong & Fry, 1998). Of the three studies, four categories emerged from the robust findings: (a) achievements/work, which includes one's commitment to work, belief in worth, and

desire for challenge; (b) relationships/intimacy, which includes one's relationship with others, ability to trust others, and ability to be helpful and express altruistic behavior; (c) religion/spirituality, which includes one's personal relationship with the Divine, belief in afterlife, and participation in a faith community; and (d) transcendence/generativity, which includes one's contribution to society, transcending one's own interests, and leaving a legacy (Emmons, 2003, p. 108).

Four Needs of Meaning

Purpose and meaning. Baumeister (1991) purported four needs must be met for the construction of meaning: purpose, value, efficacy, and self-worth. The successful satisfaction of these four needs could contribute to one's sense of having sufficient meaning in life. This purposive connection associates events that are separate and links them to a future event. An example includes steps that lead to a meaningful outcome, such as graduation helping one to obtain wealth. Furthermore, people are motivated to obtain certain types of meaning in life.

Frankl (1984) suggested, "People need a sense of purpose in order to survive and that deprivation of purpose leads to death" (p. 48). Levinson (1978) studied adult male development in relation to careers and discovered that while in their 30s, men focused attention to career goals. However, while in their 40s, men became disillusioned and were forced to restructure their lives in a way that reappraised previous goals that were no longer viable to establish new goals. The new goals often emphasized family life (Baumeister, 1991). Further, Klinger (1998) found people went to great lengths to

maintain purpose and that, when a goal was abandoned, it was followed with depression, pessimism, and apathy.

Value and meaning. Baumeister's (1991) second need is to have a sense that one's life has positive value and that one's actions in life have been justified. Society, cultures, and religion often provide a value-base that serves as a guideline for making value judgments. In this study, one of the women who was 7 months pregnant was first surprised she conceived shortly after her last treatment of chemotherapy and believed her sense of value would be in caring for her child. She believed the child would become a part of her legacy. Finding value in one's actions and behavior appears to contribute to a person's creation of meaning. Evidence of this was found in the study of mothers who abuse or kill their children and seek validation or justification of their actions from spouses, physicians treating the battered child, or grandparents (Korbin, 1986). The response in recognition that sometimes children are difficult, or the silence of a physician attending to a child's wound were often misunderstood as validation that what the woman had done was justified (Baumeister, 1991).

Self-efficacy and meaning. Baumeister's (1991) third need is for a sense of self efficacy, or the belief that one is capable, strong, and has fortitude to overcome any circumstance. Another way to interpret self-efficacy in personality psychology is locus of control (Rotter, 1954). According to Csikszentmihalyi (1990), moderately difficult tasks are the bridge between boredom and feeling overwhelmed and anxious. Researchers indicated that the experience of lack of control results in ulcers, death in lab animals, and psychological disorders included learned helplessness (Brady, 1958; Seligman, 2008).

Learned helplessness is also found within African American women who lack credible breast cancer education, and non-communicative health care professionals regarding treatment; these women either shut down or do not return for treatment. This lack of attention continues to widen the gap between diagnosis and treatment (Ashing-Giwa & Ganz, 1997). An example of self-efficacy resulted with my study participants describing the “what’s in it for me” (WIISFM), as they each became experts in their life mission with ABC to reading everything they could find to satisfy their desire to understand their diagnosis, know their treatment options, and confront their actual outcomes.

Personal freedom is associated with one’s sense of control and self-efficacy. Historical socialization of women includes the “stifling of desires and conforming of bodies to external standards” (Baumeister, 1991, p. 53). From early ages, most African American women are taught not to explore or embrace their bodies, keeping the body covered as to not attract attention (Potts, 1996). By giving permission to embrace their bodies, it appears that promoting a sense of power in the lives of women may be especially valuable in their overall sense of well-being. In addition to this, self-efficacy has been associated with higher levels of relationship satisfaction and overall life satisfaction in women diagnosed with breast cancer (Manne et al., 2006) and in lower anxiety levels in women diagnosed with advanced cancer (Mystakidou et al., 2010). Again, this underlines the importance of encouraging choice and personal freedom in the lives of women diagnosed with ABC.

Self-worth and meaning. Baumeister’s (1991) fourth and final need is to find a sense of self-worth. Baumeister (1991) believed if people have a strong sense of self, they

were better equipped to deal with life's adversities. Self-worth is found both collectively and individually, and it can be associated with parenting, career, community, and culture. One's sense of self-worth gives the impression to be related to one's sense of superiority. Patterson (1982) spoke of the hierarchical experience of slavery and slave's ability to not internalize the dreadful conditions imposed by their masters, but they "struggled to maintain any shred of dignity, or respect they could find" (p. 54). During this time of slavery, many slaves found solace in Christian doctrine and the comfort in knowing the hierarchies experienced will be *inverted* in the promise land (Braumeister, 1991).

Holding on to the belief of a promise land, gave slaves a sense of superiority and allowed them to hold on to some dignity (Braumeister, 1991). An example of superiority and a struggle for dignity is Zimbardo's (1971) study of the Stanford prison experiment. At random students were selected to be guards and prisoners. Being encouraged to exercise the privilege of being guards, the prisoners were subjected to degradation while the prisoners tried to maintain their dignity by holding on to belief that the study would be over soon or the prisoners would be rescued.

Sense of Coherence and Meaning

The work of Antonovsky (1979) suggested that there might be a dispositional component of the individual that influences how one copes with life stresses and experiences physical health. This sense of coherence (SOC), according to Antonovsky (1979):

Is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic, feeling of confidence that one's internal and external

environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected. (p. 132)

According to Antonovsky (1987), veterans with a high SOC retained the resources to best deal with stressors and to be more resilient in their post-war lives. Cotton Bronk et al. (2009) found a strong correlation between a sense of hope (trait hope) and SOC. This suggests that individuals who face the threat of death appear to be more robust when empowered with a high SOC.

The diagnosis of cancer is often followed with elevated levels of emotional distress, anxiety and depressed mood reactions (Gustavsson-Lilius, Julkunen, Keskiivaara, & Hietanen, 2007). A strong sense of coherence (SOC) lessened the development of distress in patients diagnosed with cancer in the past 8 to 14 months (Gustavsson-Lilius et al., 2007). It appears that meaning construction that is accompanied by a sense of coherence and predictability contributes to a greater sense of wellness. Boscaglia and Clarke (2007) examined 120 women with a recent (less than a year) diagnosis of gynecological cancer and found that women who possessed a strong SOC, as measured by the Orientation to Life Questionnaire–Short Form (Antonovsky, 1987), were less likely to exhibit such traits as hopelessness, helplessness, loss of purpose and meaning and existential distress. This appears to suggest that promoting the development of SOC buffers the experience of existential distress.

Strang and Strang (2001) revealed that one's ability to comprehend a situation was largely related to thought construction rather than external circumstances. The thought construction and whether or not a person has a fighting spirit is crucial in

determining what motivated them for *going on*. Additionally, manageability was best achieved by being actively involved with information gathering strategies, by experiencing social support and by employing positive reinterpretation of the circumstance. Ultimately, one's sense of meaningfulness was imperative for quality of life and was related to close relationships and faith (Strang & Strang, 2001).

Spirituality and Meaning in Cancer Patients

Fryback and Reinert (1999) found importance “when a person is facing a serious illness, because the illness itself causes permanent changes in life that force a reevaluation in any previously assumed meaning” (p. 13). A participant from Sorajjakool and Seyle's (2005) study proclaimed that “health has more to do with your spiritual outlook and positivity and less to do with physical issues” (p. 29). Fryback and Reinert (1999) noted that people who have found meaning through their illness report an increase in the quality of their lives. The use of spirituality to cope with their breast cancer was found to be extremely important for African American women with breast cancer (Ashing-Giwa et al., 2008). Sorajjakool and Seyle (2005) referred to spiritual meaning making as a theological strategy that is employed by the person to construct meaning in the experience of a terminal diagnosis, in particular breast cancer. The authors identified the three strategies as: (a) God allows illness (breast cancer) for a purpose; (b) God does not cause cancer, but there can still be meaning in the experience of the illness; and (c) cancer is just part of life and has no inherent meaning (Sorajjakool & Seyle, 2005).

Research demonstrates that spiritual beliefs influence coping with cancer, control of pain, and development of clinical depression and suicidal ideation (Breitbart, 2005;

Holt et al., 2003; Marinelli, 2009). In a study conducted by Mattis (2002), African American women were asked to describe concepts of meaning used to deal with their breast cancer experience. Holt et al. (2009) identified five major themes; including (a) survivorship, (b) purpose and destiny, (c) attitude, (d) trust in a higher power, and (e) spirituality. Although meaning-making is important in accepting a breast cancer diagnosis, the themes from the research focused more on religiosity and cancer.

Intrinsic spirituality not only helps in coping with a diagnosis of cancer, but it was also observed to aid in the flourishing of women diagnosed with breast cancer (Marinelli, 2009). While a diagnosis and treatment of breast cancer may be accompanied by physical (hair loss, sexual dysfunction, hot flashes, and night sweats) manifestations, there lingers the threat of recurrence and death (Lewis et al., 2012; Marinelli, 2009). However, even in the face of death, having a spiritual foundation appears to not only safeguard women from significant psychological distress but acts to provide opportunities to thrive despite the diagnosis. For example, in their study of 35 African Americans with various cancers, Holt et al. (2003) concluded that spirituality was integrated holistically, as well as the belief that the circle of life and death could lead to peace of mind. This would imply that providing ABC patients with the opportunity to explore their existence and questions about the spiritual nature of death as a process of life may promote a sense of comfort and inner peace. This can also lead to better outcomes.

Spirituality and African Americans with Breast Cancer

The Bible is filled with countless parables of individuals being victorious over adversity often at the loss of everything but their soul. The apostle Paul speaks of a thorn

in his flesh, being stricken with a malady so that he may not yield to the temptation of conceit (2 Corinthians 12:7-9). Job was a prosperous wealthy man of impeccable morale fortitude who was allowed by God to be tested. Job lost everything including his children; it was his trust in the Redeemer that not only restored his health but wealth more abundantly (Job 1-44). African American women may have read or are familiar with these stories and have related them to their own adversity. Like the apostle Paul or Job, they have also pleaded with their higher power to take away their dis-ease as they struggled with their cancer. It is not uncommon for faith to waiver when presented with the realities of a health crisis. One may ask and wonder, “Why me, Lord? Why now? If God can heal me, why am I not healed?” These are just three questions that arose during the participant’s interviews.

The research conducted by Sadler-Gerhardt et al. (2010) identified spirituality as playing a significant role in coping with physical, psychological, and emotional distress among 23 African American patients in various stages of breast cancer. Sadler-Gerhardt et al. also provided details on emerging themes which support the significance of spirituality and healing. These themes included the importance of social support, a connection with God, the desire to share their stories and a new self-understanding and meaning because of their illness experience (Sadler-Gerhardt et al., 2010).

In a quantitative study of 145 African American women and 177 White women with breast cancer, the measures of religiousness did not yield statistically significant results in proving a consistent pattern of non-religiousness to be more strongly and negatively related to breast cancer survival in Black compared to in Whites. However, an

exploratory model from this study confirmed that lack of both religiousness and spirituality was associated with poor breast cancer survival among African American women (Van Ness et al., 2003).

The relationship between spirituality and health is unknown, yet there has been an ongoing debate in the literature as to whether spirituality has a positive, negative or no effect on health. Church-based health interventions have been promising in promoting health within the African American community (Payne, Bergin, Bielema, & Jenkins, 1991). Researchers created the Witness Program, a program made up of African American breast cancer survivors who taught their peers about breast cancer early detection through telling stories (Erwin, Spatz, Stotts, Hollenberg, & Deloney, 1996). A study showing a negative association with spirituality and health was conducted by Koenig, Moberg, and Kvale (1988) where, among a sample of mainly White elderly women in a geriatric assessment clinic, religiosity was inversely related to health. A study of 193 multi-ethnic adults at a community center in Los Angeles found that African Americans were more likely than any other ethnicity to believe that prayer can cure a disease (Klonoff & Landrine, 1996).

Meaning and Suffering

According to Frankl (1984), the search for meaning is a primary motivator in life and is uniquely discovered by the individual. Meaning can be derived from three different pathways that include (a) creating a work or doing a deed, (b) experiencing something or encountering someone, and (c) by the attitude we take toward unavoidable suffering (p. 115). In his discussion of suffering, Frankl (1984) stated, “What matters is to bear

witness to the uniquely human potential to transform a personal tragedy into a triumph” (p. 116). Frankl (1984) declared, “If there is a purpose to life, then there is a purpose to suffering” (p. 9). It would seem to follow that an attempt to find meaning in suffering is key to a sense of wellness. Baumeister (1991) noted people were willing to experience great discomfort, endure pain, and tolerate deprivation if an apparent purpose to the suffering existed. Additionally, for people to recover from such atrocities, they would need to find some sense of understanding to the circumstances (Baumeister, 1991) and then seek to rebuild their assumptive worlds (Park, 1998).

The experience of a breast cancer diagnosis in women has been described as a time of turmoil, loss and potential for nonbeing (Crooks, 2001). In her qualitative examination, Crooks (2001) found that women diagnosed with primary breast cancer experience a process unique to their pursuit of meaning. Initially a woman may experience a period described as *facing the music*—the lump is discovered, hearing the diagnosis, and taking action. Following treatment women may attempt to get *back to normal* by doing previously enjoyed activities, assimilating changes, and selecting relationships that are supportive. A period follows when women attempt to get perspective on the disease and the overall prognosis by making comparisons of other experiences, having hope, and sharing metaphors with others who have experienced breast cancer diagnosis. Finally, women seek to feel different than before the diagnosis of breast cancer by acknowledging their aloneness in the experience of a cancer diagnosis, examining beliefs in relation to their diagnosis, and making connections with those who

have experienced breast cancer (Crooks, 2001, p. 105). This is a process that appears to be afforded by time.

