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WASHINGTON UNIVERSITY IN ST. LOUIS

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An Exploration of the Lives of Young, African American

Women with Triple-Negative Breast Cancer

by

Sarah Bollinger

A dissertation presented to the  
Graduate School of Arts and Sciences  
of Washington University in  
partial fulfillment of the  
requirements for the degree  
of Doctor of Philosophy

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**Chapter One - Statement and Significance of the Problem:**  
**Breast Cancer Disparities among Young, African American Women**  
**and the Triple Negative Diagnosis**

Compared to other subtypes of breast cancer, triple-negative breast cancer accounts for a disproportionate number of metastatic cases and cancer deaths (Bauer, Brown, Cress, Parise, & Caggiano, 2007; Carey, 2011). Triple-negative breast cancer (TNBC) is a specific subtype of breast cancer that lacks three key hormone receptors necessary for most targeted therapies, severely limiting treatment options (Carey, 2011; Rakha & Chan, 2011). This subtype of breast cancer presents at a more advanced stage, with higher median tumor sizes, and the vast majority of these tumors are poorly differentiated or undifferentiated; this is compared to breast cancer subtypes that are positive on these receptors, specifically those that are estrogen receptor positive (ER+) (Bauer, Brown, Cress, Parise, & Caggiano, 2007). All of these factors combined result in poorer prognoses and, ultimately, lower survival rates for those diagnosed (Baser, Wei, Henk, Teitelbaum, & Xie, 2012). Additionally, TNBC disproportionately affects young, minority women (Lund et al., 2009; Rakha & Chan, 2011). Those diagnosed with TNBC are more likely to be African American (prevalence of 26% vs. 16% in non-African Americans) and premenopausal (24% vs. 15% postmenopausal) (Carey et al., 2006; Irvin & Carey, 2008). This subtype accounts for approximately 15-20% of all breast cancer cases diagnosed each year (Brouckaert, Wildiers, Floris, & Neven, 2012; Rakha & Chan, 2011).

The purpose of this dissertation is to explore the lives of women diagnosed with this aggressive form of breast cancer and to begin to understand the issues of social justice that undergird such a diagnosis. The reasons that this diagnosis is overrepresented in young, minority

patients are not fully understood, but these reasons go beyond simple explanations of genetic inheritance and involve larger systemic issues. Using qualitative, in-depth interviews, this study asks questions that have not been previously asked of women who are living with a diagnosis of TNBC in order to better understand the experience of such a diagnosis. This study seeks to give voice to central issues surrounding a population of women that has historically been underserved and underrepresented, and will ultimately contribute to a larger body of literature aiming to improve care for minority patients.

This opening chapter describes the extent of the problem of breast cancer in the general population and then articulates the vast breast cancer disparities documented in minority populations, with a specific focus on young, African American women. This first chapter provides incidence and prevalence rates of breast cancer to demonstrate how impactful the issue of breast cancer is for women and for society in general, and then moves into a more in-depth discussion of disparities in breast cancer by race and age, specifically highlighting and explaining TNBC, which is the focus of this dissertation. TNBC is then linked to psychosocial phenomena, and a brief discussion regarding the impact of poverty, racism, and complex social circumstances on etiology and psychosocial outcomes of breast cancer among young, African American women is provided. Chapter 2 moves into a discussion of important theories that undergird this work and provides the theoretical basis for analyses of the data collected for this study. Descriptions of each of these theories are provided as they relate to the study at hand. This is followed by a review of the existing literature around the relevant psychosocial issues for African American women with breast cancer in chapter 3. Chapter 4 then moves into an in-depth explanation of the present study, outlining the approach to data collection and the methods chosen to answer the research questions. In this chapter, the study questions are outlined and a



detailed explanation of how these questions were addressed through data collection and analyses is laid out. This is followed by an overview of the major findings from the study in chapter 5 and a discussion of implications and next steps in the final chapter, chapter 6. This group of women with triple-negative disease has received very limited attention in the scientific community in general, and especially from social scientists. Therefore, the following chapters will outline the importance of this topic and discuss the findings from this study in order to help fill this gap.

### **Incidence and Prevalence of Breast Cancer in the General Population**

Excluding cancers of the skin, breast cancer is the leading form of cancer diagnosed among women in the United States. An estimated 232,340 new cases of invasive breast cancer (cancer which has spread outside of the milk duct) and an estimated 64,640 cases of in situ breast cancer (which means “in the same place” or cancer that has not spread outside of the milk duct) are expected to be diagnosed in the United States in 2013 (American Cancer Society, 2013a). Roughly 40,030 deaths from breast cancer are expected in 2013, making breast cancer the second leading cause of cancer death among women in the United States (American Cancer Society, 2013a). The impact of breast cancer also extends far beyond the United States; breast cancer is the most commonly diagnosed cancer in Europe and accounts for 28.9% of all cancer cases there (Ferlay et al., 2007). Breast cancer is the third highest cause of cancer death across genders and is responsible for 7.8% of all cancer deaths in Europe. Breast cancer is also the leading cause of cancer deaths among European women, at 16.7% of all cancer deaths (Ferlay et al., 2007). Breast cancer affects people of all races and age groups, and presents a significant public health concern as health professionals seek to treat the myriad issues associated with this disease.

It is estimated that 12.38% of women born today will be diagnosed with breast cancer during their lifetimes; this can also be stated as 1 in 8 women in the United States will face a diagnosis of breast cancer at some point in their lives, and the median age of diagnosis is 61(Howlader et al., 2013). As of January 1, 2010, approximately 2,829,041 women alive had a history of any type of breast cancer during their lifetime. This includes any person alive on January 1, 2010 who had been diagnosed with cancer of the breast at any point prior to January 1, 2010 including persons with active disease and those who are said to have been cured of their disease (Howlader et al., 2013). It is clear from these statistics that breast cancer is an important issue that affects the lives of millions of women around the world. Although these facts alone are startling, this is just the beginning of the breast cancer story for many women. Glaring disparities are present across various populations of women diagnosed with breast cancer and little is understood about the reasons for these differences.

### **Breast Cancer Disparities: The Impact of Race and Age**

From a social justice perspective, perhaps the most troubling facts regarding breast cancer are the glaring disparities in incidence and mortality that are present across racial lines and age cohorts. Although the overall incidence rate for breast cancer is approximately 10% lower among African American women than white women, African American women have a 41% higher death rate from the disease overall (American Cancer Society, 2013b; Howlader et al., 2013; Hoyert, Heron, Murphy, & Kung, 2006). The 5-year relative survival rate for white women is 90%, compared to only 78% for African American women (American Cancer Society, 2013b). Further, the Surveillance Epidemiology and End Results (SEER) data indicate that while 127.4 per 100,000 white women are diagnosed with breast cancer per year, 121.4 per 100,000 African American women are diagnosed per year; however, this is contrasted with the

mortality rate: 22.1 per 100,000 for white women and 30.8 per 100,000 for African American women (Howlader et al., 2013). In other words, although African American women as a whole are less likely to get breast cancer, they are much more likely to die from breast cancer.

Just as race represents an area of glaring disparities in breast cancer outcomes, differences in breast cancer outcomes because of age are equally alarming. Although a quarter of a century ago, young adults had a better overall cancer prognosis than those diagnosed with childhood cancers and those diagnosed in later adulthood, there has been a distinct lack of progress made specific to this young adult population; this has led to a reversal of outcomes in prognosis and overall survival rates for the young adult group (Bleyer, 2007). Historically, cancer research has focused on certain age groups with the 1950s bringing about a focus on the study of childhood cancers, and the 1970s focusing on cancer in adulthood (Bleyer, 2007; Bleyer et al., 2008). Although much progress was made in these younger and older groups, attention to young adults with cancer waned, and this group fell behind in cancer outcomes. Breast cancer accounts for one of the most frequent cancers diagnosed in this age group, at 14% of all cases (Bleyer et al., 2008). Bleyer et al. (2008) state, “Below age 45, the younger a woman is when diagnosed with breast cancer, the worse the expected outcome. This pattern is independent of stage and extent of disease at diagnosis, and of histological type” (p. 290). Based on their recent findings, these authors call for research agendas that specifically address the needs of this neglected age group.

When combining the deleterious effects of the disparities associated with both race and age, it becomes glaringly apparent that premenopausal, African American women face some of the most devastating breast cancer outcomes of perhaps any group. Despite a lower overall incidence rate, African American women face a greater risk of being diagnosed with early-onset

disease; 20% of white breast cancer patients in incidence studies that have been conducted to date are younger than 50 years of age, while an astounding 30%-40% of African American breast cancer patients are younger than 50 (Newman, 2005). Anderson, Rosenberg, Menashe, Mitani, and Pfeiffer (2008) refer to this phenomena as the age-related cross-over, where age specific incidence rates are higher among black women who are younger than 40 as compared to white women who are younger than 40, despite the higher incidence rate in white women compared to black women overall. In terms of mortality, the disparities in this younger cohort are profound, with African American women being twice as likely to die from breast cancer developed before menopause than white women (McClintock, Conzen, Gehlert, Masi, & Olopade, 2005). A disparate proportion of breast cancer deaths occur among young women, African American women, and particularly young, African American women (Lund et al., 2008). Differences in survival rates for this group of women have been attributed to diagnosis at later stages of disease, socioeconomic factors, differences in access to screening and treatment, potential biological difference in the cancers themselves, as well as interactions among these factors (Carey et al., 2006); however, a concrete understanding of why the differences in survival rates exist remains elusive as does an understanding of what they mean for the lives of the women to whom they occur.

### **Breast Cancer Subtypes**

One insight into these disparities comes from investigating particular breast cancer subtypes. Although breast cancer is typically classified as one specific type of cancer, breast cancer is inherently a heterogeneous disease inclusive of many different biological subtypes (Carey et al., 2006; Perou et al., 2000). Perou and colleagues (2000) assert that the differences in breast cancer subtypes are so pronounced that each subtype could potentially be classified as

different types of disease in the future, as our scientific knowledge of these differences unfolds. The rationale behind this logic is that etiology and prognosis of these subtypes varies significantly, with different subtypes predicting drastically different disease courses and survival lengths; therefore, diagnosis and treatment of breast cancer varies drastically between individuals.

The Carolina Breast Cancer Study was a seminal study that identified and categorized these biological subtypes, highlighting the differences inherent in this disease. In this study, immunohistochemical markers were used to identify the various subtypes of breast cancer, providing greater understanding about the genetic structure of different types of breast tumors (Carey et al., 2006). Four distinct subtypes of the disease were identified and these subtypes are determined by positive or negative receptor status on three biomarkers of the breast tumor, namely, estrogen receptors (ER), progesterone receptors (PR), and human epidermal growth factor receptor-2 (Her2). The identification and distinction of these subtypes has been highly consistent across studies and stratify in similar patterns across studies (Carey et al., 2006; Nielsen et al., 2004). These four distinct subtypes are characterized into two groups: those that are estrogen receptor positive (ER+) and those that are estrogen receptor negative (ER-) (Sotiriou et al., 2003). The ER+ group consists of luminal A (ER+, PR+, and Her2-) and luminal B (ER+, PR+, and Her2+) subtypes, while the ER- group consists of HER2+/ER- (ER-, PR- and HER2+) and basal-like (or triple-negative; ER-, PR-, and HER2-) subtypes. The distinction between ER+ subtypes and ER-subtypes of breast cancer have to do with critical prognostic factors, such that ER+ subtypes have increased response to hormonal therapy, increased disease-free intervals, and improved survival (Stanford, Szklo, & Brinton, 1986). With this understanding in mind, the specific subtypes of breast cancer play a huge role in determining survival outcomes.

## **Triple-Negative Breast Cancer and Psychosocial Factors**

The term “triple-negative” specifically refers to the three biomarkers of the breast tumor mentioned above: estrogen receptors (ER), progesterone receptors (PR), and human epidermal growth factor receptor-2 (HER-2). In laymen’s terms, when breast tumors are negative on these three receptors (or are found to be triple-negative), typical targeted treatments prove to be ineffective, significantly decreasing prognosis (National Cancer Institute, 2007). To clarify the terminology around TNBC, it should be understood that there also is a lot of heterogeneity within the triple-negative subtype. There is notable overlap of TNBC with the BRCA mutation, and those women with TNBC with the BRCA mutation tend to have lower rates of relapse (Atchley et al., 2008; Gonzalez-Angulo et al., 2011).

Additionally, the term “triple-negative” is often used as a proxy for “basal-like” breast cancer, although the two do not overlap completely. The basal-like profile is more difficult to identify in clinical settings because diagnosis involves gene expression profiling, which is a more complex and expensive procedure. Alternatively, immunohistochemical identification of the three biomarkers is often a routine practice in clinical settings, making triple-negative breast cancer more easily identifiable (Cheang et al., 2008). Basal-like breast cancer is a more specific diagnosis with more prognostic value than triple-negative breast cancer (Cheang et al., 2008), but there is significant overlap between the two and the terms are often used interchangeably. For the purposes of this dissertation, the heterogeneity of this subtype is recognized as significant, but it was beyond the scope of this study to differentiate within the TNBC subtype. Articles using the terms “triple-negative” and “basal-like” were used interchangeably, although the difference between the two diagnostic approaches are duly noted.

