TRANSCENDING THE NOW: A GROUNDED THEORY STUDY OF DEPRESSIVE

SYMPTOMS IN AFRICAN AMERICAN WOMEN WITH BREAST CANCER

by

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DEDICATION

I would like to dedicate this dissertation to my family for their incredible support, belief in me and their unfailing encouragement to me that has inspired me to always pursue whatever my heart desires. I would also like to dedicate this research to the nine African American women warriors that participated in this study and graced me with their innermost thoughts, which made this dissertation possible. I, like them believe that God will always make a way!

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ABSTRACT

In breast cancer patients, symptoms of depression decrease quality of life and may have other serious consequences, such as increasing mortality. Few studies have focused on psychosocial issues and their relation to breast cancer in African-American women. Thus, only limited information has been published on the breast cancer experience of African American women. A grounded theory approach was used to explicate the social psychological and social structural processes of African American women with breast cancer experiencing depressive symptoms. The sample included nine African American women with breast cancer who experienced depressive symptoms. Unstructured interviews were conducted with each participant.

Data were analyzed using the constant comparison method. The data indicated that African American women used the basic social process of *Transcending the now* to manage the basic social problem of having breast cancer and experiencing depressive symptoms. The five phases of the basic social psychological (BSP) process *Transcending the Now* that emerged during data analysis were *Relying on Faith, Being Strong, Seeking Support, Dealing with Life Too, and Enduring Breast Cancer*. The findings of this study provide nurses with new knowledge regarding the experience of depressive symptoms in African American women with breast cancer and provide a theory of transcending that can be used in building a research-based practice.

CHAPTER ONE: INTRODUCTION

Depressive symptoms present serious problems in patients with co-morbid health problems. In fact, the effects of depressive symptoms and chronic medical conditions are additive, and their combined impact is about twice of what either condition produces on its own in terms of functional limitation (Pascreta, 1997). Hjerl et al. (2003) found that in breast cancer patients, symptoms of depression decrease quality of life and may have other serious consequences such as increasing mortality. Thus, it is not only important to recognize depressive symptoms, but also to understand depressive symptoms in all women with breast cancer. Yet there is limited information in the current literature on the breast cancer experience of African American women (Henderson et al, 2003).

As few studies have focused on psychosocial issues and their relation to breast cancer in African American women, the literature regarding depressive symptoms in African American women with breast cancer is scant, necessitating the need to look at depressive symptoms in African American women and breast cancer in African American women separately. As such, several gaps exist in the literature regarding depression and depressive symptoms in African Americans.

Depressive Symptoms in African American Women

In general, few articles have addressed depressive symptomatology in African American women. Furthermore, the research that has been done on depressive symptoms among African Americans has focused largely on comparing rates with whites, rather than on determinants of depression within the African American population (Siegel et al, 2000). Numerous community-based studies have documented higher rates of depressive

symptoms among African American women than among Whites (Brown et al, 2003; Siegel, 2000). Myers et al. (2002) found that there was a greater tendency among depressed African Americans to report cognitive-affective symptoms, particularly anxiety, anger and hostility. The author proposes that such symptom expression might account for the greater risk of psychiatric misdiagnosis experienced by African Americans. Misdiagnosis places African American women at risk for either lack of treatment or inappropriate treatment. Jones et al. (2003) provides some explanation for the apparent misdiagnosis of African American women in that they tend to delay seeking treatment for depressive symptoms, fail to seek treatment at all, or report only the physical symptoms of depression, leading to misdiagnosis and missed opportunities for treatment.

<div align="center">Background of the Problem</div>

Breast cancer is the most common cancer among women in the United States (Woods et al, 2006), yet the psychological health and well-being of women with breast cancer has not been well addressed. This is in spite of the fact that poor psychological health, as evidenced by depression and depressive symptoms, is very prevalent among breast cancer patients. In fact, Hjerl et al. (2003) reported that a prevalence of depressive symptoms up to 33% has been recorded after a diagnosis of breast cancer. Additionally, Bultz and Carlson (2006) reported that research has demonstrated from the time of diagnosis to treatment, termination of treatment, survivorship, or reoccurrence and palliation, the incidence of emotional distress in North America ranges from 35 to 45%.

Ballenger et al. (2001) found that 25% of patients actually meet the diagnostic criteria for major depression due to their depressive symptoms.

However, it is important to note that depression and depressive symptoms are not the same. An individual may have depressive symptoms and not depression; yet if an individual has depression, they would necessarily have depressive symptoms. According to Warren (1994) depression is an umbrella term that refers to a disturbance of a person's mood that produces a variety of human, emotional and clinical responses that influence daily functioning. Furthermore, depression implies a formal psychiatric diagnosis based on a systematic comparison of the individual's mental health history and his or her signs and symptoms with predetermined criteria (Gary and Yarandi, 2004). On the other hand Pascreta (1997) suggests that depressive symptoms refer to varying degrees of depressed feelings not necessarily associated with psychiatric illness. However, whether an individual suffers from depression or depressive symptoms, accurate assessment of depression and depressive symptoms in medically ill patients is of paramount importance (Waller et al, 2005).

The purpose of this study was to describe the social psychological and social structural processes of African American women with breast cancer experiencing depressive symptoms, and to develop an explanatory theory of depressive symptoms in African American women with breast cancer. The remaining sections of this paper will discuss the background, purpose of the study, research questions, theoretical perspective, key concepts, and significance.

African American Women and Depression

According to Brown, Abe-Kim, and Barrio (2003) symptom patterns and expression of psychological distress are likely to be influenced by culture. Thus it stands to reason that African Americans experience depression differently. In fact, Leo et al.(1998) states that research in a wide variety of cultures and among ethnic groups in the United States suggests that cultural beliefs and practices affect the manner in which individuals both express or manifest symptoms of depression, and experience depression as a phenomenal state. Additionally, according to Myers et al. (2002) ethnic groups also differ in the expression of clinical depression assessed through self-report and interviewer-rated measures.

A woman's experience of depression will be informed by her cultural identity, culturally endorsed expressions of distress, and explanations for depression, though it is important to remember that within a single ethnic group, women will show considerable variability in the expression of symptoms (Brown et al, 2003). As such, Carr et al. (1996) found that there are indeed significant differences between African American and Caucasian women's experience of depression. In a study on the clinical presentations of major depression, Brown et al. (1996) found that African Americans experienced significantly greater distress associated with finances, place of residence, social activities, love and marriage, having children, and family relations. Furthermore, the greater tendency of African Americans to experience and report physical symptoms, lifetime panic and somatization disorder, and physical disability may reflect culturally specific manifestations of depression in African Americans (Brown et al, 1996).

Incidence and Prevalence of Depression

Depression is a common and often chronic disorder that is expected to become the second greatest cause of disability worldwide over the next decade (Harman et al, 2004; O'Malley, Forrest & Miranda, 2003; Wells et al, 2004). However, much of the data regarding prevalence of depression by race and ethnicity are contradictory with some studies reporting higher rates of depression in African Americans and others reporting lower or equal rates when compared to Whites (Brown, Schulberg & Madonia, 1996; Brown et al, 2003; Carrington, 2006; Dunlop et al, 2003; Jackson, 2006; Plant and Sachs-Ericsson, 2004; Riolo et al, 2005; Seigel et al, 2000). These diverse reports of racial differences in the prevalence of depression underscore the need for further research (Miller et al, 2004). What is certain is that women are at greater risk for depression and depressive symptoms than men (Brown et al, 2000; Carr et al, 1996; Gazmararian et al, 1995; Jones et al, 2004; Jones-Webb and Snowden, 1993; Myers et al, 2002). Furthermore, women have a higher risk than men do of initial and first onset episodes of depression that may occur at any point in a woman's life (Carrington, 2006).

Despite the increased risk for depression among women, little is known about the prevalence of depressive symptoms among women of different racial and ethnic groups (Ell et al, 2005; Myers et al, 2002; Rickert, Wiemann, & Berenson, 2000). There is a great paucity of research on African American women and depression (Barbee, 1994; Carr et al, 1996; Gazmararian et al, 1995; Warren, 1994; Carrington, 2006). One reason cited for this fact is that historically, African American women have not been included in large controlled trials in sufficient numbers to generate data that are generalizable to

larger populations of African American women (Bromberger et al, 2004; Carrington, 2006). Thus, the prevalence of depressive disorders in African American women is unclear. One of the consequences is that the lack of adequate and sufficient research data on African Americans contributes to the problems of misdiagnoses, underdiagnoses, and undertreatment of depression in African American women. Yet, regardless of actual prevalence, there is a significant illness burden from mental illness in the African American community (Jackson, 2006).

Purpose of the Study

The purpose of this study was to explicate the social psychological and social structural processes of African American women with breast cancer experiencing depressive symptoms, and to develop an explanatory theory of depressive symptoms in African American women with breast cancer. The methodology used to support this research inquiry was grounded theory.

Research Question

This study will be guided by the following research question:

(1) What are the social psychological and social structural processes of African American women with breast cancer experiencing depressive symptoms? The overall aim of this study is to explicate the process of depressive symptoms in African American women with breast cancer.

Theoretical Perspective

A theoretical perspective is the philosophical stance informing a methodology, providing a context for the process and grounding its logic and criteria (Crotty, 2003).

The theoretical perspective informing this study will be symbolic interactionism. Symbolic interactionism postulates that an individual's realities are created through attaching meaning to situations and symbols, which in turn are used to express their meanings and beliefs (Jeon, 2004). Symbolic interactionism is a theoretical perspective that stresses the interrelationships of human activity to experiences, especially interpersonal encounters (Schroeder, 1981). It is an appropriate framework to guide this study because the major emphasis is on the meaning of the situation to the person (Edwards and Saunders, 1990; Saunders, 1997). This viewpoint asserts that interactions among people over time are motivated by the symbolic meanings that actions, objects, and events have acquired for those people both individually and together (Edwards and Saunders, 1990). Symbolic interactionism seeks to explain behavior by finding what meaning and value individuals attach to specific experiences, based on the premise that human beings are constantly evaluating and acting upon events based upon their interpretation of these events (Schroeder, 1981). It is with this premise that we can be aware of which symbolic meanings and values are the most direct cause of a person's behavior (Edwards and Saunders, 1990).

Symbolic interactionism is basically a theory about human behavior and an approach to the study of human conduct and human group life (Chenitz and Swanson, 1986). In fact, it is the empirical world that is the natural world of such group life and conduct (Blumer, 1969). In symbolic interactionism, meaning is actually the major element in understanding human behavior, interactions and social processes (Jeon, 2004). Thus, symbolic interactionism is able to move scientific inquiry from the mechanistic

model of causation to a processual model (Crooks, 2001). It acknowledges that

perceptions, understandings and actions change over time as new experiences and

information are integrated, and supports the exploration of experiences, actions, and

variations across time and context (Crooks, 2001). Symbolic interactionism actually

holds that people are in a continual process of interpretation and definition as they move

from one situation to another (Eaves, 2001).

  The history of symbolic interactionism involves many contributors. Blumer first

introduced the term "symbolic interactionism" in 1937, even though several individuals

have contributed to the early development of the theoretical framework (Saunders, 1997).

The central concepts discussed by most symbolic interactionists include society or world,

self, and mind, joint or social action (Klunkin and Greenwood, 2006; Van Riper et al,

1992). An understanding of the central concepts of symbolic interactionism is important

to grasp when using this theoretical perspective.

  In regards to society or world, Blumer (1969) viewed human society as symbolic

interaction, referring to the peculiar and distinctive character of interaction as it takes

place between human beings. This peculiarity is due to the fact that human beings

interpret or define each others actions instead of merely reacting to each other's actions.

As such, their response is not made directly to the actions of one another but instead is

based on the meaning which they attach to such actions. Thus, participants in social life

are continually attempting to determine how others are interpreting their actions to

predict their responses and adapt or revise their own current courses of action (Klunkin

and Greenwood, 2006).

The second concept of symbolic interactionism is self. According to Klunkin and Greenwood (2006), the self is constructed through social interaction, first with significant others and then with others in progressively widening social circles. This self is comprised of two entities, the "I" and the "Me"(Jeon, 2004; Klunkin and Greenwood, 2006). The "I" can best be described as the active, dynamic interpreting component of the self, for example, the reflector, interpreting cues and synthesizing them with other components of the self. On the other hand, the "Me" is the object of self-reflection that can be defined to "myself" and others. In other words, the me is the object of personal, internal conversations and represents the self-image (Klunkin and Greenwood, 2006). The "I" and the "Me" constantly communicate with each other through inner conversations, before creating an act or behavior (Jeon, 2004). Thus, it is important to understand that who "I" am at any given time depends on the "Me" that is called forth by the context in which the "I" finds itself (Klunkin and Greenwood, 2006).

The last concept of symbolic interactionism has been called mind, joint or social action. Joint action or meaningful human interaction is always designed and conducted in complex dynamic social contexts (Klunkin and Greenwood, 2006). Van Riper et al. (1992) cites Mead (1934) to explain that this joint action or minded behavior arises around problems. It involves a temporary inhibition of action while the individual tries out various approaches to the problem in his or her imagination. In other words by identifying the social act or joint action the participant is able to orient himself, he has a key to interpreting the acts of others and a guide for directing his action with regard to them (Blumer, 1969).

It is essential to note that all theoretical perspectives are influenced by an epistemology. Epistemology refers to the theory of knowledge embedded in the theoretical perspective and thereby in the methodology. In other words, epistemology deals with the nature of knowledge, its possibility, scope and general basis (Crotty, 2003). My preferred epistemological view about the nature of knowledge and truth is constructionism. Crotty (2003) describes constructionism as the view that all knowledge and therefore all meaningful reality is contingent upon human practices, constructed in and out of interaction between human beings and their world and developed and transmitted within an essentially social context. According to constructionism, meanings are constructed by human beings as they engage with the world they are interpreting. Thus, meaning cannot be created, only constructed. The unitary-transformative and simultaneity nursing paradigms stem from the overall interpretive paradigm of constructionism. This epistemology posits that knowledge is derived from experience, that cognition, and perception and experience affect what is seen or conceptualized, and that observations are value laden (Monti and Tingen, 1999).

Philosophic View and Research Area

I believe that the theoretical perspective of interpretivism, informed by constructionism, is most congruent with studying African American women with breast cancer experiencing depressive symptoms. According to Crotty (2003), interpretivism emerged in contradistinction to positivism in an attempt to understand and explain human and social reality. The interpretivist approach looks for culturally derived and historically situated interpretations of the social life world. Interpretivism is often linked to the

thought of Max Weber, who suggested that in the human sciences we are concerned with *Verstehen* (understanding). Weber believed that any understanding of causation comes through an interpretive understanding of socialization and involves an explanation of relevant antecedent phenomena as meaning-complexes. The interpretivist approach to human inquiry has been influenced by three historical streams; hermeneutics, phenomenology, and symbolic interactionism (Crotty, 2003). As stated by Crotty (2003), symbolic interactionism explores the understanding abroad in culture as the meaningful matrix that guides our lives. The tenets of symbolic interactionism are based on the belief that humans should be regarded in the context of their environment (Benzies and Allen, 2001). Symbolic interactionism posits three basic assumptions; (a) human beings act toward things on the basis of the meanings that these things have for them; (b) the meaning of such things is derived from, and arises out of the social interaction that one has with one's fellows; and (c) these meanings are handled in and modified through an interpretive process used by the person in dealing with the things he encounters (Blumer, 1969).

Therefore, the implication of the symbolic interactionist perspective is that the actor's view of actions, objects, and society has to be studied seriously. The situation is viewed as the actor sees it, the meanings of objects and acts must be determined in terms of the actor's meanings, and the organization of a course of action must be understood as the actor organizes it. Accordingly, the role of the actor in the situation would have to be taken by the observer in order to see the social world from his perspective (Crotty, 2003). In order, to understand the experience of African American women with breast cancer

experiencing depressive symptoms, you have to look at it through their eyes. This is in keeping with the symbolic interactionism perspective, in that a researcher can only understand what is going on if and only if he or she understands what women believe about their worlds and their experiences (Crooks, 2001). Additionally, in order to best understand the world of African American women with breast cancer experiencing depressive symptoms, one must familiarize themselves with some key concepts first.

Key Concepts

Key concepts of this intended study of depressive symptoms in African American women with breast cancer include vulnerability, racial and ethnic disparities in health care, Black feminism, and culture. The concepts are explained as follows: *vulnerability* refers to susceptibility to poor health (Shi and Stevens, 2005). Vulnerable populations share many common traits and typically experience a convergence or interaction of multiple vulnerable characteristics or risk factors. Some of these characteristics include poor access to healthcare, uninsured status, low SES, worse health outcomes, increased health needs and the receipt of poorer quality health care (Flaskerud and Winslow, 1998).

Racial and ethnic disparities in health care as defined by Smedley at al. (2003) are differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention. Smedley et al. (2003) maintain that evidence of racial and ethnic disparities in healthcare is, with few exceptions, remarkably consistent across a range of illnesses and healthcare services.

Black feminism purports that we have to understand the differences among women before we can deal effectively with commonalities (Barbee, 1994). Accordingly,

Black feminist thought places Black women's lives at the center of analysis and allows for their self-definition (Shambley-Ebron and Boyle, 2004). It values and centers African American women's experiences and empowers African American women with the right to interpret their reality and define their objectives (Taylor, 1998). Furthermore, Black feminism considers how concepts and organizing principles, such as race, class, and gender, intersect and blend to produce material consequences for African American women's lives (Barbee, 1994). Thus it is concerned with the influence of multiple oppressions. Gibson and Abrums (2003) states that according to Black Feminist thought, researchers should conduct research with African American women by relating their lived experience to context, texture, and culture. Black feminism, which is synonymous with Womanist theory is very useful in conducting research with African American women because it encourages a sensitivity and awareness of the uniqueness of the African American woman's experience (Banks-Wallace, 2000).

Lastly, *culture* is an inextricable part of human beings and as such, must be considered when conducting research. Simply stated, culture is a set of learned behaviors and moral codes that are passed down through community and family systems to individuals via socialization. Burk et al.(1995) agrees that patterns of cultural behavior are acquired through the process of socialization. These learned behaviors generally guide the actions of individuals as they progress through various life situations and events, including those related to health care. Consequently, the culture into which an individual is born molds communication beliefs and practices from birth and remains a strong influence throughout life (Burk et al, 1995). Brown and Keith (2003) also report

that culture influences one's perceptions of the world and shapes the interpretations of life experiences. It provides a sense of identity along with norms and customs pertaining to social interactions. For this reason, culturally constructed concepts of health and illness are important aspects of health care (Burk et al, 1995), and must be considered when conducting research with ethnic women.

Only through tapping into the experiential world of individuals, such as how they interpret, evaluate, and define meanings of social interaction and formulate their behaviors can researchers come to understand human phenomena (Hall, 1990). Based on this premise a symbolic interactionist perspective can be used to aid research endeavors with African American women and therefore is the philosophical stance for this study. In keeping with the tenets of symbolic interactionism, the research questions that will guide the interviews for this study will emphasize process rather than structure with attention paid to the key concepts discussed.

Significance of the Study

Symptoms of depression in breast cancer patients are associated with lower quality of life, poorer treatment compliance, and shorter disease free intervals (Golden-Kreutz and Andersen, 2004; Wong-Kim and Bloom, 2005). Furthermore, breast cancer mortality is significantly higher in women with psychiatric diagnoses (Hjerl et al, 2003; Massie, 2004). Stressors unique to racial and ethnic minorities such as low SES, physical hardships, blocked opportunities, discrimination, and acculturation operate as sources of vulnerability for distress and mental health problems (Brown et al, 2005). The presence of concomitant depressive symptoms among members of ethnic minority groups who

have chronic conditions has also been shown to be associated with a substantially greater health burden than the burden borne by their counterparts without depression or by depressed individuals without chronic conditions (Bazargan et al, 2005).

<div align="center">Significance of the Study to Nursing</div>

A study describing the social psychological processes of African American women with breast cancer and experiencing depressive symptoms is long overdue. African American women continue to be understudied in most areas of breast cancer research, including psychological health (Underwood, 2006). Thus, the current health care literature is lacking concise descriptions and explanatory theories on depressive symptoms in African American women with breast cancer, causing depressive symptoms in this population to continue to be misunderstood, undetected and untreated. A better understanding of the context of depressive symptoms in African American women might serve to decrease unmet health needs among this populations.

Results of this proposed study can potentially be used by advanced practice clinicians to substantially improve the care of African American women with breast cancer who are experiencing depression or who have experienced depression in several ways. First the findings of such a study can guide health promoting interventions for this specific population. Second this type of study will increase awareness of the problem of depression among a specific group of women with breast cancer. Additionally it will lead to the accurate recognition of depressive symptoms in African American women with breast cancer among nurses, causing better health outcomes such as improved quality of life, increased adherence to treatment, and broader knowledge regarding preferences for

treatment among this population. This study will also impact the care of these women by identifying the barriers to health care that they face. Further, the experience of depressive symptoms in African American women with breast cancer will be explained in their own words offering a new cultural context that has not been presented thus far in the literature. Understanding the contextual nature of depressive symptoms in African American women with breast cancer may lead to improved intervention strategies reducing the incidence of depressive symptoms among African American women with breast cancer. Results of this particular study will likely advance theory in the area of vulnerable populations and health disparities by offering an explanatory theory for depressive symptoms in African American women with breast cancer that is can be immediately applied to clinical encounters as well as tested and expanded as research continues with this population and research area.

<div align="center">Summary</div>

This chapter described the purpose of this study and the background of the problem which highlights the need for this research inquiry. Depressive symptoms in breast cancer patients significantly affect their quality of life, yet little is known about the experiences of African American women. In addition, the theoretical perspective of symbolic interactionism that will inform this study was discussed as well as the epistemology of constructionism. Furthermore, important key concepts, such as vulnerability and Black feminism that are crucial when conducting research with African American women were introduced. Lastly, the potential knowledge that this study will add to the discipline of nursing was addressed.

CHAPTER TWO: REVIEW OF THE LITERATURE

The purpose of this research effort was to conduct a grounded theory study of depressive symptoms in African American women with breast cancer. I will discuss African American women as a population, the importance of culture, and the vulnerability of African American women in regards to health. Then, the current literature on breast cancer, depression and depressive symptoms in African American women will be reviewed. The search strategy for this study included a literature search of Medline, and Cinahl via Ovid which yielded 26 articles with no duplicates, using the search terms depressive symptoms, African American women and breast cancer. Interestingly the resultant articles had little to do with the search terms. A similar search in Psychinfo yielded one article related to breast cancer screening. Since, the literature regarding depressive symptoms in African American women with breast cancer is negligible. The search was conducted a second time using the terms depression and African American women and then depressive symptoms, breast cancer and African American women, in order to yield more articles.

African American Women

Blacks or African Americans are people with origins in any of the black racial groups of Africa. According to the latest U.S. Census Bureau report, of the 282.1 million people living in the United States approximately 144 million (51 percent) are women (Spraggins, 2003). Of that number, African American or Black women constitute 18 million or 12.7 percent, of all females living in the United States (U.S. Department of Health and Human Services, Office of Women's Health, 2003). African American

women hold a unique position in American society. African American women's very presence in this country is a result of slavery and their current position is still influenced by that legacy (Barbee, 1994). For over four centuries, African American women have lived in America, yet they continue to exist in the margins of society, negatively impacted by the combination of race, class and gender discrimination (Shambley-Ebron and Boyle, 2004). Not surprisingly, Black women have distinct viewpoints related to their history and position in society that warrant separate consideration (Shambley-Ebron and Boyle, 2004). However, the experiences, and voices of African American women as with other marginalized groups, have been ignored or excluded from pubic discourse (Boyle, Hodnicki, & Ferrell, 1999). Literally, very often the experiences of other groups such as White women are attributed to African American women as if their experiences are the same. Yet, Black women's experiences are diminished or trivialized by viewing them through White females lenses (Barbee, 1994) or any lens that is not their own as African American women must be viewed in their own right. The experiences and activities of Black women must be analyzed in their socially and historically specific contexts (Moore, 1988 as cited by Barbee 1994). In effect, Shambley-Ebron and Boyle (2004) suggest that it is the focus on race, class and gender that is particularly critical to illuminate in the lives of African American women. In addition to a unique viewpoint African American women also have a distinct culture. Thus it would be remiss not to mention culture when speaking about African American women.

Culture

What is culture? Culture has been defined in many ways. Papadopoulos and Lees (2001) cite the DHHS Office of Minority Health (2000) to define 'culture' as integrated patterns of human behavior that includes the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups. Kim-Godwin et al. (2001) defines culture as a learned system, comprising shared rules, values, beliefs and meanings that act as guidelines for decisions about a population's lifestyle activities. Whereas, Kleinman (2004) proclaims that culture is not a thing; it is a process by which ordinary activities acquire emotional and moral meaning for participants. In addition, he states that, cultural processes include the embodiment of meaning in habitus and physiological reactions, the understanding of what is at stake in particular situations, the development of interpersonal connections, religious practices, and the cultivation of collective and individual identity. Further, culture is also inextricably caught up with economic, political, psychological, and biologic conditions.