Spiritual Meaning Scale

Meaning can be conceptualized from a three-dimensional approach that includes implicit meaning, personal, and spiritual meaning. In this context, spiritual meaning is defined as the inherent functions attached to life. Mascaro and Rosen's (2005, 2006) 15-point Likert Spiritual Meaning Scale (SMS) can give measurements at the level of hope, depression, and anxiety for patients, who have an acute illness. Spiritual meaning does not only manifest in an individual's life, but is demonstrated beyond the human life. Essentially, the underlying truth in the SMS is that individuals cannot rely on personal goals alone to determine the essence of life. SMS can be used in providing measurements for existential meaning.

Functional Assessment of Chronic Illness Therapy: Spiritual Well-Being Scale

Peterman, Fitchett, Brady, Hernandez, and Cella (2002) constructed the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-SWB), a self-report scale designed to measure spirituality in individuals with chronic illness. The scale is based on two dimensions: (a) meaning as reflected in one's sense of meaning and purpose in life and (b) faith which involves one's perceived comfort derived from a connection to something larger than self. The authors found that the faith dimension correlated to existing measures of religiosity and spirituality, while the meaning/peace component was related more to purpose in life (Peterman et al., 2002).

This implies that meaning captures a facet of spirituality that is not strongly related to religiosity (Yanez et al., 2009).

Munoz, Salsman, Stein, and Cella (2015) described FACIT-SP as a tool of measurement used to determine the level of spirituality among patients with chronic diseases and cancer. Existential dilemma is the subject of intense concerns about life and death whenever an individual is diagnosed with cancer. The benchmark duration for existential plight is 100 days according to some researchers and scholars. However, some longitudinal studies have raised serious doubts over the impact of diagnosis of advanced cancers. Essentially, longitudinal studies raise doubts on whether a diagnosis of an advanced cancer situation can take a long period for adjustment (Hope, 2006). The idea behind the study is to find out the correlation between the quality of life and the spiritual well-being of patients diagnosed with cancer (Hope, 2006).

The Role of Narrative in Personal Meaning

The role of narrative in personal meaning cannot be over emphasized (Preston, 2002). Narrative with personal meaning provides a basis for sharing experiences and events that can derive meaning and provide a basis of understanding certain issues of concern. Preston (2002) noted that the sole purpose of personal narratives was to provide a first-hand account on an issue that directly affected another person. The essence of narratives is to demonstrate some formal impact on the life of a person depending on the situation.

The psychological impact of the experience drawn from a personal level helps in deriving meaning and understanding concerning the point of discussion. Preston (2002)

showed that patients who previously suffered from acute illness and survived had significant impacts in helping the others heal or gain hope. Meaning derived from when people can communicate and exchange ideas. Personal narrative is essentially the basis over which meaning is derived from a concept (Preston, 2002). Meaning cannot be derived in a vacuum or without components of the discussion. Narratives are critical because they provide a basis for deriving understanding over past experiences. The context of the discussion must be meaningful to the situation that is being dealt with at that time.

Qualitative Paradigm of Narrative Analysis

Sadler-Gerhardt et al. (2010) examined the life stories of eight women breast cancer survivors for posttraumatic growth and meaning making. Employing a qualitative methodology from a phenomenological paradigm, the researchers interviewed women who had been diagnosed with breast cancer 10 months to 5 years prior. Participants varied in age (30 to 80 years), and ethnicity (i.e., six Whites and two African Americans). One participant was diagnosed with metastases and was being treated during the study. The 90-minute semi-structured interview consisted of open-ended questions designed to elicit themes pertaining to the survivorship experience, the possibility of positive or negative changes during the journey, the attribution of meaning to the cancer treatment, and the dialectic of living with the uncertainty of recurrence (Sadler-Gerhardt et al., 2010, p. 269).

The recurrence of the same themes within and across participants' stories is important in qualitative research (Sadler-Gerhardt et al., 2010). Themes for women of

childbearing age included fear of chemotherapy resulting in infertility. Additional themes included the presence or absence of supportive help, changing life priorities, and altered relationships. All participants described seeing their lives in terms of pre-diagnosis and post diagnosis, and reported physical, emotional, and spiritual changes because of the diagnosis (Sadler-Gerhardt et al., 2010).

Coping and Support

Any chronic illness can cause devastation and isolation from family members and friends. Bourjolly and Hirschman (2001) conducted an interview of 25 African American's with breast cancer, several felt isolated and rejected due to lack of education and understanding regarding breast cancer. In the same study, one woman stated she lost friends because they "partially believed breast cancer was contagious and could be caught (like a cold)" (Bourjolly & Hirschman, 2001, p. 25). Patients diagnosed with cancer can feel neglected and isolated. Among teenagers and young adults, cancer can make them feel as though they are losing their sense of independence to the extent that they have to rely on other people for support (Bourjolly & Hirschman, 2001). Patients diagnosed with cancer suffer varied effects offering a complicated lifestyle for the victims.

Coping with physical and emotional support challenges is a critical issue of concern that must be dealt with whenever the need arises. Young people, diagnosed with cancer, suffer numerous psychosocial issues. A strong support network of family and friends is essential in enabling the patients to cope with the illness in the present and beyond (Bourjolly & Hirschman, 2001). Spirituality is a critical support area in ensuring that the emotional needs of the patients are catered for as appropriate (Bourjolly &

Hirschman, 2001). An individual's faith and the religious attachment are essential in meeting the emotional needs of patients.

The level of support and coping depend on the way in which the patient suffers from a chronic illness. The physical support that a cancer patient can receive is the chemotherapy sessions. Chemotherapy is a treatment that helps in killing the adverse effects of cancer cells in an individual's body. Physical support also includes being available and giving a helping hand whenever necessary and giving words of encouragement as may be appropriate (Bourjolly & Hirschman, 2001). Pain and fatigue are critical areas where support is crucial to ensure that patients can gain and meet their physical needs.

Summary

This chapter searched current theories, measurements, and research that pertain to the ideas of personal meaning, spirituality, and narrative. The focus was on the construction of meaning and employed positive psychology and health related quality of life as a framework and the role of narrative in overall well-being. This chapter has laid a foundation to examine the stories of young African American women diagnosed with ABC.

The participants in this qualitative study contributed to the field of public health by illuminating the unique experiences of women diagnosed with advanced breast cancer, and the importance of spirituality and the construction of meaning can influence. Self-efficacy and empowerment in these women and can potentially provide healing properties when incorporated into a treatment plan after diagnosis. Chapter 3 provides the

methodology to begin the process of selecting the women who want to share their stories and collecting and analyzing the research gathered.

Chapter 3: Methodology

Introduction

In this phenomenological study, I explored the lived experiences of premenopausal African American women, between the ages of 20 and 45, who were diagnosed with ABC, and I identified the inner resources, specifically, the role of sense of coherence, self-transcendence, and meaning as a source of comfort and healing. The purpose of this study was to examine the lived experiences of premenopausal African American women in Delaware who were diagnosed with ABC. This chapter outlines the phenomenological method that was used to explore experiences common to the participants, the framework of the study, the participant selection process (e.g., inclusion and exclusion criteria), the role of the researcher, the measures taken to protect participants, and the process of data collection and analysis.

Research Methodology

Phenomenology was the most appropriate methodology for examining the lived experiences of a first-hand account of spirituality and meaning-centered coping of the women in this study. Phenomenology, based on early 20th century philosophy, is rooted in rich descriptive interviews and in-depth analyses of lived experiences, which explain how meaning is designed through insight (Finlay, 2009; Giorgi & Giorgi, 2008; Reid, Flowers, & Larkin, 2005; Starks & Trinidad, 2007). Finlay (2009) posited that through phenomenological research, in-depth descriptions of lived experiences, using first person, would dispel intellectual generalizations (p. 10). After the researcher has analyzed the data, a congruent account of the general themes can be offered (Finlay, 2009).

Phenomenology offers another prospect to the positivist view of science, and presents a new way to interpret consciousness and the individual's participation in the world (Beck, 1994). Husserl (1970) rejected the belief that objects in the external world exist independently and that the information about the object is reliable. Husserl (1970) posited that people can be certain about how things appear, or present themselves to their consciousness. Husserl named his philosophical method phenomenology, the science of pure *phenomenon*. Husserl (1970) also wrote that "Realities are treated as pure 'phenomena' and the only absolute data from where to begin" (p. 55).

In contrast, Heidegger and Ricoeur's (as cited by Finlay, 2009) interpretation of interpretative phenomenology is emerged from hermeneutic, which stresses the importance of interpretation of the lived experiences by the researchers. The perception of the lived experience is detailed with rich examination, and the researcher takes an active role in process of understanding the participant's point of view while interpreting the results (Finlay, 2009; Reid et al., 2005). Moustakas' (1994) phenomenological ontology shows that within one population, participants can experience multiple realities within specific settings. This type of phenomenology is critical in interpretive analysis; it explains the study's participants because their reality included beliefs, attitudes, and health behavior experiences that affected how they managed their diagnoses.

Research Questions

The IPA tool was the method that I used in examining the phenomena, background, and ideas of spirituality and meaning-centered coping for premenopausal African American women diagnosed with advanced breast cancer. The foundation of IPA

was used to shape this study. Therefore, the research questions guiding this study focused on the following questions:

RQ1. To what degree do premenopausal African American women diagnosed with advanced breast cancer find utility in incorporating spirituality and meaning?

RQ2. How do premenopausal African American women diagnosed with advanced breast cancer find utility in incorporating spirituality and meaning?

RQ3. When do premenopausal African American women diagnosed with advanced breast cancer find utility in incorporating spirituality and meaning?

Qualitative Interviews

According to Stark and Trinidad (2007), a primary way to collect data for a qualitative research is to conduct in-depth interviews. The qualitative research questions were guided using phenomenological methodology. In contrast to quantitative interviews, qualitative interviews gather feelings, ideas, intentions, and thoughts from the participant and thus allow the researcher a view of the participant's perspective (Stark & Trinidad, 2007). Using a semi-structured open-ended interview questions (see Appendix B) allowed me the opportunity to have a set of interview questions and use these as a guide or prompt to keep the participant engaged in telling her story. Open-ended or semi-structured interviews are successful when sets of predetermined questions are used for all study participants (Reid et al., 2005).

There are limitations when using the semi-structured approach one of which is the approach does not allow for the pursuit of going in a different direction from the predetermined questions (Reid et al., 2005). Conversely, a structured approach minimizes

the ability to flesh out the nuances of the data (Reid et al., 2005). For the novice researcher with only one opportunity to meet with participants the semi-structured interview is the best option when conducting a qualitative interview (DiCicco-Bloom & Crabtree, 2006; Patton, 2002).

Participant Selection

Dalbye, Calais, and Berg (2011) suggested that interviews cannot be conducted without prior approval, and there is a method to garnering trust and access to a community and its participants. Since this study required the participation of human subjects, prior to any data collection, I submitted the application to pursue the research to the Institutional Review Board (IRB) at Walden University. The IRB scrutinized the application process to safeguard against mistreatment of human subjects and to ensure that all ethical standards are met and the research is within the U.S. federal guidelines for compliance.

I began building my IRB application by first submitting letters of introduction (Appendix C) to the breast cancer organizations, and churches throughout Delaware; in addition, 10 letters were sent in total. This letter provided personal and educational aspirations, the premise of my research, and a request to solicit cooperation from their members to participate in a qualitative research study. The introduction letter also provided the name and credentials of Committee Chair. The electronic package also included the consent form (Appendix A), and a letter of cooperation (Appendix F). This letter stated the organization's wishes to support my research and would me to recruit from their membership. This letter was signed by a director and returned on letterhead

either to me or directly to the Institution Review Board (IRB). Two organizations returned their Letters of Cooperation: the Delaware Breast Cancer Coalition (Appendix F) and Sisters on a Mission (Appendix G). The Helen F. Graham Cancer Center that indicated their women, once diagnosed, are referred to either organization.

Once the IRB application was approved from Walden University, I scheduled individual meetings with the directors to discuss recruitment and answer any additional questions they might have had. The flyer (Appendix E) was created as the recruitment tool. I asked the communications manager if the flyer could be placed in the electronic newsletter and posted in the common areas of the office. The flyer contained a synopsis of the research and the criteria needed for participants, as well as my contact name, number, and email.

Purposeful sampling techniques, as well as snowballing, were used to identify the women for this study. Stark and Trinidad (2005) described purposeful sampling as a widely-used method of choosing participants and locations. Criterion sampling was needed once potential participants were identified and selected. The criteria for inclusion included all women interested must self-identify as African American women, between the ages of 20 to 45 with ABC. The premise of my study was to understand the utility of spirituality and meaning-center coping for premenopausal women when faced with the challenge of advanced breast disease. In addition, the participants should also have a minimum of six months post-treatment, and have a strong support network. I successfully recruited 10 participants for my research; however due to scheduling only seven

completed their interviews. All study participants self-identified as African American women, diagnosed between the ages of 20 to 45 with ABC.

Phenomenological research has no set rules for the number of study participants a researcher can have (Patton, 2002); however, Creswell (2013) posited that the ideal study participant number in a phenomenological study was between 5 and 25. To understand the characteristics of the phenomenon being studied the sample size must be large enough; however, there is no set number for a sample size. Reid et al. (2005) determined that the sample size meant when the researcher collected ample comprehensive data from the participants to answer the research questions. Methodologists who specialized in qualitative research posited that this type research could be conducted with a small sample size and suggest 5 to 25 participants; others claimed that 3 to 10 was sufficient (Creswell, 2013; Patton, 2002; Reid et al., 2005; Yin 2015). The required sample size to understand lived experiences of premenopausal African American women with ABC was seven. This sample was large enough to answer the research questions of the current study.

I conducted an initial telephone interview with each woman and discussed my background, and her reasons for wanting to participate. I collected a brief demographic history and ended the call with a time most convenient for us to conduct our interview. The women were also given my contact information if questions arose or we needed to reschedule the interview. Once the selection process was completed and interviews were scheduled the details were discussed about the interview process and how data is collected and stored. Each participant was explained my semi-structured interview

method, my questions (Appendix A) were developed as a guide to keep the interview fluid, conversation-like, and on point. However, women could share how much or little they felt confident in sharing.