Of the estimated 1.3 million women worldwide who are diagnosed with breast cancer each year, 15-20% will be classified as triple-negative (Carey, 2011; Rakha & Chan, 2011). Those diagnosed are more likely to be African-American and premenopausal (Carey et al., 2006; Irvin & Carey, 2008). Triple negative breast cancer (TNBC) is more prevalent among premenopausal African American women (39%) compared with postmenopausal African American women (14%) and non-African American women (16%) of any age (Carey et al., 2006); some studies have even demonstrated that African American patients with breast cancer have nearly three times the prevalence rate of TNBC compared to white patients (Swede et al., 2011). Swede and colleagues (2011) also demonstrate that the rate of TNBC remains consistent at about 11% for white patients both older and younger than 50 years, but varies by age among African American patients (24% vs. 35% respectively). The realization of the triple-negative disparity in young, African American was discovered only recently in the afore mentioned Carolina Breast Cancer Study (Carey et al., 2006; National Cancer Institute, 2007) and demands greater empirical attention as researchers begin to address the gap in survival for this young minority group and their psychosocial needs.

These disparities are more alarming when we consider diagnostic and prognostic outcomes associated with TNBC. TNBC is known to be more lethal than other breast cancer subtypes and no known targeted therapeutic agent is effective against triple-negative tumors (Baser et al., 2012; Irvin & Carey, 2008). Although responsive to chemotherapy, targeted treatment is severely limited because triple-negative tumors are negative on all three biomarkers, greatly increasing the likelihood of recurrence (Carey, 2011; Rakha & Chan, 2011). As mentioned above, TNBC presents at a more advanced stage, with higher median tumor sizes, and

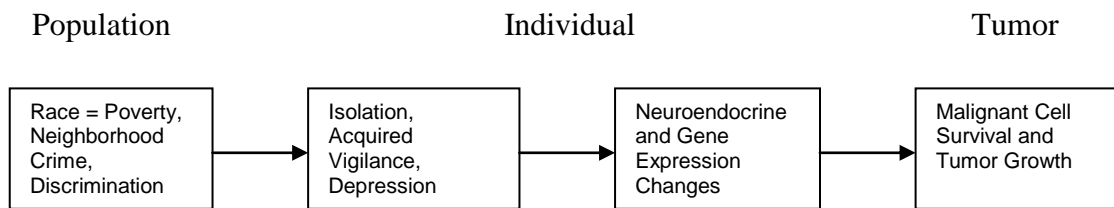
the vast majority are poorly differentiated or undifferentiated (Parise, Bauer, Brown, & Caggiano, 2009).

The occurrence of triple-negative tumors is also more common among West African women. In a recent study examining the prevalence of triple-negative tumors across ethnic groups, a comparison of African American, white American women, and Ghanaian women indicated that women from West Africa have a much higher prevalence rate of triple-negative tumors compared to all American women (82.2% for Ghanaians, 32.8% for African Americans, and 10.2% for white Americans) (Stark et al., 2010). Other studies examining the prevalence of triple-negative tumors have found similarly high rates of triple-negativity among women from West Africa (Gukas et al., 2005; Huo et al., 2009).

What is fascinating about triple-negative breast cancer as a social work clinician and researcher is the recently hypothesized link between the occurrences of these triple-negative tumors and psychosocial factors, including socioeconomic status, discrimination, isolation, depression, abuse history, and various health behaviors (Chida, Hamer, Wardle, & Steptoe, 2008; Gehlert, et al., 2008; McClintock, Conzen, Gehlert, Masi, & Olopade, 2005). Many existing theoretical frameworks that attempt to explain breast cancer occurrence assume a hierarchical arrangement of causal levels that start with the genetic level and move up to the environment, with social and behavioral risk factors viewed as less influential and/or powerful than preceding risk factors (Gehlert, Mininger, Sohmer, & Berg, 2008). This approach omits some of the critical social and behavioral determinates and deemphasizes the importance of psychosocial issues involved in breast cancer occurrence. Alternatively, Gehlert and colleagues (2008) have found empirical evidence for a model of downward causation in which determinates at the social and environmental levels influence events at the lower cellular and genetic levels of organization



(see Figure 1). This model of downward causation begins with the neighborhood and community level and moves to the genome and cellular level, with psychosocial and stress hormone response representing how the social environment “gets under the skin” to impact biology. Although these authors recognize that feedback occurs from lower to higher levels as noted in the aforementioned hierarchies, their assertion involves the recognition that environmental factors actually change the way DNA and cells function. In other words, this model demonstrates that social deprivation and harmful environmental factors lead to isolation and depression, which cause changes in gene expression and ultimately result in the triple-negative breast cancer diagnosis.



*Figure 1.* Model of Downward Causation for Triple-Negative Tumors

In the literature, social isolation and dilapidated neighborhood conditions are seen as key determinants of breast cancer in the downward causal model. Social isolation and felt loneliness have been directly linked to mortality risk in previous studies (Berkman & Syme, 1979; Berkman, 1985) and may be central to explaining pre-disease pathways in the downward model. Loneliness is associated with total activation of the sympathetic nervous system, disrupted sleep, and altered neuroendocrine function, and may be one explanation of how social environmental factors begin to “get under the skin” and affect gene regulation (McClintock, Conzen, Gehlert, Masi, & Olopade, 2005). African American women are posited to be some of the most isolated

and lonely people in the world due to the burdens of living as a minority, socioeconomic conditions, dilapidated neighborhoods, increased crime, and burdens of caring for extended family that often fall to this group of African American women (Klinenberg, 2002). All of these psychosocial conditions often render the young, African American woman more isolated and may also lead to depression and acquired vigilance due to fears of crime and lack of availability of support within the given community (Gehlert et al., 2008). Although the focus of this dissertation is on African American women, these patterns of isolation and exposure to extreme socioeconomic conditions could also be implicated for West African women who are also exposed to tremendous psychosocial stressors over time and live in a culture where violence against women is pervasive (Kristoff & WuDunn, 2009). For women living in and amongst poverty and oppression, it is critical to begin to see some of these psychosocial stressors as key to unlocking our understanding of breast cancer disparities.

The link between social isolation and breast cancer incidence has been examined and supported in recent animal studies. Recent studies have explored the idea of social isolation as a pre-disease pathway to breast cancer using female Norway rats, which are highly social creatures that live, sleep, and often even rear their young together (Hermes & McClintock, 2008; McClintock, Conzen, Gehlert, Masi, & Olopade, 2005). When the female rats were socially isolated and kept away from their female peers, they developed mammary cancer at four times the rate of their same-aged counterparts who were living in a group. The occurrence of cancer in these isolated rats began at 14 months of age. At 17 months of age, mammary cancer was affecting the isolated females at 16 times the rate of those living in a group, while those rats that lived in a group did not develop tumors until 23 months, which is the equivalent of 60-70 years of age in human beings. In this rodent model, the development of early mammary tumors could

not have been genetic because these rats were randomly selected and then placed into their social conditions (Williams et al., 2009; Yee, Cavigelli, Delgado, & McClintock, 2008). This work has greatly informed, and been informed by, Drs. Gehlert and Olopade's work with African American women newly diagnosed with breast cancer. This animal model is extremely helpful because it has allowed this team of researchers to take a life span perspective on the social determinants of breast cancer and to manipulate social conditions to test hypotheses that cannot be tested with humans.

It is clear from this information that larger contextual factors in women's lives play a significant role in the type and severity of breast cancer diagnosed among African American women. The multifaceted psychosocial issues that African American women face in their daily lives clearly impact their physical health; therefore, it is imperative that these factors are also examined in light of how African American women live with a diagnosis when it occurs. If issues such as crime, hypervigilance, poverty, discrimination, and other social environmental stressors affect the severity and type of breast cancer that African American women get, it is also critical to consider these issues after diagnosis. Because breast cancer is most common in older, white women, we have little information about how vulnerable, minority populations manage such a disease. Given the extreme stressors common to this group, it is imperative to explore the lives of those diagnosed with TNBC in light of their psychosocial environment.

The overrepresentation of this subtype among young, minority patients, the distinctiveness of the prognosis, and the hypothesized association between triple-negativity and psychosocial stressors makes this subtype of breast cancer unique from others. To our knowledge, there have been no scientific explorations of the psychosocial factors that are relevant in the lives of women facing a diagnosis of TNBC, leaving a gaping hole in our

knowledge about the experience of this form of the disease. Despite the fact that many psychosocial factors may impact etiology of TNBC, virtually nothing is known about how these factors come into play once the diagnosis has occurred. Although there have been a plethora of studies to date exploring the psychosocial ramifications of breast cancer without specificity to subtype, there are no studies that explore the contextual lives of women with TNBC or how such a diagnosis would impact this population of underserved women. The current study is the first of its kind in seeking to understand the lives of women with this specific diagnosis. To this end, the following research questions guided this inquiry:

1. How does the biopsychosocial context in which young, African American live inform how these women face a diagnosis of TNBC?
  - a. Do young, African American women with TNBC experience any common stressors?
  - b. What resources and strengths are employed by young, African American women with TNBC while facing the challenges associated with the disease?
  - c. Do these stressors and strengths differ for women with TNBC as compared to those with ER+ BC?
2. What is the trajectory of the illness experience for young, African American women with TNBC compared to women with ER+BC?
3. How do we conceptually frame the disease experience for young, African American women with TNBC?

In light of these questions, subsequent chapters will explore the underlying theory and existing scientific literature that supports this inquiry in an effort to begin to explain the foundation upon which this data was collected and analyzed. Once this ground work is laid, in-depth explanations of the study design, methods, and strategy for analysis will be provided, followed by the relevant findings that address the research questions outlined above and the implications of these findings.

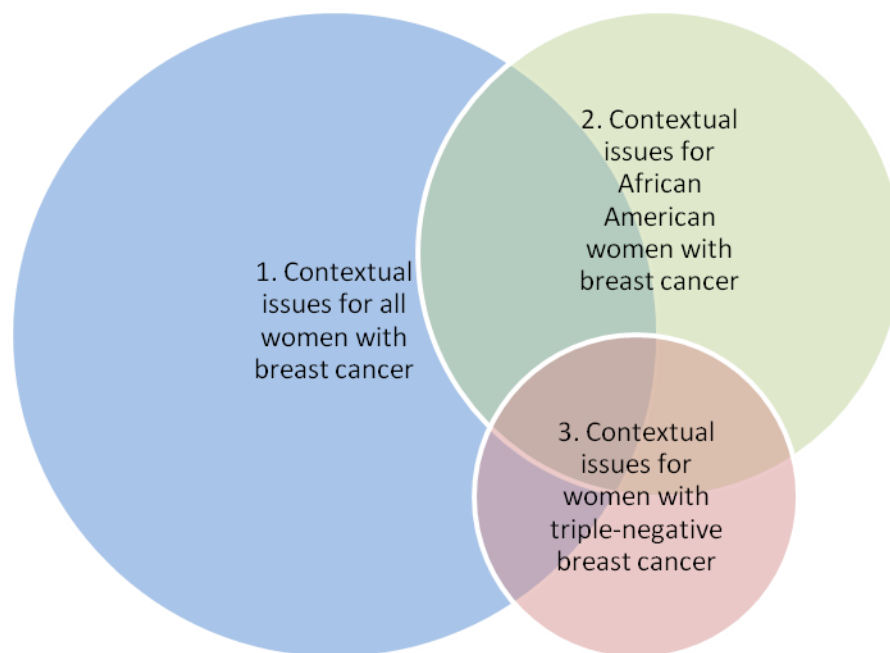
**Chapter Two - Theoretical Grounding:**  
**Orienting Theories and Frameworks for Understanding the Contextual Lives**  
**of Women with Breast Cancer and the Triple-Negative Subtype**

**Groundwork for Understanding the Overlapping Issues**

It is important to clarify the many overlapping issues at play when conceptualizing the theoretical foundations that elucidate the contextual lives of women with breast cancer, and specifically, women with triple-negative breast cancer. Figure 2 shows three overlapping areas of inquiry that depict the overlapping realms of scientific investigation important to exploring the lives of women with breast cancer and clarifies where those with triple-negative breast cancer fall within this body of knowledge.

In Figure 2, the first circle encapsulates what we know about the contextual lives of all women who face a breast cancer diagnosis, regardless of race and breast cancer subtype. This circle demonstrates a wide body of knowledge with a relatively strong theoretical foundation. This circle obviously encapsulates the largest group of women and draws from a wide range of theoretical perspectives. As seen in Figure 2, African American women with breast cancer also have many contextual issues that must be taken into account, and although there is significant overlap with women in general with breast cancer, these issues are not exactly the same. The state of this knowledge is still widely underdeveloped and although some research and theory explore this area, it is far from complete. Lastly, psychosocial issues of women with triple-negative breast cancer overlaps with some issues relevant to all women with breast cancer and some issues relevant to African American women with breast cancer, but stands as a separate area of knowledge that demands scientific inquiry in and of itself. This is the smallest group

with the least amount of knowledge available, and with a theoretical grounding that draws from diverse disciplines that inform the process wherein psychosocial factors actually impact etiology and therefore quality of life. As described in chapter 1, psychosocial issues such as poverty, crime, and victimization actually change gene expression resulting in triple-negative breast cancer. This is unique to this subtype of breast cancer, and it is therefore necessary to consider this process as critical when conceptualizing the theoretical basis for understanding this phenomenon. In this way, theories used to understand these issues differ drastically from the other two circles in that the theories used to understand this occurrence must encapsulate larger community-level variables that uniquely impact disease outcomes.