Simply stated, culture is a set of learned behaviors and moral codes that are passed down through community and family systems to individuals via socialization (Burk et al, 1995). These learned behaviors generally guide the actions of individuals as they progress through various life situations and events, including those related to health care. Consequently, the culture into which an individual is born molds communication beliefs and practices from birth and remains a strong influence throughout life (Burk et al, 1995) These cultural influences extend to one's perceptions of the world and shapes how he or she interprets life experiences (Brown and Keith, 2003). Culture provides a

sense of identity along with norms and customs pertaining to social interactions. For this reason, culturally constructed concepts of health and illness are important aspects of health care (Burk et al, 1995). Therefore, health behaviors can only be judged within the frame of the person's cultural reality (Baker, 1997). Culture actually has characteristics that include the phenomena associated with the maintenance of well-being and problems of sickness with which people cope in traditional ways within their own social networks and institutional structures (Weidman, 1982 as cited by Turton, 1997).

According to Matthews and Hughes (2001) culture is a complex and global variable that influences behavior in myriad ways. In fact, culture is an inextricable part of human beings and as such, must be considered when conducting research. For this reason, culture is an important factor to understand when exploring depression and depressive symptoms amongst African American women with breast cancer. Research in a wide variety of cultures and among ethnic groups in the United States has shown that cultural beliefs and practices affect the manner in which individuals both express or manifest symptoms of depression and experience depression as a phenomenal state (Leo et al, 1998).

Furthermore, an intricate understanding of the importance of culture on the outcome of research can lead to rich valuable data, yet often this is not the case. According to Papadopoulos and Lees (2001) a unicultural perspective in research prevails, which assumes that concepts and explanations of relationships between concepts are universally applicable across different cultures. The authors have suggested that this

perspective curtails researchers' awareness of alternative interpretations, which can lead to vulnerability in sub-cultural groups.

<div align="center">Vulnerability</div>

Aday (2001) defines vulnerability as being at risk for poor physical, psychological, or social health. Further, to be vulnerable is to be in a position of being hurt or ignored, as well as helped, by others. Implicit in the notion of vulnerability is a danger or threat to the individual and the experience of vulnerability is one that creates stress and anxiety (Rogers, 1997). Flaskerud and Winslow (1998) define vulnerability in terms of social groups who have an increased relative risk or susceptibility to adverse health outcomes as evidenced by increased comparative morbidity, premature mortality and diminished quality of life.

Vulnerability is intricately related to health. Subsequently, it has direct influences on health care access, health care quality, and health status measured at the individual and populations levels (Shi and Stevens, 2005). Ultimately vulnerability results in unmet health needs (Shi and Stevens, 2005) which lead to poor health status. Among vulnerable populations vulnerability results in early death, disability, and decreased quality of life (Flaskerud and Winslow, 1998). Other effects of vulnerability on health are stress, anxiety, feelings of hopelessness, helplessness, a lack of control over one's life, social isolation, fatigue, fear and anger (Rodgers, 1997).

<div align="center">*African American Women as a Vulnerable Population*</div>

Gender, racial and ethnic origins are factors in vulnerability (Rodgers, 1997), particularly health disparities. Stone (2002) states that African Americans and other

United States vulnerable populations in the United States experience striking health disparities. Overall African Americans have the poorest health indicators of all ethnic groups in the United States, making them the most vulnerable of all vulnerable populations (Davis and Curley, 1999). In fact, extreme differences in the health status of African Americans and White Americans are well documented (Kendall and Hatton, 2002). These differences are observed in mortality and morbidity rates, excess deaths, and health factors (Underwood, 2004). Furthermore, they continue to exist despite general improvements in the overall health status of the general population in the United States (Agency for Healthcare Research and Quality, 2002; Davis, Cook & Cohen, 2005; Geronimus et al, 1999; Penn et al, 1995). As a whole African American women experience the highest rates of mortality from heart disease, cancer and cerebrovascular disease and HIV/AIDS compared to other racial groups (Nunez and Robertson, 2003; Sadler et al, 2005). Moreover, these disparities have become the focus of many governmental agencies and their elimination has become a national initiative. Most notably health disparities exist among African American women in the area of breast cancer and depression.

<div align="center">Breast Cancer</div>

Breast cancer is a type of cancer in which cells in the breast tissue divide and grow without the normal control. Cancerous tumors in the breast tend to grow very slowly so that by the time one is large enough to be felt as a lump, it may have been growing for as long as ten years (Susan G. Komen Breast Cancer Foundation, 2006). The ability of breast cancer to grow undetected in the body for such a long period of time

makes breast cancer a serious public health problem for American women. In fact, the chance of a woman having invasive breast cancer some time during her life is about 1 in 8 and the chance of dying from breast cancer is about 1 in 33. Currently, there are slightly over 2 million women living in the United States who have been treated for breast cancer. (American Cancer Society, 2006).

According to the Susan G. Komen Breast Cancer Foundation (2006) and Maloney, Koch, Schneider, Goffman, Elkins, & Laronga (2006) breast cancer is the most common cancer found among African American women (101.5 per 100,000), second only to lung cancer and it is the second leading cause of death among African American women. Breast cancer accounts for 19% of all cancer deaths among African American women (Payne et al, 2003). Interestingly, while African American women have a lower incidence of disease occurrence overall than Caucasian women, they have a comparatively higher death rate (Henderson et al, 2003; Maloney et al, 2006; Newman, 2005), approximately 28 percent higher than among white women (Payne et al, 2003). As evidenced by the fact that the five-year survival rate for breast cancer among African American women is 73 percent compared to 88 percent among Caucasian women. (Susan G. Komen Breast Cancer Foundation, 2006). African American women have a higher breast cancer death rate (31.0 per 100,000) than women of any other racial or ethnic population. In fact, stage for stage, African American women have a worse survival rate (Middleton Chen, Perkins, Pinn, & Page, 2003) owing to many risk factors. However, much of the evidence on breast cancer risk factors has been accumulated in studies conducted with White women (Bernstein, Teal, Joslyn, & Wilson, 2003; Bondy and

Newman, 2003). Hence, information on the etiology of breast cancer among African American women is limited and what is often concluded is that their risk factors are similar to those of white women (Hall, Moorman, Millikan, & Newman (2005). Yet even so, several authors have suggested different factors that may explain the disparity seen in breast cancer among African American women even though all of the factors that may explain this difference especially regarding survival rates are not known (Newman, 2005). Some of those factors that have been proposed include lifestyle risk factors and health behaviors (Bernstein et al, 2003), biologic and genetic differences in tumors (Moormeier, 1996), hormonal factors (Moormeier, 1996), later stage of disease at diagnosis (Phillips and Smith, 2001), more distant metastatic disease (Swanson et al, 2003), earlier age presentation (Newman, 2005), and socioeconomic status (Phillips and Smith, 2001).

Several lifestyle factors have been implicated in breast cancer risk. Bernstein et al. (2003) reported that body size, obesity, physical activity level and alcohol intake are risk factors in African American women. Factors such as diet, exercise, alcohol consumption were also cited by Forshee, Storey, & Rittenbaugh (2003) as probably increasing the risk of breast cancer in African American women. Differences in breast neoplasms also exist among African American women. Specifically, Middleton et al. (2003) reports that investigators have found that tumors in African American women were larger, contained necrosis, and were more likely to have lymphovascular invasion, have high-grade nuclear atypia and a higher mitotic activity compared to tumors in white women. In addition, Newman (2005) reports that the breast cancer tumors of African American women are

more likely to be hormone-receptor negative, aneuploid, and node positive. These factors are cause for concern because lymph node involvement is an important indicator of prognosis and estrogen receptor-negative tumors are related to the higher frequency of poorly differentiated tumors in African American women (Moormeier, 1996).

Breast cancer risk normally increases as a function of age, yet African American women under the age of 45 years have a greater incidence of breast cancer than Caucasian American women in this same young age group (Newman, 2005). Furthermore, at diagnosis, younger African American women have more advanced breast cancer (Swanson, Haslam, & Azzouz, 2003). Socioeconomic status of African Americans also represents an important difference. Low socioeconomic status has been shown to be positively associated with later stage breast cancer especially in African American. Low income African American women are three times more likely to present with advanced disease than are higher income African American women (Phillips and Smith, 2001). Differences also exist in the area of psychosocial concerns. However, few studies have focused on psychosocial issues and their relation to breast cancer in African American women. Yet this is a significant issue among this population.

<div align="center">Definition of Depression and Depressive Symptoms</div>

Depression and depressive symptoms are not the same. Depression is a global term that refers to a mood disturbance that impacts daily functioning (Warren, 1994) and is formally diagnosed (Gary and Yarandi, 2004), whereas depressive symptoms refers to differing degrees of depressed feelings which may not be associated with a formal psychiatric illness (Pascreta, 1997).

Depression

Depression is projected to be the leading cause of disability and premature death, after heart disease in developed countries by 2020 (World Health Organization, 2004). Furthermore, depression and other mental illnesses are leading causes of disability and premature death in the U.S. costing more than $150 billion in 1997(Dunlop et al, 2003). Gary and Yarandi (2004) cite the American Psychiatric Association (1996, 2000) to explain that depression manifests as a disturbance in mood with common symptoms such as persistent sadness or despair, insomnia, decreased appetite, lack of pleasure, hopelessness, irritability, low self-esteem, and suicidal ideation.

While depression occurs in persons of all genders, ages and backgrounds (World Health Organization, 2004), women between the ages of 18 and 44 report more depressive symptoms and distress levels than do men, usually twice as much (Gazmararian et al, 1995; Polusny, 2000). Yet, there is no consensus as to either the exact nature and cause of depression or to the underlying reason for women's increased risk (Carr, Gilroy, & Sherman, 1996).

This disorder which affects approximately 19 million American adults each year is often unrecognized and untreated (National Institute of Mental Health, 2002). Complicating the matter, depression frequently co-occurs with a variety of other physical illnesses, including heart disease, stroke, cancer, diabetes and HIV/AIDS (National Institute of Mental Health, 2002; Miller, Malmstrom, Joshi, Andresen, Morley, & Wolinsky, 2004; Polusny, 2000; World Health Organization, 2004). Furthermore, depression is also associated with higher morbidity and mortality rates among patients

with medical illness (Leo et al, 1998), such as cancer. Depression impairs the ability to seek and stay on treatment for medical illnesses, as well as increases the risk for subsequent physical illness, disability and premature death (Massie, 2004; Miller et al, 2004). Additionally, the outcomes of depression treatment are highly variable and the long-term consequences of clinical depression can be more incapacitating than chronic physical illnesses such as hypertension, diabetes, myocardial infarction, and congestive heart failure (Polusny, 2000). Unfortunately, there is a paucity of information on the prevalence of mental disorders among minority groups (Dunlop et al, 2003) including African American women (Frank et al, 2005).

Risks Factors for Depression

Patterns of mental health are clearly associated with life circumstances, including educational and economic opportunities, access to safe and supportive neighborhoods, socially structured exposures to stressors and to supportive relationships (Cutrona et al, 2000; Schultz et al, 2006). Hence, some factors identified as significant predictors of depressive symptoms in African American women include life stress, physical health problems, environmental stress, economic status and internalized racism (Brown et al, 2003). These problems often become chronic strains that mediate other factors, with socioeconomic status being particularly important (Brown et al, 2000; Plant and Sachs-Ericsson, 2004). Cutrona et al. (2000) and Larson et al.(2006) reported that psychological distress and depression are associated with socioeconomic status and Brown et al.(2000) states that it has been consistently shown that women's vulnerability to depression is exacerbated by economic strain. In the United States, approximately 13.7% of the

population lives in poverty, and women and ethnic minorities are over-represented in this group (Frank et al, 2005). African American women experience a disproportionate burden of poverty compared with white women (de Groot et al, 2003). In fact, over one half of African American women live in poverty, in comparison to one fourth of White women (Frank et al, 2005). Additionally it is estimated that 50% of all African American families are headed by single females (de Groot et al, 2003).

Other challenges that that African American women face repeatedly are those resulting from the devastating effects of racism and discrimination. Larson et al. (2006) suggests that psychological distress, resulting from socioeconomic deprivation and unequal treatment due to racism, may be a mediating factor in disparities in morbidity and mortality. Racism may adversely affect mental health status through the subjective experience of discrimination (Williams and Williams-Morris, 2000). Discrimination has been particularly discussed in the literature. Brown et al.(2003), Cutrona et al.(2000) and Schulz et al.(2006) report that subjective experiences of discrimination are adversely related to a variety of mental health outcomes including psychological distress, self-esteem, personal control, life satisfaction and symptoms of depression.

Other factors associated with depression and depressive symptoms include family stress, lack of social support, and place of residence (Larson et al, 2006; Plant and Sachs-Ericsson, 2004) as well as racism, sexism and poverty (Carrington, 2006). African American women often have many family responsibilities that can lead to stress. Jones et al. (2003) found that family stress predicted higher levels of depressive symptoms in African American women. Social support is also an important predictor of depressive

symptoms. Low levels of social support leave people vulnerable to distress and depression in the wake of negative life events and chronic strains (Cutrona et al, 2000). Schrimshaw (2003) found that unsupportive social interactions from friends, family and a lover/spouse were each positively associated with higher depressive symptoms. Lastly, neighborhood contexts are also believed to affect mental health (Cutrona et al, 2000, Cutrona et al, 2005). Ross (2000) found that the level of depressive symptoms was significantly higher among residents of economically disadvantaged neighborhoods, such as those with a high percentage of households below the poverty line or with mother only households. This is most likely the result of exposure to disruptive or threatening life events and chronic stressors linked to economic insecurity, family stressors, and disorderly neighborhood conditions (Cutrona et al, 2000). Lastly, one other risk factor for depression that has been reported in the literature is pain (Bair et al, 2003; Das et al, 2006; Poleshuck et al, 2006). Depression and pain commonly occur together (Bair et al, 2003). Furthermore, both pain and depressive symptoms are associated with impaired emotional, physical, and social functioning (Poleshuck et al, 2006).

Treatment

The quality of depression care in the United States is poor. In fact, it is common for a person with depression to receive no treatment or to be under-treated (Harman et al, 2004, Leo et al, 1998), as primary care providers frequently do not recognize symptoms of depression or are not equipped to provide treatment when it is recognized (Borowsky et al, 2000; Larson et al, 2006). Further, the recognition of depression or depressive

symptoms can also be influenced by patient characteristics. Borowsky et al. (2000) found that patient race/ethnicity and gender influenced recognitions of mental health problems.

Whatever the reason, African Americans are particularly vulnerable to the undertreatment of depression and less likely to receive guideline concordant care (Bazargan et al, 2005; Brown et al, 2003; Cooper et al, 2003; Das et al, 2006; Harman et al, 2004; Jackson, 2006; Leo et al, 1998; Miranda and Cooper, 2004; Wells et al, 2004). Yet African Americans respond as well to guideline based treatments for depression as Caucasians (Brown et al, 1999; Rollman et al, 2002). Miranda and Cooper (2004) and Jackson (2006) suggest that the undertreatment of depression in African American women is due to a combination of factors including the lack of recognition and appropriate depression diagnosis in African American women, along with limited access to care, and attitudes towards antidepressant medication. Jones et al. (2003) also provides some explanation for the apparent undertreatment of African American women; they tend to delay seeking treatment for depressive symptoms, fail to seek treatment at all, or report only the physical symptoms of depression, leading to misdiagnosis and missed opportunities for treatment.

Other reasons cited include the stigma of mental illness, lack of insurance, high cost of care, and clinician bias as some of the reasons that racial and ethnic minorities do not seek mental health treatment (Bazargan et al, 2005; Puskar and Bernardo, 2002) are less accepting of it (Oakley et al, 2005) or prefer information about mental health from nontraditional sources (Larson et al, 2006). Lastly the socially constructed image of the "strong Black woman' may decrease the amount of emotional support available to

African American women and discourage self-perceived need for formal or informal mental health assistance (Brown et al, 2000; Carrington, 2006; Matthews and Hughes, 2001; Shambley-Ebron and Boyle, 2006). Regardless of the reason, untreated depression exacts a heavy toll as it is associated with high health care utilization, including excessive use of health care resources, and emergency room visits for self-injurious behavior (Carrington, 2006).

<div align="center">Depression and African American Women</div>

Although, epidemiological research has repeatedly documented demographic risk factors for a range of psychiatric disorders, including depression, the mental health of African American women in the United States remains understudied (Frank et al, 2005). However, health status and psychosocial stressors may be important antecedents or mediators of depression in African American women (Brown et al, 2003). African American women tend to have poorer health as they overwhelming suffer from a variety of chronic health diseases. In addition, they battle with an array of psychosocial stressors, all of which put them at high risk for depression. Still further research need to be done in order to fully understand all of the factors that contribute to depression in African American women. In fact, for more accurate and refined detection of depression among African American women, checklists of ethnically specific and symptoms, ideally generated by African American women should be developed and integrated into research measures and methods that involve them (Zhang and Snowden, 1999).

Depressive Symptoms in African American Women

Overall, few articles have addressed depressive symptomatology in African American women. Furthermore, it is important to note that the majority of research that has been done on depressive symptoms among African Americans has focused largely on comparing rates with whites, rather than on determinants of depression within the African American population (Siegel et al, 2000). When what is needed is not simply information on the mental health of African Americans compared with some other racial, ethnic, or cultural group, but instead information about mental health within the African American population (Neighbors, 1990). Other studies of depression focus on White women only or do not differentiate in their analyses according to race or class (Brown et al, 2000), yet attempt to generalize the findings to all women. However, there are legitimate reasons to question extrapolation from studies of exclusively European American samples to African American individuals (Cutrona et al, 2000). Understanding the prevalence and nature of depressive symptoms is further complicated by validity questions about psychometric instruments and diagnostic procedures. Many of the widely used survey scales and symptom checklists have not been standardized on African American samples (Reed et al, 1996).

Despite this fact, there are symptoms of depression among African Americans that are documented in the literature. Myers et al.(2002) found that there was a greater tendency among depressed African Americans to report cognitive-affective symptoms, particularly anxiety, anger and hostility. The author proposes that such symptom expression might account for the greater risk of psychiatric misdiagnosis experienced by

African Americans. Reed et al.(1996) found that depressive symptoms in African Americans were reflected as fearfulness, anxiety, depressed mood, low self-esteem, social withdrawal, and low energy level. Whereas, Carrington (2006) states that depression is expressed through hopelessness and suicide. Yet, Fiscella and Franks (1997) attributes psychological distress to hopeless affect, hopeless outlook, depression and life dissatisfaction. Additionally, several researchers have found that somatic symptoms are expressed significantly more frequently among African American women (Ayalon and Young, 2003; Brown et al,1999; Brown et al, 2003; Das et al, 2006; Jones et al, 2004). This may be problematic because Brown et al. (2003) suggests that physical symptoms contribute to lower detection of depression because physicians' recognition of depression is higher when patients report psychological distress and impaired functioning.

<div align="center">Depression, Depressive Symptoms and Breast Cancer</div>

Depressive symptoms present serious problems in patients with co-morbid health problems. In fact, the effects of depressive symptoms and chronic medical conditions are additive and their combined impact is about twice of what either condition produces on its own in terms of functional limitation (Pascreta, 1997). Forty percent of women newly diagnosed with breast cancer experience elevated psychological distress following diagnosis and surgery, and this distress persists for up to 2 years post surgery for as many as thirty percent of patients (Dausch et al, 2004). Furthermore, in women with early breast cancer, the prevalence of depression, anxiety or both in the year after diagnosis is around twice that of the general female populations (Burgess et al, 2005). Moreover,

according to Golden-Kreutz and Andersen (2004) fifty percent of women may experience depressive symptoms.

In breast cancer patients, symptoms of depression decrease quality of life and may also have other serious consequences such as increasing mortality (Hjerl et al, 2003). Further, depressive symptoms are highly prevalent among low-income, ethnic minority women (Ell et al, 2005). Thus, it is imperative that health care providers be able to not only recognize depressive symptoms, but also to understand depressive symptoms in all women with breast cancer, yet to date limited information has been published on the breast cancer experience of African American women (Henderson et al, 2003).

Stress has been implicated as a negative factor in women with depression and breast cancer. In fact, stress associated with the diagnosis and treatment of cancer can cause significant psychiatric morbidity (Dausch et al, 2004; Fallowfield et al, 2001; Wong-Kim and Bloom, 2005). As a result psychosocial distress in cancer patients has been identified as a significant and ongoing problem (Carlson et al, 2004). In general, cancer patients as a group are particularly vulnerable to psychological symptoms, depression and anxiety (Friedman et al, 2006; Golant et al, 2003; Golden-Kreutz and Andersen, 2004; Jones, 2001; Massie, 2004). This distress has been associated with demographic characteristics including younger age, female gender, minority ethnicity, lower income, longer duration of illness, and being on active treatment or newly diagnosed, few social supports, and little or no church attendance (Carlson et al, 2004; Fertig, 1997). In particular, younger age at diagnosis is a cancer specific characteristic associated with greater use of mental health services (Hewitt and Roland, 2002).

Cancer seems to be one of the several chronic illnesses that precipitates the need for and use of mental health services (Hewitt and Roland, 2002). However, clinical depression and anxiety in cancer patients are frequently not recognized by health care givers (Jones, 2001). Several factors complicate the diagnosis of depression among cancer patients. Fallowfield et al.(2001) , Fertig (1997) Pasacreta (1997) and Valente and Saunders (1997) cites physician oversight, lack of skill, viewing depressive symptoms as normal reactions and controversy regarding diagnostic criteria for major depression among patients with cancer as reasons. Rao and Cohen (2004) state that clinicians often have difficulty in separating symptoms associated with depression from those associated with cancer itself. Perhaps they should instead rely on psychological symptoms of depression which are good diagnostic indicators of depression because they are typically not caused by the pathophysiology of cancer (Valente and Saunders, 1997). Other reasons include unwillingness of patients to disclose emotional concerns, and the constraints of a busy clinic schedule, and self-report questionnaires (Fallowfield et al, 2001; Payne et al, 1999; Rabinowitz, 2002; Waller et al, 2005).

In regards to interventions, psychosocial support services for individuals with cancer are recognized as an essential component of quality care and referral for care is a key determinant of service use (Hewitt and Roland, 2002) .Yet, psychosocial interventions are not routinely offered (Badger et al, 2005). As a result unmet health need for mental health services is significantly greater among those with a history of cancer (Hewitt and Roland, 2002; Jones, 2001). Specifically, this is the case among African Americans.

Depression, Depressive Symptoms and Breast Cancer in African American Women

In general, African American women tend to face several stressors and barriers that impact their health. Stressors and barriers that have been identified in literature are economic, cultural, access to medical procedures, systemic discrimination, and lack of sociopolitical power (Flack et al, 1995; Johnson et al, 1995; Schulz et al, 2000). According to Schulz et al. (2000), the cumulative effect of exposure to multiple stressors over time has been hypothesized to contribute to more rapid deteriorations in the health of African American women. Poor health is a powerful risk factor for depression among African Americans (Brown et al, 2003; Leo et al, 1998). Moreover, the association between health status and depressive symptoms may be particularly important in understanding depression in African American women (Brown et al, 2003), but few studies have focused on psychosocial issues and their relation to breast cancer in African American women. Even though, in breast cancer patients the rate for depressive symptoms is the third highest of any cancer diagnostic group (Golden-Kreutz and Anderson, 2004).

According to Somerset et al. (2004), the diagnosis and management of depression in women with breast cancer has been intensely scrutinized due to rapidly accumulating evidence that depressive disorders or clinically significant levels of depressive symptoms adversely affect compliance with antineoplastic therapy, reduce quality of life and diminish survival. Thus, depressive symptoms in women with breast cancer are a growing area of research.

Although the psychosocial impact of breast cancer is being studied (Massie, 2004), there is little information on women from diverse ethnic and socioeconomic backgrounds (Ashing-Giwa et al, 2004). The studies that have examined psychological adjustment to cancer among ethnically diverse women have focused on socioeconomic and life-burden variables, disparities in patterns of treatment, prevalence of depression and treatment for depression (Friedman et al, 2006) and post-treatment symptoms. Depression is a common post treatment symptom among women who have undergone treatment for breast cancer (Eversley et al, 2005). However, post-treatment symptoms have not been explored extensively among minority patients with breast cancer. Yet Eversley et al. (2005), suggests that substantive ethnic differences exist.

The data consistently suggests that there is limited information on the breast cancer experience of African American women (Henderson et al, 2003). Fogel et al. (2003) reported that African American women with breast cancer are more likely to use religion to help them cope with breast cancer. Concerns and problems noted among African American breast cancer patients include physical problems financial problems, concerns related to mortality and reoccurrence of breast cancer, social support, worry about others, reactions of others to their breast cancer, and work related concerns (Shelby et al, 2006). Younger age has been associated with cancer specific distress in African American women (Halbert et al, 2005). African American women with breast cancer are also noted to have more difficultly with social functioning than Whites in relation to resuming basic household duties (Friedman et al, 2006).

Influence on Health Outcomes

Symptoms of depression in breast cancer patients are associated with lower quality of life, poorer treatment compliance, and shorter disease free intervals (Golden-Kreutz and Andersen, 2004; Wong-Kim and Bloom, 2005). Furthermore, breast cancer mortality is significantly higher in women with psychiatric diagnoses (Hjerl et al, 2003; Massie, 2004). Stressors unique to racial and ethnic minorities such as low SES, physical hardships, blocked opportunities, discrimination, and acculturation operate as sources of vulnerability for distress and mental health problems (Brown et al, 2005). The presence of concomitant depressive symptoms among members of ethnic minority groups who have chronic conditions has also been shown to be associated with a substantially greater health burden than the burden borne by their counterparts without depression or by depressed individuals without chronic conditions (Bazargan et al, 2005).