The 2x3 breast cancer toll-free helpline card (Appendix D) was provided with a pre-paid cell phone, bottle water and a box of tissue. These items were offered for the unlikely event the participant experienced acute psychological distress brought on by the sensitivity of the interview. The toll-free number was linked to a confidential counselor available to provide minimal counseling until the participant could get to her primary care or mental health provider. Lastly and as a thank you, each participant signed a compensation voucher (Appendix C). The compensation was either a \$10 gift card or a \$10 charitable donation to the nonprofit of their choice. Once again and prior to proceeding, participants were asked if there were questions about the consent form, how their information would be used, and how data would be collected and stored. To protect the privacy of the women, they were all provided a pseudonym. All research materials were kept in a locked file in my home office, including a dedicated cell phone that was purchased if a participant needed to call the breast cancer helpline number that was provided.

Role of the Researcher

Individuals tell their stories for a myriad of reasons; for example, making connections, conveying information, and wanting to be heard were the reasons given by Singer and Rexhaj (2006). My role was to create a meeting space that was quiet and convenient for the women to tell their personal stories and explore meaning related to

living with ABC. Additionally, I digitally recorded and transcribed each interview. Transcribing the interviews afforded me the opportunity to examine the constructed stories in depth and to capture intrinsic nuances of meaning in the narratives. According to Bellin (2009), it is the role of the researcher to delve into the stories fully and completely, “as a lover desiring to grasp their every detail” (p. 20). Flick (2009) stated, “The subjectivity of the researcher and of those being studied becomes part of the research process” (p. 16). Hence, it is the communication or interaction of the researcher with the narrative that becomes an explicit part of the knowledge gained.

Arrangements were made for meeting in libraries and hotel meeting rooms; however, most the women chose the safety and comfort of their homes for the interviews. I reduced the risk of introducing bias into my research by keeping my questions and body language neutral, not offering an opinion, and keeping a journal. Each interview was digitally recorded and transcribed. Transcribing the interviews afforded me the opportunity to examine the constructed stories in-depth and capture intrinsic distinctions of meaning-centered coping in each lived experience. Furthermore, each participant was given a narrative of her transcribed interview, prior to the data being analyzed.

The inductive logic of IPA requires relative similarity among participants so that they have applicable findings in the phenomenon being studied (Smith, 2011). IPA seeks rich, contextualized, and collaborating analysis of the data of a sample which allows the reader to evaluate transferability in another context (Smith, 2011). Therefore, to capture the homogeneity of my participants, the following was considered equal: time living with diagnosis, gender, education, socioeconomic status, and stage of life. Maxwell (2013)

postulated that gaining access to participants, the role of the researcher, the building blocks to a successful interview, and following ethical considerations must all be accounted for prior to going into the field. According to Creswell (2013), criterion sampling blended with a phenomenology study is ideal since all individuals sampled have the “lived experience of the phenomenon” (p. 155), which is ABC.

Interpretive phenomenology analysis (IPA) research relies on the commitment of rich, in-depth data of specific samples. It is an issue of quality versus quantity, and IPA studies focus on small sample sizes of three to six participants (Smith, 2011). In addition to this, adequacy of data in qualitative research is based on the criterion of saturation, or the lack of further emergence of information upon coding new data. Lastly, IPA is both creative and dynamic and allowed for the constant communication between myself, the participant, and data that promote rich, copious data (Flick, 2009; Smith, 2011).

Data Collection

Once I received IRB approval (IRB approval #05-11-16-0281197) from Walden University, I began data collection in Delaware. Data collection began June 2016. Moustakas (1994) theorized in phenomenological research the primary data collection tool is the researcher. Prior to interviewing my participants, each read were given time to ask questions then signed a copy of their consent form (Appendix A). A copy was also provided to every participant. All interviewees gave their consent to also allow their interviews to be digitally recorded. To protect the participants confidentially, pseudonyms were assigned to each participant. Interviews ranged from 45 to 90 minutes, and each were conducted in a convenient location chosen by the participants.

Fieldwork was the next step in the data collection process. Prior to going into the field, the researcher must anticipate and plan for obstacles or ethical issues that have the potential go wrong (Maxwell, 2013). For example, as a researcher, I was aware of the delicacy of entering a community, understanding, and gaining trust participants place in me to keep their confidence, how their data would be secured, and other ethical issues (Maxwell, 2013). Dispelling my personal bias toward premenopausal African American Women who have ABC was imperative to recognize and overcome prior to interviewing study participants.

To ensure participant's privacy, each participant was given the option of where to have their interviews conducted; a meeting room at a local hotel was secured to conduct interviews. However, most the women felt more comfortable having the interviews conducted in their homes and one woman met in a private room at the public library. When asked why the women preferred their home rather than a neutral environment, the answer was that their home provided a sense of safety and security. A semi-structured interview guided each interview. The interview questions were used as a guide to gently ease along the interview in a conversation like manner. The toll-free breast cancer helpline 866.312.3222 was given to each participant in case she needed to talk with a confidential counselor due to acute psychological distress or sadness brought on by the sensitivity of the interview. This helpline (Appendix D) provided both local and regional consumer resources. A cellular phone was also provided if needed and was handled with the same confidentiality as participant information.

Data Management and Analysis

Prior to starting a research project, the method in which the researcher plans to store, code, and decipher qualitative data needs to be in place (Smith & Firth, 2011). Smith and Firth (2011) further detailed handling qualitative data, the researcher must ensure (a) the caliber of the accessible data, (b) documentation, and (c) how long the data must be stored after the research is complete. The computer assisted qualitative data analysis software (CAQDAS) is dedicated qualitative data analysis software. There are several CAQDAS programs available, but I selected Atlas ti 8. After reviewing several software packages, I settled on Atlas ti 8 for its ease of use and the features, such as concept-mapping; this feature showed visually the relationship between participants.

Issues of Trustworthiness

Validity

The standards of validation include ensuring quality, trustworthiness, and credibility in qualitative research. Creswell (2013) stated that these standards could only be achieved by in-depth time spent in the field and by triangulating the data sources, methods, and evaluation. Triangulation involves documenting evidence from a variety of sources to explain a specific theme or perspective. Quantitative research has been evaluated in terms of reliability, validity, objectivity, and replicability (Lieblich et al., 1998). While some would posit the same criteria for qualitative research, there are inherent challenges in the concepts of *validity* and *reliability* with respect to narrative research (Flick, 2009).

The goal of qualitative research is to capture the voices of the diverse and marginalized (Flick, 2009; McAdams et al., 2001). This suggests that validity is best viewed as horizontal and not linear, as would be seen in quantitative research. This method was instrumental in validating themes and direction identified, and this is also where research is most scrutinized requiring a paradigm that promotes scientific rigor (Smith, 2011). Morrow (2005) suggested that the markers of excellence for qualitative research design included credibility, transferability, dependability, and conformability. For accuracy and credibility, I transcribed all interviews verbatim and provided the transcripts to each participant for review and edits before analysis begins.

Reliability

I transcribed interviews verbatim and to ensure fidelity provided the transcripts to each participant for review and edit before analysis. Starks and Trinidad (2007) asserted that qualitative research was fundamentally individual because the primary research tool was the researcher. They confirm this idea by showing that all decisions—themes, coding, and background—are decisions made by the researcher. I used bracketing to identify my feelings, responses, and thoughts of nonverbal communication while in the field. I kept a research journal to capture self-reflections during interviews and identify themes for bracketing, as suggested by Starks and Trinidad (2007).

Summary

This qualitative study explored lived experiences of premenopausal African American women with advanced breast cancer and the utility of spirituality and meaning before during and after treatment in the state of Delaware. Interpretive Phenomenological

Analysis was the qualitative research method guiding this study. The use of phenomenology examined the lived experiences and commonalities in a self-reflective non-judgmental was used to create a caring, self-reflective, and compassionate relationships that helped foster a thematic focus, as suggested by Moustakas (1994), for this premenopausal demographic in the state of Delaware. This chapter focused on the methodology of the study, the participant selection, the role of the primary investigator, inclusions, and exclusions of the study the necessary length of time needed to protect the human subjects trusting me with their intimate stories, and lastly, how the data was collected, managed, and analyzed.

Seven women, between the ages of 20 and 45 who experienced an advance breast cancer diagnosis and lived in Delaware, participated in the study that examined spirituality and meaning-making as meaning centered coping after their diagnosis. After the study, participants who agreed to participate had time to ask questions, as well as read and sign the informed consent form. I conducted open-ended in-depth interviews to understand their beliefs and experiences regarding while working in the fields. All data were transcribed and uploaded in to Atlas ti 8 or data management and analysis. Lastly, bracketing was used to ensure my personal bias did not find its way into my research. Chapter 4 examines the analysis and findings of this study.

Chapter 4: Results

Introduction

The purpose of this study was to examine the lived experiences of premenopausal African American women in Delaware who were diagnosed with advanced breast cancer. This chapter presents the findings from in-depth interviews with seven African American premenopausal women diagnosed with advanced breast cancer regarding their lived experiences and spirituality and meaning-making/meaning-centered coping with their diagnosis. This chapter will detail methods used for recruitment, the research instrument, participant setting, data collection process, and the themes produced through qualitative data analysis. The written and transcribed responses to these interviews became the data analyzed for this study.

Several studies have identified the significance of spirituality on the quality of life and the potential of finding purpose once challenged with a chronic and life changing illness. However, many of these studies presented data for older adult survivors of breast cancer. Previous studies examined quality of life, ethnic comparative studies, or preventative care and maintenance of breast health. Other longitudinal studies examined African American women and survivorship. However, very little is known about premenopausal women between the ages of 20 and 45 who were diagnosed with ABC and how they coped. Therefore, this study sought to elucidate their perceptions of spirituality and meaning-making and its importance to their survival. Understanding their perceptions and the utility of spirituality during the critical stage of diagnosis can reduce morbidity and mortality.

The qualitative data were collected by in-depth face-to-face interviews of seven premenopausal African American women during the months of June and July 2016. As described in Chapter 3, potential participants were screened for good fit to study criteria. To keep data collection and analysis faithful and transparent, I kept an ongoing journal that allowed me to bracket and address my professional and personal biases that informed my interpretation of the emerging themes. One example, during the analysis of data that pertained to what degree spirituality and meaning-making was utilized after being diagnosed, at that time my mother was diagnosed with breast cancer. It was important that I note my bias that being handed this diagnosis at any age is a loss as I began looking at morbidity and mortality on a personal rather than distant level. This consciousness allowed questioning and me to bracket this bias when analyzing the data that described the participant's experience related to fear. The following research questions are answered in this section:

RQ1. To what degree do premenopausal African American women diagnosed with advanced breast cancer find utility in incorporating spirituality and meaning?

RQ2. How do premenopausal African American women diagnosed with advanced breast cancer find utility in incorporating spirituality and meaning?

RQ3. When do premenopausal African American women diagnosed with advanced breast cancer find utility in incorporating spirituality and meaning?

Study Setting

Once approved by Walden University's Institutional Review Board (IRB approval #05-11-16-0281197) to proceed to the final study, I began recruiting from three counties

in Delaware. Each woman who agreed to participate and met the qualifying criteria were contacted via telephone to answer any additional questions and to set up the time and location for their interview. Every participant was reminded the study was voluntary and they could withdraw at any time and the gratuity would not be withheld if they decided not to continue with the study.

Coding Analysis

I utilized the qualitative research software Atlas ti 8. I transcribed the audio files, into a word document. I read each transcription a minimum of five times for familiarity, coding and identification of common themes. Initially, I identified participant's responses to each interview question, in a boarder sense in relation to the three research questions.

Next, I coded each transcript using an inductive coding approach. Inductive coding allows the researcher to flesh out repeated or important themes from raw data (Thomas, 2006). Thomas (2006) identified a five-step process for using inductive coding:

1. Prepare the raw data files, also called data cleaning, where the researcher formats the data files in a similar format;
2. The researcher reads the text with close detail until they are familiar with the content;
3. Create categories;
4. Overlapping codes or uncoding text as needed; and
5. Continued with refinement of the categories and within each category search for subcategories.

The initial coding categories had multiple iterations after reviewing the data. Once a new code was identified or deleted I went back to each transcript to re-read the data and made the necessary changes. I organized subcategories under each of the three main research questions. The subcategories allowed me to differentiate between each participant's responses about how they managed meaning and spirituality.

Data Verification

Using direct quotes from the transcripts of my participants that supported the lived experiences captured through the interviews was one use of member-checking protocol for limiting personal bias. The emerging themes provided a more comprehensive consideration of my participant's perceptions and behaviors toward their diagnosis and acceptance. These perceptions included the utilization of self-efficacy, transcendence, spirituality, and meaning-making.

Description of Participants

To protect the names and confidentiality of the participants, each was provided a pseudonym and number code for and throughout the study. All women self-identified as African American, heterosexual, and have a minimum of high school education. They all live in the state of Delaware and were between the ages of 21 to 45 at initial diagnosis.

Crystal is a 25-year-old single woman, non-smoker (diagnosed at age 22). A high school graduate, who has taken college courses, Crystal is currently on disability due to her illness. She lives in Delaware with her 2 children (3, and 6 years). Her knowledge of breast cancer prior to being diagnosed was "little to none." She believed there was no history of breast cancer in her family. She went to the hospital because her right breast

was red and very swollen. At the time, she was nursing her child and her doctor said it was probably milk that clogged her duct. She was diagnosed with Stage IV metastatic breast cancer in April of 2013. In addition to chemotherapy, radiation, and multiple breast surgeries, including a hysterectomy, she had no breast reconstructive surgery.

