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The Lived Experience of Intersectionality Among African American Women with Breast Cancer

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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

The Lived Experience of Intersectionality Among African American Women with Breast
Cancer

By

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Hahn School of Nursing and Health Science

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Abstract

African American women (AAW) continue to have breast cancer mortality rates that are 42% higher than White women (De Santis et al., 2015). Researchers suggest that an epistemological approach that integrates the biomedical and feminist models would be more effective in addressing health disparities. The concept of intersectionality, which grew out of the Black feminist movement, provides a lens in which to view the lived experiences of AAW with breast cancer. The intersectionality paradigm attempts to address the marginalized, oppressive, intersecting social existence of AAW through the examination of identity, social class, and power.

This qualitative study applied a descriptive phenomenological approach to examine the lived experiences of intersectionality among AAW with breast cancer. Using the phenomenological approach, 10 AAW ages 45-80, which were located various geographical areas of United States (U.S.), participated in one to one semi-structured 60-90 minute digitally audio-recorded interviews. All of the participants had a self-report diagnosis of breast cancer with varying stages. A modified Husserlian approach by Amedeo Giorgi (2009) guided the data analysis.

The following themes emerged from the data analysis. The first, altruism, descriptions of how the women's behavior reflects a historical trend of selfless giving and caring for those within their environment. The second theme: marginalization, descriptions of how the women were forced to the fringes or margins of society. Two forms of marginalization emerged: 1) passive marginalization described circumstances in which the women removed themselves either mentally or physically from societal adversity; and 2) active marginalization described circumstances in which the women

were overlooked, devalued or ostracized by others. The third theme, silent strength, describes how the women displayed strength in silence while enduring life in the intersection. The final theme, existential invisibility, describes how the women have been an essential presence in society, but remain obscured individuals.

This research indicates that AAW could have additional upstream risk factors for the development of breast cancer that stem from life within the intersection. Implications for future research as a result of this study include: a community based participatory research project to examine the psychological effects of stress, development of culturally sensitive research instruments that measure stress, and mixed method studies that examine breast cancer disparities.

Copyright

Dedication

This work is dedicated to all the magnificent enduring Black women that provided with strength during this journey; Paulyne, Pat, Fannie and Martha. I miss you Mom and Mother every day, but still I rise.

Acknowledgement

I am grateful to my committee members: Dr. Georges, Dr. James and Dr. Etland. Your guidance and encouragement during this journey was invaluable. You allowed me to grow through this enriching process and I appreciate each of you.

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To all of the women that allowed me to take a glimpse into their world as breast cancer survivors that are enduring the intersection, thank you.

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To my husband Vincent, my children Terris and Xzavier and my brother-in-law Raunja, your support has meant more to me than you could imagine. Sometimes you have to keep going for those around you; all of you gave me the purpose I needed to keep going.

Vincent, my husband of many years and friend for many more; this is it we have reach the top; we completed our PhD!! Love you immensely

Mom they were right, I am a statistic.....

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Chapter 1

Introduction

Cancer is the second most common cause of death in the U.S. The Surveillance, Epidemiology and End Results Program's latest prevalence statistics find that an estimated 13 million people in 2012 were living with a form of cancer. It was predicated that 1.6 million new cases of cancer would be diagnosed by the end of 2016 (National Cancer Institute [NCI], 2016).

Breast cancer is the most common form of cancer in American women and approximately 12% of women will be diagnosed with breast cancer in their lifetime (DeSantis et al., 2015). Approximately 231,840 new cases of invasive breast cancer and over 60,290 new cases of in situ breast cancer were diagnosed by the end of 2015 (American Cancer Society [ACS], 2015). It has also been estimated that over 40,000 deaths will occur among women in the U.S. in 2015 (ACS, 2015). Between the years 1980 and 1990, there was a drastic increase in the incidence of non-invasive (in-situ) breast cancer cases in women 50 years and older; this was largely due to improved mammography screening (ACS, 2015).

Cancer research has identified a variety of risk factors related to the incidence of all cancer types including breast cancer. Smoking, exposure to sunlight, genetics, lactation, number of pregnancies, hormones/hormone therapy, and familial history are some of the traditional risk factors. Cancer research has provided further insight to breast cancer risk factors; nutrition, physical activity, obesity, and psychological stress are all under examination as additional risk factors to the development of breast cancer (Antonova, Aonson, & Mueller, 2011).

Throughout the 1990s as obesity rates and the use of hormones increased, breast cancer rates among women 50 years and older continued to climb. In a study by Key et al. (2003), breast cancer risk was increased among postmenopausal women with an above average body mass index. Body mass index and breast cancer risk connection was also associated with increased estrogen levels which are mediators for breast cancer neoplasms (Key et al., 2003). Other studies have shown that vigorous physical activity, which decreases body mass index, has a protective effect against the development of breast cancer in postmenopausal women (Navarro, Jain, Howe, Miller, & Rohan, 2004 and Mc Tiernan et al., 2003).

A less conventional risk factor is the potential link between breast cancer and psychological stress. Antoni et al. (2006) found that stress, chronic depression and lack of social support may increase the risk of breast cancer development and progression. Other studies suggest that the link between stress and breast cancer is related to the associated increase in body mass index and waist circumference (Wing, Matthews, Kuller, Meilahn, & Plantinga, 1991). Research has provided us with ample insight on the downstream bio-physiological risk factors that lead to the development of breast cancer. Identification of these risk factors has resulted in treatment modalities that have stabilized breast cancer incidence. The stabilization of breast cancer cases has not occurred across all racial lines.

Statement of Problem

Between 2005 and 2009, an average of 205,246 cases of breast cancer were diagnosed each year; 173,970 were White women and 21,942 were Black women. Black women had a lower incident rate (116.9/100,000) than White women (122/100,000);

however Black women were diagnosed with regional or distant stage breast cancer at higher percentage rate; 45% versus 35% (Vital Signs: Racial Disparities in Breast Cancer Severity-United States, 2005-2009, 2012). During 2005-2009, Black women experienced a mortality rate that was 41% higher than White women (Vital Signs: Racial Disparities in Breast Cancer Severity-United States, 2005-2009, 2012).

Triple negative breast cancer (TNBC), a more aggressive form of the disease, accounts for 15%-20% of all breast cancer cases in the U.S. (American Cancer Society, 2013). TNBC lacks the receptors that are targeted during treatment making these cases more difficult to treat. In a study conducted by Carey et al. (2006), 39% of AAW with breast cancer were diagnosed with TNBC compared to 15% in non-African American women. Amirika, Mills, Bush and Newman (2011) find that the incidence of TNBC in AAW rose more steeply with age between the years 1998 and 2006 as compared to White and Hispanic women.

A more recent study revealed that the incidence rates between Black and White women converged in 2012 (DeSantis et al., 2015). De Santis et al. (2015) found the breast cancer rates for Black women increased 0.4% per year between 2008 through 2012, 1.5% for Asian-Pacific; however, there was not a significant change for Hispanic, American Indian/Alaska Native or White Women. The increase in breast cancer rates among Black women can be contributed to a rise in estrogen receptor positive cancers (De Santis, Ma, Byran, & Jermal, 2014). More concerning is the mortality rate for Black women was 42% higher than White women in 2012 (DeSantis et al., 2015).

Purpose of the Study

Even though the incidence of breast cancer has stabilized in the U. S., the disparity gap of breast cancer cases between AAW and White women continues to grow. Much of the treatment and research for breast cancer has focused on biophysical downstream determinants of health. Very few studies have focused on how social disadvantage and adversity, upstream determinants of health, influences the psychological well-being of AAW and the potential connection to breast cancer incidence.

The purpose of this qualitative study is to gain an understanding of how living an intersecting social existence across the axes of race, gender and class impacts the lives of AAW with breast cancer who are located in various geographical areas across U.S. The aim of the study is to capture the essence of the phenomenon of intersectionality. The study aims to put into context perceptions of living in dual oppressed roles; how these roles are processed and influence the mental health of AAW. In addition, the study aims to give meaning and make tangible the intersectional existence of AAW that have been diagnosed with breast cancer.

Research Question

The question to be addressed in this study: How do AAW with breast cancer perceive their race, gender, and class have impacted their lived experience in the U.S.? This question will be used to guide the study, while additional probing questions will be used to garner more comprehensive information. For example, “Have you ever experienced discrimination” and “were there any challenges as a result of

discrimination”. These questions will be used to gain insight into how racism, sexism, and classism have impacted their lived experiences.

Conceptual Underpinnings

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization [WHO], 2014)

Biomedical Model

Much of the research conducted to address breast cancer disparities stems from the biomedical model. The biomedical model contends that disease and therefore health disparities can be explained by measurable biological disturbances. From its inception the biomedical model espoused the beliefs of reductionism, a view that complex phenomena are derived from a single primary principle; and dualism, a belief that the mind and body are separate entities (Engel, 1977). Biomedical research employs a positivist epistemological approach to study the relationship between social characteristics and disease. Through the use of quantitative analysis, biomedical research attempts to establish causal relationships between study variables with a final goal of developing generalizable interventions that can be applied to health concerns or disease states among homogeneous populations. According to Kelly (2009), the goal of biomedical research is to identify factors that cause disease and develop interventions that can be applied primarily to individuals but also to groups and populations. The Institute of Medicine recommended additional biomedical research to develop interventions across unidimensional categories of race, ethnicity or socioeconomic lines with a goal of reducing health disparities (Smedley, Smith, & Nelson, 2003).

The traditional biomedical approaches to breast cancer disparities have focused on social economic status, life style choices, and biological factors separately. This segregated approach to breast cancer disparities views the disease process on a singular plane and does not take into account the multiplicative effects of race, gender and social location. Additionally, in biomedical research, the knowledge, biological norms, and social standards surrounding breast cancer disparities stem from the dominate race. Kelly (2009) states, “The tenets of the biomedical model that were developed by the dominate group, white males, are operationalized in a hierarchical structure; in which the researcher is the source and developer of knowledge about subjects and their illness” (p. E45). Biomedical research has provided useful strategies which has improved the incidence and outcomes of breast cancer among AAW. However, the narrow focus of the biomedical model has not been able to provide a comprehensive explanation for continued breast cancer disparities.

The Feminist Model

The feminist movement of the U. S. emerged during a time of social awakening; people began to resist the oppression of hierarchical power, challenge socially assigned identities, and subjugated inequalities. Within the feminist movement, a new body of knowledge began to emerge which viewed women’s health issues from the perspective of women. Some social science scholars suggested that an integration of the biomedical and feminist models is necessary to effectively address the complexities of health disparities (Kelly, 2009, Ruzek, Olesen, & Clarke, 1997, Weber & Parra-Medina, 2003). Kelly (2009) states, “An approach to addressing health disparities would be one that considers social and political contexts and its inherent relations of power that contribute to health

disparities” (p. E42). The feminist approach addresses health disparities through an analysis of socially constructed identities, the associated oppression that is as a result of power relations and places women at the center of the analysis.

Andrist (1997) identifies four themes of the feminist model for healthcare (1) symmetry in provider–patient relationships, (2) access to information, (3) shared decision making, and (4) social change. A symmetrical provider-patient relationship allows for equal exchange of health information which eliminates the barriers that are created by hierarchical power. Providers and patients are in symbiotic relationships which facilitates learning for both groups. Providers also allow patients access to their own health information which builds trust and lessens barriers. Providers not only share information, they evaluate learning and functional status of patients during the access and exchange of information. Following establishment of non-hierarchical relationships and exchange of information, providers and patients participate in shared decision-making. Using a shared decision making approach is essential to the feminist model; not all women will participate in this process equally or arrive at the same decisions (Andrist, 1997). Social change involves focusing research on health issues affecting women at the macro and micro structural levels to create advantageous effects on those factors that determine health and well-being. Social change will allow for the implementation of strategies that are both preventative and curative against illnesses that are impacting women’s health.

Black Feminist Thought

In order to fully understand the experience of breast cancer among AAW, a comprehensive analysis of the interaction between biology, environment, and social condition is necessary. The feminist movement provided a platform to fully address

women's health issues from the perspective of the dominant race. During this time of social awakening, AAW were marginalized in the struggle; women's issues equated to White women and Black issues equated to Black men. An epistemological approach that views disease through the lens of AAW would allow for the development of research strategies and interventions that could potentially lessen breast cancer disparities among AAW.

Black Feminist Thought (BFT) is a consciousness that elucidates the social locations and identities of AAW. BFT is a paradigm for analyzing and interpreting the lived experiences of AAW in the U.S. (Hill Collins, 2009, Chapter 1). BFT generates knowledge by Black women that explicates a standpoint of and for Black women (Hill Collins, 1986). BFT does not espouse that all AAW have the same lived experience; however, there are some distinct commonalities among AAW that have been shaped by their history in the U.S. and the patriarchal society. The goal of BFT is to empower AAW within the context of social injustice created by intersecting oppressions and to support principles of social justice that extend beyond the needs of AAW in U.S. (Hill Collins, 2009).

Hill Collins (2000) identifies six key features of BFT, which serve to elucidate the "standpoint" of AAW (p. 21-49). First, the collective identity of AAW is defined by the juxtaposition of their intersecting oppressions and political activism. BFT aim is to achieve empowerment through activism that is reflective of a collective voice and sense of consciousness among AAW.

The second feature recognizes that there is diversity that exists among African American Women's' experiences. The differences that exist among AAW do not negate

their common experiences which have been shaped by history and form their collective standpoint. This collective standpoint makes salient the voice of AAW and is a vehicle used to resist oppression.

The third feature is the commonalities that exist between BFT and critical social theory. BFT enables the collective to generate knowledge and resist oppression. The dialogical relationship that exists between BFT and critical social theory proposes that changes in thinking will lead to changes in actions. For AAW as a collective, the struggle to self-define Black feminism is a continuous dialogue in which thought and action inform one another (Hill Collins, 2009).

The fourth feature of BFT pertains to Black women's intellectuals, who produces knowledge and what knowledge is important. Generation of knowledge by and for AAW is essential to the development of BFT. A key task for Black feminist intellectuals is to ask the right questions and investigate all dimensions of Black women's standpoint and for AAW (Hill Collins, 2009). AAW need to take the lead in developing a paradigm for BFT; this position will provide a platform for activism against oppression.

A fifth feature addresses the constant state of change, as social conditions change the standpoint and voice of AAW must adapt. In order for BFT to be an effective critical social theory, Black intellectuals must continue to generate knowledge that is based on current social conditions. The dynamic quality of the social environment will force Black intellectuals to constantly define Black womanhood in the U.S.