*Figure 2.* Understanding the Overlapping Contextual Issues for Women with Breast Cancer

## **The Inadequacies of Individual-Level Theories**

Referring back to Figure 2, we can see that many theories currently used to understand the lives of women with breast cancer fall into the first circle, which applies generally to women with breast cancer without accounting for issues specific to race or breast cancer subtype. Many existing theoretical frameworks have focused on individual health behavior or personal coping patterns as the primary point of analysis. However, despite the valued contribution of these theories, many of these theories do not adequately address the multifaceted contextual lives of African American women and completely fail to capture the importance of understanding epigenetic factors for those with TNBC. Theories that focus on the personal ability to cope with stress or on the importance of an individual's behaviors alone place the burden of health outcomes solely on the individual, while neglecting larger systemic, socio-political, and social factors that contribute to health outcomes.

When accounting for these larger systemic issues, it is key to keep in mind the implications of Figure 1 shown in chapter 1, as this figure visually demonstrates how adverse environments and social factors might actually predispose African American women living in certain neighborhood contexts to more severe breast cancer outcomes, especially as they face these challenges early in life. The first box in this figure highlights the impact of the safety and availability of resources in neighborhoods, and the occurrence of these adverse circumstances across the life cycle. These observations are critical to the theoretical underpinnings used to explain the disparities seen in the triple-negative diagnosis. It is clear that individual level theories prove inadequate in explaining and addressing the impact of the social environment on breast cancer outcomes, and the lens through which the phenomenon of TNBC is understood must be broadened.



Individual-level theories are helpful to the extent that the first and second circles overlap with the third circle in Figure 2, but also fail to capture the unique portion of the third circle. They fail to capture the impact of the social environment over the life course, and are therefore limited in their abilities to explain the phenomena of TNBC. The remaining portion of this chapter will first review some existing theories that have been used to understand the lives of women in general with breast cancer. I will demonstrate how these theories are important insofar as they inform a portion of our general knowledge about women with breast cancer, but are also woefully inadequate in fully conceptualizing the specific population of women with triple-negative disease for whom there is evidence of unique psychosocial trajectories. Secondly, I will review a few critical, larger-level theories that may provide a more comprehensive understanding of the impact of the social environment and how adverse social circumstances may predispose women to TNBC. Such a theoretical foundation necessarily involves including theories that account for exposure to difficult environments early in life, which might lead to such a diagnosis. These additional theories expand the lens by accounting for the social environment, psychosocial stressors, and neighborhood and community level factors, thereby creating a more complete arena in which to understand this underserved group of women. An overview of these different kinds of theories will undergird the premise of this study, namely that adverse social environments play a critical role in the occurrence of TNBC as well as how TNBC is faced in the lives of young African American women.

**Stress and coping theories.** In light of the many stressors faced by women with breast cancer, an evaluation of stress and coping theories would appear to be informative. However, traditional approaches to understanding coping with life stressors may fail to do justice to the gravity of the extreme stressors that are at play throughout the lives of young women with the

triple-negative subtype. Traditional stress and coping theories such as the Transactional Model of Stress and Coping (TMSC) lay a basic groundwork, but also neglect to account for the fact that the women who have been diagnosed with this subtype of breast cancer have already maximized their ability to cope, and teaching them to cope better is perhaps even cruel. For example, the TMSC focuses on the concepts of primary appraisal, where the person evaluates potential threats or harm, and secondary appraisal, where the individual assesses her ability to alter the situation and manage negative emotion. In the model, these two appraisal processes lead to coping efforts, or the extent to which one engages or disengages with the stressor, which then leads to coping outcomes or how one adapts to the stressor (Glanz & Schwartz, 2008). This model has been used as the theoretical foundation for a number of breast cancer studies, including a family intervention study to promote adjustment and a study evaluating the role of spirituality in adjustment to cancer (Laubmeier, Zakowski, & Bair, 2004; Northouse, Kershaw, Mood, & Schafenacker, 2005). The samples for both studies were well educated and middle-class, and only 14% and 2% of the participants were African American, respectively.

The problem with this theoretical approach when studying women who have experienced extreme stressors throughout their lives, is that the diagnosis of a disease such as breast cancer may be the least of their concerns and may not be the focus of the coping process. For example, if a woman newly diagnosed with TNBC is also struggling to put food on the table for her family, pay the electric bill, avoid crime in her neighborhood, and acquire health insurance to follow-up with a diagnosis, coping with the actual disease may be the least of her concerns. As seen in Figure 1 in chapter 1, the majority of women with triple-negative breast cancer have experienced an overload of stressors over the course of the lifespan that have actually led to gene expression changes that caused breast cancer. Simply assessing one's ability to alter a situation

and employ coping efforts to change health outcomes is almost too much to ask at this point in the disease trajectory.

**Health behavior theories.** One example of a theory that has strong empirical support but is limited when attempting to capture the multifaceted issues involved in understanding the lives of women with triple-negative breast cancer is The Health Belief Model (HBM), which focuses specifically on individual-level health behaviors (Hochbaum, 1958; Rosenstock, 1960, 1966, 1974). The model was first developed to explain a widespread lack of participation in screening practices seen in the 1950s, but has since been expanded to explain responses to symptoms and behaviors associated with diagnosed illnesses (Champion & Skinner, 2008). This theoretical framework posits six primary constructs that are said to predict why individuals engage in prevention, screening, and illness control behaviors. These include the individual's perceived susceptibility to an ill-health condition, the perceived seriousness of that condition, the perceived benefits of a specified action to prevent or reduce the threat of an illness, the perceived barriers to engaging in a health promoting action, the cues that trigger action, and finally, the individual's perceived self-efficacy (Champion & Skinner, 2008). Regarding the measurement of these constructs in breast cancer research, Champion developed a mammography-specific scale that specifically focuses on screening and prevention of breast cancer. This scale has good construct validity and reliability with Cronbach's alpha ranging from .75 - .88 (Champion, 1999). This scale was also modified for an African American population with some cultural adjustments, and good construct validity and reliability were maintained (Champion & Scott, 1997). With this said, this scale has not been tested outside of the realm of breast cancer prevention, despite the fact that it is assumed that the HBM reflects follow-up behavior and illness control issues.

The Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975; Fishbein, 1967) and the Theory of Planned Behavior (TPB) (Ajzen, 1991) assume that behavior is immediately determined by behavioral intention. Behavioral intention is, in turn, determined by a person's attitude toward the behavior and the influence of significant others in the environment, or the social norms. Attitude toward the desired health behavior consists of two things: (1) an individual's belief that if a behavior is performed, a given outcome will occur and (2) how important the individual considers the outcome to be. Normative beliefs determine subjective norms, which are informed by significant relationships in the individual's life and by motivation to comply with those individuals (Montaño & Kasprzyk, 2008). TPB is an extension of TRA and adds an additional construct: perceived control over the performance of the behavior. TRA and TPB have been used to evaluate a large number of various screening intentions and behaviors. A recent meta-analysis conducted in the UK showed that the TRA/TPB reliably predicts participation in a variety of screening behaviors such as screening for breast and colorectal cancers (Cooke & French, 2008). Again, application of these theories to breast cancer research has been limited to a central focus on prevention and screening.

The HBM and TRA/TPB explain how to predict health behavior but fail to explain the mechanisms that change and influence behaviors. Social Cognitive Theory (SCT) attempts to explain the change mechanisms that lead to improved health behaviors, and is considered an interpersonal model with a focus on the influence of relationships on behavior. Despite the interpersonal focus, critics assert that SCT focuses too heavily on self-efficacy and lacks a more broad analysis of human action (Ewart, 2009). There are numerous key concepts that are incorporated into SCT, which can be grouped into five main categories: (1) psychological, individual-level determinants of behavior, (2) observation learning, (3) environmental

determinants of behavior, (4) self-regulation, and (5) moral disengagement (McAlister, Perry, & Parcel, 2008). Again, this theory is most well-known for its emphasis on self-efficacy, which consists of the beliefs one holds regarding the ability to influence the quality and functioning of their lives; however, Ewert (2009) believes that moving individuals toward more healthy lives requires much more than an efficacy enhancement. Additionally, this theory has not been tested extensively and the supporting research remains relatively thin (McAlister et al., 2008). One study that evaluated SCT as it predicts physical activity during breast cancer treatment showed that SCT may provide a useful framework for understanding physical activity among patients; however, there were many non-significant associations between constructs, the sample was extremely small, and 90% of participants were white, limiting the study's applicability (Rogers et al., 2005).

Although theories of health behavior such as these have proven to be informative in many ways, they center on the idea that health outcomes are primarily determined by individual behavior, which is reductionistic at best. These theories place the responsibility of disease management solely on the person with the disease without accurately accounting for community-level variables that drastically impact health outcomes. Especially when looking at disenfranchised groups such as young, African American women with an extremely aggressive form of breast cancer, personal behavior has little to do with the environmental context that has significantly influenced the disease trajectory. For example, although SCT considers the environment, the focus on behavior as impacted by self-efficacy is limiting. In their discussion of individual-level theories including the HBM and TRA/TPB, Crosby, Kegler, and DiClemente (2009), explain that, "...researchers have questioned the wisdom of relying exclusively on individual-level approaches..." and the authors continue by asserting that, "...community-based

approaches are an important complement or alternative to individual-level approaches” (p. 13). As we focus on circle 3 from Figure 2, it is clear that understanding women with triple-negative disease requires a more expansive perspective.

### **Broadening the Theoretical Lens**

A few theories help to widen this discussion beyond the influence of personal decision and behavior to include some of the larger systems-level factors. I will first discuss Ecological Systems Theory and Intersectionality Theory, which are meta-theories that will help orient the remainder of the discussion. These two theories will help to bring clarity to the placement of women with triple-negative disease within the social environment. A discussion of the General Adaptation Syndrome, leading into an explanation of allostatic load as a theoretical lens that informs our understanding of TNBC will follow. These two theoretical orientations will assist in establishing an explanation of how multiple systems of oppression affect biological processes and health outcomes. I will then discuss Social Action Theory and how it is a more comprehensive approach to understanding and implementing behavior change as compared to SCT. These theories will be directly linked to breast cancer disparities in African American women in hopes of enlarging the theoretical framework guiding our knowledge about the triple-negative subtype.

### **Ecological Systems Theory**

Urie Bronfenbrenner redefined the conceptualization of human development and set the theoretical stage for a host of helping professions including social work when he outlined Ecological Systems Theory in his seminal book, *The Ecology of Human Development* (1979). In his revolutionary, theoretical work, Bronfenbrenner outlines multiple levels of interrelations within the social environment that immediately impact the developing person. Unlike existing

theories of human development, Bronfenbrenner's theory enlarged the perspective and placed the human being within the context of an environment. The "person-in-environment" orientation that guides social work practice draws heavily from this grand theory and informs much of the work that social workers do in the field. Although often taken for granted, this theoretical approach significantly enlarged the framework of mental health professionals and highlighted the centrality of social relationships and cultural contexts in which human beings exist.

Bronfenbrenner outlines four levels of interrelations in the social environment (1979). The first is the *microsystem*, which deals with the relationships present within one's immediate environment. This level refers to the persons and the nature of the links between persons on a face-to-face, first hand basis with the individual. The *mesosystem* is a system of *microsystems*, or the set of interrelations that occur between two or more settings. For example, this may be the relations between the home setting and the place of employment. The *exosystem* is defined as, "one or more settings that do not involve the developing person as an active participant but in which events occur that affect, or are affected by, what happens in that setting" (Bronfenbrenner, 1979, p. 237). For a young child, this may include the parent's place of employment or the activities of a school board, settings in which the child does not directly participate, but have impact on the child's life. Finally, the *macrosystem* refers to the larger culture, subculture, or ideology in which these settings exist.

Ecological Systems Theory is an orienting theory that guides our understanding of how the social environment impacts women with breast cancer. The various levels articulated by the theory shed light on the interacting systems that affect health outcomes for these women. This theory is indeed applicable to all three of the circles defined in Figure 2, and is inclusive of the systems that directly impact women with triple-negative disease. Further, Ecological Systems

Theory might help in explaining differences between African American women with and without TNBC as we consider the impact of these linked systems over the life course. As we pull back the theoretical lens in order to provide a more comprehensive approach to understanding these disparities, specifically looking at the impact of violence, abuse, and adverse environments (negative experiences on the mesosystem and exosystem levels), while also considering the impact of institutionalized racism, sexism, and classism (the impact of the macrosystem level), proves critical to providing a complete theoretical basis for understanding these disparities. Including these levels of evaluation are essential in understanding why the experiences of women with the triple-negative diagnosis may be unique from other women with breast cancer.

### **Intersectionality Theory**

Another helpful theory in understanding the overlapping layers of oppression that affect health outcomes is Intersectionality Theory. According to Murphey and colleagues (2009), “Intersectionality posits that an understanding of a person’s social location, that is his or her place in society that is formed by the intersection of social constructions that mark privilege and oppression, is essential to capturing the complexity of that person’s experiences, including his or her actions, choices, and outcomes” (p.7). According to this theory, social constructions of privilege and oppression such as race, gender, and class, overlap to inform the unique life experiences of individuals. These social constructions of privilege and oppression affect the entire individual holistically, which includes the consideration of how systems of oppression affect health and mental health outcomes. Intersectionality theory also informs all of the interlocking systems articulated in ecological systems theory in that social location affects people at all environmental levels.