Gaps in the Literature

There are several gaps in the literature due to the paucity of research on African American women with depression and breast cancer. First there is a need for empirical studies. Empirical studies on effective treatments for depression in African American women are needed to begin shrinking the gap on effective depression treatments for this understudied and underserved group (Carrington, 2006). There is also a lack of contextual depression research among African American women (Barbee, 1992) with breast cancer. Contextual research provides rich, thick descriptions of the phenomena in question. Another noted deficit is the number of studies that are conducted longitudinally. Current longitudinal research regarding the race/ethnicity, depression relationship

(Gazmararian et al, 1995) and breast cancer is insufficient. Furthermore, attitudinal barriers to depression care in African Americans (Cooper et al, 2003) warrants further research, but specifically in the area of breast cancer. Lack of information on post-treatment symptoms in African American women who have undergone treatment of breast cancer (Eversley et al, 2005) is also apparent. Additionally gaps exist in the literature regarding the exact incidence and prevalence of depressive symptoms among African American women with breast cancer, as racial minorities are always underrepresented in research studies (Massie, 2004). Also, little is known about the cultural factors associated with depressive symptoms in African American women with breast cancer or even the social class differences or racial differences (Wong-Kim and Bloom, 2005) that may exist in this population with this health problem. There is also a lack of measures developed and evaluated among adequate numbers of African American patients (Shelby et al, 2006) suggesting a need for instrument development. Finally, studies about the lower rates of depression and the experiences of depression among African American women need further exploration due to the fact that numerous studies suggest that African American women have several high risk factors for depression (Gary and Yarandi, 2004).

<div align="center">Need for the Study</div>

African American women continue to be understudied in most areas of breast cancer research including psychological health (Underwood, 2006).This study will describe the social psychological processes of African American women with breast cancer experiencing depressive symptoms and offer a contextual explanation of this

phenomenon. A better understanding of the context of depressive symptoms in African American women might serve to decrease unmet health needs among this population and decrease disparities in health among this population.

Results of this proposed study will potentially add to the knowledge base of nursing, as the experience of depression in African American women with breast cancer will be explained in their own words offering a cultural context that has not been presented thus far in the literature. Understanding the contextual nature of depressive symptoms in African American women with breast cancer may also lead to improved health promoting interventions among this population and identify unknown barriers to health care in order to reduce the incidence of depressive symptoms in this population. Further, this study also has the potential to advance theoretical knowledge by offering an explanatory theory for depressive symptoms in African American women with breast cancer.

<div align="center">Summary</div>

This chapter began with a description of African American women as a population, a discussion of the importance of culture and an overview of vulnerability and why African American women can be considered a vulnerable population. Chapter two then reviewed the current literature on African American women in regards to depression, depressive symptoms and breast cancer. Current gaps in the literature were also explained. Lastly the potential contributions this study will make to nursing knowledge were discussed. In the next chapter, methodology for this research study will be presented.

CHAPTER THREE: METHODOLOGY

This chapter describes the methodology used for this study. A discussion of the history of grounded theory, the tenets of grounded theory, and data collection management will also be included. In addition, this chapter will outline the sampling plan used, recruitment strategies, human subjects protection and the criteria used for rigor.

Qualitative Research

Qualitative research is based on the belief that human realities are complex and that human experiences are significant (Walton and Sullivan, 2004). This type of research involves broadly stated questions about human experiences and realities studied through sustained contact with persons in their natural environments, producing rich, descriptive data that help us to understand those persons' experiences (Boyd, 2001). As such, qualitative research methods differ from quantitative research methods, in that qualitative research methods reflect an inductive mode of analysis or a process of moving from specific observations to a general theory (Byrne, 2001). One type of qualitative research method is grounded theory.

Grounded Theory Methodology

Depressive symptoms in African American women with breast cancer are understudied. Therefore it is more appropriate to use a methodology that is able to explicate the phenomena from the perspective of the participants actually experiencing the problem and to uncover the participants' perceptions of their own social world than to study the phenomena in another manner (Smith and Biley, 1997). Symbolic interactionism, the foundation for grounded theory suggests that individuals engage in

social interactions to which they bring their own definitions, meanings, and interpretations (Crooks, 2001). Therefore it was applicable to use grounded theory to study social phenomena from the perspective of symbolic interactionism. Furthermore, grounded theory is a methodology that is most useful in areas in which little research has been done (Chenitz and Swanson, 1986) or little is known about a subject or phenomena (Crooks, 2001). One of the primary purposes of grounded theory is to generate explanatory models of human social processes that are grounded in the data (Eaves, 2001). Since the purpose of this study was to explicate the process of depressive symptoms in African American women with breast cancer, grounded theory was an appropriate research methodology.

Several authors have described grounded theory in the literature. Chenitz and Swanson (1986) stated that the grounded theory study is contextual; that is, the researcher documents the actions and interactions that occur in a specific setting under certain conditions. Grounded theory attempts to inductively filter issues of importance for particular groups of people, creating meaning about those issues through analysis and the modeling of theory. Again this particular methodology is most useful when little research in the subject area has been undertaken (Burck, 2005; Chenitz and Swanson, 1986; Glaser, 1978; McCann and Clark, 2003; Smith and Biley, 1997). McCallin (2003) explained grounded theory as an interpretative research methodology that is useful to generate research-based knowledge about the behavioral patterns that shape social processes as people interact together in groups. It is based on the belief that as individuals within groups define situations with the self and others, common patterns of behavior

emerge. Hence, grounded theorists search for social processes present in human interaction and conceptualize the essence of complex interactional processes. The resulting theory emerges as an entirely new way of understanding and permits the development of relevant and innovative interventions in the social environment under consideration (Hutchinson and Wilson, 2001).

Overall, the purpose of grounded theory methodology is to generate theory through the process of constant comparison (Kendall, 1999). The primary aim of grounded theory is to explore basic social processes and to understand the multiplicity of interactions that produce variation in that process (Heath and Cowley, 2004). Thus, the goal of grounded theory research is to identify a basic psychological process (BSP) that occurs in response to a problem that is relevant and problematic for those involved in a specific situation and the basic social process by which persons address this problem (Ayres, 2007; Thompson et al, 2006). The main tenets of grounded theory include theoretical sampling, the constant comparative method, coding and categorizing, memo writing, and theory generation, all of which occur simultaneously throughout the research project (Jeon, 2004).

In order to have a thorough understanding of grounded theory, it is important to look at the history of grounded theory. Grounded theory methodology was originally firmly rooted in the social sciences, more particularly in symbolic interactionism, and as a result, the traditions of sociology and social psychology have been especially influenced by the development of grounded theory (Smith and Biley, 1997). In fact, the method of grounded theory originated from the work of two sociologists, Glaser and

Strauss in the 1960s (Byrne, 2001; Hutchinson and Wilson, 2001; McCann and Clark, 2003).The methodology was developed in response to the overwhelming belief held by positivist thinkers that qualitative research was unscientific because it rejected controlled experiments and appeared to embrace interpretation (Smith and Biley, 1997). Glaser and Strauss over time developed separate perspectives on grounded theory methodology. Glaser is associated with classical or Glaserian grounded theory, whereas Strauss and Corbin are associated with Straussian grounded theory. Their different perspectives surfaced publicly when Strauss and Corbin (1990) released their version of grounded theory, which Glaser (1992) aggressively argued was not in fact grounded theory, but a new method, which he called full conceptual description (Eaves, 2001; Kendall, 1999; Walker and Myrick, 2006).

Even though Strauss and Glaser diverged over time, several similarities exist between their versions of grounded theory. Common characteristics of both the Glaserian and Straussian versions of grounded theory are theoretical sensitivity, theoretical sampling, constant comparative analysis, coding and categorizing the data, literature as a source of data, integration of data, and theoretical memos (Annells, 1997; McCann and Clark, 2003). Moreover, both versions adhere to the same basic research process: gather data, code, compare, categorize, theoretically sample, develop a core category, and generate a theory (Walker and Myrick, 2006).

Additionally, several authors have described the differences between the Glasserian and Straussian approaches. McCann and Clark (2003) suggest that the differences exist in the underlying philosophical assumptions. Heath and Cowley (2004)

state that it is the methodological rather than ontological and epistemological aspect of grounded theory that have been cited as the main source of divergence. Walker and Myrick (2006) reflected that the division centers on the researcher's role, activity, and level of intervention in relation to the procedures used within the data analysis process. Kendall (1999) proposed that the crux of the debate between the two methods is the use of axial coding, whereas Annells (1997) indicated that the differences were among the philosophical perspectives, paradigms of inquiry, intended product, theoretical underpinnings, procedural steps and claims of rigor.

This study used the Glaserian approach to grounded theory. Glaserian grounded theory utilizes induction as a key process, with the researcher moving from the data to empirical generalization and then to theory (Heath and Crowley, 2004). An inductive process as opposed to a deductive process was better suited to this research enquiry, because it allowed the data to emerge via constant comparison versus forcing the data, ensuring the utility and applicability of the resultant theory.

Glaserian Grounded Theory

Glaserian grounded theory yields rich data, elaborated categories, and dense analyses with applications across substantive fields (Charmaz, 1990). It moves beyond just describing and understanding the phenomenon which is the area of inquiry to conceptualizing the issues (Ng and White, 2005). Furthermore, it places emphasis on the generation of pragmatic theory that is grounded in the data of experience (Kennedy and Lingard, 2006) and it is able to generate formal or substantive theory. Formal theory refers to theory that is developed for a conceptual area of inquiry, whereas substantive

theory refers to theory that is developed for an empirical area of inquiry (Glaser and Strauss, 1967).

Glaserian grounded theory was an appropriate method to use with African American women with breast cancer experiencing depressive symptoms because it is a means of discovering the main concern of patients and how they manage those concerns (McCallin, 2003). Grounded theory is used to study processes that individuals experience such as health issues (Ng and White, 2005). Furthermore it is theory generating and can be used to identify basic social processes (Glaser, 1978). Since, grounded theory is based on the philosophy of symbolic interactionism it is appropriate to use when the phenomena can be studied according to social interaction and when the objective is to obtain the participants' perceptions of their own social world (Smith and Biley, 1997). This is an important factor because African American women's concerns cannot be examined outside of their sociocultural experience. Symbolic interactionism and grounded theory together provide the broad lens for meaningful research into not only mainstream women's health issues (Crooks, 2001) but those of African American women as well. Glaserian grounded theory allowed the ability to conceptualize the issues of African American women with breast cancer experiencing depressive symptoms as they experienced them.

Because of unequal power relations and a social structure that rendered Black women voiceless, knowledge and understanding about Black women's lives has been either absent or seriously flawed (Shambley-Ebron and Boyle, 2004). Thus grounded theory is one means to give women a voice (Crooks, 2001, particularly African American

women. In fact, Keddy (1996) contends that grounded theory is conducive to feminist research, because it allows for the voices of the participants to be heard as they tell their stories, a facet that has been neglected in the case of African American women. Grounded theory describes the processes that people use to move through experiences over time (Glaser and Strauss, 1967) and allows the ability to develop theories of social processes "grounded" or based on the lives of individuals when experiencing the processes (Ng and White, 2005). Moreover grounded theory methods allow the researcher to view all women as full members of their social, political, economic worlds; to understand the lives and activities of women; to understand women's experiences from their own particular points of view; and finally to conceptualize women's behavior as meaningful and as a direct expression of their worldviews (Crooks, 2001).

<div align="center">Tenets of Grounded Theory</div>

<div align="center">*Theoretical Sensitivity*</div>

According to Glaser (1992) theoretical sensitivity refers to the researcher's knowledge, understanding, and skill, which foster his or her generation of categories and properties and increase his or her ability to relate them into hypotheses, and to further integrate the hypotheses, according to emergent theoretical codes. Glaser and Strauss (1967) maintained that the researcher should be sufficiently theoretically sensitive so that he can conceptualize and formulate a theory as it emerges from the data. Sources of theoretical sensitivity in classic grounded theory are knowledge of coding families, conceptual ability and literature (Annells, 1997). Glaser believes that theoretical

sensitivity is attained through immersion in the data, line by line, comparison by comparison, memo by memo, and code by code (Walker and Myrick, 2006).

Theoretical sensitivity was achieved in this study by a thorough review of the relevant literature and by using the constant comparative method throughout the data collection process. The constant comparative method enhances theoretical sensitivity by stimulating thinking about incidents, concepts, categories and their properties (Jeon, 2004).

Theoretical Sampling of Data from Participants

Glaser and Strauss (1967) defined theoretical sampling as the process of data collection for generating theory whereby the analyst simultaneously collects, codes and analyzes the data and decides which data to collect next and where to find that data, in order to develop the theory as it emerges. This process of data collection is controlled by the emerging theory, whether substantive or formal (Glaser, 1978). Hence, participants are not chosen on the basis of their representativeness, but rather because of their expert knowledge of the phenomenon under scrutiny (Smith and Biley, 1997). Thus, theoretical sampling is directed by codes that arise from the data until categories are saturated (Annells, 1997). Coding is simply labeling concepts that recur in the data (Chenitz and Swanson, 1986). On the other hand, a category is a conceptual element of the theory indicated by the data (Glaser and Strauss, 1967) or an abstraction of the phenomenon observed in the data (Chenitz and Swanson, 1986). Furthermore, categories form the major unit of analysis in the grounded theory method, such that the theory that evolves by this means consists of categories that have been linked together and arranged in a

hierarchical fashion (Chenitz and Swanson, 1986). In this study, sampling of participants was directed by the emerging theory. Thus the process of constant comparative analysis dictated the decisions that were made regarding the interview questions and need for follow up interviews with those participants that had knowledge in the intended area of study (Jeon, 2004). Furthermore, sampling continued until theoretical saturation occurred. Theoretical saturation according to McCann and Clark (2003) occurs when no new data emerge relevant to particular categories and subcategories, categories have conceptual density, and all variations in categories can be explained.

Participant Recruitment

Participants were identified through word of mouth, breast cancer support groups, and African American churches. The researcher presented the purpose and inclusion criteria of the study to breast cancer support groups to recruit participants (See Appendix A). In addition, the researcher attended local area African American churches and requested that information on the study be included in the church bulletin and requested permission to post a participant flyer in the church hall. Additionally, a participant flyer was available to any interested participant identified through word of mouth.

Participant Sampling

The sampling process differs in grounded theory research. The need for sampling of specific data sources continues until each category is saturated in order for concepts and categories to emerge during the data analysis (Cutcliff, 2000; Higginbottom, 2004). The sample for this study was a purposeful sampling of nine African American women with breast cancer, who indicated that they had experienced self-defined depressive

symptoms in the past or were currently experiencing depressive symptoms. Cutcliff (2000) suggests that the selection of participants is a function of the emerging hypothesis/hypotheses and the sample size is a function of the theoretical completeness. Theoretical sampling guided the recruitment of participants in this study and the process was dictated by the emerging theory. Therefore the actual sample size and selection was dependent on the point at which theoretical saturation occurred.

The inclusion and exclusion criteria were as follows:

Inclusion criteria

- (1) Women who self-identified themselves as African American
- (2) Had the ability to read, write, and comprehend English
- (3) Women who were at least 40 years of age
- (4) Women who stated that they experienced depressive symptoms as self-defined after the diagnosis of breast cancer

Exclusion criteria

- (1) Women who did not self-identify themselves as African American
- (2) Women that were less than 40 years of age
- (3) Women who were unable to give consent to participate
- (4) Women who did not state that they experienced depressive symptoms as self-defined after the diagnosis of breast cancer

The rationale for the inclusion criteria included was to use women from the targeted population in order to obtain the richest possible source of information to answer the research question. Women who had the ability to read, write, and comprehend

English were included in order to conduct the best possible interviews and to obtain written consent. The study was limited to adult women over the age of 40 years of age, because breast cancer risk increases with age. Lastly, only women who acknowledged that they experienced depressive symptoms after the diagnosis of breast cancer were included because the study was intended to understand the process of depressive symptoms among African American women with breast cancer. Thus, it was central to the study to identify women who experienced both conditions.

Human Subjects Protection

University of Arizona Institutional Review Board (IRB) approval was obtained prior to conducting the study. All participants completed an informed consent form prior to participating in the research study and were able to withdraw from the research study at any time without consequence (See Appendix C). Consent forms and audiotapes were maintained in a locked cabinet during the study. At the end of the study all consent forms were forwarded to the University of Arizona, Office of Nursing Research to be stored there. Furthermore, the identity of all participants was protected through the use of pseudonym names. Participants picked their own pseudonym in alphabetical order, in order to maintain the order that participants were interviewed. This research study was conducted by a researcher who had already undergone human subjects training with documentation on file in the University of Arizona, Office of Nursing Research. In addition, all audiotapes were transcribed by the researcher.

Data Collection Procedures

Interviewing Process

The initial contact with potential participants was by telephone or in person. Written informed consent was then obtained prior to the interview. Data were collected via unstructured interviews lasting approximately 1 hour. Each participant was interviewed once. Interviews eight and nine served as member checks. Unstructured interviews are a type of formal interview in which the researcher engages in a conversation with a purpose or a guided conversation with the participant, allowing the participant to control the content of the interview (Duffy, Ferguson, & Watson, 2004). Ploeg (1999) stated that unstructured interviews are used when little is known about the research topic by the researcher. This type of interview allows the participant to just tell their experience, as there is no set sequence of questions. In this study an interview guide was used in addition to allowing the participant to just tell their experience. Basic demographic information, such as age, marital status, and educational status was collected at the time of the interview. Field notes were also taken during the interview, such as mannerisms and behaviors that occurred during the interview. Initially only one interview was scheduled with each participant. However, the participants were informed that follow-up interviews might be necessary to clarify data. The location of the interview was at the participant's preference, but at a location that provided privacy. Also, interviews were scheduled at a time and place that was convenient for the participant. Pseudonyms were used to protect the identity of all participants. Participants picked their own pseudonym name in alphabetical order, to maintain the order that participants were

interviewed. All interviews conducted were audiotaped to increase accuracy for later transcription. Pseudonyms were also used in all audiotapes. Recording equipment was placed in view of the participant and turned on prior to conducting the interview. All audiotapes were then transcribed verbatim by the researcher. Lastly, each interview transcript was compared with the audiotape to assure accuracy by the researcher.

Examples of Interview Questions

Consistent with the tenets of grounded theory, in the unstructured formal interview, the researcher used an interview guide containing a set of brief, general questions, a topical outline or a major theme (Chenitz and Swanson, 1986). In this study the following general questions were asked of all participants:

1. What has been your experience with depression symptoms while having breast cancer?

2. How has depression affected the course of your breast cancer?

3. Tell me about your depression.

4. What have been some of the things that worsened your depression while dealing with breast cancer?

5. What have you found helps you?

6. What do you think health care providers need to know about African American women with depression and breast cancer?

In addition, to the use of these general questions probes were used such as "can you tell me more?". Also the researcher sought clarification throughout the interview to assure that the participant's experience was understood (See Appendix B).

Data Management and Analysis

The data analysis for this study followed the principles of grounded theory. Grounded theory uses an iterative approach, which involves cycles of simultaneous data collection and analysis, in which the results of the ongoing data analysis inform the subsequent data collection (Byrne, 2001; Kennedy and Lingard, 2006). All interview transcripts were read and analyzed by the researcher using the constant comparative method. Hutchinson and Wilson (2001) asserted that the constant comparative method is the fundamental method of data analysis in grounded theory, with the aim of this method being the generation of theoretical constructs that along with substantive codes and categories and their properties form a theory that encompasses and explains as much behavioral variation as possible. This process is advanced by the researcher constantly going over the data. Hunter, Lusardi, Zucker, Jacelon & Chandler (2002) similarly state that the ability to organize data or generate seminal ideas is attributed to the researcher's closeness to or immersion in the data. As the data were analyzed, the researcher searched for a core variable, which served as the foundation for theory generation. In grounded theory, formulating core variables is an important task. Glaser (1978) established the following essential characteristics of core variables:

1. It must reoccur frequently in the data,

2. It must have centrality or link the various data together,

3. Because it is central, it takes more time to saturate,

4. It has clear and grabbing implication for formal theory,

5. It relates meaningfully and easily with other categories,

6. It is completely variable, and

7. It has relevance and explanatory power.

Data obtained from interviews with this study population of African American women with breast cancer experiencing depressive symptoms was analyzed and coded via constant comparison analysis. The coding of data is a multi-step process. The overall intent is to form concepts by analyzing and identifying patterns in the data. This involves assigning labels to the data and then elevating the derived concepts to categories through the use of theoretical memos. The next step is to identify a core or basic psychological problem that is experienced by the participants (McCann and Clark, 2003).

The basic social process is the mechanism that individuals use to solve their basic psychological problem. There are two types of basic social processes; basic social psychological process (BSPP) and basic social structural process (BSSP). Basic social psychological processes according to Glaser (1978, 1992) are core variables that illustrate social processes as they continue over time, regardless of varying conditions, whereas a basic social structural process refers to a set of structural conditions that facilitates a social structure. In this study transcripts from the interviews were coded line by line in order to identify as many codes or labels as possible, then the codes or labels were combined and reduced to form more concise categories. The resulting categories were then be coded for their variation, range, properties and dimensions until a BSP that represented the main concern was identified (Johnson and Delaney, 2006).

Constant Comparative Analysis

Constant comparative analysis is the primary strategy in the integrated coding and analyzing stages of grounded theory (Duchscher and Morgan, 2004). The goal is to clarify concepts and test hypotheses derived from the data while producing precise descriptions (Jeon, 2004). Glaserian grounded theory uses comparative analysis as a strategic method to generate theory (Glaser and Strauss, 1967). This comparison allows for the definition of the basic properties of categories and delineation of the contexts in which they occurred and the relations among the categories (Thompson et al, 2006). The making of constant comparisons during data analysis and collection, and theoretical sampling occur simultaneously in order to ensure that the researcher can actually construct a theory that is grounded in the data (Jeon, 2004).

In Glaserian grounded theory the constant comparative method involves four stages: comparing incidents applicable to each category; integrating categories and their properties; delimiting theory; and writing the theory (Glaser and Strauss, 1967). Comparing incidents applicable to each category began with coding each incident in the data into as many categories of analysis as possible, as the categories emerged or as data emerged that fit an existing category (Glaser and Strauss, 1967). This was achieved by constantly comparing responses of the participants for similarities until a category was identified.

The second stage of the constant comparative method was integrating categories and their properties. This involved comparison of incidents with properties of the category that resulted from the initial comparisons of the incidents (Glaser and Strauss,

1967). In this study constant comparison of the data was used to progressively focus the research as the data became clearer (Chenitz and Swanson, 1986).

Delimiting theory was the third stage of the constant comparative method. Delimiting occurred at two levels: the theory and the categories. The theory was solidified through comparing the incidents of a category to its properties and discarding non-relevant properties or integrating elaborating details of properties, and then the coding categories were reduced as the analysis became more focused and theoretical saturation occurred (Glaser and Strauss, 1967).

The last stage of this method was writing the theory. The researcher began writing the conceptualization of the substantive theory after theoretical sorting and saturation, with the BSP as the central focus (Hutchinson and Wilson, 2001). The memos and coded data provided the content for the resulting theory in this study. The process of constant comparison continued until a theory with sufficient detail and abstraction was generated (McCann and Clark, 2003).

Coding and Categorizing Data

Glaser (1978, 1992) described coding as an essential aspect of transforming raw data into theoretical constructions of social processes (Kendall 1999). In Glaserian grounded theory (GT), the essential relationship between data and theory is a conceptual code (Glaser, 1978). A conceptual code is part of the researcher's larger theoretical framework in which he or she specifies conditions, offers explanations, and makes predictions (Charmaz, 1990). Additionally, Glaser (1978) proposed that coding gets the researcher off the empirical level by fracturing the data, then conceptually grouping it

into codes that then become the theory which explains what is happening in the data. Glaser distinguished two types of coding processes, substantive (open) and theoretical (Kendall, 1999).

Substantive coding consists of two sub-phases, open and selective coding, and is concerned with producing categories and their properties (Walker and Myrick, 2006). In the process of open coding, the researcher breaks down the data line by line, in order to explore all possible aspects of issues and ideas in the data, and to develop descriptive codes as labels for the meaning of the issues and ideas (Jeon, 1994). Selective coding on the other hand aims to identify a core or overarching category and then to attempts to establish a link between the core category and other categories (Charmaz, 1990). Substantive codes conceptually sum up the patterns found in the substantive incidents in the field (Glaser, 1992). Theoretical coding occurs at the conceptual level, weaving the substantive codes together into a hypothesis and theory (Walker and Myrick, 2006). It is a refitting and refinement of categories which integrate around an emerging core (Heath and Cowley, 2004). All data in this study was coded according to this cyclical process.