The last feature of BFT is its connection to other social movements. BFT, like other social movements, aims to empower oppressed groups. The struggle to move AAW off the fringes of society and elevate AAW in the U.S. cannot occur in isolation from

other efforts to achieve social justice for all oppressed people. In order to be successful, there has to be a commitment to human solidarity regarding any political movement regardless of the social location or perspective (Hill Collins, 2009).

Intersectionality

I am a Black Feminist, I mean I recognize that my power as well as my primary oppressions come as a result of my blackness as well as my womaness, and therefore my struggles are inseparable. Audre Lorde (Mindi, 2015)

Early abstractions of intersectionality were made tangible by The Combahee River Collective statement (Combahee River Collective, 1977/2016). This document highlighted the multiple oppressions that existed for AAW in the Black community; sexism, and from within the feminist movement: racism. Four major topics were covered in the paper (1) the genesis of contemporary Black feminism, (2) political views of Black feminists, (3) problems in organizing Black feminists and (4) Black feminist issues and practice (Eisenstein, 1978). The Combahee River Collective Statement served to expand the Black feminist movement.

Matters of race and racial equality have been a major social issue for the African American community. AAW's issues have been filtered through their race, obliterating concerns surrounding their gender (King, 1988). Lewis (1977) finds that if AAW perceive race as the cause of their inferior status, their interests as Blacks takes precedence over their interests as women. Subsequently, the multiplicative effects of oppressive socially constructed identities will be overlooked.

Black female intellectuals began to take notice of the unchecked social conditions that continued to stagnant progress among AAW. Crenshaw (1991) recognized the

unique social location of AAW and coined the term “intersectionality” to describe the way race, gender and social location merge to form the unique multi-dimensional lived experiences for AAW. To view experiences of AAW along a single plane conceptually tend to erase or marginalize AAW in the struggle for social justice (Crenshaw, 1991). The central goal of intersectionality is to produce social inclusion of historically ignored and excluded populations (Hankivsky & Cormier, 2009).

Studies that have used the intersectionality paradigm have identified different approaches for analysis. Crenshaw (1991) finds that intersectional experiences can be divided into three categories; structural, political, and representational. Structural intersectionality examines how social location within the intersection of race, gender, and class create lived experiences that are qualitatively different than that of the dominant race. Crenshaw (1991) states, “Intervention strategies based solely on experiences of women who do not share the same class or race backgrounds will be of limited help to women who because of race and class face different obstacles” (p. 1246). Political intersectionality is concerned with how AAW straddle the lines of two oppressed groups that are part of social movements that have conflicting political agendas: feminism and antiracism. Developing strategies to elevate womanhood without consideration of race can reinforce oppression of people of color; the antiracism movement historically has failed to take into account patriarchy which has historically resulted in the oppression of women (Crenshaw, 1991). Representational intersectionality is concerned with social-cultural construction of images that depict women of color. Women of color are confronted with dual stereotypes due to race and gender which further serves to

marginalize and obscure their social locations. Subjugation of AAW is further explicated through the collective effects of stereotypical images.

In an effort to resolve the social issues impacting AAW, activists and scholars have attempted to reduce the social inequities that exist to structural, political or representational experiences. Activists and scholars must take caution and recognize that there is a bolstering of power relations when social movements attempt to dichotomize the elements that merge to form intersectional locations. Individuals that are attempting to correct the subjugated status of AAW will need to take into account that structural, political and representation intersectionality are not the same and therefore are not reducible to each other (Crenshaw, 1991).

Oppression

Intersectionality provides a framework to conceptualize how power relations surrounding gender, race, and class merge to form oppressive social locations for women of color. Oppression is as a result of “isms” that are supported by systemic or structural power, which include government, education, legal and healthcare systems’ policies and practices (Mc Gibbon, 2012). Oppression resulting from living in the social intersections can affect mental and physical well-being. Since oppression is embedded in systemic ruling relationships, the results of oppression are persistent and toxic for the mental, physical and spiritual health of oppressed people (Mc Gibbon, 2012).

A toxic unchecked oppressive state can manifest in the form of mental and physiological stress. Unresolved levels of stress have been linked to physiological and psychological disease states (Cohen & Janicki-Deverts, 2012; Geronimus, Hicken, Keene, & Bound, 2006; Juster, McEwen, & Lupien, 2010). Perry, Harp and Oser (2013)

state, “racial and gender discrimination increases the risk for poor health and psychological well-being, working both directly and indirectly through increased vulnerability to individual stressors” (p. 25). Fernander and Schumacher (2008) report that AAW reported more perceived psychological stress when events were tied to race and therefore more health-related issues under these circumstances. Starkey, Keane, Terry, Marx, & Ricci (2012) state, “At any given time 16%- 28% of African Americans have psychological distress” (p. 84).

When individuals are exposed to psychological stress, the hypothalamic pituitary adrenal (HPA) axis is activated, which leads to a release of neurotransmitter and glucocorticoids. Prolonged activation of the HPA axis results in adrenal fatigue and physiological imbalance; this has been shown to lead to immune system dysfunction and cancer (Vanitalie, 2002). The primary glucocorticoid, cortisol, is released during pregnancy and lactation, its normal role is the development and activity of mammary glands. However, under chronic stress situations cortisol is continuously released by the HPA axis. Persistent cortisol exposure affects biological pathways within the mammary gland and therefore may indirectly contribute to tumorigenesis by altering generation or activity of estrogen (Russo, 2003).

A limited number of studies have suggested that psychological stress can increase the levels of oxidative stress (Szanton et al., 2011). Oxidative stress results when there is an imbalance between the production of reactive oxygen species and homeostatic mechanism. Szanton et al. (2011) state, “If oxidative stress is causally associated with a psychological stressor such as racial discrimination, the disparities in psychological stress could help explain some health disparities” (p. 490). Health disparities are not isolated

individual, biological events and must be examined within the context in which illness occurs (Ruzek et al., 1997). Given the fact that breast cancer incidence and prognosis vary among racial and ethnic groups and the conditions of the social environment varies from culture to culture, it is plausible that the disparity of breast cancer among AAW could be related to specific psychosocial stressors that are propagated by life within the intersection of society.

Methods

This qualitative study used a descriptive phenomenological methodology to capture the essence of the lived experiences of AAW with breast cancer living in the intersection of socially constructed identities. A phenomenological research method is the appropriate approach for studying human experiences and what it means to be human (Smith, Flowers, and Larkin, 2009). The concept of intersectionality is clearly defined in the literature; however, the research lacks an accounting of how intersectionality manifests itself in the lives of individuals. In addition, the current research has not produced an accounting of if and how intersectionality is perceived by AAW with breast cancer.

Phenomenological studies conducted by nursing researchers typically use one of two approaches; hermeneutic (interpretative) or transcendental (descriptive). The hermeneutic (interpretative) approach seeks to understand phenomena in context and views a person as a self-interpretative being (Wojnar & Swanson, 2007). The hermeneutic approach requires that the participants and researcher have forestructures (fore-having, fore-sight and fore-conception) of understanding which is shaped by their respective backgrounds (Wojnar & Swanson, 2007). The transcendental approach

revolves around describing the universal essences of phenomena and views the individual as one representative of the world in which he and she lives (Wojnar & Swanson, 2007).

In the field of research, Edmund Husserl a German philosopher and mathematician, is considered the founder of phenomenology. Prior to the Husserlian method, the study of phenomena took an objective approach. Husserl redefined phenomena as objective intentional contents of subjective acts of consciousness (Smith, 2016). Husserl introduced two Greek words to illustrate the distinction between objective and subjective ideas, noesis and noema. Noesis is the intentional process of consciousness and noema an act of consciousness (Smith, 2016). Husserl's goal was to examine the structures of our consciousness (essence) that constitute what he called the "life world" or "lived experience" (*Lebenswelt*) (Moran, 2000).

Koch (1995) identified three essential elements of Husserlian phenomenology; intentionality, essences, and bracketing. Intentionality is the notion that our minds are directed towards something and it is this directedness that forms our conscious reality (Giorgi, 1997; Koch, 1995; Reiners, 2012; Smith, 2016). Husserl's paradigm of phenomenology holds that it should be a science of descriptive psychology, which would capture the essences of what constitutes the consciousness and perception of the human world (Koch, 1995). Finally, bracketing (phenomenological reduction) calls for the researcher to set aside all preconceived notions in order to reach transcendental subjectivity (Koch, 1995; Smith, 2016; Wojnar & Swanson, 2007). Achieving transcendental subjectivity allows the researcher to analyze the phenomenon in its pure, universal sense (Wojnar & Swanson, 2007). Bracketing and transcendental subjectivity enables participant-researcher interaction to be subjective in nature and guards against

researcher bias. As a researcher with insight and experiences surrounding the subject matter under investigation, a descriptive phenomenological method is most suitable for this study.

Assumptions

The following assumptions are made by the researcher in approaching this work:

- 1) AAW are at risk for health disparities that are as a result of biophysical, psychological, social and environmental factors.
- 2) AAW are at an increased risk for poor mental health due to historical oppression and subordinate power relations along the axes of race, gender, and class.
- 3) AAW experience increased physiological illness related to the effects of poor mental health.
- 4) A qualitative study will allow for the development of an eidetic structure of the phenomena under study.
- 5) To accurately capture the essence of intersectionality and achieve objectivity, the researcher must engage in phenomenological reduction (bracketing) throughout the study.

Significance to Nursing

Addressing breast cancer disparities will require a multidisciplinary approach between, researchers, oncologists, pathologists, geneticists, and nursing. The role of nursing in this team is multi-fold which includes data collection and monitoring, facilitation of life-style changes, generation of new knowledge, and patient education. In the growing field of nursing research, nursing will play an important role in reaching out to disparate populations to capture and track data to identify trends. It is important that

nurses are part of the team that helps to mitigate factors that produce breast cancer disparities. The relationship that nursing has with the general community will facilitate collaborative efforts to generate cultural specific solutions to decrease breast cancer disparities.

Terms and Definitions

For the purposes of this study, the following terms and definitions as defined as:

African American/Black: Pertaining to characteristics of Americans of African ancestry.

Black women's intellectuals: Knowledge that is generated and deemed valuable by American women of African ancestry.

Collective: A group of individuals with common beliefs, issues, or circumstances.

Intersectionality: A term used to describe how the socially constructed categories of race, gender, and class merge to form interconnected systems of discrimination, disadvantage, or oppression.

Oxidative Stress: An imbalance between the production of free radicals and the body's ability to neutralize their harmful effects.

Telomere: The end structure of deoxyribonucleic acid (DNA) that protects chromosomes and influences the aging process.

Chapter 2

Literature Review

The vast majority of research aimed at the elimination of breast cancer disparities is focused on physiological/biomedical factors as well as lifestyle and health choices. Studies that focus on treatment and biological factors contributing to breast cancer disparities are funded at higher rates when compared to studies that focus on prevention. The National Cancer Institute's 2013 breast cancer funding portfolio identified that 22% and 23% of funding went to studies focused on the areas of treatment and biology respectively; while only 5% and 14% went to the funding of studies on prevention and etiology respectively (National Cancer Institute, 2014).

This study examines the lived experience of AAW with breast cancer that have endured an intersectional social existence. This study hopes to add to the discourse on psychosocial factors that contribute to breast cancer disparities among AAW. This chapter provides an overview of the significant literature related to breast cancer disparities among AAW and identifies gaps in the literature that substantiate a need for this study.

Breast Cancer Classification

Imperative to understanding the development, treatment, and progression of breast cancer is how it is classified. As the research surrounding breast cancer develops the classification system changes. The Interagency Breast Cancer and Environmental Research Coordinating Committee (2013) identified the following key features that should be included in classification systems: 1) an assessment of the tissue features that is

conducted by a pathologist, 2) staging that includes size and any metastasis; and 3) molecular markers found on or in tumor cells which influence prognosis.

Molecular markers are classified according to the presence of tumor receptors. Tumor receptors are targeted and dictate the course of treatment. Estrogen (ER) and progesterone (PR) hormones are attracted to receptors in normal breast and may also be found in some breast cancers. The presence of estrogen or progesterone receptors is referred to estrogen positive (ER+) and progesterone positive (PR+) respectively. Hormone receptor positive tumors are slower growing, more common in post-menopausal women and may reoccur. ER+ and PR+ tumors are treated with hormone therapy medication that slows or lowers circulating hormones. Hormone receptor negative tumors (HR-) are found more often in younger pre-menopausal women and propagate quickly. Treatment options for HR- tumors may include any combination of surgery, radiation therapy, or chemotherapy.

A third type of cellular marker is a growth-promoting protein (HER2); tumors that secrete abnormally high levels of this protein are classified as HER2-positive. HER2-positive tumors are larger and spread more aggressively and are found in one out of five breast cancer cases (American Cancer Society, 2014b). Treatment for HER2+ may include chemotherapy which eradicates all dividing cells, or target therapy drugs, which work specifically on breast cancer cells; these drugs are not effective on HER-negative tumors.

A fourth type of breast cancer that is commonly found in young pre-menopausal AAW is TNBC. TNBC tumors lack the hormone and protein receptors that are targeted during treatment. TNBC tumors tend to be larger, more aggressive, and have a worse

prognosis when compared to other types of breast cancer. Surgery and chemotherapeutic drugs are usually the treatment of choice.

Despite the multitude of research that has been conducted to decrease the incidence of breast cancer, research has not been able to provide substantial information towards the elimination of breast cancer disparity among AAW. Initial strategies have included a heightened awareness on the importance of mammography screening, maintaining a balanced nutrition life-style, limiting hormone use, and life-style modifications.

Mammography

It has been suggested that the continued breast cancer disparities are strongly related to equal access to quality, routine mammography screenings. Early studies suggested a direct link between mammography screenings and breast cancer disparities across ethnic lines. AAW tended to present with later stages of breast cancer which in part accounted for the high rate of mortality.

Hunter et al. (1993) conducted a population-based study of 1,222 participants between the periods of 1985-1986 to determine factors associated with cancer staging at diagnosis between Black and White breast cancer patients. The study focused on participants that had a histologically confirmed primary breast cancer, resided in three metropolitan areas, and ranged from ages 20-79 years. A lack of routine mammography screenings significantly ($P < .02$) contributed to the different staging on presentation between the two study groups. Routine physician examinations and delays in follow-up by participants accounted for 50% excess risk for staging among participants in the study. Contrary to a widely-held belief income was not a significant factor in this study.