Intersectionality Theory grew out of some of the shortcomings of the feminist movement, as the lens was broadened to incorporate oppression that extended beyond just gender to include race, class, etc. Kimberly Crenshaw (1995) popularized this theoretical approach as she strove to shed light on the experiences of women of color whose lives were not fully understood by the interpretation of oppression as solely being attributed to either gender or race as separate entities. Rather, Crenshaw states "...many of the experiences Black women face are not subsumed within the traditional boundaries of race or gender discrimination as these boundaries are currently understood, and that the intersection of racism and sexism factors into Black women's lives in ways that cannot be captured wholly by looking at the race or gender dimensions of those experiences separately" (Crenshaw, 1995, p. 358). In other words, multiple systems of oppression are at play in the lives of women of color, and separation of these systems from one another compartmentalizes the individual experience. The theory of intersectionality is rooted in the concept of the Matrix of Oppression articulated by Patricia Hill Collins. The Matrix of Oppression represents a continually changing set of social relations and systems that interact and change continuously (Collins, 2000). This matrix demonstrates the overlap of race, gender, class, age and other social constructions that uniquely mark the experience of individuals as they interact with the world.

Intersectionality Theory is starting to be used to inform women's health research, although the methodological practice of exploring Intersectionality Theory is often difficult to delineate and is still being solidified. McCall (2005) suggests that because of the complexity of the concept of intersectionality in that many overlapping systems are being measured at once, research methodology using intersectionality is still in its developmental phases. Even so, McCall (2005) proceeds by delineating a methodological framework in which intersectionality

should be used, articulating three different methodological approaches to utilizing this theory. Despite the preliminary state of methodology regarding the use of intersectionality, Hankivsky and colleagues (2010) discuss the usefulness of the theory in health research and cite numerous studies that incorporate intersectionality successfully. This emerging theory is becoming important in understanding health outcomes for women.

### **General Adaptation Syndrome and Allostatic Load**

Psychosocial stressors play a significant role in the disease trajectory from etiology through treatment and disease management. As mentioned above in the discussion of the TMSC, strictly evaluating coping skills does not do justice to the magnitude of the impact of these stressors on the individual, especially for those women with myriad psychosocial issues such as those facing a triple-negative diagnosis. Therefore, understanding the impact of stressors on the breast cancer experience requires a broader perspective. Hans Selye discusses the General Adaptation Syndrome (GAS) as one way of looking at the impact of stress on the body in a more holistic manner.

GAS refers to an adaptive reaction to stress that occurs over time, as compared to a one-time response to an immediate stressor; this involves a physical and psychological learning of defenses against stress and a development of constant defense against future exposure to stress (Selye, 1950). The GAS is an adaptive, normal process describing how the body deals with stress, but this process of adaptation may actually lead to disease over time due to maladaptation in the face of extreme, prolonged stressors. Selye (1955) articulates three stages of the stress syndrome, which are, “(i) the alarm reaction, in which adaptation has not yet been acquired; (ii) the stage of resistance, in which adaptation is optimum; and (iii) the stage of exhaustion, in which the acquired adaptation is lost again” (p. 626). If an individual is faced with extreme

stressors over time, the body's normal adaptation to stress is exhausted, which actually leads to disease and psychosomatic syndromes.

Although at the time that this article was published the link between stress and cancer was in very early stages, Selye (Selye, 1979) draws connections between extreme stress over time, exhaustion from stress, and the occurrence of cancer. In this article, psychological impacts of stress are evaluated in light of malignancy and the mechanisms of tumor growth are linked to stress processes. It is clear that increased psychosocial stress leads to negative physiological effects that ultimately accumulate and contribute to a number of diseases including breast cancer.

The concept of allostatic load is a more recent outgrowth of the GAS and explains the mechanisms by which stress accumulates in the body and results in negative health effects. Through the theoretical lens of allostatic load, the impact of psychosocial stressors on the body becomes central in understanding breast cancer disparities in underserved populations. By including allostatic load as one theoretical framework through which to view and understand the presence of breast cancer disparities, it is possible to begin to see the effects of larger systems of oppression on the body and how these systems impact breast cancer outcomes. This theoretical approach helps social scientists move beyond just the impact of individual behavior on breast cancer disparities and includes an evaluation of how stress, racism, and oppression affect health outcomes.

First defining a few key terms will help to explain the concept of allostatic load. The word "homeostasis" refers to the body's ability to regulate itself over time. W.B. Cannon accurately defined homeostasis as the "coordinated physiological processes which maintain most of the steady states in the organism" (Cannon, 1932). These processes include those systems that maintain tight physiological regulation such as body temperature or pH balance (Carlson &

Chamberlain, 2005). Body regulation is the central function of homeostatic processes as normal functioning is maintained throughout the day, but inevitably there are disruptions and challenges that cause the body to react in various ways. “Allostasis” is the term used to define the body’s ability to react to stressful events in an adaptive and protective way, and allostasis eventually works to bring the body back to a stable place. Sterling and Eyer (1988) define allostasis as the process of achieving stability through change. A stressful event or problem may cause a variety of bodily responses including increased heart rate, blood pressure, endocrine output, and neural activity (B McEwen & Stellar, 1993). These changes in the body are normal and healthy, and allow the body to adapt to life events. For example, when a person feels startled, their heart rate may increase and adrenaline flows as a protective measure to ensure that the individual responds adequately to a threatening situation before the body returns to baseline once the threat has abated. Allostasis is protective and normal; however, allostasis becomes problematic when there is repeated and unrelenting stress over time and the body is unable to return to baseline.

Allostatic load, therefore, is a term used to describe the accumulation of physiological and psychosocial wear and tear over time resulting from repeated efforts to adapt to stressors throughout the life span (Glover, Stuber, & Poland, 2006; Goldstein & McEwen, 2002; B. S. McEwen, 1998; Bruce McEwen & Lasley, 2003). This is essentially the process of adaptation to stress that is discussed in the GAS as well. McEwen (1998) explains how stress leads to disease by naming different types of physiological responses that make up allostatic load including frequent stress, failed shutdown of bodily responses such as persistent elevated blood pressure, and inadequate response to stress such as autoimmune and inflammation problems. When demands exceed supports, the body is often unable to turn itself on and off efficiently, leading to

the accumulation of these stressful reactions in physical manifestations in the body (Gehlert et al., 2008).

Although some accumulation of allostatic load over time is common in all human beings, most are able to minimize wear and tear in an adaptive way, but some are not. In their article presenting allostatic load as a theoretical framework for explaining health disparities, Carlson and Chamberlain (2005) assert that institutionalized racism may play a large part in understanding the existence of health disparities in African Americans via the accumulation of high allostatic load. Racism experienced across multiple spheres of life including education, housing, and employment contributes to the increase of allostatic load as African Americans are constantly exposed to hostile, stressful environments from which their bodies are often unable to recover. In a recent study comparing the accumulation of allostatic load in African Americans to whites over time, African Americans had a significantly higher mean allostatic load score at all points throughout the life course when compared to whites (Geronimus, Hicken, Keene, & Bound, 2006). When factoring in the effects of poverty, poor African Americans and poor whites had higher scores than their non-poor counterparts, however, non-poor African Americans had a higher allostatic load than poor whites, indicating that regardless of poverty levels, race plays a major role in understanding the accumulation of allostatic load. Additionally, African American women in this study bore the highest burden of allostatic load and had higher mean scores than African American men and all white participants (Geronimus, Hicken, Keene, & Bound, 2006). This accumulation of allostatic load may be one of the chief explanations of differences in disease outcomes including breast cancer disparities among African Americans.

## **Social Action Theory**

In discussing this limitation of the health behavior theories discussed above, Ewart (2009) asserts that these theories, "...do not offer highly specific (and thus useful) accounts of how people actually translate health-related expectancies values goals, or intentions into appropriate actions and, more important, into sustainable habits" (p. 360). Once women are understood and placed within the larger societal structures using Intersectionality Theory and an understanding of allostatic load, a theory of health behavior that attempts to address these shortcomings and includes larger systems-level variables is Social Action Theory (SAT). SAT encourages a social-contextual analysis of personal change by suggesting pathways by which social and other environmental factors influence cognitive processes. The model contains three dimensions: (1) self-regulation as a desired action state; (2) a system of interrelated change mechanisms; and, (3) larger environmental systems that contextually determine how personal change mechanisms operate (Ewart, 1991, p. 932). Individuals' desired states are influenced by what is necessary to achieve goals such as social influence, personal safety, material resources, and intimacy (Ewart, 1991, p.936).

While TRA/TPB views social norms as influential on health behavior, SAT considers these social relationships to be mechanisms of action, wherein others are viewed as active players rather than outside influences on behavior. This is perhaps a more dynamic way of looking at the impact of relationships on health and begins to include psychosocial factors in a way that other health behavior theories do not. SAT begins to incorporate larger environmental systems into the way behavior is understood, although the emphasis does remain pointed on understanding and changing behavior. Although health behavior is one critical component to

consider in the lives of women facing a triple-negative diagnosis, our understanding would be incomplete if our theoretical foundation rested on behavioral theories alone.

### **Toward an Integrated Conceptual Model**

Given the context provided by the theories listed above, an integrated conceptual model is needed as we seek to understand women with TNBC. Ultimately, the use and design of a more comprehensive model that encapsulates the various levels at play will assist in the development of appropriate and relevant interventions for women with TNBC. It is important to consider and integrate the significant elements of each of the above theories and frameworks in order to build a multi-level, ecological approach to addressing the complex needs of women with TNBC. These theories and frameworks inform our understanding of the challenge at hand. In answer to study question 3, one of the goals of this study is to begin building an integrated model in order to provide a structural framework for understanding the disease experience for young African American women with TNBC. The results of this study that specifically address this question will be explored in chapter 5.

**Chapter Three - Review of the Literature:**  
**Psychosocial and Contextual Issues Associated with African American**  
**Women who are Coping with Breast Cancer**

**Bounding the Literature**

With the understanding that the interactions between genes and the social environment are not only important but perhaps the crux to understanding how young, African American women experience breast cancer, the following literature review explores the various psychosocial factors that have been identified as important to consider when examining how African American women in general live with a diagnosis of breast cancer. Because research exploring the psychosocial factors of those with the triple-negative subtype is basically non-existent, the literature discussed in this chapter expands the population of interest to include African American women post breast cancer diagnosis regardless of subtype of breast cancer or age at diagnosis (see circle 2 in Figure 2). Additionally, because triple-negative breast cancer is more common in younger African American women, providing a life cycle picture of the psychosocial issues among all African American women can be helpful as we seek to understand how African American women cope with the disease over time. The literature here includes the important contextual factors that impact how African American women manage, process, and live through such an experience and explores the multifaceted psychosocial issues that impact recovery and survivorship. With this said, little research exists on African American women and their lives with and beyond breast cancer, especially for those who have experienced high levels of social environmental stress across the lifespan, despite the fact that there is so much literature on survivorship issues for white women. Although much literature exists about psychosocial



factors as they relate to screening practices, mammography, risk education, and prevention of breast cancer in minority population, this literature was excluded because the focus of this study is on the contextual factors associated with African American women who have already been diagnosed.

Studies included for review were identified by exploring the multitude of psychosocial issues that have come into play in the previous two chapters as related to etiology of the disease, and specifically the etiology of TNBC. The rationale behind this choice was that many of the psychosocial stressors that affect etiology would also be impactful after diagnosis occurs, especially given the theoretical foundation laid in the preceding chapter. These problems do not disappear when a diagnosis occurs, but rather, compound with the newly acquired life hurdle of dealing with illness and responding to treatment. Further, understanding the life context is critical as practitioners begin to understand how best to intervene on behalf of vulnerable populations. Therefore, in addition to search terms such as breast cancer, mammary cancer, breast malignancy, and breast neoplasm combined with population terms such as African American women and black women, additional terms included in the search were, racism, discrimination, poverty, neighborhood, social deprivation, stressors, socioeconomic status, income, education, mental health, culture, and survivorship. Excluded from this review were studies that did not examine breast cancer specifically but focused only on cancer in general or on other primary site cancers, studies that did not specifically evaluate African American women, and studies that focused on detection or screening practices rather than recovery and/or survivorship issues. Studies were omitted if they were published earlier than 2000 in order to provide the most current knowledge.

## **Key Concepts and Issues Found in the Literature**

With these search terms in mind, a number of key concepts and issues came to light in the literature that was found. Articles meeting search criteria fall under six broad categories, which include: (1) income, work, and financial concerns, (2) neighborhood and place of residence, (3) racism and discrimination, (4) social support, (5) religion and spirituality, and (6) quality of life and psychosocial functioning. When overlap in topics occurred, specifically with the category of quality of life, as this tends to be a blanket term for many psychosocial issues, organization of studies was dictated by the central findings and focus of the studies. These six key areas were used as “sensitizing concepts” in analysis of data (Charmaz, 2006), and helped to guide the understanding of data collected in the study.

### **Studies Exploring Income, Work, and Financial Concerns**

According to the literature, African American women with breast cancer experience significant financial burdens that influence breast cancer outcomes across the continuum of care. In general, African Americans experience poverty at much higher rates as compared to whites in the United States (DeNavas-Walt, Proctor, & Smith, 2010); this fact becomes more complicated upon diagnosis of breast cancer as financial concerns that come alongside a diagnosis may heighten the experience of poverty. As established in preceding chapters, poverty and financial concerns are critical factors that affect etiology, diagnosis, treatment, and progression of disease. It is reasonable that these concerns continue to be relevant after African American women are diagnosed with breast cancer and this is substantiated in the literature.