Theoretical Memos

Memos are the analyst's written records of the analytical process. It is in memos that hypotheses are recorded, compared, verified, modified, or changed as new data comes in (Chenitz and Swanson, 1986). Glaser (1998) describes memos as the theorizing write-up of ideas about codes and their relationships as they occur to the analyst while coding. They reflect the researcher's internal dialogue with the data at a point in time (McCann and Clark, 2003). Glaser (1978) suggests that the writing of theoretical memos,

which are written reflections of thinking is the core stage in the process of generating theory, and that if the analyst skips this stage by going directly from coding to sorting or to writing than he is not doing grounded theory. Field notes were kept throughout the research process to document the researcher's ideas, insights and observations about the data. Furthermore memoing began with the data analysis after the first interview and continued throughout the data collection and analysis process.

<div align="center">Rigor in Qualitative Research</div>

Hutchinson and Wilson (2001) observed that researchers using grounded theory methods must address the issues of believability and rigor in their research. A quality grounded theory has codes that fit the data and the practice area from which it is derived. The data then fall naturally into place. Different criteria of rigor exist in scientific inquiry. General rigor requirements for qualitative data include auditability, credibility, and fittingness.

Auditability relates to consistency of findings, meaning that another researcher can clearly follow the "decision trail" or thought processes used by the researcher in the study and arrive at a comparable conclusion (Sandelowski, 1986). Auditability is enhanced by indicating the criteria used to formulate the researcher's thinking, and by detailing how and why the participants in the study were chosen (Chiovitti and Piran, 2003). The researcher's journal that was maintained throughout the data collection and analysis period provided a record of memos and observations as well as provided a record of the researcher's thoughts and actions. This journal served as the audit trail.

Credibility in a qualitative study refers to the use of accurate descriptions or interpretations of a human phenomenon so that the individuals having the experience would recognize their experience from the descriptions or others would be able to recognize the experience after having read about it (Sandelowski, 1986). Credibility was achieved by letting the participants guide the inquiry process, checking the generated theoretical construction against the participant's meanings of the phenomenon, using the participants' verbatim words in the theory and by disclosing the researcher's own personal views and insights regarding the experiences explored (Chiovitti and Piran, 2003). Interpretation of the data was verified through follow-up with participants during the interview. In addition, during data analysis, the researcher had phone and email contact with her dissertation chair every two weeks to review notes, memos, transcripts and the analysis process or any issues or concerns that arose. All interview transcripts were read by the researcher's dissertation chair. The researcher's dissertation chair also randomly reviewed five of the nine audiotapes against the transcripts. If errors were found on the transcripts they were retyped and a second check occurred.

Fittingness refers to when study findings are meaningful and applicable to readers in terms of their own experiences and when the findings are reflective of the life experiences being studied (Sandelowski, 1986). All coded data was reviewed by the researcher's dissertation chair. The researcher's dissertation chair provided an external check to the findings by reviewing the coded data. This independent analysis of data by another researcher served to validate findings (Sandelowski, 1986). Fittingness can also be accomplished by delineating the scope of the research in terms of the sample, setting

and level of theory generated are concerned, and by describing how the literature relates to each category which emerged in the theory (Chiovitti and Piran, 2003).

The criteria for rigor vary in grounded theory. Lomborg and Kirkevold (2003) use the concepts of *fit, work, relevance* and *modifiability* to judge the quality of a theory. *Fit* can be described as categories that are generated from the data instead of a previous theoretical perspective thus ensuring that the resulting grounded theory will fit empirical situations. In this study the criteria of *fit* was automatically met as the categories arose from the data. *Work* refers to the idea that theories should provide predictions, explanations and interpretations of what is happening in the area under study. The criteria of *work* is met when the categories fit the data and explain what happened, what will happen and what is happening in the area of concern. *Relevance* relates to the idea that theories should be relevant to action in the area it purports to explain, with a focus on the emerged core problems and processes. Lastly, *modifiability* means that a grounded theory might go through changes when new data emerge, generating qualifications or elaboration to the theory. The criteria of *modifiability* are met when the theory is able to adapt as new data appears.

Summary

Chapter three introduced grounded theory as the methodology used for this study. The tenets of grounded theory were explained and a description of Glaserian grounded theory was provided. The data collection and management procedures were also outlined. Last of all, the sampling plan and criteria for judging rigor in qualitative studies was identified and discussed.

CHAPTER FOUR: FINDINGS

Introduction

The purpose of this chapter is to provide the study results from the data analysis of

nine African American women participants with breast cancer and depressive symptoms.

The first section will present a portrait of each of the participants in the study. This

portrait will provide a brief description of the lives of each woman in the study. This

research study only focused on the social psychological processes.

The next section of this chapter will present and explain the theory *Transcending*

the Now. Following the explanation of the theory the chapter will conclude with a

summary.

Participant Portraits

Nine African American women with breast cancer who have experienced

depressive symptoms were interviewed for this study. While all of the women who

participated in this study were African American their characteristics differed greatly.

Women in the study were between 66 years old and 44 years old. The self-defined

religious background of the participants included two Baptists, one Methodist, one

Catholic, two Christians, one Seventh-day Adventist, and one Non-denominational

Christian. The participants also had diverse educational backgrounds, ranging from a

Master's degree to a high school diploma. One participant was unemployed; one

participant was a homemaker; one was disabled; one was on temporary disability; two

were retired and three of the participants were currently working. All of the participants

had insurance at the time of their disease. Only two of the participants were married; the

other participants were single, widowed, divorced or separated. More than half of the

participants were diagnosed with breast cancer in their 40s or earlier. Three of the

participants had breast cancer twice. One participant was diagnosed with breast cancer at

47 years old and then again at 57 years old; another participant was diagnosed at 54 years

old and then at 58 years old; and the third one was diagnosed at 42 years old and then

again at 53 years old. Only four of the participants had a family history of breast cancer,

although one participant had a distant relative with breast cancer.

Interview # - Angela

Angela was a disabled woman in her mid-sixties. She became disabled due to a

long standing seizure history. Prior to becoming disabled she worked in an office. Her

educational level was high school diploma with some adult school. She has been

separated from her husband for years and lives alone in an apartment. Angela discovered

her breast cancer through a breast self exam. She was recently diagnosed with breast

cancer and is currently undergoing chemotherapy. She also had a mastectomy. Angela

did not know her stage of breast cancer. Her religion was Methodist. Angela received

tremendous religious support from her church. She had full insurance.

Interview #2 - Betty

Betty was a widowed woman in her early sixties. She was a retired administrative

assistant who worked in mental health. She had a high school education. Betty lived in

her own home with her adult son. She also discovered her breast cancer through a self-

breast exam. She was first diagnosed with stage II breast cancer at age 47 years and then

had a reoccurrence of stage I breast cancer approximately 10 years later. Betty was

treated with chemotherapy, radiation and a bilateral mastectomy. She was currently in remission. Betty had a significant family history of breast cancer as two of her sisters had breast cancer and died from it. Her religion was Baptist. She too had strong religious and social support. Betty also had full insurance.

Interview #3 - Carlotta

Carlotta was a married woman in her early sixties. She was retired and had some college experience. Carlotta had breast cancer twice. She was first diagnosed with stage II A breast cancer at the age of 54 and then again at the age of 58 years, but did not know the stage at that time. She received radiation but refused chemotherapy. She had a bilateral mastectomy with no reconstruction. She also had full insurance. The second time Carlotta was diagnosed with breast cancer, her mother was also diagnosed. Her religion was Catholic. She did not have a church network, but she did have a strong faith.

Interview #4 - Danielle

Danielle was a single woman in her late forties. She was currently employed and worked in an administrative capacity. Her educational level was associates degree, but she was currently in school to further her education. Danielle was diagnosed with stage II breast cancer at the age of 44. She had no family history of breast cancer. Danielle also discovered that she was pregnant at the time of diagnosis, but was unable to continue the pregnancy. She received chemotherapy, radiation and a lumpectomy. She had full insurance. Her religion was Baptist.

Interview #5 - Engrid

Engrid was a single woman in her late forties. She was also the single parent of a school age child. She was diagnosed with stage III A breast cancer at the age of 46. Engrid had a mastectomy, chemotherapy and radiation. She had no family history of breast cancer. Engrid had full insurance. Her religion was non-denominational Christian and she had a strong belief in God. Engrid was employed, but she was currently on medical leave. Her educational was graduate level. She was currently considering therapy for depressive symptoms.

Interview #6 - Francis

Francis was a divorced woman in her mid-forties. She had a high school education with some college courses. She was currently unemployed. Francis had a history of chronic health problems and had recently lost 120 pounds. She was diagnosed with stage III breast cancer at the age of 37. Francis no longer had medical insurance, but had full insurance at the time of her diagnosis. Her religion was Christian. She became very involved with her church after becoming a born again Christian. Francis struggled with being embarrassed because of having breast cancer so she tried to hide it early on from others. She was treated with a "*gosectomy*", chemotherapy and radiation.

Interview #7 - Gina

Gina was a married woman in her mid fifties. She was diagnosed with stage II breast cancer at age 47. Gina had a lumpectomy, and then against the advice of her doctors refused chemotherapy and chose to treat her cancer with alternative health practices. Her religion was Seventh-day Adventist. Gina had a very strong faith and

believed that God spoke to her and told her that she was not going to die from breast cancer. Her educational level was Master's degree and she worked in the health care field. She had full insurance during her breast cancer experience.

Interview #8 Harriet

Harriet was a single woman in her early forties. She considered herself to be a homemaker. She was the mother of a medically fragile child who died this past year. Her religion was Christian. She was diagnosed with stage IV breast cancer at age 40. Harriet found a lump while taking a shower, but waited eight months before seeking treatment and only sought treatment after the encouragement of her family. She received chemotherapy, radiation and a bilateral mastectomy. Her educational level was high school graduate with some college courses. She had full insurance during her breast cancer experience. She was currently undergoing reconstructive surgery on her breasts.

Interview #9 - Irene

Irene was a woman in her single woman in her sixties. She never married and had no children. Most of her family was deceased except for her brother and a few cousins. She worked in the health care field. She had no family history of breast cancer. Her educational status was a bachelor's degree with some graduate coursework. She had breast cancer twice first at age 42 with in situ breast cancer and then again in her 50s, but did not know the stage at that time. The first time she had cancer, she had radiation and a lumpectomy, and the second time she had chemotherapy, radiation and a lumpectomy. Her religion was African Methodist Episcopal. She talked to God on a regular basis. Irene

also had several chronic health problems. She also had a history of depression and was currently on an anti-depressant. Irene had full insurance.

Summary Participant Portraits

Nine African American women with distinct life experiences participated in this study. Their ages ranged from 44 to 66 years old. Some of the participants were currently undergoing treatment, while others were in remission. All of the participants identified a religious affiliation. The following section will present the findings of the data analysis of this study.

Overview: Basic Social Psychological Process of *Transcending the Now*

The basic social psychological process that emerged from the data analysis was *Transcending the Now* (Figure 1). *Transcending the Now* was the process that African American women used to conquer the basic social problem of having breast cancer and experiencing depressive symptoms. This process was used by each of the nine participants in this study in some form or capacity to triumph over whatever trials they were faced with, including breast cancer and depressive symptoms. The process of transcending was identified in this study using constant comparison analysis. This core category emerged from the on-going analysis in the constant comparison coding process. For the participants in this study, *Transcending the Now* encompassed several aspects such as the capacity to move beyond difficult circumstances or rise above a current situation. It also included the ability to experience peace in the midst of suffering or great hardship. It incorporated the power to overcome when it seemingly appeared that all was

lost. *Transcending the Now* furthermore includes the ability to rise above turmoil and to

surmount uncertainty and fear.

Transcending the Now involved several phases that were not mutually exclusive

in their occurrence. In fact, some phases occurred simultaneously.

FIGURE 1: Grounded Theory: *Transcending the Now*
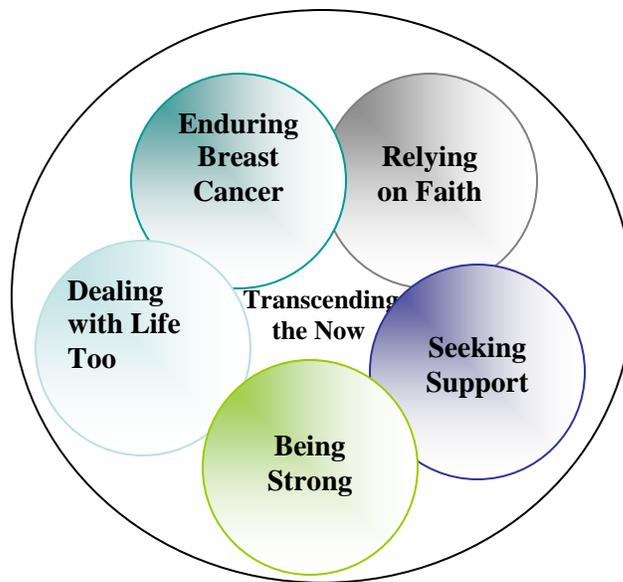
Description of Phases

The core category is the main theme of the data that helps to link the multiple

subcategories together and explains much of the data variation (Glaser, 1978). The five

phases of the basic social psychological (BSP) process *Transcending the Now* that

emerged during data analysis were *Relying on Faith, Being Strong, Seeking Support,*

Dealing with Life Too, and Enduring Breast Cancer.

Relying on Faith was the first phase of the BSP process *Transcending the Now.*

Relying on Faith referred to having a confidence and trust in a supernatural, all powerful

entity. This belief brought a tremendous source of comfort to the participants. Two sub-categories of *Relying on Faith* were identified *Practicing your faith* and *Standing on your faith.*

The second phase *Seeking Support* related to the types of assistance that the participants sought to help sustain themselves through the experience of breast cancer. Five types of support were identified: *Professional support, Social support, Family support, Informational Support, and Religious Community Support.*

The third phase *Being Strong* referred to the inner strength and fortitude that the participants possessed. *Being strong* aided in *Dealing with life too*. *Being strong* had four sub-categories: *Being Positive, Being resilient, Turning Inward and Accepting it.*

The fourth phase *Dealing with life too* related to how the participants navigated through life situations that they were faced with while going through breast cancer at the same time. *Dealing with life too* had seven sub-categories: *Family dynamics, Dating & other intimate relationships, Family responsibilities, Employment, Finances/resources, Suffering losses, and Facing challenges.*

The fifth phase *Enduring Breast Cancer* related to the various issues that the participants encountered as a consequence of breast cancer. *Enduring breast cancer* had six sub-categories *body image, worrying, taking care of your health, dealing with the residual effects, setting boundaries,* and *experiencing healthcare.*

The following section will explain each phase and sub-category of the basic social psychological (BSP) process *Transcending the Now* in greater detail. In addition data

from the participant interviews will be used to validate each phase and sub-category of the grounded theory *Transcending the Now.*

<p style="text-align:center">Phase One - *Relying on Faith*</p>

Relying on Faith was the first phase of transcending the now. *Relying on faith* referred to being confident in the belief that God is in control of all things. Two sub-categories were identified *Practicing your faith* and *Standing on your faith* (Figure 2). *Practicing your faith* entailed the activities surrounding expressing your faith such as attending church, talking to God, asking God for help, prayer, reading the bible, taking communion, listening to hymns, going to Bible study, being a pastor's aide, serving the church, and fellowship with church members. On the other hand standing on your faith referred to how the participants internalized the promises of God such as trusting it will get better, believing, being in the care of God, getting strength from God, receiving strength and peace, believing in the power of prayer, obeying God, believing God allows things to happen to you so you can heal, and being sure of your salvation. In the next section the two sub-categories of *Relying on Faith* will be illustrated with data from the participant interviews.

Relying on Faith
Practicing your faith
Standing on your faith
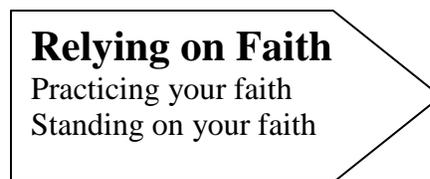
FIGURE 2: *Relying on Faith*

Practicing Your Faith

The first sub-category *practicing your faith* was defined as the participation in activities that strengthen and reinforce their faith. All of the participants in this study had an identified religion that they practiced, and they practiced their faiths in a variety of ways. For instance Angela described practicing her faith as receiving communion:

The pastor come out on usually right after the first Sunday and bring communion.

For many of the participants praying was also a central part of practicing their faith and it provided comfort and direction. Carlotta described an instance when she used prayer to get through a challenging situation:

……the nurse practitioner that saw me when I found the cancer said you know I do think that you do have cancer. She says ….I'm pretty sure it is and then she left the room and……at first I'm like I really want to cry, but I fell on my knees and started praying that I could you know get through this and get home safely and you know keep my mind on what I have to do to get home

Similarly Danielle also practiced her faith by praying:

I had the muscles, the muscles ached where you didn't want to move so…..every time that I knew it was coming….I would lay in bed praying like I can't wait for this part to be over.…I won't say like on a regular basis but yeah in the beginning I did pray, that I hoped that everything will be okay…..

Harriet also prayed:

I always prayed to God……my prayer was like God if something happen I don't want my son to be here. I want us to die together so that I won't leave him here on nobody or if or he could die before me…….so I wouldn't leave him to be a burden on nobody.

While praying was a central part of practicing faith Carlotta practiced in other ways as well. She also practiced her faith by talking to God:

There's a big support group out there plus you've got a Lord that's watching you and giving you strength…..like I told him. (talking to God) I says I can't deal with

this and you're gonna have to help me with this. I can't do it, you do it………you get that strength, you get that peace and you know you go on……

Though not as much as she thought she should, Irene attended church as a way of practicing her faith and she also spoke to God often. She stated:

I have this argument with God all the time. Never more than I can bear? Oh well, I argue about well how much do I have to put up with this time? You know never more than I can bear? Okay but we don't have to make it so much……….even when I'm not going through let's say a trying period. I talk to God about all the other things I probably should do and don't do enough……I kind of short-circuit it. Well you know where my heart is [laughs]. I may have to pay for these things later but going to church with people, frequently I really get a lot to out of going to church but I don't go as often as I probably should and then when I go to church with other people it, a lot of it depends on their denomination and you know and the constraints associated with that, but talking to God and like I said having someone pray for me oh yeah

Another aspect of practicing your faith was attending church. Angela had a strong desire to attend church but was unable to do so because of feeling weak from her chemotherapy. She discussed:

Yes, but oh yes my church and I want to get back there so bad. That's my heart's desire to get back get well and get back into my church.

Danielle like Angela and others described practicing her faith as attending church services and in addition she discussed her friends putting her on their prayer lists at their churches. She stated:

….. I was on my girlfriend's prayer list at her church.……I did attend the church and I was on her prayer list and a few others so even though I wasn't in attendance…….

Engrid also described attending church:

I was raised Baptist, but I attend a non-denominational Church of Religious Science now……..My girlfriend would fly down and we would go to church on Sunday mornings………….I tried to continue to go to church, cause that was important to me and I remember once when at one of those times when I'm like I

can't do this anymore. I went to church and I can't remember the song but it was "I can do anything"…..the words were I can do anything, I can do anything and I was like wow this was a message to me cause I was at the point where I'm like I can't do this and when I heard that song in church it was just reaffirming for me that I can do anything. I can do anything with God's help.

Engrid practiced her faith in a number of ways such as talking to God, attending church and listening to religious music. She recalled a time in which she was having a hard time with her chemotherapy and cried out to God:

I would just cry like the third day after chemo was the toughest day and I would cry halfway through chemo. I just said I can't do it Lord. I can't do this. If I have to do this, I can't do this anymore and then they switched my medication because it was time to switch it and it was better

Engrid also often asked other people to pray for her. She remembered:

asking the church to pray for me and asking my support group to pray for me and you know just continuing to have faith.

Like Danielle and Engrid, Francis practiced her faith by praying and by having others pray for her too. Francis stated that sometimes she was so sick she didn't have the energy to pray, so instead others prayed for her. She stated:

I would pray for myself, but you know I was just so out of it and a lot of times it just took all I could give to get up and just to go to the bathroom or brush my teeth or to take a shower. So a lot of times I would just be sleep, not able to really like study the Bible or pray or anything like that, so I think it was more other people praying for me.

Francis also attended church and read the bible. She described getting reading the bible to help her through hard times:

……because I know that I'm a Christian and instead of me thinking negatively or starting to get bitter, I'll just pick up the Bible and just start reading the Bible just to see me through things now, instead of being negative and bitter because that's not going to get you anywhere it just takes years off your life.

Reading God's word was an important aspect of practicing faith. Gina described reading

her bible:

> I get up every morning at four o'clock and study my bible anyway and I was doing a series where I was reading my Bible with these five books that are, that was written on different portions of the Bible. So during that time before I got sick I said when am I going to finish doing it. I was able to finish the series and I was like God you gave me this time. I wasn't thinking about I got cancer, you gave me this time…..

Harriet likewise read bible scriptures:

> I would read phrases, not phrases [to sister] what is it? Scriptures out the Bible for myself and then like you know we would do it for my son so I already knew what to do, what I would have to do to really get through this

Gina discussed serving her church as a prayer coordinator, which was another way to

practice faith:

> my pastor asked me to become the prayer coordinator and I said why me…..you know so I had to study what it is to be a prayer warrior or a prayer coordinator, and I was in all these groups of people from Australia too. It was never any Black people in none of these groups, cause we don't seem to pray in mass like some other countries. And so I was going to all these meetings and I was really learning how much they really love the Lord and how they really really pray and how we be oh Lord have mercy Jesus. No they were praying and I was learning this and it happened just at that time, so I was already prayed up and ready to go whatever come may yeah and then I was able to call my prayer partners who was all over the world to say look pray for me.

All the participants described practicing their faith in daily life and how that faith

strengthened them and enabled them to cope with the breast cancer and other hardships.

Standing on Your Faith

The second sub-category of *Relying on Faith* was *Standing on your faith.*

Standing on your fith was defined as believing and internalizing the promises of God.

Each of the participants had strong faiths that they drew great solace and strength from.

They clearly believed in the promises of God and the power of prayer. For example,

Angela believed that God would take care of her and described having faith in him:

> I have that faith that he'll work it out.

Betty also had a strong belief in God:

> I went through it fine I think because of my belief in God, my spiritual part of my life was the major part of helping me to get through this, in that I just believed in God, and that I was going to get through this thing…….You know so, my experience was a not a bad experience in terms of I mean yeah I lost two breasts, but I'm still here………….. much of it had to be because of what who I believed in and I believed. I just believed in God and I believed that he was going to be, he is my source of recovery, he's my source of protection……

Betty further discussed her beliefs about God and her faith and how they gave her hope

throughout her experience with breast cancer:

> That's where that belief in Christ that foundation of knowing who you are in Christ. You got to have the hope in him that he's going to get you through, and then the peace comes as a result of knowing that even if you don't you know where your going so that's where the peace comes in.……..it was amazing to me…….

Danielle also believed in the power of prayer and the ability of prayer to uplift you, like

Betty. She stated:

> It's kind of like the power of prayer. Just not getting yourself in a blackhole…..or just giving in saying this is it. I think if you don't claim it, then maybe you won't have it………there's women out there, who's had it 20, 30 years, 40 years and then there's some unfortunately where it does come back, but you can't dwell on that you have to keep going.

Engrid's standing on her faith was reflected in the fact that she believed that because God

had answered her prayer on other occasions she had great trust that he would continue to

do so. She also elaborated even further on her deep trust in God because of all of the

things that he had done in her life so far:

Faith, great faith in God that you know, I look at that I've been blessed. I have a job, I have a house, I have a wonderful child, I have people and that God's taken care of me all these years and there's no reason to believe that he won't continue to do that.

Francis discussed her belief in God and how that belief has helped her with trusting God for a good outcome:

……I believe in God and I believe that prayer not by me, but prayer from my mom and my mom's friends and her church helped me to get through a lot of what I did go through, and I think it also helped my cancer situation as far as my doctor telling me how severe the cancer was, and it just seemed like everything that I went through was pretty easy and it could've been a lot worse you know. The prognosis could have been worse you know, cause the doctor was very optimistic when he told me…..I don't know, you know the cancer's pretty aggressive, if what we're gonna do for you is gonna actually work. You know so I think that the prayer actually did help a lot you know for me. So I believe that it made a situation that could have been a lot worse or difficult much better because people were praying for me.

She also discussed being a Christian, her faith and why she decided to return to church.

She stated:

……I just decided I'm gonna go to church …….and I didn't know the day that I went when they had the altar call to join the church. I was just led you know, God spoke to me and I just got up there…….since I've joined this church. I've become a more active member not just going to church on Sundays. I go to Bible study I'm what they call a pastor's aide. I help the pastor………I'm going to church for myself you know because this is something that I want to do. I want to have a closer relationship. I want to be actively involved in church and I want to you know, receive all the blessings that I possibly can so

Gina stood on her faith by obeying God. For example, she refused to take chemotherapy because she believed God said to her no you are not to take it:

……..they were going to start chemotherapy. I said I'm not taking chemotherapy, so he had his nurse come in to see me and she said why you not taking chemotherapy? I said cause I prayed about it and God said no……and his nurse said I'm a Christian and you're being foolish and I said maybe God have told you not to take chemo, told you to take chemotherapy, but he hasn't told me to take

chemotherapy and she said we see so many people like you die and I said I don't think you gonna see me die.