Researchers concluded that no solitary factor could provide an explanation to the differences in staging across racial lines.

Miller and Champion (1997) conducted a study about perceptions regarding breast cancer and mammography screenings, stratified across race, income, and education. The sample size included 1,083 church women; 807 White and 242 African American, age 50 years or older with no history of breast cancer. The findings revealed that AAW had a higher belief in the risk of getting breast cancer as a result of mammography screenings and lower knowledge base regarding mammography screening. Higher income for both races proved to be beneficial in terms of knowledge regarding mammography screening and breast cancer. The lack of knowledge regarding mammography screening presented itself as a barrier for the AAW as there was a fear of radiation. Women that perceived they had control over getting breast cancer were less likely to have a mammogram. AAW with higher education perceived fewer barriers to mammography screenings, while lower income AAW perceived a higher benefit to mammography screening. The study also points out that AAW avoided mammography screenings because of the fear of finding out they have cancer. The study did not discuss how religion or belief in a higher power might influence the rate of screening among the participants.

McCarthy et al. (1998) completed a retrospective study on mammography use in older Black and White women age 67 years or older whom had received a diagnosis of breast cancer and had a Medicare claim for a mammogram. The Black participants had more advanced disease (Odds ratio [OR], 2.49 Confidence Interval [CI], 1.59 to 3.92), and had not received a mammogram (OR 3.00, [95% CI 2.41 to 3.75]). Those

participants that underwent regular mammography screenings were diagnosed at the same stage of the disease process (adjusted OR, 1.34 [CI, 40 to 4.51]). The study concluded that older Black women less frequently had mammography screenings.

Kapp, Ryerson, Coughlin, and Thompson (2009) completed a study in women less than 40 years of age. They evaluated mammography use across racial lines, descriptive characteristics, and women that had an average risk of being diagnosed with breast cancer. The study included 3,098 women; 69.3 % non-Hispanic White, 13% non-Hispanic-Black and 18% Hispanic. The study revealed that 26% of non-Hispanic Black women reported having three or more mammograms with the past six years as compared to non-Hispanic White women (19.3%) and Hispanic women (15.9%). Non-Hispanic White women (23.5%) were likely to have an abnormal mammogram when compared to non-Hispanic Black women (15.4%) and Hispanic women (14.3%). Among the women at average risk, non-Hispanic Black women (32.7%) had a significantly higher percentage of greater than three mammograms in the past six years when compared to non-Hispanic White women (13%) and Hispanic women (18.4%). Non-Hispanic Black women had 1.9 times greater chance of having a mammogram before the age of 40 when compared to non-Hispanic White women, whereas Hispanic women had a 1.57 times greater odds.

This study demonstrated that younger, non-Hispanic Black women less than 40 years of age underwent mammography screenings more frequently. The researchers conclude that repeated mammography screenings among the non-Hispanic Black group increased the likelihood of false positives. The difference in screening practices could not be accounted for by family history of cancer, educational level, health insurance coverage, or physicians' recommendations. Repetitive screenings increase anxiety

surrounding mammography, the diagnosis of cancer, and treatment and therefore may be a hindrance to breast health. Kerner et al. (2003) found that Black women that asked questions during mammography screenings were 2.73 times more likely to follow through on healthcare professionals' recommendations within 90 days. Consequently, Black women with higher levels of anxiety (OR, 0.50; 95% CI, 0.27-.92) were less likely to complete the recommended follow-up (Kerner et al., 2003).

Kapp et al. (2009) pointed out some limitations of their study; 1) mammography use was self-reported, 2) Asian, Chinese, and American Indian/Alaskan native and other races were not represented in the sample, 3) variable conditions may not have been equal at the time of each screening, 4) inability to categorize mammography as symptomatic versus screening and 5) lack of information regarding breast and ovarian cancer among second-degree relatives. Researchers pointed out that the study is representative of the U.S. population, however, the majority of the non-Hispanic Black study participants were from the southern region of the U.S.; 58.8%. Furthermore, there were low percentages of non-Hispanic White and Hispanic participants represented in the study; 33.4% and 35.6% respectively. Health practices and cultural beliefs may differ by region of the country and therefore impact the rate of mammography screenings. In addition, 61% of the non-Hispanic Black women were not married, only 27.8% of non-Hispanic White women and 32.8% of Hispanic women fell into the same category. It has been well established that individuals with life partners generally have better health practices and thus better health outcomes. Overall, the findings in the study identified distinct differences in mammography screenings across racial lines.

Socioeconomic

In 2012, 48 million people in U.S. were uninsured; included in that number are 11% of the non-Hispanic White and 19% of the African American populations (De Navas-Walt, Proctor, & Smith, 2013). Many posit that an improved healthcare system in U.S. would improve accessibility, affordability, and medical care. Researchers have hypothesized that persistent racial variations in breast cancer incidence and outcome is due to the lack of access to quality screening and treatment. In a study conducted by Smith-Bindman et al. (2006) AAW were less likely to receive adequate mammography screenings than White women, which may provide an explanation for the higher prevalence of advanced breast cancers among AAW. The American Cancer Society found that in 2010 (2014a), only 32% of women ages 40 and older with no health insurance had a mammogram within the past two years compared to 71% of those with insurance. Barriers to breast cancer screening have been identified as; 1) low income, 2) lack of access to mammography center, 3) lack of a usual health care provider, 4) lack of a recommendation from a provider to get mammography screening, 5) lack of awareness of breast cancer risks, and 6) screening methods and cultural differences (American Cancer Society, 2013).

Of all of the barriers identified to breast cancer screening, the access to affordable healthcare is a reoccurring theme throughout the literature. Low socioeconomic status has been demonstrated to have the most significant impact on breast cancer screening and follow-up care in AAW. A population based study on AAW and health care disparities conducted by researcher at The University of Nebraska found that 67.3% of AAW were

at low or very low socioeconomic indices, while only 32.1% of White women from the same geographical area were at low or very low socioeconomic indices (Watanabe-Galloway, Hill, Shostrom, & Nsiah-Kumi, 2012). Jones and Chilton (2002) suggested that the breast cancer rates can be decreased by 30% in women ages 50 to 69 years through mammography screenings and breast exams (Jones & Chilton, 2002).

The Affordable Care Act of 2010 (ACA) is intended to address some of the socioeconomic barriers to health care coverage. Beginning in 2014, the ACA required that all health insurances cover mammography screenings without any out of pocket expense (American Cancer Society, 2013). It has been estimated that an additional 6.8 million low income women would have insurance under the ACA, which would increase the demand for mammograms an average of 500,000 a year (Levy, Bruen, & Ku, 2012). The American Cancer Society recommends annual breast cancer screenings beginning at the age of 40; this recommendation has also been supported by the American College of Surgeons (American College of Radiology, 2015 and American Cancer Society, 2013). The United States Preventive Task Force (USPSTF) challenged this recommendation in 2009 recommending that biennial mammography screenings should be deferred until the age of 50; mammography before the age of 50 should be individualized (USPSTF, 2016).

These screening recommendations could have an adverse effect on women with more aggressive types of cancers at a younger age, particularly AAW. Based on the available statistical information, the recommendations for breast cancer screening would place AAW at a disadvantage. Dolle et al. (2009) found that AAW are more likely to be diagnosed with advanced stages of breast cancer before the age of 45 as compared to

their White counterparts. Bauer, Brown, Cress, Parise, and Caggiano (2007) determined that the odds of having a more aggressive breast cancer increases at a younger age; women under the age of 40 years are 1.53 times more likely than women ages 60-69 years to be diagnosed with TNBC, however AAW are twice as likely (Bauer et al., 2007),

Mammography coverage under the ACA depends on the type of health insurance plan. The law requires that those covered by Medicare receive a mammography screening annually beginning at the age of 40, and those with private insurance every one to two years (U.S. Department of Health and Human Services, 2013). Early breast cancer detection through screenings provides for the most beneficial health outcomes. Amirikia et al. (2011) found that mammography screenings resulted in an average gain of 33 life years per 1,000 women. In addition, early detection can mitigate the effects of metastatic disease. The current screening recommendations under the ACA have a potential to widen the healthcare disparities gap for those most affected by more aggressive forms of breast cancer; AAW under the age of 40.

Hormones, Pregnancy, and Lactation

Pregnancy, hormones use, and breastfeeding practices have all been implicated in discussions surrounding breast cancer risk. Studies have suggested an increased risk among women that have not participated in breastfeeding, that have higher circulating levels of hormones, and fewer births. Researchers have hypothesized that breastfeeding practices and parity across racial lines contribute to breast cancer disparities.

Palmer et al. (2014) conducted two cohorts and two case-control studies of AAW with breast cancer. The data analysis was based on four epidemiologic studies: 1) Black Women's Health Study (BWHS), 2) Multiethnic Cohort Study (MEC), 3) Carolina Breast

Cancer Study (CBCS), and 4) Women's Circle of Health Study (WCHS). The cases included ER+ (n=2,446), ER- (n=1,252) and triple negative receptors (n=567). There were 14,180 control patients; participants ranged in age from 21 to 69 years. Findings revealed that multivariable OR for ever-parous versus nulliparous in relation to ER+ breast cancers were .92 (95% CI=.81 to 1.03); lactation was not connected to a reduced risk. ER- breast cancers were linked to parity (multivariable OR= 1.3, 95% CI 1.11 to 1.59; this risk increased with additional births. Lactation was associated with a reduced risk of ER- breast cancers (OR .81, 95% CI= .69-.95). Among the TNBC cases, ORs were 1.37 (95% CI 1.06 to 1.79) for ever parous versus nulliparous, and .81 (.65 to 1.02) for ever versus never lactation.

Palmer et al. (2014) analyzed the combined effects of parity and lactation and breast cancer types. There was an increased incidence of ER- cases among parity women who had never breastfed. There was not a link between parity and lactation among TNBC cases; however, there was an increased risk among women that had four or more births and had not breastfed. Overall, the study concluded that parous AAW have a 33% higher risk of ER- breast cancers and 37% higher risk of TNBC when compared to all nulliparous women. Women in the study that breastfed had a lower risk of ER- and TNBC. The study was not able to address what length of breastfeeding is required to decrease risk or how weaning practices influence lactation glands.

The Collaborative Group on Hormonal Factors in Breast Cancer (2002) collected data on breast cancer and breastfeeding practices from 47 epidemiological studies across 30 countries. The findings from the study determined that women with breast cancer had fewer births when compared to the control group. The relative risk of breast cancer

decreased by 4.3% (95% CI 2.9-5.8; $p < 0.0001$) for every 12 months of breastfeeding, and a decrease of 7.0% for every birth. The study concluded that the incidence of breast cancer in developed countries would decrease from 6.3 to 2.7 per 100 women if women had larger families and breastfed longer.

Phipps, Malone, Porter, Daling, and Li (2008) conducted research in which they pooled two population-based, case-control studies of women 55 to 79 years to determine reproductive and hormonal risk factors for breast cancer. The analysis included 1,023 cases of luminal breast cancer cases, 39 cases of HER2-overexpressing breast cancer and 78 cases of TNBC. The study concluded that the risk of luminal (ER+) breast cancer was decreased among women who went into menopause secondarily to surgery when compared to women who had a natural menopause; and was higher for women who experienced menopause later in life. Among the women who had breastfed for greater than six months, a lower risk of both luminal and TNBC was observed. In addition, women who were using estrogen and progestin hormones experienced an increased risk of luminal cancers. There was no statistically significant link between HER2-overexpressing or TNBC and menopausal age, menopause status, or hormone therapy.

This study was limited by the numbers of HER2-overexpressing and TNBC cases; 39 and 78 cases respectively. AAW in the study were represented by comparatively small sample sizes; luminal cases ($n=17$), HER2-overexpressing cases ($n=2$) and TNBC cases ($n=3$). Finally, it was pointed out that multiple laboratories were used to classify tumors which created an opportunity for misclassification errors.

Obesity and Stress

Obesity is increasingly becoming a risk factor for many illnesses; studies have suggested body mass index (BMI) can increase the risk of certain subtypes of breast cancer. Munsell, Sprague, Berry, Chisholm, and Trentham- Dietz (2014) conducted a meta-analysis of 89 epidemiological studies to determine the relationship between BMI, menopausal state, and breast cancer. In pre/postmenopausal women, there was an association between BMI greater than or equal to 30 kg/m² and ER+ / PR+ breast cancer. The associated risk between ER+ /PR+ breast cancer and greater BMI was increased among postmenopausal women when compared to premenopausal, RR= 1.39, 95% CI: 1.14-1.70 and RR = .78, 95% CI: 0.67-.92 respectively.

Chen et al. (2016) conducted a population-based case-case study to determine how anthropometric factors influenced breast cancer risk. The study included 2,659 women 20-69 years of age, which were diagnosed with breast cancer between 2004 and 2012. Study findings revealed a positively associated risk among TNBC, increased BMI/weight and premenopausal women. An opposite effect was noted in postmenopausal women with TNBC and HER2-overexpressing tumors. For every 5 kg/m² increase in BMI, postmenopausal women had decreased risk of 9 % for TNBC tumors and 16% for HER2-overexpressing tumors.

Other studies have suggested that an increased BMI is just a contributing factor to breast cancer incidence among postmenopausal women. The Endogenous Hormones and Breast Cancer Collaborative Group (2003) found that the associated risk of breast cancer among postmenopausal women with increased BMI was correlated to elevated estrogens. Obesity and an elevated BMI have also been implicated in the metastasis of

breast cancer. Sheean, Kabir, Rao, Hoskins, and Stolley (2015) conducted a pilot study to determine the effects of obesity and metastatic breast cancer. Among the study participants, 56% were classified as overweight or obese and another 44% were concerned with increasing weight. This study pointed out that weight gain is seen as a modifiable risk factor for the development and spread of breast cancer. The information provided in these studies point to a need for nutritional and lifestyle management to curtail the effects of weight gain among women who are at risk for breast cancer.