Two pertinent articles included in this literature review discuss the impact of breast cancer on work patterns for African American women (Mujahid et al., 2010, 2011). These two research studies are based on the same sample of breast cancer survivors and the articles are

written by the same team of researchers, but the two studies cover different aspects of this issue, namely missed work due to diagnosis and treatment, and job loss as a result of breast cancer.

The sample for both articles was drawn from the Los Angeles County SEER registry, and Latina and African American women were oversampled in order to look specifically at minority issues related to breast cancer and work patterns. Eligibility criteria included (1) 20-79 years of age, (2) a primary diagnosis of primary ductal carcinoma in situ (DCIS) or invasive breast cancer (stage 0-III) and (3) ability to complete a questionnaire in English or Spanish.

The first article, “The impact of sociodemographic, treatment, and work support on missed work after breast cancer diagnosis”, used multinomial logistic regression to calculate adjusted odds ratios for missing or stopping work by sociodemographic, treatment/clinical, and work supported relational factors (Mujahid et al., 2010). The sample included 589 female participants, of which 14% were African American. Results indicate that African American women are more likely than white women to either miss more than one month of work (OR [95% CI]: 3.0 [1.3-6.7]) or stop working all together (OR [95% CI]: 3.0 [1.2-7.4]) after a diagnosis of breast cancer. Additional relevant independent variables affecting missed work were extent of treatment for breast cancer and supportiveness of work environment. Those women who received a mastectomy were more likely to stop working compared to those receiving a lumpectomy (OR [95% CI]: 4.2 [1.8-10.0]), and those without a flexible work environment were more likely to stop working compared to those who had a more supportive and elastic work environment (OR [95% CI]: 18.9 [9.1-39.4]). These findings have much significance in how we view the issues that African American women face while undergoing treatment, as these results indicate that African American women may be more vulnerable to long-term financial impact from the disease due to their patterns of work loss.

The second article written by this team of researchers entitled, “Racial/ethnic differences in job loss for women with breast cancer”, examines treatment-related job loss among a sample of 1,111 eligible women, of which 304 were African American (Mujahid et al., 2011). Descriptive statistics and a series of logistic regression models were run to determine differences between African American, Latina, and white women with the dependent variable being job loss after diagnosis of breast cancer as self-reported by women in the study. Latina women had the highest rate of job loss, followed by African American women, and finally white women (24.1%, 10.1%, and 6.9%, respectively). Although the difference between African American women and white women was not statistically significant, it is evident that there is a difference that may hold clinical significance for this group of women. Additionally, subgroup analysis by intensity of treatment indicates that there is no significant difference by race for those women who do not receive chemotherapy; however, for women who receive chemotherapy, African American women are significantly more likely to experience job loss compared to white women (OR [95% CI]: 1.3 [0.5-3.3]). Also, women with two or more co-morbidities were more likely to report job loss (OR [95% CI]: 2.5 [1.3-4.9]) compared to those without co-morbidities, and African American women were the most likely group in this sample to have two or more co-morbidities. Finally, African American women reported having significantly more difficulty paying the bills than did white women after controlling for sociodemographic, clinical, and treatment factors (OR [95% CI]: 2.2 [1.3-3.6]). Inability to work and job loss resulting from breast cancer are important contextual factors that must be taken into account for African American women facing a diagnosis of breast cancer, as these issues have longitudinal implications for overall wellbeing.

A qualitative study by Darby, Davis, Likes, and Bell (2009) highlights the financial concerns articulated by African American women themselves during interviews from focus

groups consisting of African American breast cancer survivors. A total of 36 African American women were brought together for four focus groups in three major cities in Tennessee. Thematic analysis of the audiotaped focus groups revealed three consistent themes problematic to African American women recovering from breast cancer: (1) lack of access to adequate care if unable to pay or without adequate health insurance, (2) the long-term financial impact of the disease, and (3) the impact of non-medical expenses such as childcare, transportation, homecare, and housekeeping. These concerns extend beyond the immediate impact of diagnosis and affect African American women for many years. The authors conclude that African American women often experience extreme economic hardship extending into long-term survivorship.

These studies reveal the financial impact that breast cancer has on African American women, which is an aspect of care that is often overlooked. In addition to the quantitative evidence supporting the problem of missed work days and job loss associated with breast cancer, the disease is also accompanied by a multitude of financial problems that are often overlooked such as the expenses of health care, transportation, and child care as highlighted in the qualitative study. When we consider the other various social environmental factors at play before the diagnosis ever occurs, especially for women with TNBC, the impacts of the cancer experience may compound already existing financial issues further complicating things. It is important that the results from these studies are seen in light of the complex social history leading up to a diagnosis in order to understand the complete impact. With the knowledge that many of these financial and income based stressors overlap with neighborhood demographics and the surrounding community throughout the life course, an exploration of the literature on the impact of neighborhood composition on survivorship issues follows.

## **Studies Exploring Neighborhood Composition and Place of Residence**

Haas et al. (2008) examine the impact of racial segregation in communities on both breast cancer care and mortality in African American women with breast cancer. This study used SEER Medicare data to explore the impact of neighborhood segregation on these two outcomes, and although it was specific to older African American women with breast cancer, the sample size was very large (47,866) and provides a window into these complicated dynamics. These data were then supplemented with neighborhood demographics based on the US Census. Using the isolation index, which ranges from 0 - 1.0 with higher numbers indicating greater segregation, calculations of segregation and isolation were completed for each neighborhood or small county. Findings from this study indicate that African Americans were less likely than whites to receive adequate care (OR [95% CI]: 0.72 [0.65-0.78]), and African American segregation mediated some of the disparity in receiving adequate care. For women living in neighborhoods with higher levels of segregation, both African American and white women were less likely to receive adequate care (OR [95% CI]: 0.73 [0.64-0.82], and OR [95% CI]: 0.73 [0.61-0.89] respectively). Although African American women experienced much higher mortality rates, even after adjusting for receipt of adequate care, segregation did not mediate this disparity. In other words, according to this study, racial segregation and isolation in neighborhoods have a significant impact on adequacy of care received for breast cancer, but do not impact mortality from breast cancer. It is evident from this study that not only do individual demographics and personal experiences of poverty affect outcomes for survivors, but neighborhood characteristics and larger systems level factors are also important to consider.

To build on this knowledge, a possible explanation to the lack of association between segregation and mortality found in the previous study is the possible protective factor for African

American women of social support found in neighborhoods that have a higher percentage of African American individuals. Warner and Gomez (2010) also examined neighborhood composition and segregation as it related to stage at diagnosis and mortality using the California Cancer Registry matched with US Census data. In general, there were not significant associations between segregation and stage of disease at diagnosis for both African American and white women. However, the exception to this finding was that African American women living in low percent black neighborhoods within the most segregated regions (as measured by the isolation index) had a higher chance of having distant metastases as compared to African American women living in low percent black neighborhoods within the least segregated neighborhoods (OR [95% CI]: 2.21 [1.05-4.27]). Additionally, among African American women, those living in neighborhoods with 20% or greater African American residents experience a lower breast cancer specific mortality and all-cause mortality (HR [95% CI]: 0.86 [0.76-0.97], and HR [95% CI]: 0.90 [0.82-0.99]), which is consistent across all levels of segregation. Although segregation has a negative impact on stage of diagnosis, the authors suggest that racial homogeneity in neighborhoods may have a protective factor against mortality because of the importance of social support and decreased isolation in the lives of African Americans facing breast cancer.

Another important factor to examine when looking at neighborhood composition is the degree of change experienced in neighborhoods over time. In light of gentrification occurring across the nation's cities, this dynamic is important to examine as it affects breast cancer outcomes in African American women. Barrett and colleagues (2008) examine neighborhood change over time and its effect on distant metastasis at diagnosis using multilevel modeling on census tract data combined with cancer registry data. In a multilevel logistic regression, greater

concentrated disadvantage is associated with greater odds of distant metastasis at diagnosis (OR [95% CI]: 1.23 [1.12-1.36]), while greater neighborhood affluence is associated with reduced odds of distant metastasis at diagnosis (OR [95% CI]: 0.86 [0.79-0.93]). Further, upward change in neighborhood is significantly associated with the probability of distant metastasis such that for each unit of increase in the rate of neighborhood change, the odds of distant metastasis at diagnosis increase by 9% (OR [95% CI]: 1.09 [1.01-1.18]). These findings have many difficult interpretations. While disadvantage is associated with metastasis at diagnosis, upward change in neighborhoods is also associated with metastasis. The authors assert that upward change in neighborhood may result in disruption of social ties and patterns of support for long-standing residents. Isolation and concerns about relocation may impact health and may disrupt access to health care.

Finally, Rosson, Singh, Ahuja, Jacobs, and Chang (2008) evaluate the impact of community factors and place of residence on the likelihood of obtaining immediate breast reconstruction after mastectomy. The authors use immediate reconstruction surgery as a proxy for best care, and evaluate the differences in this practice across community demographics using discharge data from the Maryland Hospital. Women who are more likely to receive immediate reconstruction are those who are younger, not African American, and live in areas with higher median household income, higher home values, and higher percentages of populations with at least some college education. Multivariate analysis was performed and results indicate that higher income and higher population density of the city in which a patient lives are associated with increased likelihood of receiving immediate breast reconstruction (OR [95% CI]: 1.11 [1.06-1.16] and OR [95% CI]: 1.04 [1.03-1.06]). Alternatively, African American race/ethnicity, higher percentage of people in the patients' neighborhood with a high school education or less,



and high levels of African American neighborhood composition had negative associations with likelihood of receiving reconstruction immediately post mastectomy. Clearly, neighborhood composition and place of residence are important factors in follow up care.

These studies demonstrate the importance of understanding women as part of a larger social context. This is in contrast to traditional views of cancer care that involve only individual level variables. Neighborhoods and communities are essential in understanding how breast cancer is experienced in the lives of women, and these dynamics are rarely included when assessing psychosocial factors of importance in the lives of African American women with breast cancer. With this in mind, it is critical to note that relationships between women and their surrounding communities are complex and not always clear-cut. While the majority of the included studies in this review demonstrate that segregation, isolation, and neighborhood poverty are associated with negative breast cancer outcomes, there is also a protective factor involved in living in a neighborhood with little variation in racial composition, as homogeneity may be a source of social support. In general, we can conclude that poverty and segregation have negative impacts on those coping with breast cancer, but neighborhoods with less diversity may provide a structure of support not present in neighborhoods with more racial differences.

### **Studies Exploring Racism and Discrimination in Relation to Breast Cancer**

Although few of these studies exist, some authors have established a clear link between the experience of racism over the lifetime and breast cancer outcomes. In a review and critique of the recent literature, Williams and Mohammed (2009) cite a multitude of health and mental health outcomes that are directly associated with perceived racism. The authors demonstrate that perceived racism as a type of stressor has a unique impact on health. Breast cancer is positively associated with perceived racism, and the authors cite Taylor et al. (2007) as a pertinent study

demonstrating this link. Participants in the Taylor et al. (2007) study were part of the Black Women's Health Study, which is a prospective cohort study. Women were asked about their experiences of discrimination, which included two categories, "everyday discrimination" and "major discrimination". Although there was no significant association between "everyday discrimination" and breast cancer incidence, there were strong associations between "major discrimination" and breast cancer occurrence. For those who experienced discrimination on the job, rates of breast cancer significantly increased (IRR [95% CI]: 1.20 [1.01-1.42]), and for those who experienced discrimination in three areas of their lives, housing, job, and police treatment, the incidence of breast cancer increased even more (IRR [95% CI]: 1.31 [1.00-1.73]). Additionally, for younger African American women under the age of 50 who experience discrimination on the job, incidence rate of breast cancer increased to 1.32 (95% CI: 1.03-1.70), and for discrimination in all three situations - housing, job, and police - the incidence rate ratio was 1.48 (95% CI: 1.01- 2.16).

Racism and discrimination based on the color of one's skin is alarmingly present in our society. These studies demonstrate the link between the experience of racism over time and the occurrence of breast cancer in African American women. Further, while isolated experiences of racism may have minimal impact overall, routine, systematic racism experienced regularly over the life course significantly impacts breast cancer outcomes. It is important to note that younger African American women were significantly more influenced by the experience of racism (Taylor, et al., 2007), which perhaps implies the impact that racism has over the life course as alluded to in the discussion of allostatic load. The need for the body to accommodate to stressors over time in the form of systematic oppression results in negative health outcomes including increased rates certain types of breast cancer. Racism is a major factor that must be taken into

account as we consider how best to intervene when providing care to these women, but has routinely been excluded from most breast cancer interventions.

### **Studies Exploring Social Support**

Although the intersection of social support and breast cancer has been studied extensively in the literature, few studies have specifically included African American samples of women; therefore, our knowledge on the subject matter is specific to white women. A few exceptions to this trend were found in the literature search. Friedman et al. (2006) examined a multi-ethnic sample of 81 women, which included 45 African American, on optimism and social support as they affected quality of life in breast cancer survivors. The authors found that satisfaction with social support networks had a significant positive effect on functional well-being and social/family well-being, and this association was significant across racial/ethnic lines. In other words, social support in general is important to improved well-being for breast cancer survivors regardless of race.