In another instance a coworker had her daughter try to convince Gina to take chemotherapy, but she said that God said no. She also discussed having a strong belief in prayer and how she used prayer to make decisions in her life:

> My faith was already strong and I had a previously experienced with God that when I pray he answered my prayer, matter-of-fact I wasn't gonna have the lumpectomy and I was soaking in the tub……and I said Lord if you want me to have this surgery then you gonna have to reveal it to me and I said and the way I want you to reveal it to me, is have my doctor call me who I know is out of the country, today. Well I got out of the tub and maybe about half an hour later the phone rang and a nurse called me and she said your doctor is in another country……but he's called me, to call you to see if you would come in and he is flying in Friday to do your surgery and I said okay, so that's why I had the lumpectomy.……..So he's always answered me you know…..

Gina also firmly believed God had a plan for her life:

> ….. I tell everybody whatever happen to you good or bad, God allows it for you to be saved and so he allowed it for me to be saved and for me to get a closer walk with him to make sure I make it to the kingdom, so he allowed it and I told people…...

Gina's belief in God was so strong that it also dictated her diet:

> My faith believes in the diet……God said *by thy faith you are healed* and he healed people different ways, some people he touched, some people he spoke……so I tell people maybe God is telling you to take chemotherapy you got to listen to him. I don't say because it worked for me, it's gonna work for you. You gotta fall down on your knees and pray and God may know that you need to go that way.……but I think eating, taking care of your body with all these things, you gotta have faith that it's gonna work.

Gina also explained how she was able to hear God's voice and how she obeys God:

> once you build a faith with God you hear his voice. His voice is your voice. It's your voice. It's like only one time have I've heard an audible voice, for the majority of time it's your voice and if you sit quiet enough he talks in a voice that is your voice telling you what to do…..

Harriet believed in God as well, and she trusted in him that she would not have a reoccurrence of breast cancer. She stated:

I believe in God, so I don't think I'll have it.

Irene believed that God allows things to happen to you so he can heal you. She had a great deal of trust in God because of her religious denomination.

> AME's are very good for getting you through such things because the trials and things that we go through in life they're not seen as punishments. They're seen as an opportunity to strengthen your faith…….God will bring you through this and I know that God will take care of me. It may not be in the manner that I would like but God is there.

All of the participants all had strong faiths that allowed them to trust God for every detail of their lives.

Summary of Phase One - *Relying on Faith*

The first phase of *Transcending the Now* was *Relying on Faith*. *Relying on Faith* describes both the outward and inward manifestations of faith that all the participants embodied. Two sub-categories of *Relying on Faith* were identified *Practicing your faith* and *Standing on your faith.*

The next section will explain *Seeking Support*, the second phase of *Transcending the Now.*

Phase Two — *Seeking Support*

Seeking Support was the second phase of *Transcending the Now*. *Seeking support* referred to the types of assistance that the participants sought to help sustain themselves. Among the participants, five different types of support were identified (Figure 3). The types of support identified will be discussed in the next section. The first type of support

identified was *professional support. Professional support* referred to support from

licensed health care providers such as doctors, psychologists, therapists, nurses and social

workers. Participants sought professional help in several ways. The second type of

support identified was *social support. Social support* referred to support from friends, co-

workers, neighbors, and associates. A third type of support was *family support. Family*

support referred to support from parents, children, spouses, siblings, intimate partners

and extended family. A fourth type of support was *informational support. Informational*

support referred to support from those with personal experiences of cancer, written

sources, the internet, professional organizations and media sources. The last type of

support was *religious community support. Religious community support* referred to

support from religious leaders and church members.

Seeking Support
Professional support
Social support
Family support
Informational support
Religious Community support
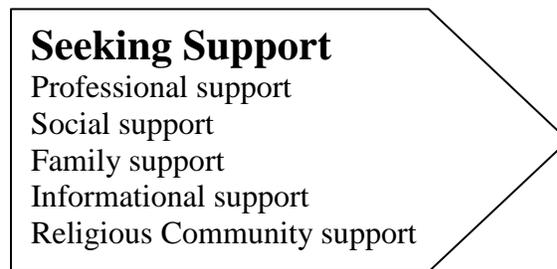
Figure 3: *Seeking Support*

Professional Support

   Professional support referred to support from licensed health care providers such as

doctors, psychologists, therapists, nurses and social workers. The participant's

experiences with professional support varied. A few participants even sought professional

support in the form of second opinions. Some of the participants on their own sought

either medical or mental health support immediately when they recognized that there was

a problem. Other participants had very compassionate and caring health care providers

who were supportive to them. For example, after discovering a lump in her left breast and

discussing it with her family, Angela sought medical attention she stated:

> I didn't hesitate. I went to my primary care physician and he suggested that I get a
> mammogram and in getting the mammogram the results then came back, but it
> came back you know there was something in the breast so he sent me to a breast
> surgeon. Well he was just a surgeon period, and in going to him he looked, he did
> a biopsy and in doing the biopsy I could tell from the expression on his face that it
> wasn't right, so I left the office that day, but I went back because my appointment
> was scheduled and he gave me the results of it, that it was cancerous.

Danielle was pregnant at the time of her diagnosis and she was faced with having to

terminate her pregnancy, so she sought professional support in the form of a second

opinion:

> I did get a second opinion at another hospital because most of the doctors that I
> had were men and not to say that men don't make good doctors, but I had wanted
> a female opinion, you know for my case and I think I saw a pretty good lady
> down there at the other hospital and she conducted another test and then she told
> me it wouldn't be in the best situation for me to continue

Betty was one of the participants that believed that her health care provider really

connected with her and therefore provided greater support. Betty described her

relationship with her health care provider:

> …..I had an excellent physician on the first go round. I'll never forget him. He
> was just really on top of it. The second person was a lady physician, she was
> okay, but she wasn't like the first one you know but my experience with him was
> great…..I mean he walked me through it and it was as if you know he was saying
> your going to make it you know…… So I mean I got a lot of support from him

Danielle recounted that her doctors supported her by trying to put the termination of her

pregnancy in a different light. Francis also received compassionate support from her

healthcare provider. She described how her doctor was supportive to her after she learned

she had an aggressive form of breast cancer:

> I was afraid to know…….when I went to the oncologist after they did the biopsy he called me into his office and he sat me down and he was like it is you know cancer, and he told me like your cancer's a stage three and he's like it's a pretty aggressive cancer and it was like it went in one ear and out the other……all you can hear is you have cancer and I wasn't comprehending all the stuff that he was telling me. You know he was like I want to this, that and the other for you but I wasn't able to comprehend. All I was hearing is that I have cancer and it's serious and he saw that I was scared and he saw that I was holding back the tears. He was like you know it's okay if you want to cry, you can cry. He was like I know it's a very overwhelming thing [starts crying] for you to go through……..even to think back now about the experience it kind of brings tears to my eyes

Carlotta was actually one of the few participants that sought out psychiatric care. She

reported:

> when I had cancer the second time I went into a very deep depression and I sought psychiatric help and it was real hard and the person that was my psychiatrist she was gonna have me committed, but then as she talked to me she realized that I was just sad and not really suicidal or anything like that, but it when she first met me I was a basket case because as soon as I found out that I had it the second time that's the first thing I sought cause I knew I needed other help to get through this.

Carlotta also confided why she felt she needed professional mental health support. She

described:

> Well just somebody listening to me and feeling my you know, my pain and letting me know that I am not cuckoo for one thing [laughs] and just that just somebody that I could tell everything to that didn't know me and I could you know get a lot of stuff off my chest that I didn't want to burden my family with. I needed somebody that I could you know vent with and I was just teary all the time and I was very upset.….

Engrid was another one of the participants that sought out professional mental health. She

reported:

> I did call today and find out. I'm gonna go see a therapist tomorrow, because I'm like okay maybe you need some more help you know.

Engrid did not want to be viewed as weak, but she came to the conclusion that she did

need professional mental health services. She stated:

> Yeah definitely I don't want anybody ever to think that I'm weak….but it's gotten better through the cancer cause it had to, but yeah I don't you know but then like I was talking to my friend on Thursday and I said you know I've been feeling sad and he's like and I can hear it in your voice, so you know at some point, though this has been a year. I do say there's only so much suppressing you can do you can only smash and smash and smash and at some point it has to come out somehow, so I thought maybe going to see a therapist might be a good thing [laughs].

Irene received professional support from her psychologist. She described the bond they

formed:

> ……..my psychologist who I'm really beginning to appreciate is fours years older than I am. She's White, but she's four years older than I am and we have some great talks about aging okay and so that's where we really make our bond, is hell we're both getting old and some of the things that I am experiencing that I think are a part of my depression she says no you're just getting old [laughs].

Gina had high accolades for her doctor and the support he provided her. She gave an

account of her experience:

> I gotta give kudos to my doctor……from the very beginning he wanted me to do certain things, but once I said no he never pushed me and everybody was saying Kaiser is gonna make you and he didn't…..I finally asked him. I said why you never push me? He said because I have to be very honest with you I agree with you totally. He said I did my thesis in Hawaii with a group of people who never would take chemo or radiation and he said 90% of those people are healed………. He said but I had to let you make that decision and I can't tell you I agree……so God gave me the right doctor, he never pushed me…….He would call me on the phone and talk and I would call him[laughs] and we would talk and I just was blessed with the with the right doctor. I could of got somebody crazy ……He said, every time I came in, he said are you doing every thing you're supposed to do? Are you eating right? Are you exercising? Are you resting? I said yes I'm doing everything. He said okay.

Harriet was able to be light-hearted with her doctors and thus was able to form a close

supportive relationship with them. She said:

my doctors used to tell my sister and my mom she's off the hook because even though I was going through cancer I was still joking with them and you know doing different things, but we had a close we had a very close relationship with the doctor

Although the participants' experiences of professional support varied, it still provided a great deal of comfort and relief.

Social Support

The second type of support was *social support*. *Social support* referred to support from friends, co-workers, neighbors, and associates. The majority of participants were fortunate enough to receive support from sources outside of their families throughout their breast cancer experiences. Yet, interestingly in this study very few of the participants used support groups for *social support*.

Angela had friends that visited her and offered their assistance:

….I have three ladies other than my good friend to come out and be with me, talk to me and bring me little goodies and see if I need transportation for anything

Betty also had an outpouring of *social support* from her coworkers and friends. She reported:

I'll never forget the second time around, the people on my job, my family, I mean whenever I came home I had somebody here dealing with my breakfast, somebody here my lunch, somebody preparing my dinner. The people on my job they came every day, so a nurse would come or a doctor would come just to see how I was doing, bring me food. They just wanted to be helpful……….. .with the love that was expressed I was able to walk through it, you know I mean the people on my job, I mean the nurses these were RN's that wanted to come and they wanted to make sure that I was bandaged right or I was this or they just, it was just one of those things that I had that kind support so………..I mean that's what got me through I mean I know that's much of what's got me through, is the people that gave me the support…..so if you don't have it, if you come from families that that don't have that, or even a church that don't give it you might be in trouble.

Betty described how support from a particular coworker helped her:

> ....There was one that that really helped me through the procedures of what
> was to take place you know because my sisters they were not able to give me
> procedures of what was to expect and all that kind of stuff but this one lady on my
> job was always there. I mean when I needed her she was there to talk to me. She
> walked me through certain steps and then when the experience happened to me
> you know as I was going through it then another employee she, we helped each
> other

Danielle described how her friend supported her after she started to lose her hair and

decided to just shave it off:

> So I was the only female sitting in there and all these men are sitting in there like
> you know why is she getting her head shaved, and my girlfriend was like well
> she'll tell you why. Just ask her, so then once I told them why I was getting it they
> complimented me on the shape of my head.

Engrid as well had support from friends and family and her child's father. She stated:

> .....I have one girlfriend who went to every doctor's appointment with me and
> then I had my other girlfriend, my sister who would go to chemo with me. I have
> one girlfriend who flew in from Oakland every three weeks to take care of me
> during my downtime, so I had a lot of family and support and my son's father
> helped out

Furthermore she acknowledged that this type of support was important when dealing with

the health care system:

> .....my other girlfriend would go with me and she would write down everything
> the doctor said. She would ask questions to help clarify if I didn't ask the question,
> so I always took somebody with me because it's hard to hear what the doctor says
> and record what the doctor is saying, so with her being there or someone being
> there with me it was always helpful

Gina received *social support* from both strangers and people that she knew:

> I had a lot of support even people I didn't even know cared, you know what I
> mean? One of the first persons from my church, a real quiet lady she's an
> occupational therapy and she came and told me all of the exercises I needed to
> do......Immediately I started doing the exercises she told me. Here at my
> job....the doctor only gave me a month off but I said I need three months.....I

need to rest for 90 days. They gave me that…..I didn't have that much sick time. People here gave me time to stay off, one particular woman that gave me time to stay off had told me she did not like me, and she was the first that gave me two weeks.

Francis realized that her *social support* was not very strong. She reported:

> I have some close friends but I don't know if it was just too much for them to come around, because my one friend I've been friends with her for like 20 years and the whole time that I was going through the cancer I never saw her and I hardly ever talked to her. I had one friend that she constantly would call, but she had a large family and she wasn't able to come because she did live a little distance…..but she would call and check on me on a constant basis and then she would talk to my mom and you know ask her how I was doing. So she tried to keep me uplifted and her husband is a nurse so he kind of knew some of the things that I was going through. So she would call and talk to me and try to uplift me and make me laugh and you know ask me if there was anything that I needed. You know tell me that I could call on her at anytime, but pretty much I just mostly went through it by myself………….I don't think the type of friends that I had were either mature enough to handle it…you have people that are in your life but are not really truly friends. You sometimes when the going gets tough that's when you find out who your true friends are………. that just showed me who really was my friend and who wasn't my friend.

Harriet also did not have much *social support* from friends. She mentioned:

> I don't have many friends.

Irene had *social support* that was available to her, but she did not always want to accept

it. She stated:

> I have a friend, who is really sick right now okay. My friend insisted upon going to my chemotherapy with me. I didn't need anybody to go. I would have preferred it if she hadn't, but it was important to her. So I knuckled under and basically between you and me I endured it okay [laughs]. ……..I had told her I don't want anybody there because if you're there I feel as if I need to say something to you know [laughs] and I need to pretend to be pleasant or something, so I just assume you not been there. So but you know like I said these are just differences in people

Irene further stated that she didn't feel like she needed a lot of support:

….I may not need as much company or association and contact as some other people, but I know they're there. It would be horrible to think that there was nobody there. There was nobody I could call.

Also part of Irene's struggle with accepting support centered on her strong need for

control. She stated:

Calling on others for support is one thing, but calling, letting others direct you is another and so you know where your limitations are, where you need help, where someone else is taking over the show and you're doing things not that you necessarily want to do or think appropriate but what someone else, so those things you have to work out.

Carlotta expressed that she used support groups at first, but then stopped because she felt

they were not useful:

I went to support groups when I had it the first time after I had the surgery and was healing I found out about a support group over at the hospital and I went there for over a year I think and then I got away from that because it was okay, but it was more or less listening to other people's problems and things like that and I'm the type of person that I want to deal with what I have…...

Danielle too had limited use for support groups because of the tremendous support she

received from coworkers and friends. She stated:

well in the beginning, yeah when I first got diagnosed like I said the hospital has a support group there for women who just get diagnosed, where you go and they show you how to apply makeup cause you lose your eyebrows and stuff but I really didn't lose much of my eyebrows or my eyelashes, but they you know show you how to put on the makeup. I went to a couple of those, and I really didn't go into any outside support groups because of my neighbor next-door and all of my friends….we started meeting like once a month and we were having knitting parties…….Yeah I got my all my coworkers and stuff to take up knitting, so we knitted a 9 x 13 or something inch panel and then we sewed them altogether and we made a blanket for me.

Danielle went on to state:

…..I had people calling me all the time and coming over and stuff….I did receive calls from a lady……she was from the American Cancer Society. She called me once a week to see how I was doing, so that was really nice and she told me about

her ordeal and stuff and so yeah I did have, I guess some support from them too, but I never really met with any group outside.

Francis attempted to attend a support group, but believed that she could not identify with the group so she stopped going. She described:

> I did attend a support, a couple of support groups but I didn't find them very helpful for me, because I didn't want anyone to like feel sorry for me and I know that there were other people there that were going through the same situation that I was going through or some that had worse situations than I was going through, but I just couldn't really identify with them so it wasn't just a good thing for me you know to go to the support groups

Harriet did report that she would be willing to attend a support group:

> well me I'm kind of nosy so [laughs] I like listening to people and I'm a people person because I could just start talking to you and my sister's like come on let's go, and I'll be like wait a minute…..I think I would of probably liked the support group, but I didn't feel like it was a need for me to go.

Irene also did not attend a support group, but it was because she felt that her doctor was not genuine when suggesting it. Irene as well reflected on why she and other African American women did not attend support groups:

> Dr. XXXX wanted me to join a support group but I got the feeling she wanted me to join it because she was pleased with my attitude and she thought I would be a good support in the support group, rather than a recipient of support.

> It's too close to mental-health or mental illness. I think so. I think so and then they don't want to go listen to a lot of other people's problems.

The majority of the participants did not receive *social support* from support groups. Instead their social support came from friends, co-workers, neighbors, and even strangers.

Family Support

The third type of support identified was *family support*. *Family support* referred to support from parents, children, spouses, siblings, intimate partners and extended family. This type of support was very important to the participants. Some of the benefits of family support were that it provided encouragement, physical assistance, and comfort. For the participants that received it they reported being better off. For example, Angela recounted that her siblings call her on a regular basis to express their concern:

> I have a older brother that lives in Missouri and he calls me every two weeks. He called me today matter-of-fact….I have a sister, a younger sister that live in Mississippi and she calls me onest a month at least sometimes she'll give me an extra call….they are quite concerned. It was a shock on my family when I told them what was going on with me and to take it easy until I could give them more information and whatever information I gave them just know that God is in the plan and he'll work it out

Receiving *family support* often encouraged the participants to provide support to others themselves. Betty described:

> …my family was supportive and everybody was supportive and that helps you get through the situation that you're in.………..You know the support that I got from my family, I got from my church family, people that I work with and so I felt that that was my best support, you know and which gave me an incentive that when somebody else came down with breast cancer I was always one that they could talk ……..

Carlotta was one of the participants that was better off because of the *family support* she received. In fact, she shared that she received both family and social support:

> my husband was a jewel and he doesn't deal with illness or death well at all but during this time he was just you know a little soldier and my parents and well my dad was dead, but my mother and my sisters, and his family. He has a large family and they were all very supportive. The people at work were wonderful and the neighbors.

Danielle described the *family support* that she received as:

> I have lots of relatives out of town that will call me all the time, so like I said again I mean I always had people supporting me whether here or out of state.

She further stated her immediate family supported her immensely:

> I mean you know tears here and there but for the most part they were strong too in supporting me in everything and like you know my Mom would take me to the doctor and pick me up, or my sister so somebody was always there during the whole time and you know if I wanted something to eat…..when I first got it, I mean they went home they got me a new bed in my old room, so I could go and stay there. I didn't stay in that bed once, [laughs] but they were prepared to take care of me so

Francis received *family support* primarily from her mother before her mother died, but as much as she could she still tried to do everything on her own.

> The first time I went in with my mom and my mother you know she's your mom. She's like concerned and she's like it's gonna be okay and I'm not that kind of a person. I don't like people to like baby me and I just want to handle it on my own, so after I went the first time I'm like I can do it. I know how long it's gonna take and I knew you know once I went to chemotherapy just come straight home and usually I would make it home and maybe I would be able to change my clothes and put on something more comfortable before I would start getting sick

A lack of *family support* also affected the participants. Francis actually had weak family support despite the fact that her mother supported her. She had this to say about her family:

> …..my sister she had like a two-year-old and a newborn so she wasn't really able to do much and my dad, he's not the kind of person that can function really well around sick people. So he didn't really do anything so it was mostly my mom. She would check on me and ask me if I needed anything or you know she constantly, you know are you okay. You haven't been out of your room in a couple a days are you, you know fine and I'm like I'm fine you know

All of the participants received *family support*, although some received more that others.

Family support appeared to increase their ability to cope.

Informational Support

Informational support was a fourth type of support identified. *Informational*

support referred to support from those with personal experiences with cancer, written

material, the internet, media sources and videos. This information provided additional

information about the disease process that the participants were experiencing.

Angela felt that she needed more informational support, but did not receive it. She stated:

> …..I could've been updated a little more with paperwork. It could of been
> documented, so I could have read it afterwards, but I didn't even get that.

Carlotta was very proactive and did a lot of research on her own to obtain *informational*

support. She described:

> ….I had done so much research and I knew so much about the cancer because I
> sought people that had cancer and I went on the Internet and like I said I went to
> the American Cancer Society and I spoke with people there and……plus my
> doctors………. if I had questions I would get on the Internet, talk to the doctor
> and things like that, or just if they tell me something I didn't understand what it
> was and they didn't give me an explanation where I could understand it. I'd go
> home and type it out on the computer and read it, so I did a lot of research, a lot of
> research.

Engrid sought *informational support* when she didn't understand something. Like for

example, when she read the word metastasize on her medical report:

> …..this morning I went online cause I was going to meet with my oncologist, to
> kind of you know understand what that meant and it's just a fancy word for that
> it's spread.

She also learned general information from media sources as did Gina:

> …..I had went and heard Lorraine Day, who was a survivor of breast cancer of
> seven years, and after hearing her, like what had happened to her….first I thought
> this lady's a quack. She had been on Oprah…..my church had her come, I listened
> to her and after listening to her, a year from the day that I listened to her, I was
> diagnosed with cancer and I decided I'm do the same thing she did, and hers was

basically eating raw, and she suggested not to have any surgery, but I wasn't that bold. So I had a lumpectomy done, but I would not have the chemo and radiation.

Francis did not seek *informational support* herself, but rather her mother used the internet to find additional information:

my mom she would look on websites and………she would like look in to different information and you know, well if you're not satisfied with what they tell you here, maybe we can go here or maybe we can go to this place like that, or my friend you know told me this, that and the other

Gina used media sources also and videos to obtain *informational support*. She also used the internet to search for information. As did Harriet:

I did go on the computer and see what it really was and you know how does it come, because I thought maybe it was something I was eating or something and then it was one lady at the church she used to bring me brochures on it and how to eat and what to eat and stuff like that.

Irene relied on her own health care knowledge, but also obtained *informational support* by doing some additional reading on the treatment for breast cancer:

What I did is I added it to the little bit of knowledge from 10 years earlier because this was such a much larger cancer and this cancer loved estrogen. So I did some reading and when they told me the medications that I was gonna be on. I looked all of them up because I was interested in the side effects as well as the steroids.

The participants in this study received professional, social, family and *informational support*, some of which helped to buffer the effects of breast cancer and depressive symptoms. One last type of support that helped as well was *religious community support*.

Religious Community Support

Religious community support referred to support from religious leaders and church members. *Religious community support* from their church congregation and pastor was apparent among the majority of participants. For Angela religious community

support was provided by the women in her church. Her church members provided

fellowship to her and kept her updated about the activities happening at her church. She

stated they told her:

> Don't stress yourself, we'll be there. The church will be there. You get well. They're concerned about me getting well. Yes, it make me feel better. Yes, it really make you feel like, they care. I am with a caring you know Bible-based church. We have prayer before they leave. They'll come and chat with me and let me know….update me with what's going on. I get a weekly bulletin from the church, and they keep me posted…….

Betty received *religious community support* from her religious leader and congregation.

As did Francis, she discussed how the support made her feel:

> it's a few people that I have met at the church that I feel close to and comfortable with. I feel comfortable talking to my pastor. I feel comfortable talking to a few people that are on the same committee as I, and my Bible study teacher. I really feel comfortable with her and it's another girl that, she joined the church around the same time that I joined the church and we've become really close friends. We talk and you know she's going through a few things medically and I'll call and I'll uplift her and we'll talk to each other and we'll pray with one another or she'll tell me oh you look depressed today or you look sad today and she'll say something or tell me a Bible verse and I'll read it and it'll uplift me so I've made some friends and it has really helped me you know along with my walk.

Gina also received *religious community support* from her congregation. She described

how her church prayed in mass for her:

> Well, the day I was diagnosed we were having an all night prayer service and I went in and they said any prayer requests? I said I was diagnosed with cancer today and we need to pray and the people started getting teary. I said don't get teary here, you better have faith because if you don't believe then I don't need you praying and yeah they prayed for me constantly.

As did Harriet's congregation:

> the church people from my mom's church, which was my church too and my sister's church. Everybody just prayed and they was real supportive…..I went to surgery they all in the waiting room praying and you know it was just like this

strong support with faith, and you know everybody was just there and I don't know….if it wasn't for them praying and being there for me.

Irene also received religious community support from her church and spoke about how her particular religious denomination provided support well:

Yes Methodist, First AME, African Methodist Episcopal and actually AME's are very good for getting you through such things

The majority of participants received religious community support from either their religious leader and or church members.

Summary of Phase Two - *Seeking Support*

The second phase of *Transcending the Now* was *Seeking Support,* which referred to the types of assistance that the participants sought to help sustain them through the experience of breast cancer. Five types of support were identified: *Professional support, Social support, Family support, Informational Support, and Religious Community Support*. The first two phases assisted the participants in getting through the experience of breast cancer along with the next phase *being strong*. The next section will explain *Being Strong*, the third phase of *Transcending the Now*.