Stress has been implicated in many illnesses such as high blood pressure, cardiac disease, and other disease processes (Diez et al., 2009; Djuric et al., 2008; Schulz et al., 2000; Seaton, Caldwell, Sellers, & Jackson, 2010). Not only has stress been shown to trigger and exacerbate the disease process, it has been shown to negatively affect life expectancy and aging through cellular structure modification. Diez et al. (2009) and Lyon, Starkweather, Montpetite, Menzies, and Jallo (2014) found that telomeres, a deoxyribonucleic acid (DNA) segment, can be used as a biomarker for aging and stress-related disease processes. Telomeres protect the DNA structure against the loss of genetic material and prohibit cellular fusion during cellular division; this protective process maintains telomere length (Blackburn, 2011). When exposed to certain influential factors, the telomeres shorten in length and the DNA structure becomes unstable which enables apoptosis (Lyon et al., 2014). Oxidative stress, psychological health, and perceived stressors are a few of the factors that have been shown to affect telomere length (Diez et al., 2009; Lyon et al., 2014). Epel et al. (2004) found that premenopausal women with the highest levels of chronic perceived stress had shorter telomere lengths. Even more significant is the plausibility of an intergenerational effect

of stress on telomere length. Entringer et al. (2011) demonstrated that stress exposure during intrauterine life resulted in shortened telomere length in adulthood, which is an important factor in understanding development of disease.

Evolving research has suggested that there may be a link between psychological stress and the development of breast cancer. According to Antonova et al. (2011), stress induced by life events is more consistently associated with breast cancer; this link is thought to be associated with the biological role of stress signaling in mammary glands. Price et al. (2001) demonstrated that women experiencing highly threatening stressors without social support had a nine-fold increase risk of developing breast cancer. Catecholamines, which are released under stressful conditions, are found to be consistently elevated in non-stressful situations among women with a family history of breast cancer (James, Van Berge- Landry, Valdimarsdottir, Montgomery, & Bovbjerg, 2004). Psychological stress has also been shown to reduce the efficacy of chemotherapeutic agents and thereby promoting metastasis (Su et al., 2005).

AAW living with breast cancer are faced with unique forms of psychological stress which are propagated by living in the oppressive intersection of society. Mc Gibbon (2012) states, “Since oppression by definition is deeply embedded in systemic ruling relations, the results of oppression are persistent and toxic for the mental, physical and spiritual health of oppressed people” (p. 31). Taylor et al. (2007) found that perceived racism was associated with a higher incident of breast among AAW; the association was highest among AAW 50 years of age or younger.

Schulz et al. (2000) conducted a study among AAW and White women 18 years or older who cared for children 18 years or younger for at least five days a week. The

study focused on the relationship of socioeconomic status, experiences of unfair treatment and acute life events by race and residential location, and the cumulative effects on health outcomes. The results indicated that regardless of residential location, AAW experienced statistically significant poorer health, ($p < 0.01$). When comparing everyday unfair treatment and acute life events, there was a negative association with general health among AAW. This study points out a need for social policies to counteract the effects of stressors and the imbalance of power, which result in health disparities.

Summary

Historically the incidence of breast cancer has been highest among White women. In 2012, the incidence of breast cancer among AAW and White women converged and was higher for AAW in seven Southern states (DeSantis et al., 2015). The mortality rate for AAW was 42% higher when compared to White women (DeSantis et al., 2015). AAW were also shown to present with metastasis more often than White women; 24% and 18% respectively.

The amount of research surrounding breast cancer and disparities is vast and provides insights on the traditional risk factors; socioeconomic status, access to care, mammography screening, hormonal use, genetics, obesity, and lifestyle choices. However, more recent statistics demonstrate that despite the available research the breast cancer disparity gap for AAW continues to grow. There are limited studies on how psychological stress connected to oppression impacts the incidence and prevalence of breast cancer among AAW. The psychological effects of stress and oppression offer a new lens in which to view breast cancer disparities. In addition, the available studies on psychological stress and its relationship to breast cancer are narrow in scope and involve

a limited number of AAW. A qualitative study would provide an opportunity to analyze how the mind and body merge to influence breast cancer disparities. Investigating the multiplicative effects that intersectionality has on the psychological well-being of AAW with breast cancer would provide a more ethnocentric comprehensive perspective.

Chapter 3

Methodology

“Zu den Sachen”

“To the things themselves”

(Edmund Husserl 1859-1938, German philosopher)

This chapter details the methods that will be used to study the lived experience of intersectionality among AAW that have been diagnosed with breast cancer. The purpose of this study is to capture essences of how race, gender, and class interlock to create a worldview among AAW with breast cancer. The discussion begins with an overview of the research design and continues with procedures for sample selection, data collection, and data analysis. The discussion will conclude with rigor and ethical considerations.

Research Design

Well defined in the literature are studies that explicate how intersectionality impacts AAW in both the political and legal systems. There is limited research on how AAW with chronic illnesses have experienced and interpreted their experiences within the intersection of society. To capture the essence of intersectionality, a qualitative study design will be used to garner knowledge on how AAW with breast cancer perceive and process intersectionality.

Method

An inductive qualitative design using a descriptive phenomenological approach based on the philosophy of Edmund Husserl was used in this study. Inductive qualitative designs are used to explore and understand the meaning of behavior among individuals and groups. Qualitative designs should be used to change the lives of individuals that are

marginalized or are confronted with oppression, domination, suppression, alienation, or hegemony (Creswell, 2013). A qualitative design was ideal for exploring the concept of intersectionality among AAW with breast cancer.

A descriptive phenomenological approach was used to capture commonalities and give structure to the lived experiences of intersectionality among AAW with breast cancer. The lived experience is captured within four existentialisms: temporality (time), spatiality (space), corporeality (body), and relationality (human relation) (Van Manen, 1997). To fully understand the concept of intersectionality it is necessary explore how this phenomenon is situated in the lives of AAW.

The phenomenological approach is a method for investigating consciousness and the types of objects that present themselves to the consciousness (Giorgi, 2009). Phenomenology is rooted in the philosophical perspectives of Edmund Husserl (1859 – 1938). The Husserlian paradigm is based on the intentionality of the consciousness (awareness) and the invariant structure (essence) of any given experience (Creswell, 2013). Scholars attempting to capture or utilize the tenets of intersectionality have struggled with how to operationalize the overlapping categories; others have debated over how to categorize intersectionality-theory vs. paradigm vs. conceptual framework (Hankivsky & Christoffersen, 2008, Hankivsky et al., 2010).

Amedeo Giorgi's (2009) method of phenomenological analysis will be used to conduct the data analysis. Giorgi's (2009) approach utilizes a step-by-step process to develop an eidetic picture (general structure) of phenomena under study (Smith et al., 2009). The eidetic picture that emerges through this approach will facilitate operationalization of the phenomenon of intersectionality.

Important and necessary in this descriptive study is the “epoche” or phenomenological reduction. Phenomenological reduction also known as “bracketing” is a process in which the researcher brings to consciousness any potential judgements or past experiences that would lead to misinterpretation of the data (Giorgi, 2009). According to Giorgi (2009), two forms of reduction are necessary: transcendental and eidetic. Transcendental reduction is an attempt to view objects in their pure form, whereas eidetic reduction is an attempt to reduce an object to its essential elements (essence).

Giorgi outlines the original four steps which are required when conducting a descriptive phenomenological analysis to the data collected from the interviewing process of a qualitative study (Giorgi, 1975):

- 1) Get a sense of the whole while incorporating phenomenological reduction or “bracketing”.
- 2) Determine “meaning units”, reading and re-reading to identify “experiences”.
- 3) Interrogate the data in terms of the specific purpose of the study; acknowledge any presuppositions.
- 4) Making the implicit explicit developing themes (p. 82-103).

These four steps will be used to guide the study and elucidate the phenomenon of intersectionality.

Overarching Research Question

How do AAW with breast cancer perceive their racial, gender, and class identities impact their lived experience?

Sample

In contrast to quantitative studies in which the research is looking for variation in empirical data to answer a research question, the goal of qualitative research is to identify commonalities. With this goal in mind, the participants for a qualitative study are selected based on predetermined criteria that have been identified by the researcher (Holloway & Wheeler, 2010). Two methods of sampling in qualitative research were used in this study: purposeful and chain referral. Purposeful sampling involves choosing participants or settings that most accurately reflect the phenomenon under study (Richards & Morse, 2013a). Chain sampling is a method that is useful in studies in which participants are difficult to access or recruit (Holloway & Wheeler, 2010). The sample size was homogenous and therefore 10 subjects were used for this study. The projected sample size was sufficient to reach theoretical saturation from the information collected. Theoretical saturation is the point in the data collection process where no new concepts, themes, or categories can be identified (Holloway & Wheeler, 2010). Theoretical saturation is important to ensure that the essence of the phenomenon is captured accurately. All participants completed the interviewing sessions, therefore no additional participants were included.

It is imperative in qualitative phenomenological research that theoretical saturation is achieved. Theoretical saturation is achieved by the collection of rich and thick data. Theoretical saturation can be accomplished through a small sample size that has well established participant inclusion criteria. For this study, the criterion was: 1) being of African American ethnic origin, 2) having a diagnosis of breast cancer, 3) female, 4) being 30-80 years of age, 5) being clear of mental/physiological impairment

that would interfere with the ability to participate in the interview/data collection process and 6) being able to give consent. All participants completed demographic information on education, social economic status, family structure, and health history.

Sample Access

The success of any study is contingent upon access to participants that meet the selection criteria and are willing to participate in research. Even more critical to qualitative research is that participants are open and have a willingness to share their experiences. The historical tie that African Americans have to research has created major barriers to recruitment and participation in studies. Many African Americans mistrust scientists and require relationship building over an extended period of time to establish trust (Adderley-Kelly & Green, 2005; Kelley, 2011). Mouton, Harris, Rovi, Solorzano, and Johnson, (1997) found that 33% of AAW agreed that scientists cannot be trusted, only 4% of White women shared the same view. Additionally, AAW had a higher preference for an African American scientist than White women; 37% and 4% respectively (Mouton et al., 1997).

In order to gain access to participants, the researcher must develop a partnership with community leaders. Moreno-John et al. (2004) suggests that going to the community rather than having participants go outside of the community is an ideal strategy for recruitment of minority participants. Pastors from local African American churches, proprietors of African American hair salons, and health organizations in the African American community were approached to gain access to study participants. Formal meetings or presentations were conducted to 1) outline the purpose of the study, 2) identify strategies for recruitment, 3) identify strategies for maintaining confidentiality,

and 4) review dissemination plan of findings. After obtaining permission to recruit participants, informational flyers (Appendix A) were posted in designated organizations. The flyers contained a brief description of the study, inclusion criteria, and the researcher contact information.

Data collection

The concept of intersectionality is esoteric in nature and is best suited for a semi-structured interview process. Semi-structured interviewing allows for some flexibility as the interview protocol is used to focus the interviewing process and can be modified in subsequent interviews as different ideas arise (Holloway & Wheeler, 2010). Following informed consent, demographic data were collected (Appendix B). The researcher then conducted private interviews that were digitally recorded. The interview protocol contained in Appendix C was designed to garner a deeper understanding of the participants' thoughts and feelings regarding the central phenomena of the study. Each interview is estimated to be 60 to 90 minutes in length. The interviews were conducted in-person at a mutually agreed upon location; a phone interview was made available if the researcher and participant were not able to find an agreeable location to meet. The interviews were recorded to facilitate recall and accuracy of information. At the conclusion of the interviews, additional data regarding the setting, body language, facial expression, and initial impression were captured in the form of note taking. If participants did not agree to the digital recording process, a manual transcription process was utilized.

Prospective candidates were supplied with the researcher's contact information by means of study flyers. Upon request by prospective candidates, additional study information was provided. Candidates were informed that the interviews would be

digitally recorded and transcribed to ensure accuracy. Contact information was obtained from candidates that voiced a desire to participate in the study. During follow-up conversations, arrangements were made to conduct the interview process. Participants received nominal remuneration for their time at the completion of the interview.

Prior to beginning the formal interviewing process, the researcher reviewed the purpose of the study, risks, and allowed time for questions. Participants were reminded that the interview is a voluntary process and could be stopped at any time. Participants were made aware of local and national healthcare resources that could support mental health services to help mitigate any emotional stress.

Informed Consent

Prior to beginning the interview sessions and in compliance with the Institution Review Board (IRB), the researcher provided an explanation of the study and consent process. Each participant was encouraged to ask questions; the researcher confirmed the participants' understanding of the study. Following the question and answer period, participants were given a copy of the consent to review and sign (Appendix D). Participants were reminded that the process is completely voluntary and they could withdraw from the study at any point. Finally, participants were given a copy of the signed consent.

Protection of Human Subjects

After obtaining IRB approval from the University of San Diego, participants were enrolled in the study (Appendix E). Once the candidate agreed to participate in the study, demographic information was obtained. Each participant was made aware that the study process may raise some emotional issues and was given information to seek assistance

from local health national care professionals. To maintain confidentiality during the digitally recorded interview sessions, participants were asked not to use their names.

The digitally recorded sessions were transcribed precisely by a trained transcriptionist and will be retained for a period of four years. To ensure confidentiality, the identity of the participants was protected through a coding process and any descriptors that could be identifying was removed. Each form, field note, and digital recording from the interview sessions was given a numerical identifier. A key which matches the subject's name to the corresponding numerical identifier was kept in a locked location and a password protected computer was used.

Data Analysis

The phenomenological method is an analysis of phenomenon of the consciousness, how phenomenon is experienced by the individual, and what experiences emerge to form the structure of a phenomenon (Giorgi, 1997, Koch, 1995, Wojnar & Swanson, 2007). Giorgi's 2009 descriptive phenomenological approach involves a step-by-step analytic procedure to understanding the meaning of human experiences. Giorgi (2009) finds that descriptive analysis attempts to capture phenomenon based only on what is presented in the data and does not go beyond what is given. In contrast to interpretive analysis, gaps in descriptive data are filled by collecting more data, not by theoretical speculation (Giorgi, 2009).

Giorgi has described his method as a modified Husserlian approach which performs phenomenological analyses that are relevant for psychology; Husserlian analysis is rooted in philosophy (Giorgi, 2009). Giorgi's method requires two attitudinal shifts: 1) a scientific level of analysis as opposed to a philosophical level and 2) the

analysis needs to be psychologically sensitive and not philosophically sensitive (Giorgi, 2009). A phenomenological psychological method, as Giorgi (2009) termed it, is responding to combination of philosophical phenomenology, a human science perspective and psychology.

In order to begin the steps of analysis, the researcher needs to be present within the context of the phenomenological approach. The researcher needs to regard all observations from the perspective of how they are experienced regardless of whether or not they are actually the way they are being experienced (Giorgi, 2009). Giorgi defined a modified version of the three concrete steps required to conduction descriptive analysis: 1) read for the sense of the whole, 2) determination of meaning units, and 3) transformation of the participant's natural expressions into phenomenologically psychological sensitive expressions (Giorgi, 2009).