Given this information, it is logical to conclude that social support is important for all women living with breast cancer, but differences in the types of social support needed for African American women are significant as compared to the types of social support needed for white women. These differences have historically been overlooked, which is a disservice to African American women who may have different needs regarding psychosocial interventions. Bourjolly and Hirschman (2001) note numerous differences in the structures and types of social support needed in African American breast cancer survivors as compared to white women. Both the structure of the social network and the function of the social network were significantly different for African American and white women in their study. These authors conclude that white women are more likely to receive support from a spouse, children, or friends, while

African American women are more likely to receive support from God, even when controlling for marital status, belonging to an organized religion, and having children. More white women also reported receiving all three types of support, concrete, emotional, and informational, from spouses, children, and friends as compared to African American women who reported receiving these three types of support mostly from God.

Hamilton and Sandelowski (2004) confirm that the types of social support used by African American women when undergoing treatment and recovery from breast cancer are different from those typically portrayed in the literature. The authors used open-ended questions and semi-structured interviews with 28 participants, 15 of whom were African American women with breast cancer (the remaining 13 participants were African American men with prostate cancer). African American women reported the need for instrumental support in the form of offering prayers and assistance to continue religious practices, the need for emotional support in the form of “presence”, and the need for informational support in getting information about what to expect about the disease. Although these three types of support are clearly articulated in the literature (i.e. instrumental, emotional, and informational), the expression of these forms of support differed for African American women such that instrumental support in the form of prayer and assistance with religious participation and emotional support in the form of “presence” has not been previously articulated in studies with mostly white samples.

Lastly, Shelby, Crespin, Wells-Di Gregorio, Lamdan, Siegel, and Taylor (2008) demonstrate the function that social support may play in moderating the relationship between optimism and adjustment to breast cancer in African American women. This study included 77 African American women with breast cancer who completed measures of optimism, social support and adjustment. The research team ran multiple linear regressions to assess the

relationship between optimism, social support, and adjustment. The authors conclude that social support might be an important resource for women with low optimism in that social support buffers the relationship between low optimism and increased psychological distress, reduced well-being, and poorer psychosocial functioning.

These studies indicate that social support is critical in understanding how women deal with a diagnosis of breast cancer; however, it is critical to note that the definition and measurement of social support varies widely. These issues will be discussed at length in chapter five, which will discuss the findings from the present study in light of this literature, but from these studies, we can conclude a number of things about the importance of social support in the lives of African American women with breast cancer. First, social support is critically important to all women coping with breast cancer regardless of race. Secondly, types of social support needed vary according to race, and finally, African American women rely on God, their spiritual community, and their experience of spirituality as a significant source of social support more than white women; however, we do not know if these various forms of support offer equal protective health benefits. Important to note is that the studies discussed here are limited in that they only explore the presence of social support once the diagnosis of breast cancer has occurred. It might also be relevant to explore social support over the life course and how breast cancer outcomes may differ based on early experiences of support verses later. This topic of support throughout the life course will be discussed in the findings section of this dissertation.

### **Studies Exploring Spirituality and Religion**

Although identified as critical in understanding how African American women address survivorship issues, there are still gaping holes in our knowledge about the mechanisms of spirituality in the lives of women living with breast cancer. In the literature, one integrative

review article by Gibson and Hendricks (2006) on topics of spirituality was found, and this review article was able to identify only seven relevant studies pertaining to this topic. This review covered all literature written between 1994 and 2004 found when searching the key words spirituality, African American women, breast cancer, and breast cancer survivors in the following databases: Medline, Cumulated Index of Nursing and Allied Health Literature (CINAHL), Psychology Abstracts, Sociology Abstracts, and the Religion and Philosophy index. Of the seven studies located in the review article, three were qualitative, three were quantitative, and one used mixed methods. In these studies, four central domains of spirituality were identified which include caring; belief, faith, and healing; coping; and support.

In a recent qualitative study where multiple themes of spirituality were identified, Levine, Yoo, Aviv, Ewing, and Au (2007) found that African American and Latina women are more likely to consider themselves spiritual or religious when coping with breast cancer compared to white women and Asian/Pacific Island women. Additionally, spirituality has been found to be important to African American women with breast cancer across all stages of the breast cancer experience. Simon, Crowther, and Higgerson (2007) use qualitative methods to explore spirituality across three phases of the cancer experience, namely diagnosis, treatment, and post treatment (survivorship). Results of the study indicate that spirituality is an important, positive coping mechanism throughout all phases of the breast cancer experience, and is a source of support and hope for African American women.

### **Studies Exploring Quality of Life and Psychosocial Functioning**

Quality of life is perhaps one of the most well studied areas for this population, and yet, gaping holes in the literature still exist. The literature search resulted in only one review article that summarizes the major themes around quality of life for African American women (Russell,

Von Ah, Giesler, Storniolo, & Haase, 2008). The authors of this review article found 26 relevant studies written from 1998 to 2007 relating to quality of life concerns for African American women who have breast cancer. The authors highlight 5 major areas of importance that were evident across the literature. First, physical symptom distress is significant; African American women report more comorbidities than white survivors, and some of the most common of these include fatigue, pain, cognitive dysfunction, physical dysfunction, and sexual dysfunction. Second, life stressors were a significant problem for African American women. Such stressors mentioned in the literature include urban living environments, financial concerns, social disruptions, work-related problems, and disruptions in social support resources. Third, provider-patient relationships between African American patients and their doctors were found to be inadequate and a major factor in predicting quality of life. Fourth, spirituality was found to be a source of strength and support, and is commonly mentioned in the literature as a way that African American women improve their quality of life. Lastly, compared to white survivors, African American women experienced more positive growth and were fairly optimistic throughout the course of the disease.

Three other recent studies confirm some of the findings found in this review article. In multiple regression analysis, Rao et al. (2008) found that African American women reported worse physical and social well-being, but better emotional well-being as compared to their white counterparts ( $p < .01$ ). In this study, African American women were more likely to have a better outlook on life and experienced less fatigue and treatment side effects, but reported more feelings of illness and inability to work. Bowen et al. (2007) also reported statistically significant lower physical functioning scores in African American women compared to white and Hispanic women ( $p < .01$ ), but higher mental health scores ( $p < .01$ ). Using linear regression

models, the authors demonstrated that these two domains of quality of life are significantly different for African American women. Lastly, Janz et al. (2009) also demonstrate the differences in quality of life among African American women with breast cancer using regression models. In their first model, African American women reported lower functional well-being compared to white women, but after controlling for sociodemographic characteristics, these differences were no longer significant. Even after controlling for all other variables in the model, African American women had higher levels of emotional well-being than white women. Also of interest were the findings in this study that regardless of race/ethnic variation, all young women (< 50 years of age) had significantly lower levels of physical and emotional well-being than older women in the study.

The overlap of quality of life issues and spirituality is important to explore, and two studies were located in the literature that demonstrate the impact of spirituality on multiple domains of quality of life for African American women with breast cancer. These studies were placed in this section as opposed to the spirituality section of the chapter because quality of life was used as the main outcome variable of interest in both studies. Morgan, Gaston-Johansson, and Mock (2006) used spearman-rho correlations to show the association between spirituality and quality of life in a small sample of African American women with breast cancer. Positive associations between spirituality and three other domains of quality of life were found, such that women with higher levels of spiritual well-being experienced higher levels of physical, emotional, and functional well-being. This study also examined negative religious coping and found that those women with higher levels of negative religious coping experienced decreased physical well-being (Morgan et al., 2006). Leak, Hu, and King (2010) also examined the correlations between spirituality and found similar results. In Pearson correlations, the authors



found that spirituality was positively associated with quality of life; as spirituality increased, so did quality of life. Drawing from these studies, constructive spirituality positively affects quality of life while negative religious coping has harmful effects.

The next study of interest examines the impact of socioeconomic status and socioecological stress on health-related quality of life in breast cancer survivors (Ashing-Giwa et al., 2010). The study sample includes participants drawn from the California Cancer Surveillance Program, Los Angeles area hospital, and community agencies; 135 of the 703 participants are African American. ANCOVA is used to assess differences in quality of life across four ethnic groups including European-, Latina-, Asian-, and African- American women with a specific emphasis on how financial status impacts quality of life. Patterns across ethnic groups were similar in that lower socioeconomic status was associated with lower quality of life in survivorship, and increases in socioeconomic status resulted in increases in quality of life. Notably, African American women in this study reported poverty rates at three times that of European Americans. Additionally, hierarchical regression analysis was used to determine the impact of socioecological factors such as neighborhood stress, use of public services, crime and violence, and relationships with police. Across all ethnic groups, socioecologic stress was the most important factor influencing mental and physical quality of life explaining 32% and 35% of the variance respectively.

Similar findings were seen in a study by Rosenzweig, Wiehagen, Brufsky, and Arnold (2009), who demonstrated through qualitative interviews that low-income, African American women have unique experiences in dealing with metastatic breast cancer. The authors broke their sample into four groups: white low income, white non-low income, African American low income, and African American non-low income. As compared to high-income African

American women and all white women, African American women with low income report experiencing more physical distress and social distress. Physical distress included the experience of pain, nausea, and other chronic physical symptoms; social distress included problems with financial concerns, poor relationships as a result of the cancer, and social stigma.

Finally, Coggin and Shaw-Perry (2006) conducted a qualitative study that examined the central psychosocial needs of African American women with cancer and provide a summary of five common themes expressed by this group. These themes were identified by ranking the need statements provided by participants. Findings show that African American women express a need to (1) have a full range of appropriate medical care and support services, (2) have a loving and caring family, (3) know who to contact for symptom management and health problems, (4) have a strong relationship with God, and (5) have an adequate income.

From this chapter, it is clear that many psychosocial issues are important to consider in the lives of African American women coping with breast cancer and that some theories might be more useful in the case of African American women with TNBC. The six major categories of life stressors found in the literature include (1) income, work, and financial concerns, (2) neighborhood and place of residence, (3) racism and discrimination, (4) social support, (5) religion and spirituality, and (6) quality of life and psychosocial functioning. These six categories form a basis for scientific inquiry and begin to shed light on the various aspects of African American women's lives that are necessary to explore as these women are impacted by a diagnosis of breast cancer. It also is important to consider when these life stressors occurred during the life course, based on the knowledge that African American women with TNBC were more likely to experience stressors early in life than those with other types of breast cancer. Some of the key findings from the literature review include the stress of missed work and job

loss, the impact of the surrounding neighborhood and racial discrimination, the need for specific types of social support, specifically spiritual support, and the difficulties that African American women face in terms of physical well-being and quality of life. This literature review provides key concepts used as sensitizing concepts for the present study, which informed data collection and analyses.

## **Chapter Four - Methods:**

### **A Grounded Theory Approach**

The following chapter will outline the methods used to collect and analyze data for this qualitative study. Grounded theory was the methodological approach to data collection, and primary data were collected from women receiving services at the Siteman Cancer Center of Barnes Jewish Hospital in St. Louis, Missouri. This study had the following aims:

#### **Specific Aims**

1. Explore the biopsychosocial stressors and strengths of young, African American women with TNBC as compared to those of young, African American women with ER+ BC.
2. Understand the illness trajectory over time for young, African American women with TNBC and ER+ BC.
3. Build a conceptual framework for understanding the contextual lives of young, African American women with TNBC.

#### **Approach**

This study utilized grounded theory as the methodological approach for data collection and analyses. As defined first by Glaser and Strauss (1967), grounded theory is “the discovery of theory from data,” which necessarily involves a systematic approach to obtaining and analyzing data. Grounded theory uses inductive logic intricately linked to the data to build new theory in the social sciences. As opposed to relying heavily on existing theory, most hypotheses and concepts found using the grounded theory approach are drawn directly from the data and are worked out in relation to the data. Coding, memo writing, and critical analyses are used to

develop theory; guided by sensitizing concepts and theoretical ideas, grounded theory seeks to develop theory rather than test existing theory (Strauss & Corbin, 1998).

This methodological approach was explicitly chosen because of the lack of existing theory in this area of research and because the aims of the study necessitate an approach that allowed for theory building. Because TNBC was only recently discovered, and to date, there has never been a study exploring the unique psychosocial experiences and challenges associated with this subtype of disease, it is critical at this juncture to build an integrated theoretical model. This model will be based on key findings from the data while also synthesizing and incorporating any relevant existing theories or frameworks.

## **Design**

After obtaining IRB approval from Washington University in St. Louis on March 14, 2012 (IRB# 201111182), data collection was begun. A prospective, longitudinal design was employed to address the three specific aims. Interviews with participants occurred in three waves of data collection. Wave 1 involved in-depth interviews where the participants discussed their current life circumstances and their initial experiences with breast cancer. Wave 1 interviews took place between 1 and 4 months after initial diagnosis. This first round of interviews included questions about participants': (1) social support networks, (2) families of origin, (3) past exposure to any history of violence or abuse, (4) neighborhoods, (5) spiritual beliefs and practices, and (6) any pertinent additional psychosocial events prior to the diagnosis. This interview was the longest interview for participants in the study, lasting from 1 to 1.5 hours. Wave 2 interviews were scheduled to occur 3 months after the first wave of interviews at 4 to 7 months post diagnosis. Finally, wave 3 interviews occurred roughly four months after wave 2 interviews at 8 to 11 months post diagnosis respectively. These interviews were shorter in length

(approximately 30 to 40 minutes) and followed up on themes specific to the disease progression and experience of cancer discussed in the wave 1 interview. This design was intended to capture the cancer experiences of women with TNBC and ER+BC over time. Women with ER+ disease were also examined longitudinally in order to gain insight into how these trajectories differed for these two groups of women.