Phase Three — *Being Strong*

Being strong was the third phase of *Transcending the Now*. *Being strong* referred to the inner strength and fortitude that the participants possessed throughout their experience with breast cancer. Four subcategories of *being strong* were identified (Figure 4). The first sub-category of *being strong* was *Being Positive. Being positive* referred to not having doubts or not thinking negatively. *Being resilient* was the second sub-category of *being strong*. *Being resilient* referred to the ability to cope with stress and to recover

from difficulties. *Turning Inward* was the third sub-category of *being strong*. *Turning inward* relates to how the participants quieted themselves and then focused in on the mind and soul. The last sub-category of *being strong* was *Accepting It*. *Accepting It* related to acknowledging that you have cancer and moving forward.

Being Strong
Being Positive
Being Resilient
Turning Inward
Accepting it
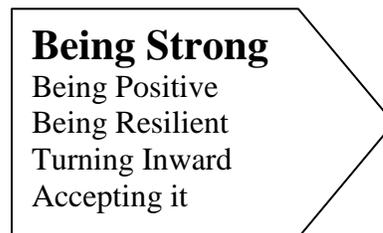
FIGURE 4: *Being Strong*

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Being Positive

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The first sub-category of *Being Strong* was *Being Positive*. *Being positive* referred to not having doubts or not thinking negatively. All of the participants strived to remain positive throughout their experience by keeping busy, not thinking negative thoughts, and not succumbing to fear.

Betty remained positive by not letting her breast cancer get to her:

> ……I just believed that I could overcome this……... I got up and I kept going and I've always been on the go, you know so I never let it get to the get me to the point that it was going to drag me down. My thing was if is that you have to fight this thing, and I guess I'm a fighter you know so I was determined that I was not going to get me down.

Danielle had a positive attitude too. She described:

> I'd just a positive attitude I think and my friends for the most part. ….I don't know why but I just did what I had to do and didn't really look back. My thing was you know you can survive it. I had positive feedback from the doctors, so I just went with that. That I was going to make it…..I was under the premise, I guess it is kind of a blessing in disguise. The reason for the pregnancy was for the cancer to show up at that time.

Gina was able to maintain a positive attitude because of her faith:

> ……one of the reasons we make it, cause I think Black women are very special we don't have the tendency to have what we call pity parties, majority of Black women. I don't think they have pity parties. I think the majority of women say how I'll make it through, you know I'm gonna make it through this, because our faith help us make it through. I think faith heal you more so than anything else……

Harriet limited her stress which helped her to have a positive attitude:

> I think that what really got me through too because I didn't stress, when you stress you tear your body down. So like me like I said I just went to the doctor and they said you need to do this. I said okay when, what time and you know I didn't stress.

All of the participants reported that *Being Positive* assisted them in dealing with breast cancer.

<div align="center">Being Resilient</div>

The second sub-category of *Being Strong* was *Being Resilient*. *Being resilient* referred to the ability to cope with stress and to recover from difficulties. All of the participants in this study displayed overwhelming resilience in the face of adversity. They considered their circumstances to be just another hurdle to clear or bump in the road to get past. Angela was in the middle of her treatment and experiencing difficulties, but still believed she would be okay:

> I'm just I'm still trying to cope with what happened to me and what's happening to me still……. but I'm trusting it will get better

Betty's resilience was documented by her statement:

> You know so, my experience was a not a bad experience in terms of I mean yeah I lost two breasts, but I'm still here.

Carlotta, another resilient woman discussed the importance of being strong and resilient

among African American women and stated:

> …..if you read Black history and you know the women were always set to do things ……. they had to take care of the family, they had to work, they had to do everything and they've always had to be, even when they're sick they had to continue to keep that family together, and you know a lot of times you don't even know their sick. You know cause they just keep on, they just keep on going and it's like that little Energizer rabbit. ……that's just the way I mean we were brought up, to just you know face adversities and do what you have to do and be. We're not you know, privileged to be…..able to crumble.….

For Francis breast cancer was just one more thing to overcome:

> as a Black woman it seems like I'm just constantly always going through something…..I'm currently going through something right now…..now that I've overcome the cancer. I'll sometimes tell myself you know if you can go through that by yourself, you can get through this…..You know it's just another hurdle that I just have to overcome. I don't even share with some people that I'm a breast cancer survivor because most people can't even relate to it, like the other lady said it's just another bump that she overcame. It's just another hurdle that I've overcome I hate to take it lightly, but sometimes it just feels like….Just something that in previous time, I just overcame…..I try not to think about it

Francis also believed that working through situations on her own made her more resilient:

> I think it comes from me not ever being able to depend upon anybody. You know I pretty much have to do everything on my own…..my mom's famous saying was God bless the child that has its own……when you have difficulties in your life….You realize that there is really not too many people that you could depend upon, and as long as you take care of your own self and you're able to see your own self through it and pull your own bootstraps up, and you know pick up the pieces and go, you can do it ……I have to always figure out how to do things on my own you know, and every time you overcome something it just makes you a stronger person I feel.

Irene had already suffered through many other health challenges so she was able to use

that same resolve when it came to breast cancer. She reported:

> So when we found the cancer it just wasn't a biggie and actually what I did….. what I started doing is something that I had done frequently, is I started planning a trip….I might as well get something out of this right? I'm going to be out on sick

leave, so I can go someplace. So I didn't have time to worry about any of this other crap…..it's just not a biggie, cause I was really sick and thought I was gonna die back in the early 80's.

Additionally she felt that past challenges gave her the experience to overcome new challenges:

….the more things, times you've had to use the process to get from there to here. The better you are at being able to do it and call on it and so the better you're able to work it…and the better you can work it by yourself kind of independently.

The participants in this study were very resilient women, and their resiliency increased their capacity to cope.

Turning Inward

Turning Inward was the third sub-category of *Being Strong*. *Turning inward* relates to how the participants quieted themselves and then focused in on the mind and soul. For these participants *turning inward* took the form of focusing, keeping their minds busy, and distancing themselves from others to rest from outside influences in order to build their strength to get through the experience of breast cancer. For example, Angela turned inward by keeping her mind busy. She stated:

…..it's been difficult…..I usually keep a preoccupied mind all the time

Betty focused by being determined and by developing a strong mind:

Half the battle of going through any kind of cancer or any kind of sickness is the mind, you know…….I tell that to anybody if you're not determined you won't make it. You know I mean half your battle is lost because your not ready to fight for it…..

Carlotta went inside herself:

……depression just takes you out. I was just sleeping all the time and that's what I do when I'm depressed and not feeling good. I go inside myself and go to sleep

or whatever but I was sleeping all the time. I had no energy and I had you know I didn't want to face the next day and it was just you know rough.

Danielle used alone time to turn inward:

Yeah people were in and out and then sometimes I just wanted to, you just want to lay in bed and be alone.

Engrid put her thoughts and feelings down on paper:

I would do journaling. I try to do journaling and I rested a lot, which was a good thing for me I spent a lot of time resting.

Harriet turned inward by focusing on her child:

like I say I didn't, I didn't it didn't affect me, because like I said my mind was just living for my son. So I knew once I got through it I'd be able to fully take care of him again so

The participants in this study turned inward in a variety of ways, so that they could

restore themselves for the challenges ahead.

Accepting It

Accepting it was the last sub-category of *Being Strong*. *Accepting It* related to

acknowledging that you have cancer and moving forward. All of the women in this study

amazingly accepted the hand that life dealt them from the very beginning of their journey

with breast cancer.

Angela gave an example of her acceptance of breast cancer when she stated:

……I realize I'm no better than any other black women You know, so and there are other black women that's going through the same thing or that has gone through the same thing…..So here it's my turn, here I go…..In spite of it, I'm just trying to cope with it. Honey that's all I can do you know can't run away from it No can't run around it. You just have to deal with it one day at a time.

Betty accepted her breast cancer because she considered it to be just one more thing in

her life, as did Irene:

It wasn't a shock to me because I guess I'm just not shocked by such things. It's just another bump in the road.

Carlotta easily accepted her breast cancer because she believed that Black woman had a natural capacity to manage adversity:

one thing with Black women that I know that with the Black women that I know their a strong breed and they've been through so much already that they just face it as another bump in the road and it sets them back, but they bounce back and go on with their lives. Most strong most women that I know that are Black

Danielle basically just took her diagnosis in stride, as did Harriet:

I'm not a real emotional type of person. So when they told me I was like okay what I need to do and they look like are you okay and my sister was with me and she was the one crying not me. So I think just because I'm not really emotional and I just knew I had to be strong, and get through this and be here for my son.

Gina's acceptance was supported by faith:

….. the blind man accepted he was blind. When they told me I had the cancer, I accepted I had cancer, but where I'ma go from here now is that I'ma go to my Savior, who can save me……

All of the participants easily accepted their breast cancer because of their faith and the belief that breast cancer was just one more thing to deal with in their lives.

<div align="center">Summary of Phase Three - Being Strong</div>

The third phase of *Transcending the Now* was *Being Strong* referred to the inner strength and fortitude that the participants possessed throughout their experience with breast cancer. *Being Strong* had four sub-categories: *Being Positive, Being resilient, Turning Inward and Accepting it.* The next section will explain *Dealing with Life Too*, the fourth phase of *Transcending the Now*.

Phase Four - *Dealing with Life Too*

Dealing with Life Too was the fourth phase of *Transcending the Now. Dealing with Life Too* had seven sub-categories (Figure 5). *Dealing with Life Too* related to how the participants moved through life situations that they were faced with while experiencing breast cancer and depressive symptoms at the same time. The first sub-category of *Dealing with life too* was *Family dynamics. Family dynamics* referred to the relationships that the participants had with different members of their family. The second sub-category was *Dating & other intimate relationships. Dating & other intimate relationships* referred to the social and romantic relationships that the participants had. The third sub-category was *Family responsibilities. Family responsibilities* referred to the on-going obligations that the participants had to their families. The fourth sub-category was *Employment. Employment* referred to the job responsibilities of the participants and how they gained income. *Finances/resources* was the fifth sub-category. *Finances/resources* referred to the amount and types of monetary support that the participants had. The sixth sub-category was *Suffering losses. Suffering losses* refers to the various detriments that the participants experienced. The seventh and last sub-category of dealing with life too was *Facing challenges. Facing challenges* refers to how the participants confronted stressors.

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Dealing with life too
Family dynamics
Dating & other intimate relationships
Family responsibilities
Employment
Finances/resources
Suffering losses
Facing challenges

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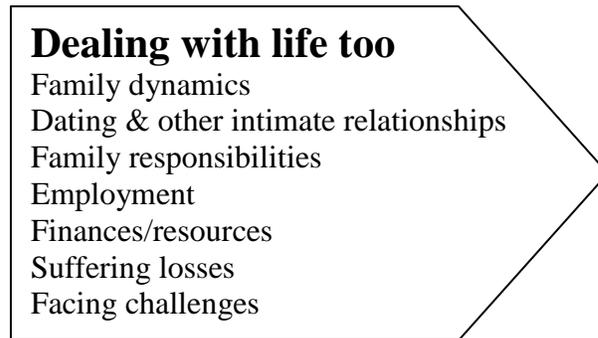
FIGURE 5: *Dealing with Life Too*

Family Dynamics

The first sub-category of *Dealing with Life Too* was *Family Dynamics*. *Family dynamics* referred to the relationships that the participants had with different members of their family. *Family dynamics* or the quality of the relationships the participants had with their family members played a role in their recovery. For the most part, all of the women except one had amicable family relationships.

Francis was a participant that had a dysfunctional relationship with her family and since her mother died, she was no longer able to act as a buffer in those relationships. Her family did not understand the toll that cancer took on her. Francis described her relationship with her father and sister in this way:

> ……….unfortunately some of the people that are in my life are not that strong. It's like I'm the person that holds my little bit of family….it's just me, my dad and my sister now that my mom is gone. It's like I'm the one that holds us pretty much together and they depend upon me for everything and if I can't do it, it's you know what's wrong with you? You know oh you, you're not cooperating. So I could see my sister you know holding it over my head like, you know when you were sick, I used to take you for your treatment….

Poor family dynamics can increase stress and decrease coping. In this study only one of the participants had a poor relationship with her family, in that they did not support her.

Dating & Other Intimate Relationships

The second sub-category of *dealing with life too* was *dating and other intimate relationships*. *Dating & other intimate relationships* referred to the social and romantic relationships that the participants had. *Dating and other intimate relationships* had the capacity to provide additional support and comfort if they were present. However, if those relationships were absent, forming new relationships and being intimate created concern for some women.

Angela believed that women of other races were more likely to have intimate partners:

> They're married. They have their sole support you know there and I'm separated long-time separation

She reflected that it would be better if she had an intimate partner:

> ……I don't have that extra support like if I had a nice husband, a good husband you know, that mate….to show some concern for me to let me know…..I told you it was going be alright or before I go its going to be okay.

Francis described how she felt not having a husband:

> It is very traumatic and it's scary [starts crying again] you know and especially when you don't have somebody like a husband or partner to go through, you know to go through

Francis also discussed dating and intimacy as did Engrid:

> ……. I'm not anticipating being with someone that I haven't been with before, but you know even if I thought about that, you know it's just like ohh what would that feel like? What would that be like? You know intellectually I know that I am not my body and that whoever wants me should want me for who I am, but it's still that emotional level that you know says will I be seen as damaged goods?......You know so that's a big, that's a big area of concern.….

Gina was married and discussed how the intimate relationship she had with her husband helped her:

….probably he was the most supportive he's ever been in my whole life.

Harriet described a dating situation that did not work out well:

> at the end part of my chemo, my very last. I got involved with a partner and he was really stressful and I could see mood changes then, so I got rid of him and said I got to do this for me. So I think if your partner or whoever is not supportive to you, you need to get rid of him you know cause that was stressful right there, that part dealing with somebody else who wasn't as supportive to you as you are to yourself.

For Irene breast cancer was not the only concern when it came to dating:

> …..I never married. I used to date quite a bit, but HIV-AIDS kind of put a curtailment on my dating as well. So even before the body configuration thing became an issue. Also the first time around I was a lot thinner than I am now. My body issues, [sighs] that little scar on one side is gone, is nothing compared to all of this hundred pounds of extra flesh that I'm carrying around………but it's surprising that when you talk to men some of them couldn't care less. I mean those are more internal things that we have then external okay.

Several of the participants discussed their experiences with *dating and other intimate relationships* and how those relationships affected them.

Family Responsibilities

The third sub-category of *dealing with life too* was *Family Responsibilities. Family Responsibilities* referred to the on-going obligations that the participants had to their families. The participants in this study had more to consider than just themselves. They belonged to family units. They were wives, mothers, daughters, and sisters too. Consequently being a part of a larger family unit brought responsibilities and concerns. Carlotta realized that what was happening to her was also happening to her family:

> ….I knew I couldn't handle it myself when you're sick or there's somebody that's ill in your family…….You're not the only one involved. I mean whole circle is involved in it and I didn't want them to see me in that state, so I tried to keep most of it hidden which I couldn't so that's why I sought help as fast as I could so I could get better and they wanted to put me on medication and stuff, but I refused I

says that with prayer and the inner strength that I had. I could combat it, but I needed some help and some guidance to get through but I didn't want medication.

Carlotta also had to deal with illnesses that her family members were experiencing as well, as did Francis:

maybe about six months after I went into remission, my mom got sick and we couldn't figure out what was wrong with her and she kept going back and forth to the hospital cause she had asthma and she had diabetes and she would go to the hospital and she would be in the hospital for like four or five days and they would get her well and then she'd come back home and then she would go back downhill……. I was like it doesn't make sense for you to go to the hospital and then come back and then you're sick again. So she did that and they did some thorough tests and they found out she had cancer and they think that it originated from breast cancer.

Engrid was a single mother of a school age child. She described the challenges she faced:

It's pretty tough because my son and I, his dad doesn't live doesn't live with us so it's just he and I and so it's trying to balance you know what to tell your child about what's going on with you and for him to understand you know why mommy can't do the things that she typically does for him. I remember him telling one of his friends who had come to spend the night my mommy's been a little cranky lately and so just being able to talk with him. My son's pretty bright, so initially his father's like we're just not going to tell him. I'm like no that doesn't work for me. We have to tell him the truth. You know so I talked with him every step of the way about you know what was going on, what the outcome is going to be……. so it's just, for me being able to balance my feelings of sadness and anxiety and depression in such a way that it doesn't negatively impact his emotional state.

Like Engrid, Harriet was also a mother, but she had the extra added burden of caring for a severely disabled child:

…..like I say my main focus was being here for my son cause he was like five at that time when I found out and he had a trach, a G-tube, a shunt, he didn't walk, he didn't talk. So I knew I had to live to take care of him………. like I said, he had a trach, so he needed suctioning and then he got fed through his stomach through a G-tube.

Engrid also spoke about how a lot of Black woman are caretakers:

……Black women are caretakers. We end up putting ourselves last, so when you're dealing with the Black woman particularly a woman who might be a single mom or the primary role caretaker for her family or taking care of her mom and her dad you know, what does that mean in terms of her treatment is she saying I can't do chemo because that means you know I can't take care of my family you know what are all the factors that weigh in and I know that's probably the same for other women, other nationalities but I think it's a extra burden for Black women because there are a lot of Black woman who don't have support….

Many of the participants had tremendous family responsibilities that they continued to meet even though they were all dealing with breast cancer too.

Employment

Employment was the fourth sub-category of *Dealing with Life Too*. *Employment* referred to the job responsibilities of the participants and how they gained income. Only three of the participants were currently employed. The toll of breast cancer took more than half of the woman out of the workforce. Carlotta ended up taking an early retirement because of her breast cancer. She stated:

I did have to take a disability retirement after the second time because I couldn't stay at work. I couldn't function. … I wasn't doing the job any good with the way I felt……

Engrid also stopped working, but for a different reason. She described why she stopped:

I stopped working immediately…..I work with a lot of depressed women…… I have a small private practice and I have a lot of depressed women that I work very well with, I'm an excellent therapist but I thought you know what, I could not sit up and listen to another depressed woman whine about their life when I'm dealing with breast cancer, because I'm gonna want to say you think your life sucks? Let me tell you about suck, so for the first time in my life as a professional. I sent everybody a letter saying effective immediately I am taking a medical leave…….so I've been off a year basically to take care of myself…..

Francis experienced periods of unemployment and it caused strife with her father who had to financially support her:

one thing after another I've experienced, and I just recently got laid off from the mortgage industry and it took me awhile to find a job and he was just like you know why have you been off of work for so long? You know you were off of work for this many years and you were off of work now for this many years, and I was like I was off of work because I had cancer….

Harriet had to stop working because she needed to be home to take care of her child:

you know I used to work, then when my son got sick I stopped working to take care of him then I got sick…

The employment status of several of the participants changed because of breast cancer, which is important to note because employment impacts financial, resource ability and insurance.

Finances/Resources

The fifth sub-category of *dealing with life too* was *Finances/Resources*. *Finances/Resources* referred to the amount and types of monetary support that the participants had. For some participants a lack of finances or resources increased stress and made them more vulnerable.

Angela felt that her resources were not adequate:

….yes if my resources were better and sometimes my environment and you know just being able to function the way I was it would help me a lot………You know, finance makes a lot of difference too, you know when you're going through some things….

Danielle worried about her finances as a single woman when she had to go on disability:

Financially I was worried yes, that I would be off with the disability

Francis had the most financial and resource related issues. She described her difficulty as:

I had to move back here with my parents because of financially I wasn't able to maintain myself, my by myself. So I moved back here and that was like devastating for me and then once I would start working and I was you know able to start saving again and getting things back on track financially with bills and

everything. Here comes another blow. I have cancer and I was just like why do I keep going through these situations.

She also reported that even now she continues to have resource related problems:

….I don't have insurance and I can't afford to pay the co-pay to go see the doctor you know…….So I feel that people that don't have insurance they don't get the same treatment as people that do have insurance I think that …..they're not even really willing to like talk to you…..

Some of the women in this study experienced a lack of finances or resources which increased their vulnerability.

Suffering Losses

Suffering Losses was the sixth sub-category of *dealing with life too*. *Suffering Losses* refers to the various detriments that the participants experienced. Several of the participants experienced impactful losses in addition to the challenge of breast cancer. These included the death of other family members.

Betty lost two sisters to breast cancer:

….when my first sister we was all devastated to find out that she had breast cancer and then after two years she passed away and then my sister that was six years older than me, she was diagnosed probably in 87 and she died in 92

Danielle, Irene and Francis also had family members that died. Francis described the loss of her mother:

….by the time they found it, it had spread throughout her entire body. It was in her brains, her bones, everywhere and they told her that she was gonna die from it and I think when they told her, she might of survived maybe two months and she just died. It just happened so quickly. It was like……..my mom is like sick and then she died and it was just like overwhelming….

Harriet's child also died:

he passed away March of last year. He lived for seven years.

When Carlotta had to stop working she felt like she lost the companionship of her

coworkers:

> I had to stop working……it was almost like you just lost a whole family at one
> time because a lot of people you see every single day more times than you see
> your own family and then all of a sudden they're just cut off….

Danielle who was a single woman suffered multiple losses:

> I noticed my dog couldn't go to the bathroom, so I took her to the vet and they
> said maybe it could be a kidney problem or something, but anyway on Friday
> when I went to go pick her up she died after 14 years. So I lost my pooh-pooh and
> I got diagnosed with breast cancer……The male doctor pretty much said well if
> you have it, you won't raise it so ….. I think I had my surgery, but then I had to
> have the abortion first, before I did the chemo…..

Both Irene and Engrid had friends die of cancer. Engrid stated:

> One of my, one of my good friends from junior high school died nine years ago
> from breast cancer and I've known a couple of people, but you know I lived in
> you know like most of us la-la land, that wouldn't happen to me you know, why
> would it happen to me and you know we had no family history and you know I
> don't smoke, drink occasionally

The participants in this study suffered a variety of losses that affected their ability to cope

with breast cancer. In addition to suffering losses, they also faced many challenges.

<p align="center">*Facing Challenges*</p>

Facing challenges was the seventh sub-category of *dealing with life too*. *Facing*

challenges refers to how the participants confronted stressors. The women in this study

encountered multiple stressors that challenged their ability to cope with breast cancer.

Although the stressors they faced were all different they were each afflicted in their own

way.

Angela was incredibly burdened by not having the proper clothes that allowed easy

access to her picc line:

> Yes, I do get depressed sometime….it's not a cheerful thing at all and then I find myself not being able to wear so many of my clothes especially see its winter and then I have to wear, when I go for chemo or to get the picc line flushed short sleeves and I wasn't prepared for all this because I have sweaters for the winter, long sleeves…..so that too has kind of been a problem for me yes that has been somewhat of a hardship, like a little crisis hardship on me

Danielle described when she finally came to terms with having to terminate her

pregnancy and the procedure didn't work:

> because of the fact that I was pregnant and then I had one attempt at having an abortion, but they had to like dilate me or something, and….my cervix or something was closed and it wouldn't open up, so I went this one particular day ready to do this and I couldn't do it. I had to go back, so that was kind of a downer…..

For Engrid being incapacitated was an incredible stressor:

> ….just being so incapacitated brought on a lot of you know feelings of sadness and helplessness and for me, because I'm so self-sufficient and so independent and I had to start depending on people, and so it brought up a lot of like I said, feelings of sadness and helplessness, because I couldn't……really do anything for myself so like eating and fixing food and taking care of my son….

Francis had a long history of medical problems and negative experiences with health care

providers, so just going to the doctor was a stressor for her:

> You know I had a lot of medical problems prior, you know I have diabetes and I was extremely overweight and going to the doctor was always a negative thing for me, you know whenever I go to the doctor ohh you're too fat. You need to go on a diet. Your diabetes is out of control, so I just did not like going to the doctor and I didn't want to go to the doctor to have them tell me something else was wrong with me you know so I was I was really hesitant about going to the doctor and I think that's one of the reasons why I procrastinated

Harriet had the stressor of caring for her severely disabled child:

> the only challenge I had was, which really wasn't a challenge like I say trying to still take care of my disabled son at the same time, knowing what I'm going through, but like I said my mom and my sister and my dad we all worked through this together.

More than half of the participants faced challenges in addition to their breast cancer. Facing these challenges often created additional stress for these women and influenced their ability to cope.

<div align="center">Summary of Phase Four - Dealing with Life Too</div>

The fourth phase of *Transcending the Now* was *Dealing with Life Too.* This related to how the participants navigated through life situations that they were faced with while going through breast cancer at the same time. *Dealing with Life Too* had seven sub-categories: *Family dynamics, Dating & other intimate relationships, Family responsibilities, Employment, Finances/resources, Suffering losses, and Facing challenges.* The next section will explain *Enduring breast cancer*, the fifth phase of *Transcending the Now*.