Alexandra is a 35-year-old married woman, non-smoker (diagnosed at age 30). She is a high school graduate, with no college experience. Alexandra lives in Delaware with her husband of 16 years. Together, they have 6 children (16, 15, 14, 13, 12, and 10). Prior to being diagnosed, she knew someone who had and survived breast cancer. She has no history of breast cancer in her family. Alexandra went to her general practitioner because the side of her breast was red and sometimes felt warm. She was told to change her laundry detergent. After getting another opinion, she was diagnosed with invasive ductal carcinoma in February of 2010. In addition to chemotherapy and radiation, her treatment included a hysterectomy and no breast reconstructive surgery.

Monica is a 34-year-old, divorcee, non-smoker (diagnosed at age 28). She has a B.S. degree in social work. She lives in the Delaware with her four children (14, 12, 11, and 10). Prior to being diagnosed, she experienced her twin sister being diagnosed 3 years earlier. Monica's partner, at the time, discovered the lump on her breast. She was first diagnosed with Stage 1 DCIS breast cancer in September of 2010, and then with ABC in November of 2010. Prior to her twin sister being diagnosed, she knew little about breast cancer. After her diagnosis and genetic testing, results showed she carried the BRCA I gene. In addition to chemotherapy and radiation, her treatment included a bilateral mastectomy with reconstructive surgery.

Summer is a 47-year-old single woman, non-smoker (diagnosed at age 45).

Summer has a B.S. in marketing. She is employed in management and lives in Delaware with her mother and daughter (14). Prior to being diagnosed with triple negative breast cancer, she was relatively familiar with breast cancer. After vacation, she was having trouble lifting her arm and thought it was a pulled muscle. After going to the doctor and having multiple tests run, she was diagnosed in December 2014 with triple negative breast cancer. In addition to chemotherapy and radiation, her treatment included a bilateral mastectomy, hysterectomy, and breast reconstruction.

Lauren is a 26-year-old single woman, non-smoker (diagnosed at age 21). Lauren is a full-time college student; at the time of this study, she was 6 months pregnant with her first child. She lives in Delaware with her parents. She was diagnosed with invasive ductal carcinoma in 2010. She knew nothing about breast cancer prior to her diagnosis and later discovered that breast cancer was prevalent in her family genetics. Her only treatment was chemotherapy and radiation. Prior to finding out she was pregnant; the doctors suggested that she have her ovaries removed.

Inez is a 34-year-old, married woman, non-smoker (diagnosed at age 25). She has completed some college. She lives in Delaware with her husband and one son (9). Prior to being diagnosed inflammatory breast cancer, she had no knowledge of breast cancer or believed there to be a history of breast cancer in her family. Three years after her diagnosis, her twin sister was diagnosed. They are both carriers of the BRACA I gene. In addition to chemotherapy and radiation, her treatment included a hysterectomy but no reconstructive surgery.

Sandy is a 49-year-old, married woman, non-smoker (diagnosed at age 39). Sandy is a high school graduate and lives and works in Delaware. There are no children living at home, but she is the mother of a 27-year-old son. Sandy did not have a working knowledge of breast cancer prior to being diagnosed; after her diagnosis, she allowed her husband to take charge of her disease. She preferred to be more hands-off with her treatment and disease. She was first diagnosed with stage 2 DCIS in September of 2005 at age 39, and then with invasive ductal breast cancer in November of 2010. In addition to chemotherapy and radiation, her treatment included a hysterectomy and bilateral mastectomy. She chose to employ prosthetic breasts. Table 1 provides a summary of the demographic and background highlights of the seven participants in this study. Table 1 provides a summary of the demographic and background highlights of the seven participants who participated in this study.

Table 1

Participants' Demographics and Backgrounds

Participant	Age at diagnosis	Partner status	Children	Primary breast cancer diagnosis	Years since diagnosed with ABC
Crystal	23	Single	2	No	3
Alexandra	27	Married	6	No	7
Monica	30	Divorced	4	No	3
Lauren	21	Single	1	No	5
Summer	45	Single	1	No	3
Inez	30	Married	1	No	7
Sandy	39	Married	1	Yes	5

Themes Identified

The thematic concepts of the need and utilization of spirituality and meaning before a diagnosis of breast cancer, while going through prophylaxis and support and living after the diagnosis, was examined through the interview. These seven women, all diagnosed with Stage III or stage IV before the age of 45, spoke of the fears and challenges during the time together. Commonalities with all seven interviews were found, even though these women lived in various locations in Delaware and had different life experiences and socioeconomic backgrounds. The recurring themes included but were not limited to knowledge, lifestyle, family, prayer, dark days, and purpose.

In Table 2, a summary listing of the themes that emerged from the data analyses is provided for each participant. The themes were examined for embodiment and language that echoed emotional interdependence. Following the table is a description of the themes. All quotations within this section have been taken directly from the transcripts of the participant's interview.

Table 2

Emergent Themes

Themes	Participants
Theme 1: Life before cancer	Crystal, Alexandra, Monica, Lauren, Summer, Inez, Sandy
Theme 2: Healthcare and the diagnosed	Crystal, Alexandra, Monica, Lauren, Summer, Inez, Sandy
Theme 3: Our bodies as medical/feminine objects	Crystal, Alexandra, Monica, Lauren, Summer, Inez, Sandy
Theme 4: Being Honest and Accepting	Crystal, Alexandra, Monica, Lauren, Summer, Inez, Sandy
Theme 5: The joy in purposeful living	Crystal, Alexandra, Monica, Lauren, Summer, Inez, Sandy
Theme 6: Wounded to Mended	Crystal, Alexandra, Monica, Lauren, Summer, Inez, Sandy

Theme 1: Life Before Cancer

The women in this study reflected on their young adult experiences. Some described this period as “happier times.” Not every childhood story was reflective of an uneventful and happy youth. However, five of the participants inferred that their childhood experiences had contributed to the development of a skill that gave them strength, which proved helpful during the difficult times that accompanied the diagnosis of advanced cancer. Each of the five referred to the life before cancer story as a “time of preparation” for the diagnosis of advanced cancer.

Crystal did not speak about her life before cancer in this manner. She described the period leading up to her diagnosis as full of struggle and challenges, never being a favorite of her mother, and kind of the black sheep. Yet, she referenced prior to her diagnosis as “happy” and the onset of cancer as “hell.” Crystal stated that her life before cancer was a struggle but filled with good times with her daughters: “You know it’s like I

have this new baby, a young daughter and my boyfriend, and we are getting along good, then damn, he finds a hard lump in my breast then life got real.”

It is interesting to note, Crystal did not have a primary breast cancer diagnosis, and at that time had no knowledge of any cancer in her family. She described the experience as,

No real worries ... to, shit, I'm gonna die, so this is really crazy ... I went from my doctor's office to the liquor store and bought alcohol and told myself I might as well kill myself since I'm gonna die anyway.

The apparent abruptness of her diagnosis, the lack of information, given to her by the treating physician, and the lack of time to process her prognosis were factors that contributed to her early struggle for the construction of meaning for her illness and where cancer fit in her life story.

Alexandra indicated that her childhood was relatively happy; raised in the church, her life was filled with helping others and a love for God. Her father continues to play a big role in her life health and wellness. She is a wife and mother of six children: “I meet my husband at a young age and we married when I was 21; so I have to include him as part of my growing up story.” Alexandra was diagnosed with Stage III breast cancer; she said, “My struggle was not the diagnosis of breast cancer but my will to live and see my children grow to be well rounded and happy adults...My family is where I derive purpose and meaning.”

Monica indicated that her childhood and young adult life was characterized by good family with “no boundaries”: “We were very close growing up my siblings and

cousins were close knit. I am a twin so I had an extra bond with my twin.” She talked about college and relationships and the marriage of her husband who is the father of her first two children:

I learned a lot about my life what I will and won't tolerate in a relationship and in life generally ... One thing I want to say about my life before cancer is I lived for me, hair, make-up, clothes I went to church but I was always seen. I was a superficial Christian. That all changed once “it” happened to me.

Monica was diagnosed with breast cancer 4 years after her twin sister, who was also a part of this study. While Lauren grew up a Pastor's Kid, so

I was always looked at, judged or whatever. I guess my life was happy, but what's happy. There wasn't a lot of talking in my house, not about health, or life; you just kinda grew up and hoped for the best.

Lauren is a full-time student and is currently pregnant with her first child. When asked how she felt about being pregnant, she stated,

It's here now, not happy or sad, but I want to try to be a better parent than what I had ... I was not prepared for a cancer diagnosis and didn't really have anyone to talk to. My parents either treated me like I would break or wouldn't talk about it at all, so I don't really talk to my family about my diagnosis, all I know is I'm taking care of myself, focused on school and having a healthy baby.

Lauren is finding purpose after her diagnosis as mother and student. While Summer said,

My life was full before my diagnosis. I am a mother of a 14 year-old daughter very active in my sorority and civically engaged. Cancer was the last thing on my

mind; I was always physically fit and I eat right, me having cancer was the last thing on my mind ... I lived every day to the best of my ability and didn't really worry about my health.

Summer expressed that her purpose and determination to stay healthy and alive was from her daughter and the love and support she received from her mother and daughter.

Inez stated her pre-cancer story is almost the same as it is today:

I've always been in the church; I think getting diagnosed with cancer drew me closer to God and my family. I was afraid of my diagnosis at first because I had a husband and I didn't want to be needy or him leave me because I was sick. It was the exact opposite; my husband knows more about my health and body than I do. He and his family and mine were an unmovable force in my life. My pastor told me I wasn't going to die from cancer and that has been my mantra. Cancer has given me an added peace that I don't think I had before.

Sandy said,

Well, this is the second time I've been diagnosed with cancer, the first time it was in my right breast now it's in the left my world was rocked. I use to wonder why me, what I did, because I think I'm a good person ... My mother told me, "Don't question God, and why not you, why do you think you should be beyond this."

When Sandy lost her mother, she felt she could not go on, and it was the strength of her husband that kept her moving forward:

My husband is my rock, I didn't think I could talk to you about my cancer because I don't talk to people and I feel really insecure so I wanted my husband

here with me and he gently nudged me and told me I'd be okay. Before cancer because I work in the health care field, I was used to taking care of people and encouraging them when they needed it. I felt my life lead up to me being able to practice what I preached. I encouraged people until it was me, I prayed with people until it was me. I had to come to the understanding that there is something greater than me and I am still alive to fulfill some purpose.

Sandy's story was interesting because she believed she had nothing to offer by way of educating people about cancer, yet when she began to open up, she imbued such a wealth of knowledge about where she had been and why she believes she was still here.

What these seven women captured in the interviews was the shyness or behind the scene personalities that they had until they became emboldened with wanting to get the message of living before, while going through, and beyond breast cancer. Another observation was these women believed that being diagnosed with breast cancer gave their lives new meaning and purpose. Upon further investigation, the conclusion showed that these women believed adversity evolved their contentment toward purposeful living.

Theme 2: Missed Opportunities with Healthcare Professionals When Communicating with Newly Diagnosed Patients

Being given a diagnosis of breast cancer is a critical event, but not having a person at the office that can immediately link one to care and other resources is a crucial part of the plan that is missing. The first thing the women mentioned was who would take care of their children. Crystal mentioned she was stunned because she was not given any additional information other than a pink binder. The women described needing to have

someone there that was both culturally sensitive, as well as someone to discuss “what’s next.” There is a huge gap missing when one is sitting in the doctor’s office. Crystal stated she was stunned about her diagnosis:

The doctors here I don’t really trust, when I was told my milk ducts were blocked it was only by God’s grace and I call her my angel that a nurse came into the room when the doctor stepped out and said she heard what the doctor said and I should get a second opinion because it sounds more serious. At my second appointment with another doctor, the first thing I noticed was a big pink binder of the doctor’s desk. She told me I had Stage IV breast cancer and asked if I had any questions, when I didn’t know how to follow up with a question she scheduled my next medical appoint, very matter-of-fact with the oncologist. I took the binder home and sat it on the kitchen table. I don’t drink, but I closed the shades and stayed drunk for almost a week, and said since I’m gonna die anyway I might as well drink.

In addition to this, Crystal said that she wished there was someone at the doctor’s office that could have made the transition a little easier. She said,

Everything I learned about breast cancer I got from the Internet and finally reached out to the Delaware Breast Cancer Coalition. It was terrible, I felt the doctor should have done a better job preparing me or making sure that I don’t know wasn’t gonna kill myself.

Alexandra shared,

I was completely stunned. I had my father and husband with me so they heard what I did not. I could not believe I had cancer. I said how will I tell my kids I might die that she I'm glad they were there because I didn't hear anything but I was gonna die even though my husband said that wasn't said. The doctor although I think she's a really good doctor, gave me a binder and just said I should contact my local breast cancer organization for support and help through this difficult time. Perhaps because I had support with me her job was done and she left me to my family. I went home and drank a bottle of wine, and I don't drink.

Monica stated,

I was stunned because I really took care of myself and I just thought I must have cancer because my twin sister had it. I wished the doctor had resources for me. I was given a big pink binder but being in the office felt perfunctory. The doctor's I think should have some sort of sensitivity training and understanding that cancer isn't a one size fits all. I was really disappointed with my general practitioner.

Lauren said,

I just took the binder from the doctor and sat stunned when I got the news. I was thinking God was punishing me for something, because I was so young and never heard of young people with breast cancer. My doctor was ok.

Summer said she got her cancer diagnosis but did not believe at first: "I'm always took care of myself, did BSEs every month, and am in relatively good shape. I

immediately went for a second opinion, my Doctor was encouraging and recommended several Doctors on top of the oncologist.” While Inez shared,

Imagine being 22 and being told you have aggressive breast cancer. I didn’t understand what the Doctor was telling me. I didn’t know anything about cancer so I listened, and the Doctor sound real matter of fact, talking about cutting my breast and hysterectomy, I took the material she had and went home. I tried to read the binder and understand what the Doctor was talking about. I found out after telling my parents I have breast cancer that several family members on both sides had breast and ovarian and prostate cancer but no one told me. It was like a big secret. After my diagnosis, I discovered I was pregnant.” Besides the pink binder, the Doctor didn’t have much more to offer. I remember coming home and thinking she [doctor] should have given me something more.