The timing of each of the three waves reflects three critical points of the cancer treatment trajectory of women with breast cancer. Wave 1 (1 to 4 months post diagnosis) concentrates on the experiences of women immediately following diagnosis, during their first course of treatment. This wave was designed to reflect the initial feelings about diagnosis, the decision making process around various treatment options, and the impact of the initial round of treatment, which may either involve surgery or neo-adjuvant chemotherapy. Wave 1 was also timed to capture the experiences and emotions around first finding out about and coming to terms with such a diagnosis. Wave 2 (4 to 7 months post diagnosis) was designed to capture participants around the adjuvant treatment phase, which may involve adjuvant chemotherapy after surgery, surgery after neoadjuvant chemotherapy, or radiation depending on the individual. Wave 3 (8 to 11 months post diagnosis) captured the participant when she was nearing or done with the complete course of treatment and entering into reconstruction if applicable. This final interview shed light on post active treatment issues of survivorship or palliative treatment where relevant. Although these three waves varied significantly for each woman in the study depending on the stage and progression of their disease, each wave reflected progression through the breast cancer trajectory and represented a unique and critical step in an iterative process of building knowledge about change over time as these women walked through the major milestones of treatment (J. Margenthaler, personal communication, September 16, 2011).

## **Recruitment of Participants**

Purposive, criterion sampling was used to recruit African American female participants under the age of 50 years from the Siteman Cancer Center at Barnes Jewish Hospital in St. Louis, Missouri. Potentially eligible women were identified in collaboration with Dr. Julie Margenthaler and her medical assistant. Dr. Margenthaler is a breast oncologist and surgeon at Siteman, and a member of the current dissertation committee. Access was granted to potential participants' medical charts in order to check subtype of breast cancer and to ensure that all eligibility requirements were met. ER status, PR status, and Her2 status at the clinic are determined by standard immunohistochemical methods and were available in patients' medical charts (J. Margenthaler, personal communication, September 5, 2011). During recruitment, bi-weekly visits to Dr. Margenthaler's clinic and with the assistance of her medical assistant, medical charts of all breast cancer patients were examined in order to find those who were eligible for the study.

Once eligible women were identified, they were invited to participate via patient recruitment letter mailed to their homes. The patient recruitment letter asked that interested women contact us for further information and informed potential participants that there would be compensation for their involvement in the study. Letters were followed by a recruitment phone call by the research team for additional follow-up if eligible women did not call first. Recruitment was done without specifying the emphasis on subtypes of breast cancer to participants in order to avoid selection bias. After women expressed interest in the study, the potential participant then agreed to meet in the participant's home in order to provide written consent and begin the interview process. If the participant felt uncomfortable with conducting the interview in her home, alternative locations were available (i.e. an office at Washington

University), but these alternative locations were never utilized in this study. Recruitment took approximately seven months.

### **Enrollment and Attrition**

**Initial phone conversation and consent with participant.** Upon expressing interest in participating in the study, women received a thorough explanation of the study during the initial phone conversation. During the call, they received information about the time commitment, eligibility criteria, and compensation for participation. Participants were also given the opportunity to ask questions during this phone conversation. Those giving verbal consent scheduled a time to meet and begin the interview process in their homes. During this initial meeting, any remaining questions were answered, written consent was obtained, participants were officially enrolled, and the first interview was conducted. Women were enrolled based on breast cancer subtype and divided into either the study group or comparison group according to their status.

**Study group - women with TNBC.** A total of six African American women with TNBC were enrolled in the study. Sampling concluded once data saturation was reached. Data saturation is defined as the point at which analyses of data yields redundancy and no new information is gleaned (Morse, 1995). Eligible women were all under the age of 50 years. Women were interviewed at least one month after their initial diagnosis to ensure that they would have time to manage the immediate crisis, and no more than four months past initial diagnosis in order to best capture the experience of the first course of treatment. Exclusion criteria included other co-occurring primary site cancers, prior history of breast cancer, cognitive dysfunction (dementia, etc.), and inability to speak English because English was not the native language.



**Comparison group – women with ER+ breast cancer.** A total of six African American women with ER+ BC (either luminal A or luminal B subtypes) were enrolled to allow identification of elements that might be shared by all African American Women with breast cancer. Eligible women were also under the age of 50 years. Again, women were interviewed at least one month post initial diagnosis to ensure time to manage the immediate crisis, and no more than four months past initial diagnosis to capture the experience of the first course of treatment. Exclusion criteria were other co-occurring primary site cancers, prior history of breast cancer, cognitive dysfunction (dementia, etc.), and inability to speak English because English was not the native language. The eligibility criteria for enrollment in the comparison group mirrored exactly those of the study group except for breast cancer subtype.

**Sample size, data saturation, and attrition.** The exact sample sizes of both the study group and comparison group were left open and were ultimately determined by the achievement of depth and richness of data balanced with the parameters of a doctoral dissertation. As mentioned above, the total sample size was ultimately 12 women, with six women in the study group and six women in the comparison group. This sample size allowed the research team the time and flexibility to explore in great fullness each of the participants' individual experiences over time within the framework of the longitudinal design of this study. As common themes began to emerge across cases, recruitment would halt and these themes would be explored in more depth in subsequent interviews. Six women in each group is a relatively small sample, but what the study lacked in numbers was balanced by the multiple interviews conducted over time. Multiple interviews over time allowed the research team the ability to concentrate on depth rather than breadth, a crucial goal of this study. The sacrifice of recruiting a larger sample was justified, to some extent, by the longitudinal nature of the study, which allowed for deep

exploration across the long and often arduous experience of cancer treatment. This design afforded the research team the opportunity for prolonged engagement with a disenfranchised and underserved group, which is a unique contribution of this study given our limited knowledge of women with TNBC.

With this said, the idea of data saturation is a key marker of credibility in qualitative studies and the research team was conscious of upholding standards of rigor while at the same time recognizing the goals and scale of this study (Padgett, 2008). Saturation is determined by redundancy in the data, which occurs when repetition of codes and common themes become evident (Dey, 2007; Morse, 1995). Although data saturation is one way of ensuring the robustness of qualitative data, given the scope and the longitudinal nature of this study, which required three interviews from each participant over time, achieving complete data saturation was not necessarily a reasonable goal for this study given these parameters mentioned above.

Even with the limited ability to achieve full data saturation in this study, the team looked for repetition within the data to ensure depth, richness, and credibility in a number of ways. First, NVivo, the software used for this study, has numerous ways in which to explore and analyze transcripts and codes as data is collected. One helpful tool used by the research team to determine data saturation within NVivo is a charting feature that allows one to analyze the most utilized codes by percentage of coverage in each data source. In other words, the research team could evaluate each interview by most utilized codes. As the research team collected interviews, these charts would be run for each interview within the data management program in order to see which codes were most commonly used within cases, and then comparatively, which of these codes were recurring across cases. As the team compared codes across cases, repetition of a number of key codes began to emerge. The team was able to recruit women with ER+BC first

because there are more of these women. As some common codes for those with ER+BC were being repeated as seen in these charts, recruitment paused as the team assessed whether there was enough data to produce meaningful findings. At six total women with ER+BC, the research team found enough repetition that the team felt comfortable closing enrollment for the comparison group. In much the same way, repeated codes for women with TNBC were identified across the first wave of interviews and the team eventually felt that they had enough repetition in codes and an acceptable level of data saturation had occurred after six participants had been enrolled.

In addition to these charts of most commonly used codes, the research team began to identify common themes that were repeated both within groups and across groups, and also across waves of interviews as the team held weekly meetings after independently co-coding each of the interviews. As the team evaluated each of the first wave interviews, the team began to see common patterns emerge from the data, which were noted in weekly memos. The repeated codes that were noted provided the building blocks for these themes, and the team was able to identify and build common ideas that were repeated across cases. These major themes and repeated codes will be discussed at length in the findings chapter.

Although additional recruitment would have taken place if there had been high attrition in this study, very little attrition occurred and additional recruitment was not required. It was expected that the initial sample size might diminish as the study continued based on disease progression, which inevitably impacts participants' physical and emotional ability to participate. It was possible that some participants would experience physical decline and/or severe side effects of treatment, and therefore, would become physically unable to complete the study. Physical and cognitive ability to continue in the study were determined by the participants' self-

report of their physical condition and clinical observation in collaboration with Dr. Margenthaler and her medical assistant, but ultimately, no women withdrew from the study for these reasons. Although some interviews had to be rescheduled due to illness, there was never a need to eliminate any participants from the study.

## **Data Collection**

**Wave 1: First course of treatment.** After written consent was obtained, initial interviews with women with both TNBC and ER+ BC were conducted. As mentioned above, women were interviewed in their homes unless otherwise requested by the participant. The location of the interview was negotiated with each participant, with the goal of finding a quiet, confidential place to talk. Basic demographic information was collected from each participant prior to beginning the initial interview. A very simple, short questionnaire was used to collect basic information that could be further explored in the interviews. The initial interview lasted between 1 and 1.5 hours and participants were given a grocery store gift card for \$40 to compensate for their time. This interview asked questions about the experience of diagnosis, the first course of treatment, and also asked questions about the participants' personal history, family of origin, and life prior to the diagnosis. After the interview was concluded, the participant was given a rough time frame for their next interview and informed that they would receive a call to schedule the following interview as it got closer to time.

**Wave 2: Adjuvant treatment.** The second round of interviews took place approximately 3 months after the initial interviews during active adjuvant treatment for all participants. Women were asked questions about the experience of the continuation of treatment and any pertinent themes found in the first wave of interviews were revisited. These interviews were shorter in length, lasting from 30 to 40 minutes. Participants again received a \$40 gift card

for their participation. The final interview time was discussed and the participants were told that they would receive a phone call to schedule the final interview.

**Wave 3: Survivorship or palliative treatment.** The third round of interviews with all participants occurred roughly 4 months after wave 2 interviews, when most patients had completed or were nearing the end of their full course of treatment and entering into survivorship and reconstruction surgery. Again, existing themes were followed up on and new information was elicited regarding the experience of either completing treatment or entering palliative care. Change over time was assessed with regard to disease progression and the participants were asked about their treatment decisions. The remaining questions of this interview focused on their experiences with the medical system and any oncology social workers they may have interacted with during treatment. Women were asked how their diagnosis and treatment experience could have been improved with the assistance of a social worker. Participants were also given a \$40 gift card for participation in this wave of interviews. Once interviewing concluded and all wave 3 data were collected, participants were given a list of psychosocial, community resources designed for women dealing with breast cancer. Participants were referred to programs such as the Young Women's Breast Cancer Program through Siteman Cancer Center, the local chapter of the American Cancer Society, and The Breakfast Club, a support program for African American women with breast cancer.

**Grounded theory questions.** Interviews were in-depth and open-ended, allowing the participant to guide the majority of the conversation. All interviews were conducted by the principle investigator. Questions posed were for the purposes of exploring the participants' experiences and allowing participants to reflect on their personal history and cancer journey. A

general and flexible interview guide was created to provide guidance and address the study questions.

Questions included on the interview guide were listed with the understanding that they provided a starting point for an in-depth conversation and were used with flexibility as the interviews took shape. Many of the questions were based on key ideas found in the literature review, which are known as “sensitizing concepts” (Blumer, 1969; Charmaz, 2006). Sensitizing concepts provide the premise for questions and a launching point for interviews, helping to set up a framework for data collection. Sensitizing concepts used in this study were those that were discussed in the literature review in chapter 2, which included (1) income, work, and financial concerns, (2) neighborhood and place of residence, (3) racism and discrimination, (4) social support, (5) religion and spirituality, and (6) quality of life and psychosocial functioning. The research team expected that the groups would differ on factors such as neighborhood, social support across the life course, experiences of racism and discrimination, or other factors associated with living in poverty. These questions reflected the concepts found in the literature and were designed to address each of the specific aims articulated above while looking for differences across groups, but were also amended upon each individual interview based on previous interviews and subsequent analyses by the research team.

In addition to the questions on the interview guide that were guided by the sensitizing concepts found in the literature review, critical to the interview guide were questions that centered on early life and the experiences of the participants as they were growing up, especially as these experiences related to socioeconomic status and the reality of poverty. These questions about early life were guided by the relevant theory explored in chapter 2, which demonstrated the impact of poverty, abuse, and discrimination on the body throughout the life course. These

questions on the interview guide explored the women's neighborhood in which they were raised, family of origin, relationships with parental figures, and experiences of poverty in youth. These questions were designed and included to provide insight into the effect of stressors on the body over time and to allow the women space to personally reflect on these experiences as they related to their physical and mental health, specifically related to breast cancer.

The interview guide was not formal or stringent, but instead, questions flowed naturally from the interview experience and were refined, edited, and added to as the data were analyzed. Given this flexibility, there were some basic guidelines for the types of questions asked in each wave of interviews. Wave 1 questions included inquiry about the participants' family history, growing up experience, neighborhood in which they were raised, social supports, and events prior to the diagnosis in addition to questions about the cancer experience itself. Wave 2 questions followed up on some of the themes specific to the cancer experience and inquired about their progression of treatment. Wave 3 added questions about their reflection on the experience of treatment overall, care received at the Siteman Cancer Center, and the presence of an oncology social worker, if one was present during diagnosis and treatment.