<div align="center">Phase Five - Enduring Breast Cancer</div>

Enduring Breast Cancer was the fifth and final phase of *Transcending the Now.* *Enduring Breast Cancer* related to a range of issues that the participants encountered as a consequence of having had breast cancer. *Enduring breast cancer* had six subcategories: *Body image, Worrying, Taking care of your health, Dealing with residual effects, Setting boundaries, and Experiencing healthcare* (Figure 6). The first sub-category of *Enduring Breast Cancer* was *Body image*. *Body image* related to how participants perceived their bodies after having breast cancer. *Worrying* was the second sub-category of the fifth phase. *Worrying* referred to the persistent troubling concerns that each participant dealt with. The third category of enduring breast cancer was *Taking care of your health.* *Taking care of your health* referred to the actions that the participants took to be

responsible for their own well-being. *Dealing with residual side effects* was the fourth

sub-category. *Dealing with residual side effects* related to how the participants managed

the remaining after effects of having breast cancer. The fifth sub-category was *Setting*

boundaries. *Setting boundaries* related to how the participants set limits to protect and

shield themselves. The last sub-category of *Enduring Breast Cancer* was *Experiencing*

health care. Experiencing health care related to the encounters and experiences the

participants had with the health care system.

Enduring breast cancer
Body image
Worrying
Taking care of your health
Dealing with the residual effects
Setting boundaries
Experiencing healthcare.
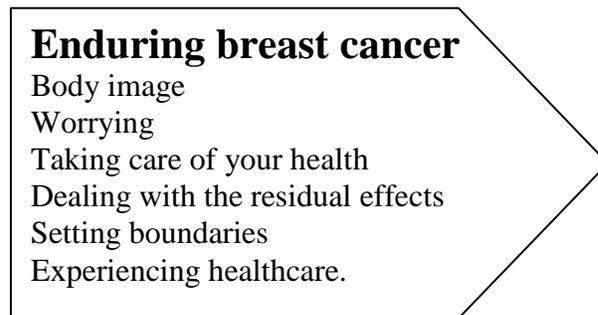
FIGURE 6: *Enduring Breast Cancer*

Body Image

The first sub-category of *enduring breast cancer* was *body image*. *Body image*

related to how participants perceived their bodies after having breast cancer. Every single

participant's appearance in this study was altered by breast cancer. They lost their hair,

some lost breasts, they ended up with scars and they saw their hands take on a necrotic

appearance. Some of the women dealt with the physical changes better than others.

Angela lost her hair and her nails turned black. She described:

> the chemo took all my hair left me completely bald [takes off scarf and shows me
> her head] and my fingernails are turning……It's really no joke what it's doing. No
> it's no joke, but I just don't bother to polish them. I just leave them so that they
> can breathe…..so I can notice the color. It's really bad

Francis described how she felt when she lost her hair:

> …..I think the one, the really most humiliating thing was when I had to go buy a wig [laughs] I still had like a little bit of hair here and there, and I just went ahead and I just pulled it all out…...I was like I'm gonna go buy a wig because I didn't like the scarf look, so I went and I bought a wig and I just looked so weird with the wig on, and it took a long time for me to get accustomed to looking at myself with the wig on and then the fact that I didn't have eyebrows, and I didn't have eyelashes.……

Harriet tried to make the best of going bald, but still was saddened:

> when I went bald, first I tried wearing scarves and they kept turning and twisting and then I tried hats, then I was having the hot flashes…..I went and paid $45 dollars for a wig wore it one time, with the hot flashes you get hot so I said you know what? I don't care what nobody think and I went bald.……and then I had my granddaughter and she looked and then she said Tucci all your hair came off and then I kind of got sad then

Betty's perception of her body did not change after she lost her breasts. She stated:

> I'm not a person vain, so it didn't bother me I mean I guess it would bother some people but I'm mean I have my prosthesis….I'm not vain so it didn't bother me….so you don't have them you can live without them so that was my thing

Engrid reported feeling lopsided after she lost a breast:

> Ohh Lord that was difficult. That was very difficult and even now, the scar is great. I was really surprised about it, but I feel lopsided so sometimes I feel like I should of had them both removed, because at least I would feel even.

Irene actually gained weight:

> it wasn't the second time, it was the first time I was having radiation. I'm in there and they're a couple of other patients and each time, day we came in they'd weigh us and there's this little old lady. Ohh I've lost another pound. [laughs] I was gaining two to 3 pounds a week and then when I went through it the second time. They said oh but you don't look sick at all. I said honey it's hard to look weak and emaciated when you're up over 220 pounds [laughs]. Of course I don't look sick I'm fat. If I dropped a few pounds I'd only look better [laughs].

Many of the participants struggled with body image changes. The physical changes that

they experienced altered how they saw themselves.

Worrying

Worrying was the second sub-category of *Enduring Breast Cancer. Worrying*

referred to the persistent troubling concerns that each participant dealt with. Despite the

incredible resolve that each participant possessed worry still managed to creep into the

lives of each woman at some point in time.

Angela *worried* about practical matters:

> …..there were times I've had to wonder whether my ride was going to be here on time or not. I have a car downstairs but I'm disabled to drive so I was wondering, wondering, wondering. I have to call. Are you coming? Where are you? Very stressful….You know it create a headache for me so I don't need that but I have to make do with what I have for right now

Betty *worried* about being given the ominous diagnosis of cancer as did Francis:

> just being scared you know to think that you have cancer, for somebody to tell you that you have cancer, it's just a very scary thing you know so I mean I know I was very lucky and most people don't have the same results that I have because the doctor told me that my stage of cancer was pretty severe and if it had of went untreated you know it probably would of wound up spreading throughout my entire body

Angela *worried* about not knowing as did Engrid:

> even though I'm done with chemo. I did the surgery. I finished the radiation. It's the fear, the uncertainty you know all those feelings that for me that I can't keep stuffing. I'm a stuffer. I'm like just suck it up you know suck it up, suck it up and move on, but at some point you can't keep doing that……..so I have to for me, help myself to work through it, say it's okay to feel those feelings you know helplessness, sadness, you know not sleeping at night, fear, anxiety, all those feelings that come up.

Carlotta, Gina and Francis all *worried* about having to go through the experience again.

Francis stated:

> I just still like have flashbacks of the symptoms from the chemotherapy. I don't know if they told me you know tomorrow. You have cancer again you need to have chemotherapy and go through the whole process again. I don't even know what I would do because it is just such a hard thing to go through. It is very hard……sometimes you know, I'll just think about it. Just like when I was talking to you. It just brought tears to my eyes that just to think how scared I was……

For the most part Irene spent her time strategizing so she didn't have to worry:

> if I have a problem I come up with an action plan, actually it's just a plan, then I start working on it and I'm okay. I'm not going to fret about it, if something goes and I have to change my plan then I change it.

However, surprisingly she did *worry* about having to accept help:

> ….I never worried about not having support I worried about having to accept support, although I tell you one thing no matter where I am along this illness curve. You can always call and pray for me.

All of the participants in this study experienced worrying at some point and like some of the other sub-categories of enduring breast cancer; such as body image, dealing with the residual effects of cancer and experiencing health care it affected their ability to cope.

Taking Care of Your Health

Taking care of your health was the third sub-category of *Enduring Breast Cancer*. *Taking care of your health* referred to the actions that the participants took to be responsible for their own well-being. The diagnosis breast cancer changed the way that some of the participants managed their health and for others it didn't. Betty took care of her health by completely subscribing to the health care directives that she was given:

> …..like when they told me when I was going through chemo you have to feed chemo……you have to eat right, you have to drink your liquids, you have to do all that. There were times when I didn't want to eat going through chemo, but I knew that I had to survive. So whether I wanted to eat it even when it tastes like I was eating spoons, I said I got to eat this food, because they kept saying you got to feed chemo, ……I forced myself to eat, I forced myself to drink, I forced myself because I knew I had to….

Gina began following a complete naturopathic course. She reported:

> two years before I was diagnosed, a friend gave me this book called *God Amazing Diet* and that's when I decided, I was already vegetarian but to become a stricter vegetarian. And I started drinking wheatgrass twice a day and of course it's no scientific background to say wheatgrass kill cancer, but in the nutritional world, it says wheatgrass kill cancer… ….also I started running marathons and they say oxygen kill cancer and my doctor says what was so surprising was the tumor was the size of an egg that it was nothing wrong with none of my lymph nodes and when you study nutritional stuff from the osteopathic natural doctors. They say that oxygen kill cancer in the lymph nodes……

For Francis nothing changed she still did not do breast self exams, even breast cancer did not alter the way that she managed her health:

> …. I always have like lumpy breast tissue, so I never could tell whether or not it was a lump or no. So I never really regularly did them you know I would go for thorough check-ups. My doctors would do them and I don't know how it just crept up on me that I had the lump, and I just happened to brush up against my breast cause I didn't do them on a regular basis and even though I've had breast cancer. I still don't do them on a regular basis.

Taking care of your health can prevent additional health problems. Some of the participants in this study took better care of their health as a result of experiencing breast cancer, but not all.

Dealing with the Residual Effects

The fourth sub-category of *Enduring Breast Cancer* was *Dealing with the Residual Effects*. *Dealing with Residual Effects* related to how the participants managed the remaining after effects of having breast cancer. Breast cancer took an exacting toll on so many of the participants. The after effects of breast cancer were visible to the participants in a variety of ways from depression to loss of function to obvious scarring. Angela reported depression:

….I do get depressed sometime and it's not a cheerful thing at all…..

Danielle also suffered depressive symptoms residually:

> I think I was depressed about not being able to have kids and not having any kids and then knowing that I will never be able to have kids, that was the most, I guess hard thing

Irene became depressed and started taking an anti-depressant as well:

> ……...I went all through the chemotherapy, but with the radiation at one point it was like I hit a wall. I just was exhausted. They didn't describe it as depression, but I was just exhausted and then to flow on from that I had the realization yeah I'm depressed ……a psychologist referred me to a psychiatrist and I'm still seeing the both of them and I'm on an anti-depressant and as I'm beginning to reconnect. I realize I've been depressed for quite awhile. Yeah so it could be the cancer. It could be, it could be just a combination of things……..

Carlotta had a loss of function residually and Gina reported a loss of sensation. She

stated:

> ….only residual I have is that, I have some numbness from when they took the lymph nodes. Some numbness under my armpit, but other than that the doctor told me never to lift weights and I have never stopped.

Carlotta also had residual pain:

> you know the burning is a lot of the problem and the pain and stuff that I'm having now and they said it was caused by radiation and that was part of the reason I couldn't get the
> implants either because the reconstruction because of the radiation the scarring and everything that's in there.

Irene also had residual left lower lobe infiltrates that resembled tuberculosis:

> …I came up with this x-ray that shows infiltrates in my left lower lobe and it turns out that it's from the radiation therapy. I wasn't upset, just another pain in the butt. So now I carry my x-rays [laughs] around with me, well I had to start doing that anyway. Because I have too many doctors and so you know I just tell them. I have left lower lobe infiltrates, so and it's probably from the radiation and Dr. XXXX said she thinks it's probably from the radiation. Okay but I don't have TB……

All of the participants experienced some residual effects from breast cancer, such as body image changes or depressive symptoms. These after-effects were new challenges that they had to learn how to manage.

Setting Boundaries

Setting boundaries was the fifth sub-category of *Enduring Breast Cancer*. *Setting boundaries* related to how the participants set limits to protect and shield themselves. The traumatic experience of breast cancer caused the women to limit contact with outside influences.

Angela confined herself to home:

> I don't have the stamina to get up or the desire to get up and go out right now…. I'm more or less home. I wouldn't say confined, but I am confining myself to home quite a bit I just don't care to get up and go out and hear too much right now

Francis also *set boundaries* by isolating herself:

> ……… basically when I first found out that I had breast cancer I was scared and very depressed and more than being scared, I was embarrassed for anybody to know. I didn't tell most people except for my immediate family, so like my friends and neighbors they didn't know until I was like pretty much in remission that I had breast cancer, and I think they only kind of knew because they saw some of the symptoms you know that I had lost my hair and like the purple nails and toenails and stuff like that…..so it was more for me just being embarrassed and…I just didn't want anybody to know…

Betty *set boundaries* by limiting negative influences:

> I just couldn't deal with the support group that was going through the negative that they just knew they were that some of them just they were they were out of here and I'm thinking oh no I don't want that…..I don't want to hear that.

Like Betty, Francis tried not to listen to others' experiences with cancer:

> ……..when I would go for the chemotherapy some people would like be in little groups where they could chitchat. I wanted to be far away. I didn't want to see other people going through chemotherapy. I didn't want to hear their stories. I just

wanted to get my treatment and I wanted to leave……it was just too much you know. I was feeling a little sorry for myself and probably a little depressed and I just I didn't want to hear what other people were going through, or I didn't want to see them taking their chemotherapy or oh you know I don't feel so good, I didn't want to hear that I just wanted to get my treatment and get out of there.

Engrid *set boundaries* by only giving the information about her health that she wanted to disclose:

…….by sending out those weekly e-mails I reduced the anxiety of other folks….. cause they didn't have to call me, because I sent out the weekly e-mails giving blow-by-blow updates but I just sent it to the people I know and I would tell them everything…..you know just for lack of a better word I kept it real. I didn't you know say oh this is a cup of tea, it's like I had a rough day

Irene just simplified her life. She stated:

People go through stuff that I couldn't deal with and that maybe a part where I have for the most part simplified my life because I really don't like to deal with a whole lot of stuff or if I am going to deal with something I want it if at all possible to be something of my choosing.

The majority of the participants set boundaries to protect themselves from external influences by mostly limiting contact with others, so that they could cope with what was happening to them.

Experiencing Healthcare

The sixth sub-category of *Enduring Breast Cancer* was *Experiencing health care*. *Experiencing health care* related to the encounters and experiences the participants had with the health care system. The participants had a myriad of experiences with the health care system. However, interestingly the majority were not offered mental health services or even asked about the state of their mental health. Some of the participants had poor experiences that only served to increase their stress level while others had great experiences that helped them along their trajectory.

Angela had a difficult experience with the health care system. She reported:

> …….I was like In and Out Burger. In for surgery, they prep me, surgery. I had to stay in the hospital overnight because I had little problem, you know I guess they said it's you know an outpatient procedure, but I had a little problem…..with my blood, kind of overflowing. So they kept me overnight and I went home I came home the next day, but no they weren't so kind honey, they were ready to throw me out of that hospital. You got to go. You have to go, not that I wanted to stay, because the hospital is not my best friend.….

Carlotta also had a difficult health care experience. She recalled:

> Well the hospital to me is the worst place in the world for sick people [laughs]…..it isn't conducive to healing…. the patients don't get the care that they need to have… the nurses they really don't come, when you really need them…..I've only been in for those two times more or less, but I checked myself out because I was too upset to stay there in the hospital when I found out I had the wrong surgery….

Angela also believed that she did not receive enough information regarding her health care. She stated:

> ……..Right today I don't know if I'm stage one, two, or three…. No I do not know. All I know is he said, he told my family that that he got the cancer and when I visited with him in the office he didn't tell me what stage I was in, if so I truly don't remember…..No, I really don't, so I don't believe I was told

Betty, Danielle, Engrid and Irene did not receive information about mental health. Irene stated:

> ………I don't think people look at Black people and think about mental-health.

Engrid also felt she was not considered as a person. She stated:

> I'm tired of seeing doctors who don't know me…..not that they don't know what they're doing, but they don't know what they're doing with me and so they're practicing medicine as they see fit, but they don't practice medicine on a personal basis, so instead of making decisions about my care, based on the four days that you've seen me. For me it was like why don't you find out from me you know what I think about what's going on.

Irene felt that she had to really work to make sure her insurance give her everything she needed:

> I am the patient from hell okay. I believe I have an HMO. I also have a PPO and out of network, but that HMO you have to work that HMO like it was your job. I want to go see a specialist. I call my HMO and tell them that I want to do this and ask them now what do I have to get to you in order for you to authorize this……and to some extent they're so pissed and annoyed at me it was like just go on and do it rather than having to spend a lot of time on the telephone with me, but you have to work and then it's real important for you to have a clinician that you like, that you respect and that you trust because without that, medicine isn't too much of a science.

Francis, Gina and Harriet all had good experiences with the health care system Gina stated:

> ……my doctor never gave you the impression that he was rushing. He would lean up against the wall and say how are you today and he gave you the impression, take your time and even though I didn't want to really use all his time, he gave you the impression…..whatever you need take your time. God sent him to me……..He just gave you the impression that I'm here for you.

All of the participants described some experience with the health care system, the majority of which were negative.

<center>Summary of Phase Five - *Enduring Breast Cancer*</center>

The fifth phase of *Transcending the Now* was *Enduring Breast Cancer* which related to the various issues that the participants encountered as a consequence of breast cancer. *Enduring breast cancer* had six sub-categories *body image, worrying, taking care of your health, dealing with the residual effects, setting boundaries,* and *experiencing healthcare.*

Summary

This chapter presented the findings from the data analysis of this research study. The chapter began with a brief portrait of each of the participants. Following the participant portraits an explanation and description of the basic social psychological process of *Transcending the Now* was provided. The grounded theory *Transcending the Now: African American Women with Breast Cancer and Depressive Symptoms* was explained. The phases of *Relying on Faith, Being Strong, Seeking Support, Dealing with Life Too, and Enduring Breast Cancer* were also explained and illustrated with data bits from the interviews with participants.

CHAPTER FIVE: DISCUSSION AND RECOMMENDATIONS

This final chapter will provide an interpretation of the results of this study and the integration of the findings with the literature. In addition, the theoretical perspective, implications for nursing theory, research and practice will also be discussed. Lastly, this chapter will conclude with a discussion of the limitations in this study and a summary.

Integrating the Literature

The basic social psychological process that emerged from the data analysis was *Transcending the Now* (Figure 4.1). *Transcending the now* was the process that African American women used to conquer the basic social problem of having breast cancer and experiencing depressive symptoms. This process was used by each of the nine participants in this study in some form or capacity to triumph over whatever trials they were faced with, including breast cancer and depressive symptoms. This section will compare the results from this study with the literature review that was presented in Chapter two.

Vulnerability

The study results are consistent with the vulnerability literature regarding the at risk nature of vulnerable persons (Aday, 2001). Several of the participants in this study reported poor psychological health. Shi and Stevens (2005) have also suggested that vulnerability results in unmet health needs. This study supports that finding as well. The majority of the African American woman participants would have tremendously benefited from psychological services if they would have received them. Many of the women experienced stress, fear, social isolation, and feelings of helplessness. These

findings were consistent with the explanation given by Rodgers (1997) of the effects of vulnerability on health. Gender and race have been shown to be factors in vulnerability and even health disparities (Rodgers, 1997). My study results also echo these findings. The participants in this study were African American women with unmet health needs.

Depression

For those with breast cancer, the rates for depression symptoms are the third highest of any cancer diagnostic group (Golden-Kreutz and Anderson, 2004). Brown et al. (2003) identified life stress, physical health problems, environmental stress, and economic status as significant predictors of depressive symptoms in African American women. This finding was consistent with the results of this study. The participants that experienced stressful life situations, chronic health challenges, unemployment and financial resource issues reported experiencing depressive symptoms. Brown et al. (2000) found that women's vulnerability to depression is exacerbated by economic strain. This finding corresponds with the study results of this research. The participants that lacked financial resources reported experiencing depressive symptoms as well.

Larson et al. (2006) and Plant and Sachs-Ericsson (2004) reported other factors associated with depression and depressive symptoms include family stress, lack of social support, and place of residence. This finding was partially consistent with the study results, in that participants with family stress and low or absent social support experienced depressive symptoms. However, place of residence was not reported as a contributing factor.

Additionally, Jones et al. (2003) found that in African American women family stress predicted higher levels of depressive symptoms. This finding parallels the results of this study. Cutrona et al. (2000) found that low levels of social support leave people vulnerable to distress and depression in the wake of negative life events and chronic strains. Likewise this finding was evident in the study results also. The participants without adequate levels of social support experienced more distress. Schrimshaw (2003) found that unsupportive social interactions from friends, family and a lover/spouse were each positively associated with higher depressive symptoms. This finding was as well congruent with the results of this study particularly in regards to intimate partner relationships.

Reed et al. (1996) found that depressive symptoms were reflected as fearfulness, anxiety, depressed mood, social withdrawal, and low energy level. These findings were consistent with the findings of this study. On the other hand, Carrington (2006) reported that depression was expressed through hopelessness and suicide and Fiscella and Franks (1997) attributed psychological distress to hopeless affect, hopeless outlook, depression and life dissatisfaction. However, in this study none of the African American women participants reported thoughts of suicide, life dissatisfaction or hopelessness, which may be due to their strong religious beliefs and level of support that they experienced. These results support Kaslow et al. (2004) who found that spirituality, religiosity and adaptive strategies such as seeking social support had a protective role against suicide.

Consistent with the results of my study, several researchers found that cancer patients as a group are particularly vulnerable to psychological symptoms, depression and

anxiety (Friedman et al, 2006; Golant et al, 2003; Golden-Kreutz and Andersen, 2004; Jones, 2001; Massie, 2004). The African American women with breast cancer in this study were definitely vulnerable to psychological symptoms. In fact, many of the participants actually experienced a variety of psychological symptoms such as anxiety, worry, and depressive symptoms.

Depression Treatment

Depression and depressive symptoms are common post treatment symptoms among women who have undergone treatment for breast cancer (Eversley et al, 2005). The majority of the African American women breast cancer patients in this study were not offered mental health services nor were they asked about their mental health needs. This finding is consistent with previous research. As several authors have reported in the literature that African Americans are particularly vulnerable to the undertreatment of depression and less likely to receive guideline concordant care (Bazargan et al, 2005; Brown et al, 2003; Cooper et al, 2003; Das et al, 2006; Harman et al, 2004; Jackson, 2006; Leo et al, 1998; Miranda and Cooper, 2004; Wells et al, 2004). Yet, African Americans respond as well to guideline based treatments for depression as Caucasians (Brown et al, 1999; Rollman et al, 2002).

Breast Cancer, Depression & Depressive Symptoms

This study's results concur with previous depression and breast cancer research regarding the increased incidence of depression and depressive symptoms among women with breast cancer (Burgess et al, 2005; Dausch et al, 2004; Golden-Kreutz and Anderson, 2004). The majority of African American women in this study reported

experiencing depressive symptoms at some time throughout their experience with breast cancer.

However, my study results contradicted the literature regarding the association of psychological distress in cancer patients to be primarily among women of low income, younger age, little or no church attendance and few social supports (Carlson et al, 2004; Fertig, 1997). The African American women participants in this study were primarily middle to late age women, primarily of middle income, with strong religious institutional support, and large social support networks.

Additionally, the results of this study were synonymous with Shelby (2006) in regards to African American breast cancer patients' concerns and problems. The participants in this study faced unemployment, financial and resources issues, other health challenges, caretaking responsibilities and worry about breast cancer reoccurrences. Yet, the study results differed with the literature in regards to social functioning (Friedman et al, 2006) The participants in this study were caretakers themselves and therefore were apt to resume their previous duties as soon as possible.

Health Outcome Influences

Consistencies with the literature regarding the increased health burden of minority persons with concomitant depressive symptoms and chronic disease (Bazargan et al, 2005) were also evident in my study results. The participants in this study who experienced depressive symptoms along with their chronic health conditions did worse than the other participants who did not.

Transcending the Now

The BSP that emerged from this study describes a number of phases that women process through as they deal with breast cancer and depressive symptoms. The five phases of the basic social psychological (BSP) process *Transcending the Now* that emerged during data analysis were *Relying on Faith, Being Strong, Seeking Support, Dealing with Life Too,* and *Enduring Breast Cancer*. The next section will link the specific phases of the BSP *Transcending the Now* to the literature.

Spirituality and Faith

The reliance on religion and spirituality was pervasive in the lives of the women in this study. The belief and faith in God among African Americans has been previously reported in the literature (Ashing-Giwa et al, 2004; Gibson and Hendricks, 2006; Leak et al, 2008; Lewis et al, 2007). This study found that African American women with breast cancer and depressive symptoms particularly relied on faith to transcend their current circumstances. The participants both practiced their faith in a variety of ways and rested on the promises of their faith. Historical and theological literature supports the existence of a personal relationship with God among African Americans that dates back to slavery. In fact, the belief that God is a deliverer of oppression and sickness continues today among African Americans (Ashing-Giwa et al, 2004; Banks-Wallace and Parks, 2004; Hamilton, 2007; Holt et al, 2003). Thus, the strong religious convictions of the participants in this study are not surprising. Previous research has documented similar findings. Taylor (2001) suggested African Americans have been found to benefit more from religious coping strategies. Henderson et al. (2003) and Simon et al. (2007) found

that in African American women, prayer combined with spiritual beliefs played a major role in assisting women to cope with every phase of breast cancer. Fogel et al. (2003), Gibson and Hendricks (2006), Lackey et al. (2001), Morgan et al. (2006) and Simon et al. (2007) found that African American women with breast cancer are more likely to use religion to help them cope with breast cancer. All of the women in this study expressed a religious faith.

Additionally, all of the African American women in this study engaged in some type of religious practice such as praying, reading the bible, and attending church as coping strategies. These findings are similar to other studies. Meraviglia (2006) found that prayer was positively related to psychological well-being in breast cancer survivors. Banks-Wallace and Parks (2004) and Gibson and Hendricks (2006) found that talking to God on a personal level is an important way African American women cope with distress. Im et al. (2008) also reported that African American women cancer patients received emotional comfort and managed fear by praying and reading the bible. Polzer-Casarez et al. (2008) found the same in African American women with other catastrophic illnesses. Lawson and Thomas (2007) also found African Americans received comfort from reading the bible and talking to God. Spirituality and religious expression appears to have mitigated the way in which the women in this study viewed the circumstances in which they found themselves. This is also a previous finding in the literature. In fact, Leak et al. (2008) found a positive relationship between spirituality and quality of life in African American breast cancer survivors.