The first step of phenomenological data analysis was to “get a sense of the whole” while incorporating phenomenological reduction (Giorgi, 1975, 2009; Koch, 1995; Smith, 2016; Wojnar & Swanson, 2007). Reduction, also termed bracketing or epoche, requires that the researcher set aside previous experiences, knowledge, or judgement regarding the research topic. Bracketing allows the researcher to view data as new and removes any prejudgments (Holloway & Wheeler, 2010). The goal is to be objective about the data and put aside any presuppositions. Getting a sense of the whole was achieved by listening to the interviews repeatedly and re-reading the transcripts several times. During the reviewing and re-reading process, highlighted notes were placed on the transcripts margins regarding the changes in emotions, expressions, and intonation of the participants' voices. The transcribed interviews were compared to digital voice

recordings for accuracy. The goal of this step is for the researcher to read the data and get a sense of the “whole” while sensitively discriminating the intentional objects of the lifeworld description provided by the participant (Giorgi, 2009).

Due to my own lived experience, it was critical that phenomenological reduction was employed throughout the study. My experiences as an African American woman could have significantly biased the outcome of the study. I am aware of the historical struggles that AAW have encountered and shared some of the same lived experiences. However, for this reason, a descriptive approach, which employed bracketing, was chosen over an interpretive approach as not to negatively impact the lens through which the research was viewed.

The second step of phenomenological data analysis was determination of “meaning units”, reading, and re-reading to identify “experiences” (Giorgi, 1975 and 2009). The goal of this step is to identify parts (meaning units) within the description that correlate with the phenomenon of intersectionality. The meaning units are developed with the attitude of the researcher and therefore the researcher must assume an attitude of phenomenological reduction and be mindful of the phenomenon under investigation (Giorgi, 2009). To begin the process, while meticulously examining for a shift in the text for meaning, each of the transcribed interviews was re-read from the beginning. A slash mark was placed after sections of text that demonstrated a transition in meaning. The end result of this process was the identification of smaller parts of the phenomenon that is subjective in nature, as they are presented in the participants’ own words.

The final phase of this analytical process was the transformation of the participants’ natural attitude expressions into phenomenological psychologically sensitive

expressions. The natural attitude expressions can be described as reflections of an “ordinary” or “everyday” way of being in the world (Applebaum, 2012). This final step is time consuming and the result is a precise description of the features of the experienced phenomenon as they present themselves to the consciousness of the researcher (Giorgi, 2009). In this step, the researcher returned to the meaning units to scrutinize each meaning unit to define the psychological implications of the lived experience. During this phase, the researcher looked for invariance of the variable meaning and generalizability of the data to develop phenomenological structure (Giorgi, 2009). This phenomenological structure allowed the researcher to understand how living in the intersections of society shapes the lived experiences of AAW with breast cancer. The success of this method requires that the researcher maintain an attitude of phenomenological reduction, sensitivity to the phenomenon under study during the identification of meaning units which will result in a general structure of the experience (Giorgi, 2009).

Trustworthiness

In quantitative research, there are test instruments that can be used to test reliability and validity. In a qualitative study, the researcher *is* the instrument and therefore the study can be influenced by the researcher’s experiences, emotions, and prior knowledge. Trustworthiness is a parallel term used to discuss rigor in qualitative studies. Lincoln & Guba (1985) determined that credibility (internal validity), transferability (external validity or generalizability), dependability (reliability), and confirmability (objectivity) are necessary to establish trustworthiness. The literature is unclear if all the steps are required to establish trustworthiness (Morse, 2015). Creswell (2013)

recommends that the researcher employ at least two of the aforementioned strategies to establish trustworthiness.

Lincoln & Guba (1985) consider member-checking to be the most important feature of trustworthiness. Member-checking is used to establish credibility; participants are allowed to review the completed analysis with a goal of providing insight and ensuring accuracy of the information. However, member-checking can be awkward for the researcher and may impact the outcome of the study or may delay the final analysis; for these reasons, it is not recommended (Morse, 2015). Triangulation is an alternative method for determining credibility (Lincoln & Guba, 1985). Credibility under this method is established through the use of various sources, theories, and investigators to corroborate themes of a study (Creswell, 2013; Morse, 2015).

Validity, reliability, and stability of the research findings are addressed through the establishment of dependability (Lincoln & Guba, 1985). Dependability is established through the use of an audit trail and includes an external auditor. The audit trail provides a process for the researcher to validate study findings through the use of tangible data. The auditor examines whether or not the analysis and conclusion is supported by the data (Lincoln & Guba, 1985).

Confirmability refers to the degree to which the findings can be confirmed or reproduced. Confirmability uses strategies of triangulation and the audit trail (Morse, 2015). If this approach is selected to ensure trustworthiness, the researcher should document the steps used to check data throughout the study. The triangulation process and audit trail will support the establishment of confirmability in this study which will establish trustworthiness.

Finally, transferability is a process for ensuring generalizability or external validity of the study (Lincoln & Guba, 1985). The researcher develops thick descriptions through the synthesis of data collected through the interviewing process, field notes, and observations. Thick descriptions allow others to transfer the findings to additional settings or studies. In order to achieve generalizability, validity, and abstraction (theme development), there must be consistency between the researcher's observations, reports from the participants, and information in the literature (Richards & Morse, 2013b). To ensure transferability, a semi-structured interview process with open-ended questions was used as guidance and to facilitate an open dialogue; probing questions were also incorporated to garner thicker, richer descriptions.

For this study, the researcher maintained clear, concise notes and an inventory of the data that was collected. This audit trail process will facilitate future examination of the information collected if an external evaluation of the research process is required. As a final step to ensuring trustworthiness during the study, a dissertation committee was used to provide guidance and feedback through the research process.

Ethical Implications

The historical connection between the African American community and healthcare raises many concerns with trust. As with any study, informed consent was obtained and documented. There was a full IRB approval, which included a full detailed description of the study. All participants had a clear understanding of the study and were given assurance that their identities and the information gathered will be protected. The data gathered will be kept secured and the demographic information will be kept separate. Memos, notes, and jottings were de-identified and coded to maintain confidentiality.

Caution was taken to represent the data as intended to the highest degree possible; misrepresentation of published data could result in further mistrust amongst the African American community and impeded future research efforts.

Chapter 4

Data Findings and Analysis

The purpose of this descriptive phenomenological study was to capture the lived experience of intersectionality among AAW with breast cancer. This study was an attempt to fully understand the essential elements of the concept of intersectionality among AAW with breast cancer. Giorgi's 2009 method, a modified Husserlian descriptive phenomenological approach, was used to identify themes that characterize how intersectionality manifests in the consciousness of study participants. As part of the research process, eidetic reduction was employed to develop an invariant structure of intersectionality among study participants. Data were gathered through nine, one-on-one digital voice recorded phone interviews and one in-person interview. Each of these interviews lasted between 60 and 90 minutes and was guided by open ended semi-structured questions. The time varied depending on how much information was offered by the participants. The interviews were subsequently transcribed by a transcription service, which were then reviewed for accuracy and completeness by the researcher.

The Sample

The sample consisted of 10 AAW females with a self-reported history of having been diagnosed with breast cancer. The stages of their disease varied from stage I to stage III; there was an equal representation of stage II and stage III breast cancer participants, with 40% in each category. Forty percent of the participants had a maternal family member that had been diagnosed with breast cancer. The time that had elapsed since receiving their diagnoses varied from less than a year to greater than 10 years. These women ranged in age from 41-80 years, with 50% between the ages of 51- 60 years. The

participants resided in various geographical regions of United States; 80% from the Southwest region and 10% from each of the Midwest and Southern regions. Table 1 provides a complete overview of the participant data.

Table 1
Participants Demographic Information

Characteristics	N	%
All Study Participants		
Age		
40-50	2	20
51-60	5	50
61-70	2	20
71-80	1	10
Breast Cancer (BC) Stage		
I	2	20
II	4	40
III	4	40
IV	0	0
Diagnosis Years		
<1	1	10
1-5	3	30
5-10	3	30
>10	3	30
Family Member with BC		
0	5	50
1	2	20
2	2	20
UNK	1	10

The study began with a collection of demographic information, which included information on psychosocial status. All participants reported having family, friends, or children that provided strength or support during their breast cancer “journey”. The majority of the participants were employed when they were diagnosed with breast cancer (80%); with average annual income ranging from less than \$20,000 to over \$100,000. The majority of the participants describe their health status as “very good” (70%), 50% were currently in a relationship, and all of the participants had children. Sixty percent of

the participants described having ended or not in a relationship near the time of receiving the diagnosis of breast cancer. Nearly all of the participants described feeling “stressed” at least once a month (80%); however only 30% felt depressed during any one month period. Table 2 provides additional psychosocial data.

Table 2
Psychosocial Demographics

Characteristics	N	%
Relationship		
Single	3	30
Married	4	40
Divorced	1	10
Separated	1	10
Widow	1	10
Children		
1-2	6	60
3-5	4	40
Employment status		
Employed	4	40
Student	1	10
Working student	1	10
Retired	3	30
Yearly Income		
< \$20, 000	3	30
\$20,001-\$40,000	0	0
\$40,001-\$60,000	4	40
\$60,001-\$80,000	2	20
\$80,001-\$100,00	0	0
>\$100,000	1	10
Education		
High Grad	1	10
Some College	4	40
College Grad	5	50
Times stress/month		
0-1	2	20
2-3	6	60
>4	2	20
Times depressed/month		
0-1	7	70
2-3	2	20
>4	1	10
Health Status		
Excellent	0	0
Very Good	7	70
Fair	3	30
Poor	0	0

Discovery of Themes

Each interview began with the question, “Can you tell me a little bit about yourself?”. An interview protocol was used to guide the process and probing questions were used to garner more comprehensive, deep responses from the participants. Rubin and Rubin (2012) state, “Probes are used to clarify, regulate the length of answers, fill in missing information and keep the conversation on topic” (p. 139). The responses to this question varied in details and probes such a “Can you tell me more about that?” and “How did that make you feel?”. The first participant chose to respond to the question at the point of receiving her breast cancer diagnosis:

***Participant 1:** When I found out I had it I was driving and I had to pull over to the side of the road. The doctor said he needed to tell me something so I went right over to his office.*

This was the first participant; responses were brief and required extensive probing throughout the interview process. The researcher surmised the participant was feeling uncomfortable with the process, so the researcher made an adjustment. For subsequent interviews, the researcher’s position as an insider was utilized to facilitate the interview process. The role of insider can be helpful in crossing cultural boundaries, place the interviewee at ease, and remove communication barriers (Rubin & Rubin, 2012). For the remaining interviews, all participants were informed that the researcher was an *African American* student. Following this adjustment, one participant responded to this question:

***Participant 8:** “I am an African American female that grew up in Los Angeles my grandparents were part of my upbringing; I knew my father but he was not part of my life. I have two siblings a brother and a sister. I am 26 years older than my brother; many people he was my son. The age difference was taxing on my mother. I knew my father but he wasn’t around but I knew who he was; I later developed a relationship with him. I am currently going through a divorce.”*

Another participant responded:

Participant 7: *“I am an African American woman that grew up in New Orleans. I was raised by both of my parents my mom died at the age of 43 from an aneurysm; I have two siblings a sister and a brother. My mother’s death really affected me emotionally as we were very close. I don’t think I received any advice on being a Black woman because my mother was not there.”*

This minor adjustment in the data collection approach created a trusting environment for participants to share their experiences.

Breast Cancer Diagnosis

Each participant’s breast cancer journey varied based on their belief systems, family responsibilities, or professional obligations. Participants were asked to describe their experiences after receiving the diagnosis of breast cancer. The experiences in dealing with the diagnosis of breast cancer varied from *“feeling lucky”* to *“devastation”*.

One participant, although she felt *“lucky”*, had trouble processing receiving the diagnosis:

Participant 1: *“I had to prepare myself for what the doctor was going to say, when he told me I had it, it did not hit me. So I thought what I could do about it; there was nothing I could do to change the situation. I had good doctors I was lucky, one lucky Black woman.”*

Two of the participants described feeling *“blessed”* but each provided a different explanation for this emotion:

Participant 4: *“I feel that getting cancer was a blessing; I feel like I was meant to spread the word to younger women; every year I spend time with my daughter’s cheer club talking about breast cancer. I enjoy working with teenage girls and they open up to me. I feel like I was meant to spread on the knowledge about breast cancer.”*

Another participant stated:

Participant 8: *“I felt blessed to be diagnosed with breast cancer early so they could get it out; everything happened so fast.”*

All of the participants described themselves as having “*routine*” check-ups with healthcare providers or “*regular*” mammograms or practicing self-breast examines. For those that had a family history of any form of cancer, they described being “*on the lookout*” or “*I knew it was going to happen*”. Many of the participants described feeling “*shocked*”, “*afraid*”, “*devastated*”, or “*in denial*” at some point in their breast cancer journey:

Participant 2: “*I was in denial because we were dealing with my father having cancer and I thought this could not be happening now, my father has cancer.*”

Another participant stated that “*even though my mother had breast cancer*”, because of her faith, chosen life style and routine exams she did not expect to have breast cancer:

Participant 3: “*I was devastated to find out that I had breast cancer, my mother had it and because of that my sisters and I were always on the lookout. I had faith in God that I would not get it; I was consistent with my mammograms and pelvic exams. I thought it would be alright.*”

Another participant stated:

Participant 7: “*I was very upset when they told me; I did not understand I always took care of myself. I thought the diagnosis of cancer was odd. So I questioned the nurse asking her how could I have cancer; the doctor told me that I was lucky to have caught it early; I cried.*”

Feeling “*stressed*” was common among all of the participants, with the exception of one. Participants described feeling stress related to family responsibilities or work obligations. Those that had additional family responsibilities expressed feeling stress with the added responsibility of having breast cancer.

Participant 10: “*I remember feeling shocked and then began to feel the stress of worrying about my daughters; I needed to be here for them. Who was going to take care of them if I am not here?*”

Another participant with family concerns stated;

Participant 2: *“It was very stressful that I have cancer I was trying to take care of my father; it is still stressful the whole family was stressed trying to take care of my father.”*

Participants that provided financial support to the family or were sole source of income, expressed “worry” or “feeling stressed” related to job security or having “time on the books” to take off for treatment.