Sandy stated,

Although I’ve been through cancer before, hearing it’s returned and more aggressive was not something I wanted to hear. I was given my diagnosis over the phone, ‘what the hell’. I dropped the phone and just started screaming. I called my husband and when he got home he called the Doctor and got more detail on my diagnosis. I was angry that my Doctor’s staff, and their insensitivity. At that instance, I didn’t want to live. For a week, I didn’t get out of bed, shower, or comb my hair.

The study participants all agreed there was a missed opportunity for the medical staff/team and engage them, in some basic breast cancer education, ensure they understood their diagnoses and were given ample time to process the news.

Theme 3: The Tension Between the Perception of Body as a Medical Object and Body as a Feminine Object

The treatment of breast cancer and advanced breast cancer for my participants included surgical removal of breast tissue and nipples. Some chose reconstructive surgery, and others opted for prosthetic breasts. Reconstructive surgery, although gives the illusion of breasts, does not retain the physical sensation. Participants described a lack of feeling or numbness, such as “prickly like when your hand or foot is asleep.” Some reconstructions did not include nipple replacement and not one of the participants who opted for reconstruction was satisfied with her reconstructed breasts. The body was described as a medical map subjected to many (unnecessary) procedures. In addition to this, several participants described the removal of their ovaries as vague in their understanding as to what an oophorectomy or hysterectomy had to do with breast cancer re-occurrence.

The women in this study also described the loss of hair during chemotherapy treatments, their skin turning dark, and weight gain that resulted from either steroid treatments or direct result of early menopause after removal of the ovaries. All the women described the scars that were inflicted on them by surgeons and the change from a previously sensual experience of body to that of a sterile clinical canvas. Some of the women began to question their femaleness, as they struggled to redefine their relationship

with their new bodies. Some of the women described feeling detached from their bodies in a way that allowed them to lift their shirts without reservation to doctors, nurses, and curious family and friends. Others indicated that their new awareness of their body contributed to better lifestyle choices and the experience of healthier, stronger bodies despite the presence of advanced cancer. All the participants described their bodies as having been cut, poked, and prodded in such ways as to resemble cutting through meat similar to a lifeless, body of tissue, skin, and bones, as if the body were an anesthetized living cadaver (i.e., medical object). From this emotionally detached experience of body as a medical object, the women described attempting to connect to their bodies as feminine and sensual persons. There appears to be a tension between detaching emotionally from a body that is scarred, wounded, and the re-engagement of embracing the body in a new way that is feminine and womanly.

Crystal spoke of her experience with breast cancer and her body:

Because of the cancer, I see myself as stronger. It's like I can face whatever. I had to fight my way back to health. I found out I had breast cancer when my daughter's father found a lump, when I asked my doctor she said, I had a blocked duct since I was nursing. When the lump continued to grow, I had a mammogram which came back positive for stage IV breast cancer. So here I am 23 years old, two kids, and stage IV metastatic breast cancer. Once they [doctors] were able to put in a port that got infected. I had surgery after surgery. I gained a lot of weight and I had a feeling the foods I was eating contributed to my cancer, so I changed our diet, we started eating more vegetables and cut out soda and all around started

eating better. My kids and I are happy and we make it one day at a time. I'm not gonna die from this. So, in a way I have a strength that I didn't have before diagnosis.

She continued to describe her body:

I didn't have a mastectomy but my body and breast are so mis-shaped. I think when you have a breast cancer diagnosis, you have so many doctor appointments that you start feeling more like a specimen and not a woman, your body and I think as a cancer survivor after you struggle with your body not being sexy because it appears so battle scarred.

Alexandra described herself as a warrior:

I still have my breast, but I am fearful of reoccurrence, because I still have my breast. I continue to make better food and snack choices and drink plenty of water. I exercise three times a week and once a month I add something more strenuous. My husband says my body is beautiful and kisses my scars. I would see my scars and say this is not me, or remember a time before cancer. But when you hear a positive message over and over you begin changing the tapes that play in your head. I am grateful to be alive, I believe in self-preservation and family. I want to live. My scars allow me to see strength and determination to fight.

Monica stated,

I feel bad because I know that... but I think that having babies early in life... I have the genetic mutation and I didn't know this until after I was already diagnosed and everything. They did all the genetic testing after but my twin Inez

and I do have the BRCA I mutation and so I think...my tumor is estrogen and progesterone receptive So I think that having babies so close together...they were just back to back...I think that that probably made it progress than it may have otherwise. Which kind of sucks...but I wouldn't have done it any other way. I have my kids and I love them and I would never tell them that and I would never want them to feel like it's because of them. I think that played into it though, for sure.

Lauren struggled with observing her body as feminine. She shared, Although I am pregnant, I think my body is unattractive because of my scars. This makes me feel self-conscious about people especially my age seeing me. It's like the Doctors operate but there's no real communication, maybe I don't know the right questions.

Summer first talked about her reconstructive surgery and said, "I know they are not mine but I'm happy with the outcome. I had a really good plastic surgeon. I will talk about my scars, but there is a story there so bear with me." She was most inspired by a desire to stay fit and healthy, so she joined a running group. She thought a fitness program could help her monitor her cancer more efficiently, and she decided that when the day came, "and I can't breathe, I'll call the doctor ... So what happened was ... all the exercise I was doing stretched the scar tissue. I actually healed and my breathing is better than before cancer." She continued,

So, I run every morning a minimum of 3 miles; if there happens to be a 5K on the weekends I do that. I did my first ever ½ marathon and it was an incredible mile

stone. Along with running I joined the YMCA and am learning to swim, so I'm in amazing shape. I want to live a long and healthy life, not just for me, but for my daughter. I would have never achieved these goals if it wasn't for the cancer.

Summer described how empowering this message has become for her and other women. I am very confident in my appearance and in my physical appearance when I am dressed. The rest is a work in progress.

Inez commented,

In my uneducated opinion being on the pill for many years, when I was young, how our food and grown and manufactured the environment...there's a link somewhere. They're starting to do research on it but I think in time they will discover that messing with people's hormones may not be a good scientific idea.

In addition to the physical changes that occurred as a result of the treatment for advance breast cancer, Monica and Sandy discussed their concern about how birth control, fertility treatments, and successive pregnancies might have contributed to their cancer diagnosis. Sandy said that she had a lumpectomy when she was diagnosed with primary breast cancer. However, she could compensate for the absence of tissue with the remainder of her 34 D structure. Following the diagnosis of ABC, she incurred a bilateral mastectomy:

I found that when I went ... to Cancun in just a bathing suit that pretty much looked like I was just flat chested...and I have scars up to my armpits...no one really paid attention to that and I think that if anything they noticed my port which is really prominent...rather than me not having breasts.

In addition to this, Sandy chose not to have reconstructive surgery:

I didn't want anything foreign in my body, so I decided to face my scars every day and when my husband and I go out I wear my prosthesis. I am much freer about showing my scars than I ever was about showing my breasts and I think a big part of it is because this is how the surgeons left me. This is what they left rather than this is kinda how I look. It was like someone else forced me to look like this and for some reason that was more comfortable for me.

Body changes, as a result from ABC treatment, resulted in scars, ovary and breast removal, and in a few cases, unsatisfactory reconstructive surgery. There was a feeling by the participants of being mutilated and somewhat violated by both the cancer and the surgeons. The participants expressed feeling detached and experimental during times of treatment and surgeries. Each woman described her struggle with these changes, which was met with the question of how to address her diminished feminine identity. This resulted in either a tendency to dress more "girlie" or to engage in more physical activity that promoted the identification with a stronger, more powerful body image. Two women had questions around fertility and hormone ingestion, as they continued to make sense from the physical changes their bodies went through as a result of ABC.

Theme 4: Honest and Accepting Versus Alienating Relationships

ABC diagnosis: Critical event. Being given a diagnosis of ABC represented a critical event in each of the participant's life story. None of the women, except for one, had a previous breast cancer diagnosis. As previously mentioned, Sandy, who had a previous cancer diagnosis, viewed her reoccurrence as "rocked." All the women referred

to their diagnosis of advanced cancer. This second chance was viewed as not only life changing but also a period of beauty, purpose, and liberation. The function of time appears more precious when faced with one's mortality. Re-prioritizing all aspects of life was essential as expressed by the participants. Priority shifts the pre-prioritization of time appears to be manifested and expressed in the way the women experienced relationships with themselves and with others. The women described wanting to spend their time engaged in more meaningful relationship and the challenges that accompanied this desire. The participants described that there were times when their desire to engage more honestly with family and friends was met with the discomfort from others when discussing their reality of living with ABC. This resulted in the women feeling isolated and alone. Crystal said,

I spend my time more the way I want to on what makes me feel good, I help in my daughter's class since I can't work anymore due to my illness, and I want to get more involved with the breast cancer coalition to help other women.

Alexandra said, "I spend my time more the way I want to on what benefits my purpose of being a cancer fighter and helping others...or my church." In addition, Monica stated, "In some ways I've gotten a lot closer to people that I was friends with before but who have really rallied around me and I've seen just the good in people." Lauren described how some of her closer friendships have become more distanced:

I just see them really going on living their lives when I feel like I may not get there... it's really hard because I can't keep up with them and ... they can't relate

to being in their 20s...they can't relate to having breast cancer...they can't relate to having all of this while pregnant for the first time.

In addition to this, she questioned the value of being in a relationship with her: "Why would you want to stay here and be a part of my life when you know I could cause so much pain when I die?"

Sub-Theme A: Self-protection. The women described how necessary it was to set boundaries in all relationships. One very important aspect was being honest and letting people know what they needed and wanted regarding their illness. Oftentimes, this was difficult because family and friends would frequently avoid discussing topics related to breast cancer or death.

Summer described herself as having to be assertive:

You've got to understand that I am the one going through this and I can't worry about dancing around your feelings. I don't want to make time for that. Another thing on relationships is after deep contemplation there are ones that aren't worth trying to caress or sustain, in that instance they are my social media buddies where I'm in touch but not really.

Inez described how people appear to not "get it":

I keep trying to explain you don't know how I feel because I'm always smiling and out in public (church), so people assumed I have everything under control, so they don't get it when I feel overwhelmed or tired...my feelings are right out there. I am beginning to see that people don't like that. People don't want that. People are more comfortable when I put on a brave face...well, I put on a brave

face is what happened...and keep what's really going on for my intimate relationships and not the world.

Sandy said,

When I'm having a bad day, I want everybody to know today's not good.

Tomorrow might be better. If those in my life can experience these ups and downs and I want them to experience what it's like to live with advance breast cancer without having to.

Physical, financial, and emotional challenges of living with ABC can strain the most tested relationship. Some of the participants indicated that their relationships became closer and more authentic as the couple explored the meaning behind the vow "till death do us part," and there was a push toward honest communication about family issues and intimacy. Moreover, sexual intimacy appeared as a source of frustration. The women described being surgically forced into early menopause that resulted in lower to non-existent sex drives. This combined with the physical alterations resulting from a mastectomy, hysterectomy, or oophorectomy appeared to create a vulnerability that may compound the issue of sexual intimacy. In addition to this, Monica, who divorced, discussed the changes in her dating patterns because of living with ABC. She described not feeling as comfortable being casual with her sexuality would require her to invite a stranger into her "privately scarred world."

Theme 5: The Joy of Purposeful and Living

Few things, such as facing a life-threatening illness where the prognosis is grey, make the essence of time so relevant. The participants of this study described making

efforts to spend their time sharing in meaningful activities. Of interest, many of the women described a dichotomous relationship between choosing to live in a meaningful or extraordinary way and choosing to live “ordinary.” It appears that there are times when temporarily shifting the focus away from the breast cancer diagnosis may allow a welcomed experience of the normal, even mundane, activities of life. In addition to this, there appears a desire to normalize some of the experience of living with ABC. The women of this study referred to this phenomenon as their “new normal.” Crystal explained that when she was first diagnosed, she spent time being attentive to priorities in her life:

I do have control over that (attitude) and how I emotionally handle anything that comes at me. You have to find the things that you are grateful for and it needs to take up the space otherwise saved for focusing on negativity.

As the acute phase of her diagnosis passed, she found herself becoming more lax and returning to her older patterns: “There’s a tendency that as you’re feeling well...you take things for granted and get caught up in the rat race.”

Alexandra explained that when she was first diagnosed, she realized this was an opportunity to focus on things she could control and release negative people and influences in her life: “Learning and appreciating the ability to set healthy boundaries or just say, ‘No,’ felt really liberating. I want to live my life and be the example for my children of healthy.”

Monica spoke of maintaining a realistic attitude while not becoming anchored in the prognosis:

So, I mean you still have to maintain that realism that I will die of something eventually sooner or later. So, it is always sitting in the back of your head ...it's still there! But I just try to push that part back and try to move on. There's nothing I can do about it...I've done everything that I can possibly do. I'm not gonna die tomorrow. So, live with me! I want to be treated like a normal person. I call it "new normal." I am always gonna have to go for PET scans and stuff, but I am not constantly thinking about cancer and allowing it to run my world.

In addition to this, Monica described using humor to help provide levity to the discomfort of chemotherapy: "We would just sit there crackin' ourselves up and other people are looking at us like, 'this is not a fun place! What's wrong with you people? This is chemo!'"

Summer talked about making a choice in her attitude daily:

Life doesn't just happen...you must choose it. You have to say, 'You know today I could wallow and I could pull the covers over my head because I feel a little anxious' or I could get up and face the day and I could say, 'You know what, I feel great. Thank God for that. Today is a good day!' I always scoff at people that said, 'Attitude is everything.' But it's true! I look at my daughter and I have to be the best example for her as well as myself. She needs to see strength in vulnerability and know shit isn't always easy but face it anyway. Knocked down doesn't mean knocked out.

In addition to this, Summer stated,

I'd tell my friends, "I'm not dying today. Live with me...not wait for me to die!