Seeking Support

Five types of support were identified as being important among African American women with breast cancer. Family and social support were acknowledged as important sources of support in this study. Informal supports such as peer support and support from family and friends help navigate the emotional course of breast cancer (Barg and Gulatte, 2001).

The African American women participants in this study most often sought informal sources of support, such as support from friends, family and their religious community. This study result was consistent with the literature. Knobf (2007) reported that family members are viewed as a major source of support among cancer patients. Henderson et al. (2003) found that in African American women social support tended to consist of family members, friends and support groups specifically designed for African American women. Knobf (2007) also identified social support as an important factor influencing coping with breast cancer, and the tendency of Black woman to use informal sources of support. Ashing-Giwa et al. (2004) reported on the importance of support from immediate and extended family to emotional well-being and treatment adherence among ethnic minority women. Particularly African Americans reported that close family friends were important in offering comfort.

Likewise, the majority of African American women in this study described supportive relationships with their friends, extended and immediate family, coworkers and even strangers. Additionally, the support that these women received encouraged them to in turn be supportive to others. This finding is consistent with the findings of

Hamiliton and Sandelowski (2003) who found that African Americans with cancer often participate in reciprocal supportive relationships.

Religious community support was also a persistent form of support among the participants in this study. Hamilton and Sandelowski (2004) found that African American women were more likely to receive religious support in the form of offers of prayers from others and the assistance to continue religious practices. Similarly, Gibson and Hendricks (2006) reported caring from others, or care receiving involved support provided by church members. Many of the participants in this study received support from their church members in the form of fellowship, physical assistance and overall encouragement. Banks-Wallace and Parks (2004) found spiritual based relationships with other African American women were particularly valued as an integral source of support and guidance. Furthermore, Ashing-Giwa et al. (2004) reported that the church family is often a part of African American breast cancer survivors fictive kin support network.

Additionally, the women also obtained support from informational sources. According to Barg and Gullatte (2001) patients cope best by seeking information and educating themselves about disease and treatment. Hamilton and Sandelowski (2004) reported similar findings that African Americans actively sought information about what to expect when diagnosed with cancer primarily from their relatives or friends who had personal experiences with cancer. Accordingly, the women in this study sought information about cancer from individuals who had personal experience with the disease.

Further, the internet was a common information source. In fact, the internet has facilitated information seeking as a coping strategy by making available state of the art

information about most types of cancer (Barg and Gullatte, 2001). Fogel et al. (2003) found that minority individuals find that internet use for breast health issues offers them a sense of perceiving that someone is there to talk with about their breast health issues. Moreover, minorities perceive that the internet offers them tangible benefits of possible concrete advice or directives relating to breast cancer (Fogel et al, 2003). Morgan et al. (2005) also found that African American couples used the internet as a resource when dealing with breast cancer. Many of the participants in this study used the internet to research information about breast cancer and treatment options. However, the participants also described the use of mainstream media sources, written material and videos.

Professional sources of support were also reported by the women in this study. Support from health care providers has the ability to decrease depressive symptoms. Knobf (2007) reported lack of or limited communication with health care providers about physical and psychological symptom distress can result in adverse psychological morbidity. Morgan et al. (2005) found that a supportive health care provider can have an effect on the coping of African Americans. Wilmoth and Sanders (2001) described support from health care providers as a positive form of support. The majority of participants described supportive relationships with their health care providers. However, Ashing-Giwa et al. (2004) found that the majority of African American breast cancer survivors did not express receiving significant support for recovery from their doctors. In this study, all but two of the participants described receiving support from their medical provider. This finding is different from the literature.

Being Strong

African American women demonstrate a history and legacy of physical, emotional, and psychological strength that has enabled them to survive in less than optimal conditions (Shambley-Ebron and Boyle, 2006). Thus not surprisingly, the women in this study exemplified being strong in the face of adversity. The strategies used by the participants included being positive, being resilient, turning inward, and accepting it. The participants in this study strived to remain positive by not thinking negatively, not allowing themselves to have fear and by keeping busy. These findings were similar to the findings of other studies. For example, Henderson et al. (2003) found that in African American women having a positive attitude, avoiding negative people and having a will to live assisted in coping with breast cancer. Furthermore, Ashing-Giwa et al. (2004) found that women with breast cancer cope with psychological problems by engaging in activities for distraction.

Strong determination, trust in God and inner strength were consistent findings among the women in this study. These findings are consistent with several other studies. Gibson (2003) reported higher levels of hope in African American breast cancer survivors. Simon et al. (2007) found that a positive and hopeful attitude increased coping among African American breast cancer patients. Ashing-Giwa et al. (2004) found that among African American women having an overall attitude of survival and determination was important. Im et al. (2008) found that culturally African American women were educated and encouraged to be strong and to survive. African American women also identified God as a source of strength in their lives (Banks-Wallace and Parks, 2004).

Furthermore, several of the women reported their experiences as just another bump in the road, another hurdle to clear or as just one more thing to deal with in their lives. This finding has been explained in other studies about African American women. Shambley-Ebron and Boyle (2006) reported that because of their cultural history and indwelling strength African American women often view their circumstances as just another hurdle to rise above. This study also revealed that turning inward by focusing and distancing themselves these participants were able to transcend their experience. In addition, the majority of the women also described their acceptance of breast as not being difficult to embrace.

Dealing with Life Too

Several of the women in this study encountered seemingly insurmountable challenges in addition to their breast cancer that most certainly impacted their experience, which were namely the life situations that they faced. According to the literature, concerns and problems noted among African American breast cancer patients include physical problems, financial problems, concerns related to mortality and reoccurrence of breast cancer, social support, worry about others, reactions of others to their breast cancer, and work related concerns (Shelby et al, 2006) inability to attend to one's own health, unfamiliarity with breast cancer and racism in the health care system (Ashing-Giwa et al, 2004). Several of these concerns were reported by the participants in this study.

The majority of the participants in this study were also caregivers in their families. As such, their care-giving responsibilities often created stress among these

women. Some of the participants discussed distress about their family worrying about them, maintaining normalcy for their family, and being able to meet their responsibilities. These findings have also previously been reported. Yates (1999) reported that living with a family member who has cancer is an especially difficult coping challenge, and such strains have a significant impact on the day-today lives of family members. Ashing-Giwa et al. (2004) reported African American women also had concerns about illness affecting their roles as caregivers and the impact on their families. Bourjolly et al. (1999) found that African American women with breast cancer had lower levels of social functioning in regards to resuming household activities. This finding was inconsistent with the results of this study. However, this may be due to sampling differences related SES, age, and type of treatment received by the women. Im et al. (2008) found that African American women often gave priority to family members needs over their own. Additionally, Mellon et al. (2006) found that family stressors were a significant contributor to breast cancer survivor's quality of life. Moreover on-going concerns and problems facing the individual and family are important determinants of adjustment and quality of life.

Inadequate finances or other resources in addition to employment status can potentially impact persons with serious illnesses. In fact this has been found in other studies. Ashing-Giwa et al. (2004) reported that financial status was an important determinant in the quality of care received among all ethnic groups. However only three of the participants in this study expressed concerns about their finances and only one of them was unable to financially support herself. In fact, all of the participants had full insurance at the time of their diagnosis and treatment.

Significant other relationships can also be challenging and have the potential to cause great deals of stress. Ashing-Giwa et al. (2004) found that African American women had challenges in dating relationships and even fears regarding disclosure of breast cancer to potential partners. These findings are similar to the results of this study, the participants discussed the difficulty they felt in disclosing their breast cancer, allowing intimate partners to see their bodies and desiring an intimate partner but not having one. Lastly this study also revealed that many of the participants experienced impactful losses and other hardships in addition to breast cancer that certainly had bearing on their development of depressive symptoms. The losses that were described by the study participants were deaths of significant family members, friends, children and pets, and the forced termination of a pregnancy. Other challenging hardships included chronic health problems, being newly divorced, not having necessities, single parenthood, and parental responsibilities for young children.

Enduring Breast Cancer

Participants in this study reported body altering changes and expressed concern over those changes. The concerns expressed by the participants in this study are similar to previous reports. Wilmoth and Sanders (2001) reported that concerns about body appearance in African American breast cancer patients included hair loss and body scars. Lackey et al. (2001) also reported hair loss as a major concern in African American breast cancer patients in addition to their resulting sexual unattractiveness to men. Ashing-Giwa et al. (2004) as well reported that many minority breast cancer survivors described negative feelings about their bodies after breast cancer and its treatments such

as decreased self-worth, attractiveness and feeling deformed whereas Halbert et al. (2008) reported weight gain in African American patients was a concern and stressor.

Several of the women in this study expressed worrying at some point in their breast cancer experience. This finding is similar to other studies. Bradley (2005) found varying degrees of worry about breast cancer symptoms in African American breast cancer patients. Furthermore, Ashing-Giwa et al. (2004) reported that women's responses to breast cancer often include fear, worry, denial and anxiety about reoccurrence.

Experiences with the health care system can either help or hinder the recovery of African American breast cancer patients with depressive symptoms. In fact, Maly et al. (2004) suggest that patient-provider interaction may even perpetuate or moderate health disparities. Several participants in this study described negative experiences with the health care system. The participants believed that they were not provided with enough information, that their care was rushed, that their providers were too forceful with them, that they did not feel considered as people, that they were ignored, that they received the wrong treatments, that they did not receive information about mental health, and that they felt that they had to fight with insurance companies. These findings are consistent with other reports. Ashing-Giwa et al. (2004) found that many African American breast cancer survivors described negative relationships with doctors. They reported that their doctors lacked sensitivity, really did not care about them and that they were treated disrespectfully for asking questions, their concerns were discounted, and that the care they received from medical staff was below standard. In addition, many African American breast cancer survivors expressed concerns about economic related

discrimination, and disparate treatment related to race (Ashing-Giwa et al, 2004). Only two of the participants indicated that race may play a part in the manner that health care is received.

Other findings of this study were the ways in which some participants changed the way they managed their health care, the residual effects of breast cancer that the participants experienced, and the strategies that the women used to set new boundaries in their lives.

Theoretical Perspective

The theoretical perspective that informed this study was symbolic interactionism. The major emphasis in symbolic interactionism is on the meaning of the situation to the person (Edwards and Saunders 1990, Saunders, 1997). Symbolic interactionism seeks to explain behavior by finding what meaning and value individuals attach to specific experiences, based on the premise that human beings are constantly evaluating and acting upon events based upon their interpretation of these events (Schroeder, 1981). This study remained consistent with the symbolic interactionist perspective by seeking to understand what African American women believe about their experiences and world in regards to breast cancer and depressive symptoms. Symbolic interactionism dictates that situations must be seen as the actor sees it, the meanings of objects, and acts must be determined in terms of the actor's meanings, and the organization of a course of action must be understood as the actor organizes it (Crotty, 2003).

Implications for Nursing Theory

Grounded theory derives from real world experience (Nathaniel and Andrews, 2007). The African American women in this study offered contextual descriptions of how breast cancer and depressive symptoms impacted their lives that has not been described previously in the literature. The grounded theory that emerged from this research is significant because it adds to the theory base for designing future intervention studies to address symptom management of depressive symptoms in African American women with breast cancer. Furthermore, it contributes to the emerging knowledge about African American women. This study incorporated Black Feminism because it allowed African American women to have a voice.

Grounded theory methodology allows theories to evolve as newer facts emerge, creating dynamic tools which remain useful over time and continue to be applicable even when situations change (Nathaniel and Andrews, 2007). Thus, the results of this study also have the potential to guide the exploration of instrument development that may lead to tools that can better predict psychological distress levels in African American women with breast cancer and lead to earlier intervention.

Implications for Nursing Research and Practice

Cultural competence dictates that nurses should develop mechanisms to help African American women with breast cancer and depressive symptoms to increase their spiritual expression. Therefore, health care providers should consider in African American women with breast cancer and depressive symptoms how religion and also personal support networks assist them through the experience. African American women

tend to utilize informal networks for support over more formal sources. Thus, it is recommended that both nurses and other health care providers be aware of the support preferences of African American women. The findings of this study suggest that programs that integrate the use of informal networks in order to provide culturally sensitive care may benefit African American women more than traditional strategies. Additionally, partnering with religious institutions may expedite that effort. Therefore, it is recommended that religious-based support groups be developed for African American women. Such programs can build on the traditional strengths of this population. Future research should explore the therapeutic benefits of informal sources of support for African American women with breast cancer and depressive symptoms. The results of this study also suggest that supporting religious expression in African American women may decrease symptoms of depression. Strategies for treating post-treatment symptoms have not been adequately explored among African American women with breast cancer. Further research is needed to understand what interventions work best with African American women. Lastly, this research is specific to a group of African American women living in Southern California thus future research should also include participants of other geographic areas and religious preferences as their experiences may be different.

<div align="center">Summary</div>

This chapter provided a comparison of the current literature on African American women with breast cancer and depressive symptoms and the findings of this study. It also discussed the theoretical perspective of symbolic interactionism used in this study. Symbolic interactionism fit particularly well with this study. Crooks (2001) stated

research based on symbolic interactionism reveals the world view of participants by seeking to understand the social construction of meaning and action by asking questions about point of view, influences on action, problem-solving strategies, definition of action and situation, effect of past experiences, and finally future plans. This was clearly evidenced by the research findings of this study. In addition, implications for nursing theory, research, and practice were presented as well.

<div align="center">Limitations of the Study</div>

This study was based on the in depth interviews of nine participants. The most obvious limitation of this study was the inexperience of the researcher. The undertaking of a grounded theory study is a significant endeavor that requires a variety of skill sets. Most importantly it requires the ability to conduct clear and concise interviews that capture the complete perspective of participant. As a novice researcher my interviewing skills and abilities were not always apparent in the early interviews, but improved as the study progressed as subsequent interviews focused on the emerging core categories. Another limitation of this study was that the participants were only interviewed once. Additional interviews with each participant may have generated more concise data. One more limitation was that social structural processes were not included in the data analysis. A secondary data analysis may provide reveal additional processes. Lastly grounded theory studies are specific to the population studied. However, the results of this study may have transferability, in that the findings may fit other contexts as judged by readers or when readers find the report meaningful in regard to their own experience (Germain, 2001).

Conclusions

Grounded theory is a respectful methodology in which the participants views are sought, listened to, and valued (Crooks, 2001). This type of methodology was used in this research to study African American women with breast cancer and depressive symptoms. This study provided new insights into how African American women manage breast cancer and depressive symptoms. The explanatory theory that resulted was *Transcending the Now*. The theory *Transcending the Now* offers a new contextual view on depressive symptoms and breast cancer in African American women. This new perspective will serve to increase understanding of these disease processes among this population.

APPENDIX A:

PARTICIPANT FLYER

Participant Flyer

You are being offered the opportunity to participate in a research study that is designed to explore the experience of depressive symptoms in African American women with breast cancer.

If you would like to participate in this study please contact Joda H Weathersby, RN, NP, who will describe the study, and ask you to sign a consent form.
What will you be asked to do?

- Participate in one or two 1-hour audiotaped interview when and where convenient for you.

- Each interview will be conducted privately and all information will be confidential

- There is no cost to participate in this study, nor is there any compensation for your participation in the study.

Your willingness to consider participation in this study is greatly appreciated. You may withdraw from this study at any time if you choose.

If you have questions about this study, you can call the nurse researcher, Joda Weathersby, RN, NP, at 714. 493.9907. Or if you have questions concerning your rights as a research subject, you may also call the University of Arizona Human Subjects Protection Program office at 520.626.6721.

APPENDIX B:

INTERVIEW QUESTION GUIDE

Interview Question Guide

1. What has been your experience with depression while having breast cancer?

2. How has depression affected the course of your breast cancer?

3. Tell me about your depression.

4. What have been some of the things that worsened your depression while dealing with breast cancer?

5. What have you found helps you?

6. What do you think health care providers need to know about African American women with depression and breast cancer?

APPENDIX C:

PARTICIPANT INFORMED CONSENT

Informed Consent
[A Grounded Theory of Depressive Symptoms in African American Women with Breast Cancer]

Introduction
You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?
You are being invited to participate voluntarily in the above-titled research project. The purpose of this study is to describe what happens to African American women with breast cancer when they are experiencing depressive symptoms, leading to an explanatory theory of depressive symptoms in African American women with breast cancer.

Why are you being asked to participate?
You are being invited to participate because you have self-identified yourself as an African American woman and you have indicated that you have experienced depressive symptoms after the diagnosis of breast cancer. Criteria for inclusion in this study include: women who self-identify themselves as African American; the ability to read, write, and comprehend English; age 40 or older; and having experienced depressive symptoms after the diagnosis of breast cancer.

How many people will be asked to participate in this study?
Approximately 8 to12 persons will be asked to participate in this study.

What will happen during this study?
If you agree to participate, you will be asked to consent to the following: participate in an interview with the primary investigator concerning your experience with depressive symptoms after the diagnosis of breast cancer. The interview will be scheduled at a time and place that is convenient for the participant and will last one hour. A second interview may be requested at a later date during the course of the study if more information is deemed necessary. The interview will consist of two phases. The first phase is designed to provide general background information, such as age and marital status. The second phase will allow you to describe your experience with depressive symptoms after the diagnosis of breast cancer. While the investigator will ask some questions and guide the interview, you will have the opportunity to tell your story. The interview will also be tape recorded and later transcribed for review by a professional transcriptionist. The investigator may also take a few notes during the interview to supplement the information from the taped interview.

How long will I be in this study?
About one hour will be needed to complete this study. However for some participants an additional interview lasting one hour may be necessary.

Are there any risks to me?
The things that you will be doing have minimal risk. The risk may be emotional or psychological. Although we have tried to avoid risks, you may feel that some questions we ask you to do may be stressful or upsetting. If this occurs you can stop participating immediately. We can give you information about individuals who may be able to help you with these problems.

Are there any benefits to me?
You will not receive any benefit from taking part in this study, or you may feel relief as you talk about experiences, especially if you have not told anyone before. There are also societal benefits. You will be contributing to the development of a theory that will be used to help other African American women who may be experiencing the same problem.

Will there be any costs to me?
Aside from your time, there are no costs for taking part in the study. The total time commitment will range about one hour per interview. A maximum of two interview will be conducted will all participants. However, most of participants will only require one interview.

Will I be paid to participate in the study?
There will be no monetary compensation.

Will video or audio recordings be made of me during the study?
We will make an [audio] [video] recording during the study so that we can be certain that your responses are recorded accurately only if you check the box below:

☐ I give my permission for audio/video recordings to be made of me during my participation in this research study.

☐ I do not give my permission for audio/video recordings to be made of me during my participation in this research study.

Will the information that is obtained from me be kept confidential?
The only persons who will know that you participated in this study will be the research team members: the principal investigator and the co- principal investigators. Your records will be confidential. You will not be identified in any reports or publications resulting from the study. It is possible that representatives of the sponsor that supports the research study will want to come to The University of Arizona to review your information. Representatives of regulatory agencies (including The University of Arizona Human Subjects Protection Program) may access your records.

May I change my mind about participating?
Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Also any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

Whom can I contact for additional information?
You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator Joda H. Weathersby, R. N., NP, Ph.D. Candidate at (714) 493-9907. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the research team, or want to talk to someone other than the research team, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website: http://www.irb.arizona.edu/contact/.

Your Signature
By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

_____
Name (Printed)

_____   _____
Participant's Signature   Date signed

Statement by person obtaining consent
I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

_____
Name of Study Personnel (Printed)

_____   _____
Study Personnel Signature   Date signed

APPENDIX D:

UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD (IRB)

THE UNIVERSITY
OF ARIZONA.

Human Subjects
Protection Program

1235 N. Mountain Ave.
P.O. Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
http://rik.arizona.edu

29 January 2008

Jedia Weathersby, Student
Advisor: Terry Badger, PhD
Nursing
PO Box 210203

RE: PROJECT NO. 08-0038-02 DEPRESSIVE SYMPTOMS IN AFRICAN AMERICAN WOMEN WITH
BREAST CANCER: A GROUNDED THEORY STUDY

Dear Ms. Weathersby:

We received your research proposal as cited above. The procedures to be followed in this study pose no more
than minimal risk to participating subjects and have been reviewed by the Institutional Review Board (IRB)
through an Expedited Review procedure as cited in the regulations issued by the U.S. Department of Health and
Human Services [45 CFR Part 46.110(b)(1)] based on their inclusion under research category 7. As this is not a
treatment intervention study, the IRB has waived the statement of Alternative Treatments in the consent form as
allowed by 45 CFR 46.116(d)(2).

Although full Committee review is not required, notification of the study is submitted to the Committee for their
endorsement and/or comment, if any, after administrative approval is granted. This project is approved with an
expiration date of 29 January 2009.

The Institutional Review Board (IRB) of the University of Arizona has a current *Federalwide Assurance* of
compliance, *FW00004218*, which is on file with the Department of Health and Human Services and covers
this activity.

Approval is granted with the understanding that no further changes or additions will be made to the procedures
followed without the knowledge and approval of the Human Subjects Committee (IRB) and your College or
Departmental Review Committee. Any research related physical or psychological harm to any subject must also
be reported to each committee.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area
designated for that purpose by the Department Head or comparable authority. This will assure their accessibility
in the event that university officials require the information and the principal investigator is unavailable for
some reason.

Sincerely yours,

Elaine G. Jones, PhD, RN, FNAP
Chair, Social and Behavioral Sciences Human Subjects Committee

EGJ/mm
cc: Departmental/College Review Committee

Informed Consent

[A Grounded Theory of Depressive Symptoms in African American women with Breast Cancer]

Introduction

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?

You are being invited to participate voluntarily in the above-titled research project. The purpose of this study is to describe what happens to African-American women with breast cancer when they are experiencing depressive symptoms, leading to an explanatory theory of depressive symptoms in African-American women with breast cancer.

Why are you being asked to participate?

You are being invited to participate because you have self-identified yourself as an African American woman and you have indicated that you have experienced depressive symptoms after the diagnosis of breast cancer. Criteria for inclusion in this study include: women who self-identify themselves as African-American; the ability to read, write, and comprehend English; age 40 or older; and having experienced depressive symptoms after the diagnosis of breast cancer.

How many people will be asked to participate in this study?

Approximately 8 to 12 persons will be asked to participate in this study.

What will happen during this study?

If you agree to participate, you will be asked to consent to the following: participate in an interview with the primary investigator concerning your experience with depressive symptoms after the diagnosis of breast cancer. The interview will be scheduled at a time and place that is convenient for the participant and will last one hour. A second interview may be requested at a later date during the course of the study if more information is deemed necessary. The interview will consist of two phases. The first phase is designed to provide general background information, such as age and marital status. The second phase will allow you to describe your experience with depressive symptoms after the diagnosis of breast cancer. While the investigator will ask some questions and guide the interview, you will have the opportunity to tell your story. The interview will also be tape recorded and later transcribed for review by a professional transcriptionist. The investigator may also take a few notes during the interview to supplement the information from the taped interview.

How long will I be in this study?

About one hour will be needed to complete this study. However for some participants an additional interview lasting one hour may be necessary.

Are there any risks to me?

The things that you will be doing have minimal risk. The risk may be emotional or psychological. Although we have tried to avoid risks, you may feel that some questions we ask you to do may be stressful or upsetting. If this occurs you can stop participating immediately. We can give you information about individuals who may be able to help you with these problems.

Are there any benefits to me?

You will not receive any benefit from taking part in this study, or you may feel relief as you talk about experiences, especially if you have not told anyone before. There are also societal benefits. You will be contributing to the development of a theory that will be used to help other African American women who may be experiencing the same problem.

Will there be any costs to me?

Aside from your time, there are no costs for taking part in the study. The total time commitment will range about one hour per interview. A maximum of two interview will be conducted will all participants. However, most of participants will only require one interview.

Will I be paid to participate in the study?
There will be no monetary compensation.

Will video or audio recordings be made of me during the study?

We will make an [audio] [video] recording during the study so that we can be certain that your responses are recorded accurately only if you check the box below:

☐ I give my permission for audio/video recordings to be made of me during my participation in this research study.

☐ I do not give my permission for audio/video recordings to be made of me during my participation in this research study.

Will the information that is obtained from me be kept confidential?

The only persons who will know that you participated in this study will be the research team members: the principal investigator and the co- principal investigators.

Your records will be confidential. You will not be identified in any reports or publications resulting from the study. It is possible that representatives of the sponsor that supports the

3

research study will want to come to The University of Arizona to review your information. Representatives of regulatory agencies (including The University of Arizona Human Subjects Protection Program) may access your records.

May I change my mind about participating?

Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Also any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

Whom can I contact for additional information?

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator Joda H. Weathersby, R. N., NP, Ph.D. Candidate at (714) 493-9907. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the research team, or want to talk to someone other than the research team, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website: http://www.irb.arizona.edu/contact/.

Your Signature

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

_____

Name (Printed)

_____   _____

Participant's Signature   Date signed

Statement by person obtaining consent

I verify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

_____

Name of study personnel

_____   _____

Study personnel Signature   Date signed

1/28/08 Version 1

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