Participant 3: *“I thought I would be able to receive some sort of financial help from one of the breast cancer organizations, but I did not. My family told me not to work, but I did not have enough time on the books. There were too many hurdles and forms to fill out if I wanted any kind of help and I did not have the energy.”*

It was important to discuss out how receiving the diagnosis of breast cancer affected the psychological well-being of the participants in the study. The descriptions presented demonstrated a wide variety of emotions and experiences that altered each participant’s conscious reality.

Intersectionality

As described in earlier sections, intersectionality is a term used to describe how the socially constructed categories of race, gender, and class, merge to form interconnected systems of discrimination, disadvantage, and oppression. The data collected revealed a variety of emotions, perceptions, and issues associated with the phenomenon under investigation. The lived experiences of these women were as a whole similar, but processed in very dissimilar methods. This is in agreement with the intellect of BFT which espouses that there is a collectiveness among the lived experiences of Black women in the U.S., however, there is a component of individuality that each Black woman experience within the collective (Hill Collins, 2000). Using Giorgio’s (2009)

method for analysis, the data uncovered four essential themes that merge to form the invariant structure of intersectionality among AAW with breast cancer. These themes were: 1) altruism, 2) silent strength, 3) existential invisibility, and 4) marginalization.

Altruism

The first essence that was uncovered was the theme of altruism. Merriam-Webster describes altruism as “unselfish regard for or devotion to the welfare of others” (Merriam-Webster, 2017). Individuals that display altruistic behavior will act for the sake of others rather than for public recognition or internal well-being (Post, Underwood, Schloss, & Hurlbut, 2002). Most of the participants displayed altruistic behavior when asked, “What has it been like for you to have breast cancer”. Many of the women made choices or statements that indicated that their first priority was to others; in some cases, treatment was delayed.

***Participant 2:** “I did not want to worry my family so I kept it to myself. I found the lump earlier that year, but did not say anything to my doctor until almost near the end of the year.”*

***Participant 3:** “My family asked me not to work and take care of myself, I did not have any time on the books and I did not want to be a financial strain on my family so I continued to work.”*

***Participant 5:** “When I found out, I had a traumatic fear of not being her for my family or my kids.”*

***Participant 6:** “It was like a dream world, this could not be happening to me I am a mother, I have children.”*

When the participants were asked to provide a definition of discrimination, some of the participants displayed an additional element of altruistic behavior. The participants provided definitions that contained phrases such as, “not getting the same thing because of color”, “being treated less than” and “being treated differently”. However, in

providing examples to clarify the definition that were provided, the participants provided examples of how Black men are treated. This provided another example of how the participants acknowledged the concerns of others before their own.

***Participant 10:** “I feel there is a difference in how Black men are treated different versus Black women and that is tied to the police. I am glad I do not have a son, but I do worry about my daughters in an all-White school.”*

***Participant 1:** “it is what the police are doing to our Black men, shooting them for no reason or because they are Black. I wish there was something I could do, I makes me upset.”*

***Participant 4:** “My sons are African American men in this world, I am constantly giving them advice on how to present themselves to the police, and not to stop in dark abandoned places if they are stopped by the police.”*

It is interesting to note the participants that equated discrimination to poor treatment of Black men relate those experiences to encounters with law enforcement. This could be due to a heightened awareness surrounding highly publicized encounters between law enforcement and the African American community.

Marginalization

In social setting, marginalization is a result of oppressive, discriminatory behavior that is directed to non-dominated individuals within a group. Marginalization is a process of exclusion which relegates a group of people to the edge of society and is most often tied to race (Young, 2004). Marginalization results in decreased access to basic resources, powerlessness and exposure to disrespectful treatment (Young, 2004). The data analysis revealed two forms of marginalization: active and passive. In a situation of active marginalization, participants described, “*having to try harder*” for career advancement and in the classroom and “*feeling like they did not belong*” in social settings. In active marginalization, individuals are forced to the margins by the dominate group.

Participant 2: *“It occurred in the classroom with a Hispanic teacher; the teacher spoke in Spanish and I was the only Black in the class. “The teacher spent very little time explaining things to me; he was not interested in engaging me.”*

Participant 3: *“In corporate America being Black means doing more working longer hours, going above and beyond to prove you are worthy, getting passed over for promotions. White American still does not feel I am entitled to certain things because of the color of my skin. I am seen as a second class citizen.”*

Participant 8: *“I noticed when we are out in public White people move away from us or they cross the street when they see us coming. Like when you are in the elevator and the White women pull their purses closer, I remember pulling my purse closer to show them they are scary too, If I were White when I go out in public I would be acknowledge faster for the right reason.”*

Participant 9: *“When I first applied for my first job as a nurse, my instructor said there were three openings at a local hospital. My white classmate went in first. She was hired, by the way. I went in second. I was told - there’s no opening. The third girl went behind me, she was white, and she was hired right away. So, I said to my instructor there must be something wrong; you told me that there were three openings, but there’s only, only two, I was told.”*

Participant 10: *“As a person in academia I know, they do little funny things to the kids, the assignments they make them harder for minority kids, and the kids don’t even know they are being discriminated against.”*

In a situation of passive marginalization, participants would remove themselves from the dominate group in social settings. Most often, passive marginalization occurred in the work setting, but it also was a factor if participants wanted to seek out the help of organizations that provided psychosocial support for breast cancer patient. A few of the participants felt like they “*did not belong*” or were “*not valued*” at work or other social settings.

Participant 3: *“I don’t think those breast cancer support group are made for Black women, I don’t think they can relate to us, so I did not even bother trying to go.”*

Participant 9: *“I would leave the area for lunch and keep to myself just to have some peace and quiet. Black men are paid more than Black women, as it was explained to me Black men are the head of the household so they needed to make*

more money, I am the head of my household so why don't the same rules apply to me, I don't understand that rule."

Participants described feeling like they were pushed aside, ignored or treated differently during her breast cancer treatment:

Participant 5: *"I went to doctor after doctor for two years telling them to check me because there is something wrong and they just ignored me and said it was a cyst . . . I hate to pull the race card but and I don't know if it was a race thing, but some of them were very cold to me, one doctor told me to go home and tell my children and prepare to die."*

Participant 9: *"I guess the doctor did not realize that I was a nurse and he put the wrong type of sutures in and as a result I had a wound infection, when I found out what happened I confronted him about it."*

Participant 10: *"There was something on my mammogram, and I received a call to repeat the test and then when I arrived I was told never mind I did not need to repeat the test. So when I went back for my yearly mammogram, they caught it I think had I been."*

Participant 10 also shared description that contained elements of sexism:

"It was the plastic surgeon, I was crying and he said to me you should be happy many women want to have plastic surgery to get new breast and they can't and you did, and then he turned around and left the room."

As much as discrimination and oppression is a real part of the life-world of African Americans, if not directly perhaps indirectly, there were participants that stated, *"I am not bothered by it"* or *"have never experienced or seen discrimination"*. This was perhaps another form of passive marginalization; participants mentally removed or disassociated themselves from society's discriminatory, oppressive behavior.

Participant 1: *"I have not had any racist encounters; I am just an observer of how they treat our Black men."*

With additional probing questions regarding possible experiences with discrimination, participant 1 was noticeably distressed, *"don't question me about it"* and emphatically stated, *"I am a happy black woman, and I love being Black."*

Participant 7: “. . .you know I am a Katrina survivor, I have a cousin that is just angry about the whole thing she thinks it just happened to us but I don't it happened to everybody. I have just never been exposed to or have seen racism. I just don't think about things like that. I just don't deal with it.”

This participant also emphasized her pride in being a Black woman, “*I am just as good as anyone else*”; she repeated this statement several times. Both participants 1 and 7 responded in ways that would indicate the topic of discrimination, racism, or any form of oppression was and is not a factor in their everyday experiences. However, there was an obvious discomfort regarding the question, “*Have you ever experienced discrimination in your life*”?

Existential Invisibility

Participants in the study had a strong sense of the importance their presence played in their families and in other social settings. Even though the participants recognized the value of their presence, they described feelings of “*being ignored*”, “*not wanted*”, or “*overlooked*”. Existential invisibility is the term that was coined to explicate the feelings “*being ignored*” or “*overlooked*”, yet indispensable. For these participants, existential invisibility is defined as having significant human presence/significance while simultaneously being forced into social obscurity. Most of the participant encountered existential invisibility in work settings.

Participant 3: “*I was my boss's liaison for 5 years, he developed cancer and left I was sure I was going to be his replacement, but I was not considered for the position it went to a less qualified 30 year old White woman that had only been there 11 months I was crushed. Being Black in corporate America means doing more working longer hours just to prove you are worthy and then being passed over for promotions.*”

Participant 4: “*I feel like I would be further in my career if I was a White woman and I feel like I would have been given more opportunity at work. They always seem to put someone less qualified than me into positions. I feel like if I were a man it might have been a little different. It is very upsetting to me.*”

Participant 8: *“If I were not Black I would be acknowledged more for what I do at work, I would have already been promoted, I have to make myself seen if I were white I would be making more money.”*

Participant 10: *“They put more demands on me at work, but I am not given a chance to advance to the role of administrator.”*

Some of the participants describe being an integral part of the family structure. There was a sense or tone of *“this is what is expected”* from those around them. Their statements indicated that they accepted this family role without question. It was clear that without the efforts of these women, the family unit would have been impacted negatively. The women were accepting when talking about the extra duties or “expected” roles they played in the lives of their families; this was in contrast to the descriptions of their work environments.

Participant 3: *“I was very busy raising children mine and three of my sibling’s children, and my husband was in the military so I traveled with him where ever he went. It took me 7 years to get my bachelor’s degree, and that was because of all the traveling.”*

Participant 5: *“Men expected you to do .”*

Participant 6: *“Women take on more than men when it comes to the family we are expected to work, take care of the kids and deal with the other stuff around the house.”*

Silent Strength

There was a sense of needing to be strong or having strength to deal with distressing experiences that accompany life in the intersection of society. The strength these women have can be traced back the historical treatment of African Americans within the U.S.; AAW more often than not found it necessary to embody strength to survive and maintain the family unit. Silence is fundamental to this embody strength; silence was also linked to their altruistic behavior, *“I don’t want to worry my family so I*

keep it to myself". Participants described strength as being a necessary characteristic that was passed on to young AAW from the maternal figures in their lives. Silent strength was a virtue that was explicitly taught and passed on to the next generation or a behavior that was learned through observation.

Participant 2: *"Being a Black woman was a factor in my dealing with my cancer, because I had too many things to deal with, that is why I kept it to myself and delayed my treatment. Because I am the only girl in the family I have a lot to deal with including my sick mom."*

Participant 3: *"I wish I had someone to talk to when I was going through my breast cancer journey, it would have made a difference. African American women just don't share with their families because they don't want to worry them. I was not willing to share my emotions; I did not want my family to know how it was affecting mentally or physically. I did not want to share with my children, my brother and I are really close and I know he could feel my pain, but I just chose to keep everything to myself. You know I endured a very high level of stress in a previous relationship it was brutal and very violent, I never experienced anything like that; I am convinced that is where my cancer came from. I was told as a young girl be strong, be bold and brave and know what is expected out of you."*

Participant 5: *"I was sexually abused as a child, but I dealt with that secretly independently. I came from a strong person that taught me to be strong on my feet and I needed to be strong when I was growing up because my mother was only 16 when she had me. I used to walk around with my fist balled up and I stayed to myself. My step-father use to beat us; my mother did not say anything so I figured if she did not say anything then nobody would care so I kept it to myself; it became a shared suffering. I think she was more concerned with keeping a husband she was ashamed of having a child at a young age". Black women are expected to be strong take all that is thrown at them that is the difference between Black women and Black men, we are treated like a branch in the wind, like a weeping willow, just swing back and forth."*

Participant 6: *". . . my mother was the disciplinarian at home, I was one of five children, if there was punishment to be had it was my mother. My mother told me to be able to take care of myself, and I would tell young Black girls be prepared to go it alone, without a partner."*

Participant 8: *"I had a very strong grandmother, that I received guidance from on being Black women in America, she told me that things would be harder for me, she said that I would have to try harder, study longer."*

Participant 9: *“At work I was in charge of the skills training, they were always giving me a hard time, I had to train the doctors too, I think it was that they did not want to take orders from a Black woman. I would pray every morning before I went there and I would come in with a positive attitude. I didn’t let their meanness affect what I was there to do. So, I did a lot of ignoring. And they would say, say things. For instance, I had copied something out of a book, I put it back on my desk, when I came back it was gone, and no one, no one saw anything; no one knew anything. I found what I had copied about two months later, someone had put it behind a cabinet, and I knew who did it.”*

Participant 10: *“I feel like my greatest source of stress is my job they put more demands on me, but that is ok because I am made stronger by their behavior.”*

Summary

The data analysis revealed that the lived experience of intersectionality among the study participants influenced their perceptions of how they are perceived and situated in the world. The participants were transgenerational, from various regions of the country, and possessed different belief systems; however, there was a commonality in their life-world. The essence of the women’s experiences emerged as four distinct themes; 1) altruism, 2) marginalization, 3) existential invisibility, and 4) silent strength. The textual descriptions presented in this chapter provided a deeper understanding of life within the intersection of society for AAW with breast cancer.

Chapter 5

Discussion

The purpose of this phenomenological study was to explore and understand how AAW with breast cancer experience intersectionality. The researcher examined how intersectionality is perceived, processed, and effects mental health and potentially health outcomes. This chapter includes a discussion of the study results, limitations, and clinical implication. A conceptual framework, which outlines how the themes of altruism, marginalization, existential invisibility, and silent strength emerge to impact psychological and physiological health, is presented.

Breast Cancer

As pointed out in chapter one, breast cancer has traditionally been linked to hormone use, number of pregnancies, genetics, and lactation (Antonova et al., 2011; Key et al., 2003). Other studies suggest that access to mammography screening and follow-up are linked to breast cancer disparities among AAW (Kapp et al., 2009; Mc Carthy et al., 1998; Miller & Champion, 1997). These studies also point to a lack of knowledge or fear surrounding mammography screening as a risk factor for breast cancer disparity among AAW.

The 10 participates in this study provided some insight on the findings in the literature. The information provided by all 10 participants indicated that mammography screening was an important factor for maintaining breast health. However, as the literature suggested, there was some evidence of delays in follow-up with suggested treatment. Some of the participants indicated that other family concerns or dynamics that took precedence, interfered with breast cancer care or follow-up. Two the participants

made references to a delay in treatment due to “*lack of attention*” from a healthcare provider or their healthcare system. Many of the participants described not having “*enough time available at work*”; what was not clear is how this impacted their ability to follow through on the recommendations of the healthcare providers.