It's not catching. I don't have to talk about it all the time and if you feel uncomfortable, I won't ...but I'm still me. I have a disease."

Candace spoke of her choice to improve the quality of her life experience:

I didn't want to just live. God has a purpose for my life, and we're still figuring it out, perhaps cancer showed up so that I could self-correct, so I really focus on making great quality of life and my quality of time be significant...be legendary.

We're so consumed with everything. You tune out those magical little moments especially me with my son. So, to me that is really important.

However, Inez commented that invasive breast cancer did not define who she was: "My friends gave buy me things with pink ribbons, or asked if I wanted to get a tattoo of a ribbon, and I asked, 'Is that all you can think of for me...is a pink ribbon?'"

Sandy described how she grew up in the church but did not consider herself religious. However, she continued to create an atmosphere in her home where there was prayer at thanksgiving and gratitude for the comforts found in the mundane activities of daily life: "There's something to be said about that normal stuff. I feel more love and appreciate for everything that I once took for granted."

The participants described the confluence that existed between making each moment meaningful and living with some degree of normalcy with an advanced cancer. There appears to be a relationship between feeling well and elapsed time from diagnosis and defaulting to a new normal lifestyle, and the harsh reality of PET scans that refuel the desire to live with intention.

Theme 6: Wounded to Mended

The women of this study described their diagnosis of ABC as being a pivotal experience in their lives. Interestingly, many of them had a sense of being chosen to experience this illness; as a result, they felt compelled to testify to cancer being the catalyst for a life changing experience. In addition to this, many of the participants felt that their diagnosis has resulted in them making significant and powerful changes in their lives that have brought them closer to God. Alexandra stated,

Cancer has helped me find my purpose as to help others. My cancer is invasive ductal carcinoma which means it can easily spread but in the mean-time this doesn't have to be the end of the world. I will tell anybody that since my diagnosis I've become a better mother, wife, friend. There are not a lot of people who can say things like that when they are in the middle of a terminal diagnosis. So that's part of the second chance I've been given and I'm trusting that whatever my outcome is, it is God's Will and I'm ok with that.

Crystal described nursing her baby pregnant with her youngest son awhile discovering a tumor in her breast. Misdiagnosed as a plugged milk duct, Crystal was not diagnosed with metastatic breast cancer shortly after the birth of her daughter. She shared, "After my mammogram, that's when all hell broke loose."

Monica described her diagnosis with cancer as liberating: "I spend my time doing things that are valuable to me. My time is a really precious commodity so I don't waste a lot of time doing things that I'm not passionate about. I don't waste time with stress."

Sandy differentiated between her experience with primary breast cancer (D-Day1) and her diagnosis with advanced breast cancer (D-Day 2):

D-Day1 was anger. Everything about it made me angry. I was 39 years old. I was told in one week and I found a lump and by 6 days later after finding a lump I was told that I had breast cancer and I was gonna lose my breast. I mean I was mad. I was dating my best friend after we had reconnected so many years later. I had waited a long time for him...and I blamed God. I felt I was being punished for something I'd done in the past. Being an independent person like I am and someone who always had to have it together it was just devastating for me.

Sandy indicated that she began looking for support and started attending church during this time. Sandy described being cancer free for almost 5 years when she began experiencing abdominal pain, and she was diagnosed with breast cancer in her ovaries (D-Day 2): "A lot has changed and I'm learning just to be a better person, but that was only after I went thru a crisis."

Summer said that she had always wanted to be a motivational speaker, but felt that she had nothing to say. Fourteen months later, she was diagnosed with ABC, and she wrote that now, ABC was a huge part of her life. She worked "to get the word out for awareness and to get support." She continued,

Hey, they're looking for someone to speak as a survivor. And I was like...I didn't seek it out...it's almost like God knew my heart's desire and he gave me my heart's desire... So, I'm a peer, I've written several articles in the local newspaper

and joined a running group when we talk about wounded to beauty. How I can be emotionally and physically scarred and yet the beauty to radiates is powerful.

The participants described their cancer diagnosis as having a life-altering experience that propelled each into the unexpected world of change. For many of the participants, it was a time to re-evaluate and prioritize. For Inez, it was a world that she felt ill-prepared to enter.

Data Collection

The data collected from the seven interviews answered the three research questions. To answer these research questions, I asked a series of semi-structured open-ended interview questions from the interview guide (see Appendix A). To determine a baseline of what premenopausal African American Women's beliefs are about spirituality and meaning-making as coping tools, I asked them what they perceived as health-related quality of life.

Evidence of Quality

As previously discussed for this study to be credible and to make a contribution to the existing literature in the field of spirituality and meaning-making it was dependent on the quality of the data collected, data analysis, and verification of findings. The goal of phenomenological research focuses on lived experiences (Dalby et al., 2011). Therefore, to ensure this study was credible, confirmable, and dependable, certain procedures were strictly adhered to throughout data collection and data analysis.

Process for Credibility

The credibility of this study was verified through data triangulation of the sources for data collection. Data triangulation involves using different sources to increase the credibility of a study (Patton, 2002). This process involved using different participants from Delaware and several quotes from the participants to support findings.

Process for Confirmability

To ensure confirmability in this study I used rich descriptions from the study participants and reflexivity. This study includes verbatim transcriptions of each interview to provide contextual and rich data. Notes were taken during the interview on the interview guide and during data analysis, highlighting themes as these emerged. Direct quotes provided a rich detailed description of the data from the participant's perspective. Reflexivity also required a conscious self-reflection occurred when the results were analyzed.

Process for Dependability

The procedure to ensure dependability was confirmed using a voice activated digital recorder device, which captured verbatim what each participant said during the interview. The use of a digital recorder produced a more reliable account of the data collected and created a permanent recording of the interview that I can go back to if needed. Audio recording also eliminated the dependence of recall basis after the interview. Permission to audio record each interview was granted from each participant when they signed the informed consent form prior to beginning the interview.

Summary

The purpose of this study was to examine the lived experiences of premenopausal African American women in Delaware who were diagnosed with ABC. Chapter 4 provided an overview of the processes used to collect, manage, and analyze data collected from seven participants and the utilization of spirituality and meaning as a form of coping with their terminal illness. Participants were selected based on purposeful sampling techniques and all participants were informed of their rights and signed informed consent forms prior to beginning the interview process.

Responses from in-depth interviews examined how premenopausal African American women managed their health using spirituality and meaning-making coping skills during and after diagnosis. All participants had a basic understanding of the necessity of peer support and the importance of spirituality and meaning. All participants felt prayer and the connection to a higher power was needed to survive their diagnosis. These women believed after the initial shock of the diagnoses subsided, an action plan was needed to ensure survival; in some instances, that meant changing their diet, where in others it meant physically pushing their bodies to new limits. Most women stated helping other young women understand the importance of breast health gave purpose and meaning. While others found meditation and physical activity brought long lasting meaning. The women of this study identified the use of spirituality and meaning almost immediately after the initial diagnosis of their cancer. They discussed the importance of finding their space and place within the realm of spirituality and meaning that allowed them to not only find but live on purpose.

The last section in this chapter identified evidence of quality. The first measure to ensure quality was a process for credibility. To ensure credibility, I used data triangulation. The second process to ensure quality was confirmability. For this measure, I used rich accounts from the study participants and reflexivity. The third measure used to ensure quality was dependability. To ensure dependability in my study, I used digital recording to capture verbatim what each study participant said during the interview. Chapter 5 will offer an interpretation of the study findings, limitations of the study, recommendations, social change implications, and researcher's experience.

Chapter 5: Discussion

Introduction

The purpose of this study was to examine the lived experiences of premenopausal African American women in Delaware who were diagnosed with advanced breast cancer. Chapter 5 offers a thorough discussion of the results of the study, its limitations, and the recommendations for future research. Six themes emerged from the data: (a) considering the pre-cancer story as preparation for their diagnosis of ABC, (b) the tension between healthcare professionals and the newly diagnosed, (c) being honest and accepting, (d) knowing there is a Higher Presence as a source of comfort and strength, as these women transition from being wounded to being mended; (e) the joy of purposeful and living; and (f) wounded to mended. These themes will be closely examined based on current research and the participants' experience.

African American women have the lowest breast cancer survival rate compared to any other ethnic group. According to the ACS (2017), an estimated 231,840 new cases of invasive breast cancer should have been diagnosed in 2015. In addition, the ACS (2013) expected 82,080 cases to be African American women. The CDC (2013) reported that although breast cancer was less prevalent in African American women compared to in other racial groups, it was at a more advanced stage when diagnosed, thus leading to poorer prognosis and a lower rate of survival (Bourjolly & Hirschman, 2001; DeSantis et al., 2013).

Another reason for the higher morbidity/mortality rate within this younger demographic is that malignant tumors are more aggressive and likely to be triple

negative. Triple-negative tumors do not respond to hormonal therapies, and the growth of the cancer is not supported by the hormones estrogen, progesterone, or the presence of HER2 (human epidermal growth factor receptor2). The HER2 gene makes HER2 protein, which, when normal, helps control how the breast cells grow, divide, and repair (Breastcancer.org, 2014; CDC, 2013).

Over the past decades, emphasis has been placed on the prevention and early detection, for example, the importance of mammograms (Bourjolly & Hirschman, 2001; Komen, 2017). Although this has contributed to a significant decline in the amount of breast cancer diagnoses very little research was available on spirituality and meaning-making as coping tools that form part of an integrated intervention of supportive care for breast cancer patients (Breitbart, 2002; Thuné-Boyle et al., 2013). Newly diagnosed African American women not only experience increased incidence of depression but are more likely to take a fatalistic approach to their diagnosis, especially those on the lower end of the socioeconomic continuum (Levine et al., 2007; Northouse et al., 1999; Taha et al., 2011). Women who are stuck in lower socioeconomic circumstances with limited access to quality healthcare, battle with fear and anxiety for longer compared to women who are more informed about breast cancer and have easier access to medical care (Thuné-Boyle et al., 2013).

What I identified was the effects of inner resources, such as spirituality and meaning-making coping strategies, became sources of comfort and healing. W. Breitbart (personal communication, September 2, 2014) stated that spirituality (e.g., faith) and meaning-centered coping had a significant role in the healing process. Similarly, Levine

et al. (2007) concluded that faith provided an “emotional blanket of support for a person that may feel alone, as well as the idea that God is always there and in control” (p. 57). African American women who had good support systems and a strong spiritual foundation ended up being less fatalistic in their approach to dealing with breast cancer than those without these resources (Bourjolly & Hirschman, 2001).

Summary of Findings

Spirituality and meaning-centered coping positively impacted the lives of the seven participants in dealing with their illness. The participants discussed how their diagnosis caused them to make constructive changes in their lives; and these changes allowed them to seek a more spiritual and purposeful outlook. The women also expressed the need to become a voice within their community to women in their age-group about the importance of breast health and there can be live after a breast cancer diagnosis.

The first research question explored what degree premenopausal African American women diagnosed with advanced breast cancer found utility in incorporating spirituality and meaning. All participants had a basic understanding of the necessity of peer support and the importance of spirituality and meaning. All participants felt prayer and the connection to a higher power were needed in order to survive their diagnosis. These women believed that after the initial shock of the diagnoses subsided, an action plan was needed to ensure survival; in some instances, that meant changing their diet or physically pushing their bodies to new limits.

The second research question looked at how premenopausal African American women diagnosed with advanced breast cancer found utility in incorporating spirituality

and meaning. Most women stated that helping other young women understand the importance of breast health gave purpose and meaning. While others found meditation and physical activity brought long lasting meaning.

The third research question explored when premenopausal African American women diagnosed with advance breast cancer found utility in incorporating spirituality and meaning. The majority of the women identified the use of spirituality and meaning almost immediately after the initial diagnosis of their cancer. They discussed the importance of finding their space and place within the realm of spirituality and meaning that allowed them to not only find but live on purpose.

Emergent Themes

Theme 1: Life Before Cancer

The importance of this theme was to obtain a sense of how participants felt about their lives before diagnosis with ABC. Most of the young women that took part in this study referred to their lives before cancer as a “happier time.” Five of them even stated that they felt there were certain experiences in their childhood that contributed to adding skills that were helpful in dealing with the struggles that came with the breast cancer diagnosis. However, one participant described the time leading up to her diagnosis as full of struggle although inferring that, before diagnosis, she was “happy,” especially because of good times with her daughters. She went on to say that upon diagnosis, life became “hell.”

For several of the participants, the abruptness of their diagnosis and the lack of information given to them by their doctor were too much to bear. This made some resort

to drinking, while others exhibited signs of depressive behavior. It would seem that the participants perceived their prognosis as a death sentence at first because the perspective was still focused on how life was before diagnosis. Participants testified that after the initial shock, the making of a mind shift toward finding new meaning in their life helped them to find true happiness. This would suggest that meaning-centered coping does have a positive effect on patients with ABC.

Theme 2: Missed Opportunities With Healthcare Professionals When Communicating With Newly Diagnosed

Many of the participants in the study expressed that their doctors did not furnish enough information about their prognosis upon diagnosis. One participant actually stated that she thought it was important that healthcare professionals should have the necessary social skills when it came to breaking the bad news of breast cancer to their patients. Another participant said she felt the doctor could have provided her with more resources. And yet another participant said, “The doctor could at least have done a better job preparing me or making sure that, I don’t know, I wasn’t gonna kill myself.” Although this theme might be a recurring one, it did not highlight on how, when, and to what degree premenopausal African American women diagnosed with ABC found utility in incorporating spirituality and meaning in their lives.

Theme 3: The Tension Between the Perception of Body as a Medical Object and Body as a Feminine Object

As can be expected, patients of breast cancer have to go through many different medical procedures in an attempt to treat the illness. These may include blood tests,

mammograms, positron emission tomography (PET) scans, chemotherapy, radiation, and the removal of breast tissue, nipples, and sometimes ovaries. As a result, many of the participants in the study reported a sense of losing their feminine identity and feeling similar to a medical object. Hair loss, weight gain, darkening skin, and early-onset menopause—all a result of medical treatments—made the patients lose their sense of sensuality and left them feeling similar to a sterile medical canvas.

Identifying and analyzing this theme was important for the purposes of this study because it highlighted what these women went through during and after treatment. They spoke about how they had to make new sense of their mutilated bodies. Some found meaning in becoming more fit; others found it in eating more healthily; and others went for reconstructive surgery. In all the cases, there were varying degrees of acceptance and meaning found by the patients regarding their changed bodies. The overall sense is that it is an ongoing process to gain acceptance and confidence in their altered body.

Theme 4: Honest and Accepting Versus Alienating Relationships

Shock of diagnosis. After the initial shock of being diagnosed with breast cancer the participants said that because they were now faced with mortality they realized that time was more precious and should not be wasted. Therefore, most described a desire to spend time in more meaningful relationships. The participants described that they wanted to engage in more honest communication with friends and family that was sometimes met with discomfort which resulted in feelings of isolation and loneliness.

Sub-Theme A: Self-protection. The participant also described the necessity to set boundaries in relationships to facilitate healthy communication. Family and friends

would often avoid talking about topics relating to the disease or death to try and accommodate the participants. One of the participants expressed a need to be acknowledged as the one who is going through this ordeal and that she did not have time to dance around others' feelings. In some of the other subjects, the focus was on intimate relationships with their spouse or boyfriend, which proved frustrating because of the changes their body was going through. This theme proved helpful in answering the study questions by showing how participants chose and ran meaningful relationships post-diagnosis.

Theme 5: The Joy of Purposeful and Living

Because of their diagnosis, some of the participants expressed a desire to live extraordinary lives, as opposed to others who wanted normality regarding experiences of a life associated with ABC. Many ways to deal with the day-to-day living with the illness were identified. Some of these coping mechanisms included the use of humor, prayer, thanksgiving, and choosing to live in the now (i.e., enjoying all the “magical little moments” in life). This theme highlighted how these women found meaning and happiness in the small things in life as well as in a higher power (God) to reach a state of living with purpose and joy. No doubt the future will bring its ups and downs, but it seemed that the participants employed a “taking it one step/day at a time” philosophy.

Theme 6: Wounded to Mended

Most of the women in this study described a belief of being chosen to be diagnosed with ABC. They felt that the experience, although difficult, brought on significant changes in their lives and brought them closer to God. In all the interviews, an

appreciation for life and a desire to spend time more wisely on meaningful activities and relationships were identified. All participants conceded that it took time to get to a place of peace and joy within their new normal, and they knew that there were still some challenges that remained ahead.

Interpretation of the Findings

The study's results confirmed and supported the suggestions that spirituality and meaning-making strategies was meaningful in helping the participants cope with their diagnosis. Although not all participants felt as positive about the future, finding meaning in their new reality did help in dealing with their situation. As Sadler-Gerhardt et al. (2010) found, a spiritual connectedness was what empowered young women to find meaning during life-changing events like being diagnosed with advanced breast cancer. Because of this life altering event, a self-transcendence opens them to look past their circumstance to live fuller, meaningful lives (Breitbart, 2002). This was almost exactly what most of the participants in the study felt they experienced. Because their diagnosis came as a shock, the initial reaction to the news was characterized by self-destructive behavior (drinking) and signs of depression. But as soon as the women acquired more information about their disease and felt supported by family and friends, they began making intentional steps towards living and healing.

Researchers viewed meaning-making and spirituality as both a phenomenon and a transformative experience (Carter, 1990; Lin, 2008; Wong, 2010). Most of the women in this study stated to how cancer made them reevaluate their lives, prioritize their time, and identify meaningful relationships. Killoran et al. (2002) concluded that a belief existed in

North American culture, which implied that faith and true resolve could have a significant impact on healing. In addition, Levine et al. (2007) concluded that faith provided an “emotional blanket of support for a person that may feel alone, as well as the idea that God is always there and in control” (p. 57). Based on the information available, it was logical to say that the findings were in alignment with other studies and outcomes. The only way that this study extended knowledge was that it acquired data that could be added to literature about whether spirituality and meaning-making were indeed helpful in the emotional regarding breast cancer.

Of the all the participants, only one seemed to have a more negative outlook on life post-diagnosis. However, she did state finding happiness and meaning in time spent with her daughters. The only reason for her apparent negativity would be that she was still in the mindset: “Why me?” She still did not want to have breast cancer, as opposed to working through and/or accepting the diagnosis, while finding peace despite of it. With regards to sampling, measurement and procedural issues, this participant was recruited from the same area, fulfilled the same criteria, and answered the same as all the other participants. The only confounding variable was she felt her relationship with her mother was strained which could have made her feel unsupported in critical times during her treatment and health insecurities.

The findings of the study fit the literature review. The findings showed a focus on women who have been diagnosed with advanced breast cancer and how these women utilized spirituality and meaning-making to cope with their diagnosis. What made this study different was that it solely focused on premenopausal and African American

participants between the ages of as young as 20 and 45. Previous research had not necessarily endeavored to study such a young demographic with breast cancer, as the illness was most often diagnosed in older women. Thus, the findings will add to the research already available in a very specific way. To come to even more accurate answers on the questions posed, the same study should be conducted in other parts of the United States using the same participant criteria, sound parameters, and the same effective methods.

Seligman's (2008) concept of positive psychology and Ajzen and Fishbein's (1980) TRA and the TPB were the two-theoretical frame works used. These served the objective of the study. The philosophy of these two frameworks included that people with a positive outlook would experience better health and improved prognosis when diagnosed with a life-threatening disease (Seligman, 2008; Underwood & Teresi, 2002).

Appropriately, the study was approached from a phenomenological stand point which focused on lived experiences of the participants (Dalbye et al., 2011). The researcher also went to great lengths to insure the credibility, transferability, dependability, and conformability of the data collected. To analyze the accumulated data, the researcher made use of the computer assisted qualitative data analysis software (CAQDAS) called Atlas ti 8, chosen for its ease of use and features, such as concept-mapping that showed visually the relationship between participants.

Implications of the Findings

As a result of this study's findings, significant impact could occur on all social levels if healthcare providers were to recognize, provide, and refer patients with advanced

breast cancer to culturally and spiritually sensitive supportive services. These results could shed light on how newly diagnosed individual and their families can navigate the healthcare system to access resources in the form of printed booklet. This would help alleviate the initial shock experienced by the patient and their loved ones and lead them into the right direction about what the next steps may be for them. Organizations such as the ACS (2017), National Breast Cancer Foundation (2016) and many others could be the ones providing this information to new patients. Healthcare professionals should point their patients in the direction of such organizations.

The issue of healthcare professionals not giving enough information to newly diagnosed patients was a definite Theme in this study. Research does not give enough attention to answering whether spirituality and meaning-making helps in the coping and healing process, it was a hurdle for the participants in dealing and coming to terms with their diagnosis. Doctors should do all they can to comfort their patients or, at the very least, they should immediately refer patients to a person or organization that can. If there are procedures in place, young women can be immediately linked to services and resources. The participant's revealed feeling annoyed by the physician's lack of sensitivity after the breast cancer diagnosis was given.

Another recommendation would be that patients should connect with other breast cancer patients through support groups where the focus is especially on discovering meaning and strengthening spiritual foundations through self-efficacy. The aim should be that these support groups give emotional support as needed and the healthcare professionals should give medical/physical support and information.

Theory and Research

As this study was based on the phenomenon that spirituality and meaning-making helped breast cancer patients in the coping and healing process; however, it was not 100% scientifically provable. The only way to determine if this could be true was to rely on the personal experiences of the sample at hand. In this study, the conclusion was that spirituality and meaning-making did help the participant in the coping and healing process. This was in perfect alignment with what other studies found and the theoretical frameworks used; namely, Seligman's (2008) concept of positive psychology and Ajzen and Fishbein's (1980) TRA and TPB were also soundly chosen as a basis for the study.

Patients, their families, healthcare professionals, and appropriate organizations, such as the ACS (2017) and the National Breast Cancer Foundation (2016), would benefit from the information this study provides. The research and its outcome could help traumatized patients and any other person associated with a breast cancer diagnosis (e.g., family and friends) to transition from a pre-cancer to a post-cancer reality with more ease. It would also make these people aware of the fact that spirituality and meaning-making was proven to help in the coping and healing process for breast cancer. The findings do not necessarily lead to changes in the way people do things but will certainly add to information available to aid premenopausal African American women between the ages of 20 and 45 dealing with advanced breast cancer.

Limitations of the Study

The delimitations for this study were as follows: premenopausal African American women diagnosed with ABC, between the ages of 20 to 45 at time of

diagnosis, with survivorship based on the time of diagnosis to the time of participation in the study. All participants self-identified as African American women. The research participants were in various regions of Delaware.

Seeing that this qualitative research was based on specific delimitations, its generalizability was greatly lessened. Firstly, the participants were African American, which limited the research's applicability only to this ethnicity. Secondly, the study was about breast cancer, which meant the findings could not be generalized to other sorts of cancers. Thirdly, the researcher decided that, although other software programs, such as NVivo 9, MAXQDA, and HyperRESEARCH, were available specific to qualitative analysis, the ease of use and familiarity with Atlas ti 8 made this the software program of choice. The researcher also conceded that if the study was to be reproduced and analyzed with different software, it would not yield the same results.

Sampling did not seem a problem, as research showed that in a qualitative study design, only 5 to 25 participants were necessary (Creswell, 2013); this study had seven participants. Sound procedures were in place regarding recruitment of participants and the research designs, as well as methodologies utilized, which were all perfectly suited to serve the study. The findings were valid inside the parameters of the study itself but would most likely only be similar for participants from the same age group, ethnic group, and with the same kind of cancer. The findings could therefore not be generalized outside of the framework of the study because of these specific delimitations.

The only other limitation that might be of some concern was the differences in personality the participants exhibited. If the study was conducted in exactly the same

manner with the same parameters, methodology, and research design, but with different participants with new personalities, the outcome might slightly change. However, seeing that this was a phenomenological study one could never obtain an absolute outcome. For that reason, the results of this study could not be statistically measured.

Recommendations for Future Research

Future recommendations would be to conduct the same study with the same delimitations, parameters, methodology, and research design elsewhere in the United States. This would verify the reliability of the findings and close the gap in research regarding African American women diagnosed with breast cancer and how they use spirituality and meaning-making to cope. Otherwise, I would suggest that a study be conducted to determine why African American women have a lack of trust and feel discriminated against due to poverty, race, and minimum knowledge and understanding about their disease, which could keep some from being proactive in their healthcare (Ashing-Giwa et al., 2007).

The study could also branch out to other ethnic groups of different ages, backgrounds, and areas in the United States to determine how, when, and to what degree spirituality and meaning-making helped with coping and healing. It also did not have to focus solely on breast cancer, but could ask the same interview questions to patients suffering from any other sort of cancer or life threatening disease. A quantitative study could also be conducted to determine how often women went for mammograms and their reasons for not going if they had not gone in the last year or two. This would highlight

women's level of education about breast cancer and why they just did or did not go for regular check-ups.

Summary and Conclusions

This study was approached from an IPA stand point, which aimed to examine the lived experiences of its subjects. The foundations of IPA include phenomenology (the focus of the lived experience); and focuses on the experience of a similar population (Smith, 2011). IPA is interested in looking at the unique experience of the participant to understand the information gathered from the participants, considering that it is influenced by the relationship between the researcher, the participant, and the data collected.

There were two theoretical frameworks utilized in this study. The first was Seligman's (2008) concept of positive psychology. Seligman posited that when one faced challenges in life with a positive attitude, that attitude could significantly change one's outcome. Moreover, Seligman and Csikszentmihalyi (2000) stated that positive psychology defined an individual's well-being as happiness, enthusiasm, love, uniqueness, and purposeful living.

The second included Ajzen and Fishbein's (1980) TRA and TPB. This theory is an assessment of human behavior as well as the relationship between beliefs, attitudes, intentions, and behavior. This historical perspective of the TRA/TPB model has its purpose in examining the role of social reinforcements, beliefs, attitudes, and intentions on the health behavior (Ashing-Giwa, 1999, p. 60).

This qualitative study explored the lived experiences of premenopausal African American women between the ages of 20-45 diagnosed with advanced breast cancer. The aim was to identify the inner resources derived from spirituality and meaning-making as a source of comfort, coping and healing. As other research has shown, by engaging these women in a meaning-making/meaning-centered coping process as soon as possible after diagnosis they showed positive effects in their self-efficacy, personal growth, and life satisfaction while minimizing depression, anger and stress (W. Breitbart, personal communication, September 2, 2014). While Levine et al. (2007) concluded that faith provided an “emotional blanket of support for a person that may feel alone, as well as the idea that God is always there and in control” (p. 57).

The study, when looking at research and literature available, was anticipated to conclude that inner resources such as spirituality and meaning-making would have a positive effect on patients in terms of their health and life satisfaction. It was the intent of the researcher to illuminate how positive psychology and spirituality influenced the cognitive and emotional processes (meaning-making) of African American women as they went from normalcy to being diagnosed with ABC. She was especially interested in the role spirituality and meaning-making had in empowering women living with ABC.

As expected the findings did yield the same results as previous research. All participants testified to finding purpose in: positive and meaningful relationships, spending their time more wisely, living healthier lives, and taking part in making the public aware of breast cancer and its risks. Creating awareness among especially African

American women is of great concern as research has shown that they have the lowest survival rate when it comes to breast cancer.

One of the major reasons for this is that African American women are generally less knowledgeable about breast cancer. Although the Affordable Care Act is in effect, many women do not follow through with regular check-ups; even when a lump is found. Oftentimes once they determine to seek treatment that cancer which once could have been treated has now potentially grown into a more aggressive tumor. Other reasons for this public health crisis can be socioeconomic conditions for example time off from a job could mean there is less money coming in to support her family (Ashing-Giwa et al., 2007). The findings should help organizations and individuals who dedicate their time to create awareness in preventing late diagnosis specifically premenopausal African American women between the ages of 20 and 45.