All of the participants in the study had a practice of completing routine mammograms and were knowledgeable on the importance of regular screenings for early detection of breast cancer. In addition to routine breast care, they described themselves as having a health-conscious life style. All but three of the participants described their health as very good; the three that classified their health as fair attributed this rating to their diagnosis of breast cancer.

Some research suggests that a genetic component is responsible for the increased incidence and mortality of breast cancer among AAW (Amirikia et al., 2011; Carey et al., 2006). Forms of breast cancer that are considered difficult to treat and more aggressive such as TNBC, are prevalent among AAW with a family history (Ademuyiwa et al., 2011; Dolle et al., 2009; Gaudet et al., 2011; Lipkus, Iden, Terrenoire, & Feaganes, 1999). However, cancers that are due to inherited mutated genes represent only 5%-10% of all forms of cancer (American Cancer Society, 2014a). Higher grades of breast cancers or breast cancer with distal tissue involvement have been associated with increased risk of recurrence when compared to lower grade and stages, 33.9% vs 20.4% respectively (Dent et al., 2007).

As the literature suggests, six (60%) of the participants had higher stages of breast cancer, stage II or III; four (40%) identified themselves as having stage III. Dent et al. (2007) found that more aggressive forms of breast cancer had a recurrence at 2.6 years.

Many of the participants, 60%, were aware of a family history of breast cancer, but were not clear on which family member. Two of the participants that were diagnosed with advanced stages of breast cancer also reported having a recurrence. In total, four (40%) of the participants were in the recurrence range, having received their diagnosis within the last 1-5 years. It was clear that regardless of the diagnosed stage, the women were faced with acknowledging their mortality and found the breast cancer journey emotionally challenging.

Intersectionality and Health

As discussed in chapter one, there are common risk factors for developing breast cancer, but not every woman that develops breast cancer has the common risk factors for the disease. This study examines how intersectionality impacts AAW on their breast cancer journey and provides insight on how AAW have endured life within the intersection. Intersectionality is a concept that elucidates how ubiquitous societal factors vis-à-vis discrimination, oppression, and power relations, coalesce to form the lived experiences of AAW. When examined separately, the effects discrimination, oppression, and power relations have proven to have a negative impact on psychological and physiological health (Geronimus et al., 2006; Pieterse, Carter, & Ray, 2013; Szanton et al., 2012). Other researchers have demonstrated that psychological stress that is tied to racism leads to disease and shortens life expectancy (Djuric et al., 2008; Harding et al., 2014; Juster et al., 2010). Psychological stress, which is a precursor to oxidative stress, has been linked to cellular damage, inflammation, and tumorigenesis (Eleftheriou, 2016; Federico, Morgillo, Tuccillo, Ciaediello, & Loguericio, 2007).

Important to this study is the link that has been described in the literature between breast cancer risk, tumor size, and metastatic breast cancer (Feng et al., 2016; Sephton et al., 2009). Gelhert et al. (2008) suggests that inherent societal stressors disproportionately affect African Americans; it is these stressors that lead to social isolation and activation of biochemical pathways that lead to cancer. The University of Chicago's Center for Interdisciplinary Health Disparities Research (CIHDR) developed a model to illustrate the link between breast cancer disparity and social stressor (Gelhert et al., 2008) (Figure 1).

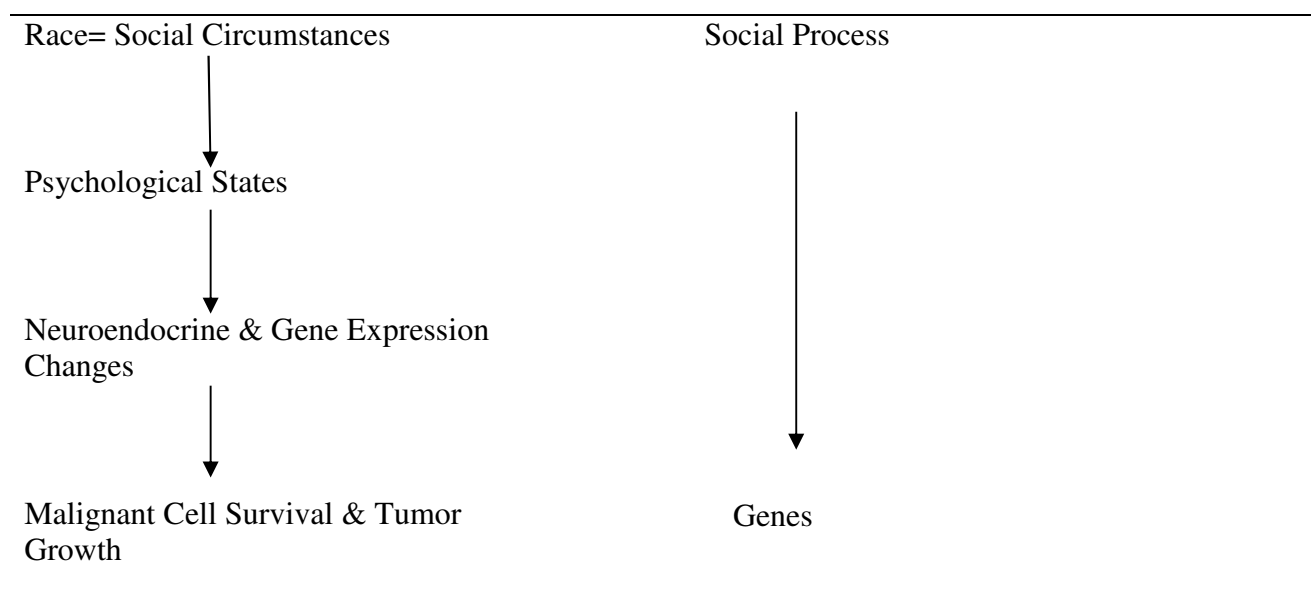


Figure 1. CIHDR Model for Health Disparities in Breast Cancer

Adapted from "African American Women and Breast cancer: Intervention at Multiple" by S. Gehler, E. Small and S. Bollinger in A. J. Lemele et al. (eds.) *Levels Handbook of African American Health: Social and Behavioral Interventions*; 2013, New York: NY, Springer.

Participants in this study have all described experiencing or having an awareness of discrimination, sexism, or classism in varying degrees. Some of the participants stated they were "*not bothered*" or "*don't get involved with*" racism or racist acts, but did acknowledge they are concerned with how Black men were treated. One participant had a desire to "*do something*" about discrimination but concluded that she could not and

resigned to *“just watch”*. Other participants voiced concerns for their husbands or sons fearing they would be mistreated by public officials. Descriptions of public encounters also contained descriptions of being treated differently when accompanied by husbands or sons; women of other ethnicity would *“grab their handbags”* or *“move away”*. Interestingly the participants were concerned that these daily microaggressions were directed towards the men in their lives or perhaps they felt the treatment of their men was a greater concern. These findings support a perspective of Black feminist scholars which is; in the fight to achieve social equality Black men’s issues take precedent over Black women’s issues. The women seemed to unintentionally create situations of marginalization (passive) in dealing experiences of discrimination. Under these situations, some of the women would remove themselves from situations, either physically or mentally, that would heighten their awareness of discriminatory or oppressive behaviors. For example, *“I would leave the area for lunch”* or *“I just don’t think about it, I sit on the side-lines and watch”*. This passive marginalization is perhaps a method of coping.

Most of the discriminatory experiences participants described stemmed from their interactions in the work environment. There were repeated descriptions of *“having to do more”* and *“being treated less than”*. Participants at times implied they expected to be treated in a discriminatory manner at work and that strength was required to deal with the everyday *“stress”* of the work environment. A lack of career advancement also presented itself as a source of frustration; participants felt that if they were White or even a man they would have been promoted. One participant shared that she was not classified as *“head of household”* in her single parent home because she was not a man; this in turn,

affected her ability to earn the same income as her male counterparts. These findings are not unlike other studies that have demonstrated how workplace behavior serves to marginalize (active) AAW (Hall & Hamilton-Mason, 2012; Thomas & Hollenshead, 2001).

Participants shared they had early instruction from parents or grandparents to be prepared to give more in life and use strength as a coping strategy when faced with challenges or unfair treatment. More importantly, participants learned coping strategies through observing parental figures. Black and Woods-Giscombe (2012) found that strength as a reaction to stress may be aligned with a “Strong Black Woman” ideal in which Black women are expected to be resilient, self-reliant, and psychologically resistant. One participant recalled how her mother remained in a physically and mentally abusive relationship and watching her mother endure the physical and mental abuse provided her lessons on strength. In dealing with their breast cancer diagnosis, nearly all of the participants voiced a need to be strong for other family members. Participants did not want to “worry” other family members; instead they chose to keep their concerns regarding their breast cancer diagnosis to themselves. As mothers, many of them needed to be a source of strength for their children. Participants shared how they would become emotional when left alone, but this was not something that was shared with family. A few participants had a desire to discuss their feelings with “*someone*” but did not feel comfortable going to the few available support groups; and therefore, turned to a “*higher power*” to stay strong in their silence.

Historically, Black women have been a source of constant strength of the AAW culture. With little resources, AAW have been tasked with maintaining the family unit

and often taking in the children of other family members. Researchers have demonstrated that AAW maintain the “strong Black woman” image through daily acts that put the needs of others ahead of their own, which leads to delays self-care (Black & Woods-Giscombe, 2012; Rose Black & Peacock, 2011).

Participants in this study displayed the same altruistic behavior of putting the needs or concerns of others before their own. One participant delayed breast cancer follow-up for greater than six months to care for sick family. Participants voiced having other family or employment obligations that required them to put their health needs second. Another participant chose to work through chemotherapy treatment refusing to take the offered financial help from family as it might create “*a financial burden*” for her family.

The strength and adaptability that AAW have demonstrated and maintained throughout history has proven critical to maintain the family unit in the African American community. AAW have undertaken the responsibility of head of household while living in the intersection with limited resources. AAW were placed in the roles of provider, nurturer, and protector, which were necessary for survival of the Black family unit in a White male dominant society. Participants implied they felt a sense of obligation to care for ailing family members or take in additional children. In addition, some felt they were expected “*to do more*” than their significant others or other males relatives, even during their breast cancer treatment. Almost all of the participants commented or alluded to “*doing what needed to be done*” in the work place and home setting.

Unfortunately, the result of this multiple role position is the development of stereotypical images of AAW as “the angry Black women”, “pushy”, or “aggressive”.

These images are in direct conflict with the images that the dominant race has constructed for women, mothers, or wives. In our patriarchal society, men are recognized for their importance as head of the household; the important role that AAW have in maintaining the family is overshadowed by expectations of the role of women in our society. The negative stereotypes of AAW also manifest within the workplace. Research has demonstrated that AAW disproportionately experience job strain that is linked to race and gender (Linnaberry, Stuhlmacher, & Towler, 2014; Mays, Jackson, & Coleman, 1996).

Some of participants in this study voiced a feeling that they were “*to be seen and not heard*” in both the home and work settings. One participant felt that her “*passion*” was seen as “*aggression*”; this perception negatively affected her ability to openly communicate in the work setting. Many of the participants expressed the feeling that they were looked upon or treated differently due to race or gender. Though the participants held critical roles in both the home and work environment, their importance seemed to go unnoticed resulting in existential invisibility.

When analyzing intersectionality and its link to physical and mental health, it is important to consider how it is perceived and processed by AAW. The women in this study demonstrated resilience and strength while maintaining multiple roles in the home and work environment. When considering mental well-being, 80% of the participants described feeling stressed at least twice a month. It was not clear to what extent the participants were impacted by this perceived stress on a physiological level.

Intersectionality the Lens

As stated earlier in chapter one, much of the research on breast cancer disparities stems from the biomedical model which espouses that the mind and body are separate

entities (Engel, 1977). In an attempt to address health disparities, the biomedical lens provides a unidimensional view of health disparities across race, gender, or socioeconomic status. An approach that only examines health disparities through the lens of a single attribute negates the cumulative effects of race, gender, and class. Furthermore, the biomedical module examines disease processes from the standpoint of the dominant race; this does not necessarily provide comprehensive insight into the health care issues impacting AAW. Some researchers suggest that an approach to health disparities that examines the multiplicative effects of race, gender, and class would be more effective in addressing health disparities (Crenshaw, 1991; Hankivsky & Christoffersen, 2008; Kelly, 2009; Mc Gibbon, 2012; Ruzek et al., 1997; Weber & Parra-Medina, 2003).

Other researchers suggest the biomedical and feminist intersectional research models are dichotomous and scholars from each discipline generate knowledge in isolation (Kelly, 2009; Weber & Parra-Medina, 2003). It has been suggested that to effectively decrease or eliminate health disparities, the biomedical and feminist intersectional modules would be applied simultaneously. The biomedical and feminist intersectional modules conduct research within the contextual categories. Kelly (2009) found that both the biomedical and feminist intersectional modules have a goal of eliminating health disparities; however, health is the domain of biomedicine and disparities are the domain of feminist intersectionality. Table 3 outlines the differences between the biomedical and feminist intersectionality approaches.

Table 3*Categories of the Biomedical and Feminist Intersectional Approaches*

Biomedicine	Feminist Intersectionality
Independent variables	Social identities
Predetermined, inherent, natural state	Socially constructed
Status, stable dichotomous or linearly Continuous	Emergent shifting qualitatively Variable
Singular, should be separated	Multiple, cannot be separated
Effects are additive	Effects are multiplicative
Context immeasurable	Context is critical and must be considered
Strive for homogeneity	Strive for recognition of difference

Adapted from “Integrating Intersectionality and Biomedicine in Health Disparities Research” by U.A. Kelly, 2009, *Advances in Nursing Science*, 32, p.E48.

Two studies that integrated the biomedical and intersectional approaches were conducted by Kelly (2009) and Williams et al. (2012). Kelly (2009) examined the impact of intimate partner violence among Latina women and Williams et al. (2012) sought to understand how multiple social status impact lung cancer disparities. Both studies collected traditional quantitative biomedical data; health history, social demographics, severity of disease, or issue. In both studies, the researchers looked beyond the quantitative data to examine cultural differences and belief systems that may influence health choices. In addition, factors that support an intersectional approach such as social support, isolation, exposure to stressors, socioeconomic status, and acculturation, were examined as potential factor in the disease process. These two studies demonstrated that incorporating an intersectional approach can provide new knowledge that stems from the

perspective of study participants and serve to enhance cultural competence among the researcher.

Overall, the participants for this study felt they received medical care that was appropriate for their disease process. A few of the participants made reference to feeling like they were being treated differently or did not have access to the appropriate resources throughout their breast cancer journey. The most significant issue for most of the participants was having the financial resources or enough available time at work for a leave of absence. The fear of losing employment or being “*harassed*” for taking time off to recover, interfered with their recovery following treatment; others continued to work through chemotherapeutic treatment. Unclear was to what extent this preoccupation with finance or employment impacted their disease process.

The findings of this study also demonstrated that AAW with breast cancer still lack access to resources that would provide them support during periods of emotional stress or physical changes that accompany the disease process. Most of the participants voiced concerns over the lack of breast cancer support groups for AAW. A few of the participants attended breast cancer survivor support group meetings, but felt out of place or did not think the other non-Black members could understand their breast cancer journey. A few participants in the study had a desire to “talk” to somebody, but felt it was not an option for them.

The physical changes that accompanied breast cancer treatment are particularly disturbing for women. To help with the after effects of disfiguring breast tissue removal and hair loss, rehabilitative services provide breast prosthetic devices and wigs. The participants did not feel that these items were made for Black women. The colors of the

breast prosthetic did not match their skin tones and the wigs were the wrong textures. Participants that chose to use these products stated they felt “*more out of place*” or “*uncomfortable*” in public. A few participants acknowledged that there are places where appropriate products could be purchased, but the cost of these products presented an obstacle. The lack of suitable resources to deal with the emotional and physical changes of breast cancer served to further marginalize AAW and may have contributed to delays in care.

Summary

In this study, intersectionality was examined as a research tool to better understand breast cancer disparities among AAW. The concept of intersectionality espouses that race gender and class are irreducible and have a multiplicative effect on individuals. Intersectionality, when viewed as a potential causative factor to breast cancer disparities, points to the effects on psychological well-being and resulting health outcomes. As a lens to view breast cancer disparities, intersectionality guides research to analyze the upstream determinants of health; specifically, race, gender, and class. Whether intersectionality is viewed as a causative factor or lens of analysis, its essence is manifested in the consciousness of the participants as altruism, marginalization, existential invisibility, and silent strength. Figure 2 provides a conceptual framework of the lived experience of intersectionality among AAW with breast cancer.

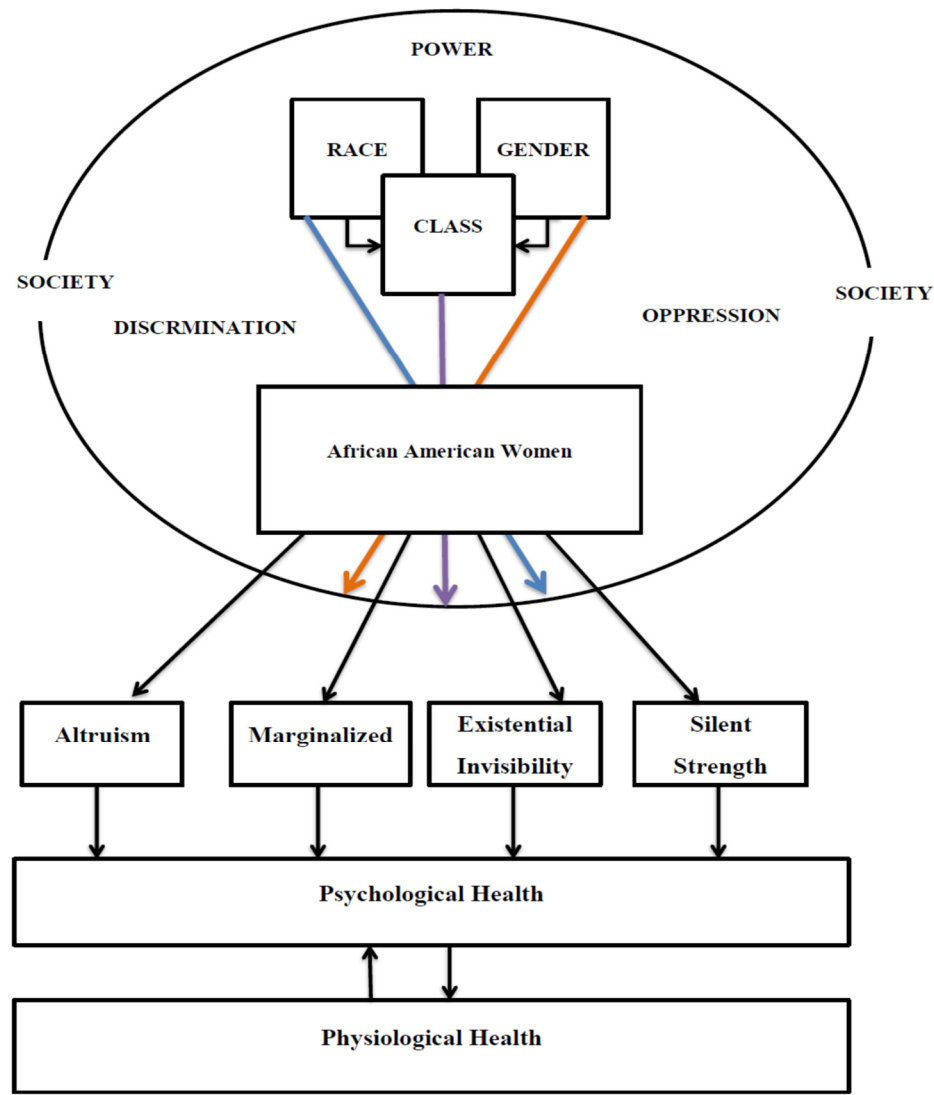


Figure 2. Conceptual Framework of the Lived Experience of Intersectionality among African American Women

Limitations of the Study

The findings of this study represent the lived experience of intersectionality among AAW with breast cancer from various geographical locations across the U.S.. The limitations of the study are related to the interview process, brevity of the interviews, and inexperience of the researcher.

The interview process posed one limitation on the findings. The historical connection that African Americans have to research may create feelings of distrust and make it difficult for the participants to share openly all of their experiences. To address these issues, participants were repeatedly given reassurance that the information was confidential and their views would be accurately represented. To help establish an environment of trust and comfort, participants were made aware the researcher was also African American.

Another limitation was the brevity of the interviews. Some of the participants were open and willing to share; the time limit may have hindered additional information-sharing. At times, some of the participants had difficulty providing descriptions or examples; paraphrasing was used as a method of clarification. Other participants seemed reluctant to share and provided brief or vague descriptions. Probing questions were used to garner richer descriptions.

The inexperience of the researcher presented a limitation in the initial interview. As the interviews progressed and researcher gained more insight into the sample population, adjustments were made to the research process technique.

Implications for Nursing Practice

Intersectionality provides a paradigm for examining the multiplicative effects of socially constructed identities and the associated inequalities that are a result of oppressive power relations. The concept of intersectionality provides us with a lens in which to view the lived experiences of AAW with breast cancer. Elucidating the connection between intersectionality and health outcomes could redirect the focus of nursing research by developing strategies to lessen the effects of upstream risk factors for

breast cancer among AAW. Nursing strategies that stem from an integration of the biomedical and feminist intersectional models would be more effective in addressing breast cancer disparities. Black Feminist Thought instructs researchers to collaborate with AAW to generate knowledge that explicates their lived experience; community-based participatory research would be an idea. Finally, in the context of breast cancer disparities, the findings of this study point to a need to eliminate the dichotomous methods of inquiry between qualitative and quantitative research.

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Appendix A- Research Flyer

BREAST CANCER STUDY




Teri Armour-Burton RN CNML NE-BC
Doctoral Student
University of San Diego
Hahn School of Nursing and Health Sciences

I am a doctoral student doing a research study on the day to day life experiences of African American women that have been diagnosed with breast cancer. I would like to interview you.

Who is eligible?

-  African American women
-  30 – 75 years of age
-  Have received a diagnosis of breast cancer

What is involved?

-  A casual one to one interview about your day to day life experiences.
-  The whole process will last about 45 minutes.
-  Phone interviews available

This research study will help health care professionals to better understand the life experiences of African American women with breast cancer.

Contact Information:

TDARMOURBURTON@SanDiego.edu

(619) 372-8268



A \$20 Gift card will be given to qualified participants



Appendix B – Demographic Sheet

1

Name _____

What is your racial or ethnic background? (Check all that apply)

 White Black or African American Asian Native Hawaiian or other Pacific Islander American Indian or Alaska Native Other, describe: _____

How old are you?

 18-30 31-40 41-50 51-60 61-70 71 years or older

What is your relationship status

 Not in a relationship In a relationship not married Married Separated Divorced Widowed

Do you have children?

 No Yes _____ How many ?

Highest level of education?

- Elementary school
- Some junior high school
- Graduated from junior school
- Some high school
- Graduated from high school
- Some college
- Graduated from college

What is your employment status?

- Student
- Employed
- Employed and attending school
- Retired
- Disabled
- Unemployed

What is your yearly household income?

- Less than \$20,000
- \$ 20,001 - \$40,000
- \$40,001 - \$60,000
- \$60,001 - \$80,000
- \$80,001 - \$ 100,000
- More than \$100,000

Who was your primary care giver as a child? _____

How often a month do you feel depressed?

Never

Twice

Three times

Four times or more

How often a month do you feel stressed?

Never

Twice

Three times

Four times or more

Have you ever been diagnosed with mental illness?

Yes

No

If Yes what ?

Do you have a person or persons you can confide in when you feel stressed or depressed?

No

Yes, If yes what is your relationship with that person or persons (ie sister, friend etc.)

What form or name of breast cancer do/ did you have?

What was/is the stage of your breast cancer?

When were diagnosed with breast cancer?

Less than 1 year

1 year to 5 Years

5 Years to 10 Years

10 years or more

Have any blood relatives been diagnosed with breast cancer?

Mother: No Yes Not sure

Sister: No One 2 or more Not sure

Daughter No One 2 or more Not sure

How would describe your health?

Excellent

Very good

Fair

Poor

What is your current height? feet inches 11.

What is your current weight? pounds

Appendix C – Interview Protocol

1

Interview Protocol

1. Please tell me a little about yourself.
2. Tell me where you grew up.
3. Tell me about your relationship with your parents.
4. Do you have siblings?

Probe: Tell me about your relationship with your siblings.
5. What's it been like for you to have breast cancer?

Probe: How did that make you feel?
6. What type of medical treatment did you have for your breast cancer?
7. How have your experiences as a Black woman impacted your healthcare choices in dealing with breast cancer?
8. As a child, what guidance did you receive on being a Black woman?

Probe- From whom?
9. Have you had challenges in life?

Probe-Tell me more about that
10. How do you think your life experiences are different than Black men?

Probe - what about White women?
11. What is your definition discrimination?
12. Have you experienced discrimination your life?

Probe- How did that make you feel?

13. How do you think your life experiences would be different if you were not a Black or a woman?

14. What things or issues in your life cause you stress?

15. Have you achieved all of your life goals?

Probe- Why (if yes or no)

16. What advice would you give other women about breast cancer?

17. Is there any advice that you would give young black women about life?

Appendix D – Study Consent

Consent version 9-13-16

1

Appendix C
University of San Diego
Institutional Review Board

Research Participant Consent Form

For the research study entitled:
“The Lived Experience of Intersectionality Among African American Women with Breast Cancer ”

I. Purpose of the research study

Teri Armour-Burton is a doctoral student in the Hahn School of Nursing at the University of San Diego. You are invited to participate in a research study she is conducting. The purpose of this research study is to examine how African American women with breast cancer experience and process intersectionality. Intersectionality means what it’s like to be both Black and a woman and what that means to you.

II. What you will be asked to do

- If you decide to be in this study, you will be asked to:
 Participate in a private interview describing your experiences with intersectionality. A typical question you will be asked is, “Have you experienced challenges/obstacles in your life?”
- Your interview will be digitally recorded. If you do not wish to be recorded, please tell the researcher and written notes will be taken instead.
- Your participation in this study will take a total of 60 to 90 minutes.
- You can choose to be interviewed in person, over the phone, or via computer using a program like Skype. Please let the researcher know your preference. Whichever way you choose, you and the researcher will make arrangements to conduct the interview at a time and place in which privacy can be maintained.

III. Foreseeable risks or discomforts

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call 24 hours a day:

San Diego Mental Health Hotline at 1-800-479-3339

OR

National Lifeline Crisis Chat at 1-800-273-8255.

IV. Benefits

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While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be knowing that you helped researchers better understand what it is like to be an African-American woman with breast cancer.

V. Confidentiality

Any information provided and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher's office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually.

VI. Compensation

If you participate in the study, the researcher will give you a \$20 Walmart gift card in the following way: either personally (for in person interview), or via the USPS or email (for phone or Skype interviews) at:

_____ (your preferred address)

You will receive this compensation even if you decide not to complete the entire interview. Teri will destroy your contact information as soon as the card is sent to you.

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you're entitled to, like your health care, or your employment or any other benefits. You can withdraw from this study at any time without penalty.

VIII. Contact Information

If you have any questions about this research, you may contact either:
Teri Armour-Burton tdarmourburton@sandiego.edu or (619) 372-8268
Dr. Jane Georges (Teri's advisor) at jgeorges@sandiego.edu or
(619) 260-4566.

****For participants doing an in person interview who choose written consent:****

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant

Date

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Name of Participant (Printed)

Signature of Investigator

Date

****For participants choosing to give verbal consent:**

This form has been read to me and I understand it and consent to the research it describes to me. I have received or will immediately receive via email/mail a copy of this consent form for my records.

Appendix E - Institutional Review Board Approval



ENTRUSTED
8/31/16

Institutional Review Board Project Action Summary

Action Date: August 31, 2016 *Note: Approval expires one year after this date.*

Type: New Full Review New Expedited Review Continuation Review Exempt Review
 Modification

Action: Approved Approved Pending Modification Not Approved

Project Number: 2016-08-282
Researcher(s): Teri Armour-Burton PhD student SON
 Dr. Jane Georges Fac SON
Project Title: The Lived Experience of Intersectionality Among African-American Women with Breast Cancer

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

Modifications Required or Reasons for Non-Approval

None

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited review at any time.

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