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Appendix A

Informed Consent Form

Informed Consent for Dissertation Research Project Participation: Lived Experiences of Pre-Menopausal African American Women with Advanced breast cancer Study Participants

I, _____, agree to participate in a research project regarding my experiences of meaning making which is being conducted by Carmelita Whitfield (Doctoral candidate) of Walden University. The purpose of this study is to understand individuals' experience of how young women who are living with advanced breast cancer create meaning and overall well-being using personal written and narrative stories.

I understand that to participate in this study, I will be asked questions that pertain to the date of my diagnosis, my level of education, my marital and family status, and my overall emotional and psychological well - being to determine if the study is right for me. I understand that Ms. Whitfield will only select individuals who she believes will fit best into the following criteria for participation in the study.

- Pre-menopausal African American women between 20-40 years of age.
- Pre-menopausal African American women diagnosed with advanced breast cancer within the past 2-5 years
- Pre-menopausal African American women who define survivorship as from time of diagnosis to time of study participation

I understand that if I am not initially selected for participation in the study that my information will be kept until the completion of the study should the need for additional participants arise. If more participants are requested, I will be contacted to assess my interest in participation in the study.

I understand that my participation in this study will involve answering (typed) questions provided to me (digitally or hard copy) about my life story (see Attachment A). One (1-1/2 total hour) open-ended semi-structured interview with the researcher will be scheduled 2-3 weeks after receiving the written assignment. This interview will be audiotaped. Tapes will be transcribed for analysis and destroyed when the study is complete.

I understand that if for any reason I feel uncomfortable or experience psychological distress before, during or after my interview a breast cancer crisis helpline will be made available to me.

I understand that the reason for this study is to contribute to the lack of research pertaining to how young women living with advanced breast cancer make sense out of

their diagnosis, live well with their diagnosis, and establish and maintain a sense of empowerment. It is the researcher's hope that this information will contribute to the development of new ways to provide physical, psychological, social, and spiritual support to young women who are diagnosed with advanced breast cancer.

I understand that all information obtained in the study will be recorded and kept confidentially in a secured and locked location. I will be identified using a pseudonym and at no time will my identity be revealed. I understand that Ms. Whitfield will give me an executive summary of my transcribed interview at the completion of her dissertation. I have the right to withdraw from this study at any time.

I understand that at the end of this study all documentation that is matched with my name will be destroyed along with all written documentation, computer files, audiotapes, identifying information, and all other information related to me. The reason for this is to ensure confidentiality. Under this condition, I agree that any information obtained from this research may be used in any way thought best for publication or education, provided that I am in no way identified and my name is not used. I understand that the study will be shared with Ms. Whitfield's dissertation committee at Walden University. By consenting to participate in this study, I agree that any information obtained from this research may be used in any way thought best for publication or education, provided that I am in no way identified and my name is not used.

I understand a gift card in the amount of \$10 will be provided as a gratuity for my participation in this study. I understand whether I complete the research study or decide to withdraw I am still entitled to the gift card.

I understand that there is minimal personal risk and no physical discomfort that is directly involved with this research. Because of the risk involved, therapeutic intervention will be made available immediately if required.

I understand a 2x3 size card with a toll free number of a regional breast cancer helpline will be given and the use of a cell phone for immediate temporary crisis intervention is available if necessary. At any time and for any reason I am free to withdraw my consent and discontinue my participation in this study.

I understand that if I have any question or problem that arise in connection with my participation in this study, I should contact Ms. Whitfield, the researcher at 916.217.9726 (email at Carmelita.whitfield@waldenu.edu) or Ms. Whitfield's Doctoral Committee Chair, Dr. Clarence Schumaker, Jr. at c.j.schumaker@waldenu.edu. If I have questions about my rights as a participant, and wish to speak privately, I can contact Dr. Leilani Endicott at 800.925.3368 extension 3121210, or via email at irb@waldenu.edu. She is the Walden IRB representative who can discuss my rights as a study participant. Walden University's approval number for this study is 05-11-16-0281197 and it expires May 10, 2017.

I consent to be interviewed:

Date: Signature of Participant_____

Date: Signature of Investigator_____

Appendix B: Semi-structured Interview Questions

Diagnosis

1. How old are you?

2. At what age were you diagnosed

18-25 26-32 33-40

3. What is your marital status

married single divorced widowed

4. How many children do you have?

0-2 2-4 4-6 6+

5. Highest level of education

GED High School Some College AA, BA, MA, above

6. Which type of breast cancer were you diagnosed with

Invasive Ductal Carcinoma in situ Hereditary BRCA I or II

Inflammatory Breast Cancer Don't know

8. Do you smoke

Yes No, if yes how much _____

7. How soon after diagnosis did you begin treatment

Immediately 2-4 weeks 5-8 weeks No treatment sought

If no treatment sought; why?

Meaning –Making and Spirituality

1. What makes your life meaningful?
2. Do you ever wonder why breast cancer happened to you?
3. How did you make sense of your chronic disease?
4. What role did or could your healthcare providers play in helping you cope with your diagnosis?
5. Describe your turning point when you transitioned from anger to purpose?
6. How can your diagnosis help others in your situation?
7. What aspects of your breast cancer experience stand out for you
8. How has this experience affected you?
9. What changes have you made in your life since being diagnosed with breast cancer
10. What does spirituality mean to you and has your spirituality changed since your diagnosis; if so how? Why?
11. Describe what you felt or heard immediately after you were given your diagnosis
12. What did you do once you were given your diagnosis
13. Looking back at your initial diagnosis to now, what has changed?
14. Prior to being diagnosed what did you know about breast cancer/did you know anyone who had or died from breast cancer
15. Is there anything further you wish to share?

Appendix C:

Organization Request Letter

07 December 2015

Ms. Cheryl Doucette Education and Outreach
Program Director
Delaware Breast Cancer Coalition
165 Commerce Way; Suite 2
Dover, DE 19904

Dear Ms. Doucette:

I am currently a PhD Student at Walden University, School of Health Sciences. I have completed all course requirements and am in the Dissertation phase for my terminal degree in Public Health. Delaware Breast Cancer Coalition has a highly-regarded reputation in the community as a premier provider of support and education for individuals diagnosed with breast cancer. I will be conducting a phenomenological study on Spirituality and Meaning-making of pre-menopausal African American women with advanced breast cancer. The purpose of this letter is to request your organization's cooperation by allowing me to sample from your database of members. I am looking for a minimum of 10 individuals that meet the qualifying criterion: (a) African American women, (b) diagnosed with Advanced breast cancer, (c) between the ages of 20-45 at the time of diagnoses, (d) have a minimum of 3 months post-treatment, and lastly (e) live in throughout the state of Delaware.

Your consideration to allow Delaware Breast Cancer Coalition member's to participate in this study would be greatly appreciated and will enhance my research. The research will examine pre-menopausal African American women diagnosed with advance breast cancer, their lived experiences and the utility of Spirituality and Meaning-making as they journey through their diagnosis and healing process.

If your organization agrees to cooperate, I will provide language for the electronic email and a study participant flier with my contact information to be posted in the general areas. All data collected will be secured in a locked file and each participant will be given a unique identifier to ensure confidentiality. Once the targeted sample size is met, I will no longer recruit for the study. The selected participants will be contacted to discuss the study and the consent form. At anytime and for any reason participant may discontinue the study.

By allowing your organization to participate in the study, as the researcher here are my guarantees:

- Ms. Whitfield, you have guaranteed to ensure the confidentiality of our women by keeping their confidential information secured and locked. All selected participants will be contacted individually, with a detailed explanation of the study and if they agree a formal consent will be signed. Participants will also be informed that if any time they wish to discontinue the study, they can do so at any time during the study without prejudice or malice.
- Discontinuing the study has no adverse bearing on the study or relationship between Ms. Whitfield and Walden University.
- A donation to a charity or non-profit of the participants choosing will be donated on behalf of the participant regardless of participants continuation or withdraw from the study.
- If at any time the participant experiences acute stress or psychological distress due to the interview questions or process, the number of a local breast cancer helpline will be offered. (See bottom of letter). This number provides resources and confidential assistance in various languages for both the breast cancer survivor and or caregiver.
- Participant will be asked to give permission to have their interview digitally recorded.

If my request is agreeable, I ask that you provide on letterhead a letter of cooperation. Listed below is the following contact information: Scholar, Committee Chair, and the University's IRB. I am always available for questions and clarification.

Research questions are available upon request.

Sincerely,

Carmelita Whitfield, PhD Candidate

Appendix D: Compensation Voucher

I, _____, acknowledge that I have received \$10.00/gift card for my participation in the research study “Lived Experiences of PreMenopausal African American Women with Advanced Breast”

Date: Participant

Date: Principal Investigator/Researcher

I, _____, acknowledge that a \$10.00/donation

on my behalf will be made to _____ Non-profit

for my participation in the research study “Lived Experiences of Pre-Menopausal African American Women with Advanced Breast”

Date: Participant

Date: Principal Investigator/Researcher

Appendix E:
Breast Cancer Helpline Information

BREAST CANCER HELPLINE

Toll-free

866.312.3222

BREAST CANCER HELPLINE

Toll-free

866.312.3222

BREAST CANCER HELPLINE

Toll-free

866.312.3222

BREAST CANCER HELPLINE

Toll-free

866.312.3222

BREAST CANCER HELPLINE

Toll-free

866.312.3222

BREAST CANCER HELPLINE

Toll-free

866.312.3222

Appendix F:
Recruitment Flyer

Phenomenal Women!!
Research Participants Needed



Are you African American between the ages of 20-40 and have been diagnosed with advanced breast cancer? If so, a qualitative phenomenological research study is being conducted in your area viewing the perceptions of meaning and spirituality as contributing factors to healing and strength. Your participation is strictly **CONFIDENTIAL**.

If interested contact me at (916) 217.9726 or Email:
carmelita.whitfield@waldenu.edu

Carmelita Whitfield
(916) 217.9726
Carmelita.whitfield@waldenu.edu

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Carmelita.whitfield@waldenu.edu

Appendix G:

Delaware Breast Cancer Coalition Letter of Support



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The Delaware Breast Cancer Coalition, Inc. is a 501 (c)(7) non-profit organization.

4/28/2016

Carmelita Whitfield
 PhD Candidate
 1506 McGovern Terr
 Wilmington, DE 19805
 Carmelita.whitfield@waldenu.edu

Dear Ms. Whitfield

I am happy to provide a letter of cooperation to assist in your phenomenological study of Lived Experiences of Pre-Menopausal African American Women in advance stage breast cancer. You are requesting **Delaware Breast Cancer Coalition** to send a request for participation announcement via email to our database. You will be responsible for providing the email language that we will accompany your flyer to be forwarded to our membership. The flyer will be sent as an email attachment and posted in our general meeting (common) area. You are looking for the qualifying criteria: (a) African American women, (b) diagnosed with Advanced breast cancer, (c) between the ages of 20-40 at the time of diagnoses, (d) have a minimum of 3 months' post-treatment, and lastly (e) live throughout the state of Delaware.

Ms. Whitfield, you have guaranteed to ensure the confidentiality of our women by keeping their confidential information secured and locked. All selected participants will be contacted individually, with a detailed explanation of the study and if they agree a formal consent will be signed. Participants will also be informed that if any time they wish to discontinue the study they can do so at any time during the study without prejudice or malice.

Additionally, a choice of a gift card in the amount of \$10, or a donation to their charity for the same amount will be provided to participants choosing to participate regardless of participant's continuation or withdraw from the study. If at any time the participant experiences acute stress or psychological distress during the interview questions or process, a toll free number of a local breast cancer helpline will be offered as temporary crisis assistance until participant to reach her health/mental health care provider. (See bottom of letter). This number provides resources and confidential assistance in various languages for both the breast cancer survivor and or caregiver.

Sincerely,

Cathy Scott Holloway
 Program Director

Delaware's Most Trusted Breast Cancer Resource

111 West 11th Street, Suite 2 Wilmington, DE 19801 402.778.1102 Fax: 402.778.1104	165 Commerce Way, Suite 2 Dover, DE 19904 302.672.6435 Fax: 302.672.7030	16329 Coastal Hwy., Suite 116 Lewes, DE 19958 302.644.6064 Fax: 302.644.6016
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Toll Free 1.866.317.DBCC • dbcc@delbreastcancer.org • www.delbreastcancer.org

Appendix H:

Sisters on a Mission Letter of Cooperation



Joyce D. Rickards

Home: 308-945-0750 Cell: 308-745-8634

Carmelita Whitfield
 PhD Candidate
 1506 McGovern Terr
 Wilmington, DE 19805
 Carmelita.whitfield@waldenu.edu

Dear Ms. Whitfield

I am happy to provide a letter of cooperation to assist in your phenomenological study of Lived Experiences of Pre-Menopausal African American Women in advance stage breast cancer. You are requesting Sisters on a Mission to send a request for participation announcement via email to our database and post a flyer in our general meeting space. You are looking for the qualifying criteria: (a) African American women, (b) diagnosed with advanced breast cancer, (c) between the ages of 20-40 at the time of diagnoses, (d) have a minimum of 3 months post-treatment, and lastly (e) live throughout the state of Delaware.

Ms. Whitfield, you have guaranteed the anonymity of our women and you will keep their confidential information secured and locked. All selected participants will be contacted individually, with a detailed explanation of the study and if they agree a formal consent will be signed. Participants will also be informed that if any time they wish to discontinue the study, they can do so at any time during the study. Participant will be asked to give permission to have their interview digitally recorded.

For over a decade, Sisters On A Mission, a Wilmington-Kent-Sussex County based non-profit organization, has worked to raise awareness about breast cancer and other forms of cancer that afflict our communities. Although our emphasis has been on breast cancer awareness among African Americans, we have expanded to educate entire families.

Thank you for your consideration and I look forward to speaking and/or hearing from you soon.

Sincerely,

Joyce D. Rickards
 Joyce D. Rickards, President
 Kent-Sussex County Chapter