**Observation.** Observation of the surrounding environment, neighborhood, family structure, physical ability, and housing situation was a critical part of data collection. Extensive care was taken to visually note the conditions in which participants lived in order to acquire knowledge about the biopsychosocial context in which TNBC occurs in the lives of young, African American women. This is one of the major strengths of this study, as data collection in women's homes afforded the opportunity for greater depth of understanding about the participants' life circumstances. Although this was a time consuming and elaborate process, the importance of sights, sounds, key informants, and "field observation" cannot be overemphasized

(Padgett, 2008). In their pertinent discussion on the imperative of observation in qualitative research, *Essential Ethnographic Methods: Observations, Interviews, and Questionnaires*, Schensul, Schensul, and LeCompte (1999) recommend observing settings, events, and indicators of socioeconomic differences in order to obtain a thorough understanding of the lives of study participants. These data were included as an integral piece in analyses and informed theory building throughout all three waves of the study. Observation is the critical reason that interviews took place in participants' homes and this data added a layer of depth that would have otherwise been impossible to achieve.

Observational data was documented and analyzed in similar ways as interview data such that collection and analyses of observational data was iterative and informed ongoing research processes, data interpretation, and theory building. Extensive field notes were taken after each interview, which included documentation of what was seen in women's homes and the surrounding environment. This information was then brought to the weekly team meetings and shared with the research team. These observational data were then used to identify major themes, highlight ideas found in the interview data, and illustrate things that were said by participants. Observation provided the opportunity for greater depth as the interviewer was able to visual witness those things that were being discussed during the interviews.

### **Data Analysis**

Grounded theory calls for the iterative, ongoing process of analyses, which in turn, guides the data collection process. As data was gathered and audio recordings of each interview were transcribed, these data were continually analyzed in an effort to iteratively build working theory. Creswell and Maietta (2002) assert that data analysis involves a "zigzag" process where the researcher engages in a back and forth process of collecting data and analyzing it throughout the



entirety of the study. Information gleaned from each interview and each wave of data collection informed the questions asked at following interviews. Questions were added, edited, and adjusted according to the developing theory formed while analyzing the data, and these questions were individualized for each participant.

**The research team.** Two research assistants assisted with verbatim transcription of each interview, coding of all interviews, data analysis, and memo-writing on all of the data collected. Weekly meetings with these research assistants formed the core of analysis and laid the foundation for theory building. The meetings allowed for in depth analyses of each interview and informed the interviews that followed. Each week was dedicated to the in-depth evaluation of one participant's interview after coding was completed by all members of the research team, which created an iterative process of informing how data was collected moving forward. As themes began to emerge in these meetings, the research team evaluated the upcoming questions in light of the information gleaned, and would then add or edit upcoming questions in order to adequately explore pertinent ideas found in the data. The research team was absolutely critical in the analyses process and these weekly meetings were the core of the analysis process.

**Coding.** Coding was completed using NVivo 9 software. Coding took place in two phases, which included initial coding and focused coding (Charmaz, 2006). Initial coding involves naming each segment of the data and sticking close to the data. Charmaz (2006) asserts that "initial codes are provisional, comparative, and grounded in the data" (p. 48). During this first stage of coding, the data were analyzed in small segments and much flexibility was employed in determining the codes to be used as theory first begins to emerge from the data. Focused coding is the second phase of coding and involves using more pertinent and significant codes identified in the initial stage of coding. This process of identifying significant codes

involves making decisions about which codes are most relevant and important to the building of theory. This second stage of coding is broader and allowed for sifting through larger amounts of data with specific themes in mind. This stage of coding also allows for a broader comparison of the data across interviews, observations, and waves.

In order to ensure reliability of codes and reduce bias, all three of the members of the research team independently co-coded all interviews and met weekly to compare findings. Weekly meetings involved a collaborative effort of consensual validation as opposed to calculating inter-coder agreement. Consensus is the recommended approach to validity of coding, as this process will best “honor the richness of the data and take into account the inevitability of multiple standpoints” (Padgett, 2008, p. 155). Where irreconcilable disagreements about coding occurred, the final decision was made by the lead researcher, while taking into account and giving voice to the differing opinions. In general, as discussion unfolded around these codes and major themes, the research team was able to come to consensus on most topics and provided mutual insight to one another as the group found common ground through in-depth analytical discussion. This was an insightful and enlightening process for all involved.

**Memo-writing.** Memo-writing was completed in tandem with the interviewing and coding processes by the research team. Extensive memos were kept throughout the entire study and were reviewed often as the research team progressed through the study. Memo-writing is an integral piece of the grounded theory approach to research and allowed the team to reflect critically on the experience of data collection and analysis while forming theory. In her discussion on the importance of memo-writing as a piece of the grounded theory process, Charmaz (2006) states, “Memo-writing constitutes a critical method in grounded theory because it prompts you to analyze your data and codes early in the research process. Writing successive

memos throughout the research process keeps you involved in analysis and helps you to increase the level of abstraction of your ideas” (p. 72).

Memos were kept by the entire research team. During interviews, notes on the interviews themselves were kept. These memos included thoughts on how the participant responded and felt, and also note on the observations seen in the field during the interview experience. All significant observations were noted in memos, which included documentation on the surrounding neighborhood, housing conditions, family structure, physical demeanor of the participant, etc. Research assistants also kept notes as they were listening to the interviews and coding the interviews. Finally, when the team came together for weekly meetings, memos were kept to document the common themes and findings that were emerging from the data.

Esterberg (2002) asserts that there are two main types of memos, which include procedural memos and analytic memos. Procedural memos focus on the research process and help researchers to track and document what has been done in the study. Analytic memos focus on the data and contain thoughts, ideas, and analyses about the meaning behind the data. As noted, the research team kept both types of memos throughout, documenting both the process of the interviews themselves and the meaning and themes found in the interviews during the team meetings. Through memo-writing, the team was able to reflect on information gleaned and on the codes that presented themselves in the process of analysis.

These memos were used as critical pieces of data that informed the formation of theory. Memos informed coding and also helped to determine when data saturation was reached because the team was able to look back and identify how and why critical codes and themes developed and when there was repetition in what was found. As the theoretical model began to develop, memos were one of the defining ways in which the team could look back over their thoughts and

ideas in order to identify ways that theory was emerging from the data over time. Memos captured and documented the themes found in the data throughout both the collection and analysis processes, and were key to mapping the iterative process of this research method.

### **Data Storage and Analytic Software**

Participant information collected at the Siteman Cancer Center was stored digitally in an encrypted excel file on my computer, which was password protected. All interviews were audio recorded and transcribed verbatim by the research team, and these were stored and analyzed in the analytical software, NVivo 9. After each interview, audio recordings were loaded into NVivo on my laptop and shared digitally with the research assistants. All memos and codes were also created and stored in NVivo for use in analysis. Hard copies of the questionnaires and audio recordings of the interviews were transported safely, and were stored under two locks in a file cabinet in the principal investigator's office. The research assistants' laptops and my personal laptop were all password protected.

### **Strategies for Rigor**

Many of the methods described above are included in the design of the study in order to ensure that the study was rigorous and the findings trustworthy. For example, independent co-coding is a form of analytical triangulation that was used to confirm findings and check for researcher bias. Additionally, the longitudinal design is intended to cultivate prolonged engagement with all participants; engaging with participants for a greater amount of time at multiple time points, assisted with reducing researcher bias as reactivity was minimized. As participants became increasingly familiar with the interviewer and progressed through the breast cancer experience, greater rapport was built leading to richer data.

## **Synthesizing Data and Constructing a Conceptual Framework**

In her chapter articulating the methodological process of growing grounded theory, Stern (2007) outlines several vital elements that must be employed in this process. These key elements of developing theory include "...making sense, connection to the target group, groundedness in data, integration, abstraction, modifiability, relatedness to existing theory, and delivering the message to the reader by skillful writing" (p. 115). This study used these elements to guide the construction of a new conceptual framework intended to build our understanding of young, African American women with TNBC, as articulated in Aim 3. Information derived from the data first and foremost makes logical sense and strives to be relevant to the target group of young, African American women with this unique subtype of breast cancer. It is modifiable and able to be integrated into practice settings as applicable. The building of this conceptual framework involved sticking closely to the data and abstracting relevant information collected from these women, while also drawing from the existing theoretical frameworks mentioned above to inform interpretation of this data.

When using existing theoretical models or frameworks to inform the formation of a new conceptual model, Ware, Wyatt, and Bangsberg (2006) suggest four primary questions to ask of the existing model. Although these questions are specifically asked of adherence behavior models in HIV-infected patients in her research, they help to frame an approach to the use of existing theoretical models in building new conceptual frameworks from qualitative data. The questions asked of existing models can be summarized as follows: (1) Are the model's basic concepts relevant in the new setting/population?; (2) Are basic concepts important to the new setting/population represented in the model?; (3) Are the meanings of the model's basic concepts accurate for the new setting/population?; and (4) Does the model capture the full complexity of

the new setting/population? (Ware et al., 2006). These questions will be asked of the existing theoretical models and frameworks being used to guide understanding of the new data that is collected, specifically, those outlined in chapter 2. The appropriateness of the aforementioned theories will be determined using these questions as guidance.

As a concrete strategy to building this conceptual framework, codes derived from the data were systematically synthesized and used to develop theory about the lives of the participants using a collaborative, creative process. The weekly meetings with research assistants were used to brainstorm about how to understand and organize the information being discovered in the data. An engaged, inventive approach to understanding the data were encouraged, and the research team worked together closely to understand common themes, ideas, and concepts found in the data. This theoretical model will be outlined in detail in the following chapter.

## **Chapter Five – Findings:**

### **Answering the Research Questions and Outlining a Conceptual Framework**

#### **For Understanding the Triple Negative Breast Cancer Experience**

##### **Domains for Analysis**

Before addressing the major findings of the study and answering the research questions, it is essential to first refer to Figure 2 in chapter 2 to frame the analyses. It is important to note that there are three central, overlapping domains of analyses at work, the first being the contextual issues for all women in general who are experiencing breast cancer, but then more specifically, the contextual issues for African American women experiencing breast cancer, and then African American women with TNBC. A clear attempt will be made to parse out these distinctions as they were uncovered in this study, but this analysis will proceed with the understanding that these domains inform one another and often overlap. With this understanding, the important and unique contribution of this study is the identification of those pieces of the puzzle that are potentially exceptional and specifically relevant for women with TNBC. Framing these findings in a synthesized and helpful way that builds on the overall knowledge about this unique group of women was the central goal of this study, and the present chapter seeks to clearly articulate these discoveries while recognizing the complexity of overlap.

##### **The Sample – Descriptive Observations**

Purposive, criterion sampling was used to recruit women in order to find those who met the selective eligibility criteria. Those who met criteria were enrolled on a first come, first served basis, with those who first expressed interest being enrolled in the study first. Twelve women were enrolled in this study. All participants were African American females under the

age of 50 years with a recent diagnosis of breast cancer, and were between one and four months post initial diagnosis. All lived within a 45 minute drive of the Siteman Cancer Center within the St. Louis Metro area. Six women were enrolled in the study group, as those diagnosed with TNBC, and six women were enrolled in the comparison group, as those diagnosed with ER+BC. All 12 participants completed wave 1 interviews, 11 completed wave 2 interviews, and ten completed wave 3 interviews on schedule, and all were within the allotted window for each wave of data collection with the exception of one woman in the comparison group who was approximately two months behind due to delayed enrollment. One woman in the study group, participant #TN\_12, completed the wave 1 interview, but would not return follow up phone calls to schedule the second and third interviews with the PI. One woman in the comparison group, participant #ER\_8, participated in the first two interviews, but could not be reached for the final wave 3 interview. These data were considered missing. Thirty-three interviews were conducted of the projected 36. Given the severity of these women's illness and other co-occurring, psychosocial challenges in the participants' lives, the attrition rate for this study is considered to be low.

**Study group – participants with TNBC.** Women in the study group ranged in age from 23 years old to 49 years old, with the mean age of 35.8 years (SD = 10.01). With the exception of one woman in the study group, all participants in this group had completed at least a high school education, and four of the six had either completed a bachelor's degree or were actively taking classes toward completion of a bachelor's degree at the time of first interview. Although job status changed throughout the course of the three interviews for many of the women due to illness progression, four participants were gainfully employed at the beginning of the study. All



women in the study group had at least one child, and four of the six participants lived with a domestic partner. None of these women lived alone.

**Comparison group – participants with ER+ BC.** Women in the comparison group ranged in age from 42 years old to 49 years old, with the mean age of 46.3 years ( $SD = 2.58$ ). Four of the six participants had completed high school, but only two had completed a bachelor's degree or beyond, or were actively taking classes toward a degree at the time of first interview. Four of the six women were gainfully employed at the beginning of the study. There was little fluctuation in employment status in this group throughout the study. Two of these women had never had children and three of the six were living alone at the time of enrollment, although this fluctuated during our time of engagement.

This simple chart demonstrates how the two groups compare in terms of the basic demographic information collected through the initial questionnaires at the point of first interview. There are some obvious differences between the women in the study group and the women in the comparison group on these variables. Noticeably, women in the study group overall had more education and are more likely to be actively pursuing college degrees than those in the comparison group. Women in the study group were also all mothers and none were living alone, which is markedly different from the comparison group. These differences became significant as the research team began to understand this information in light of the interview data. These findings will be explored in more depth in the following analyses.

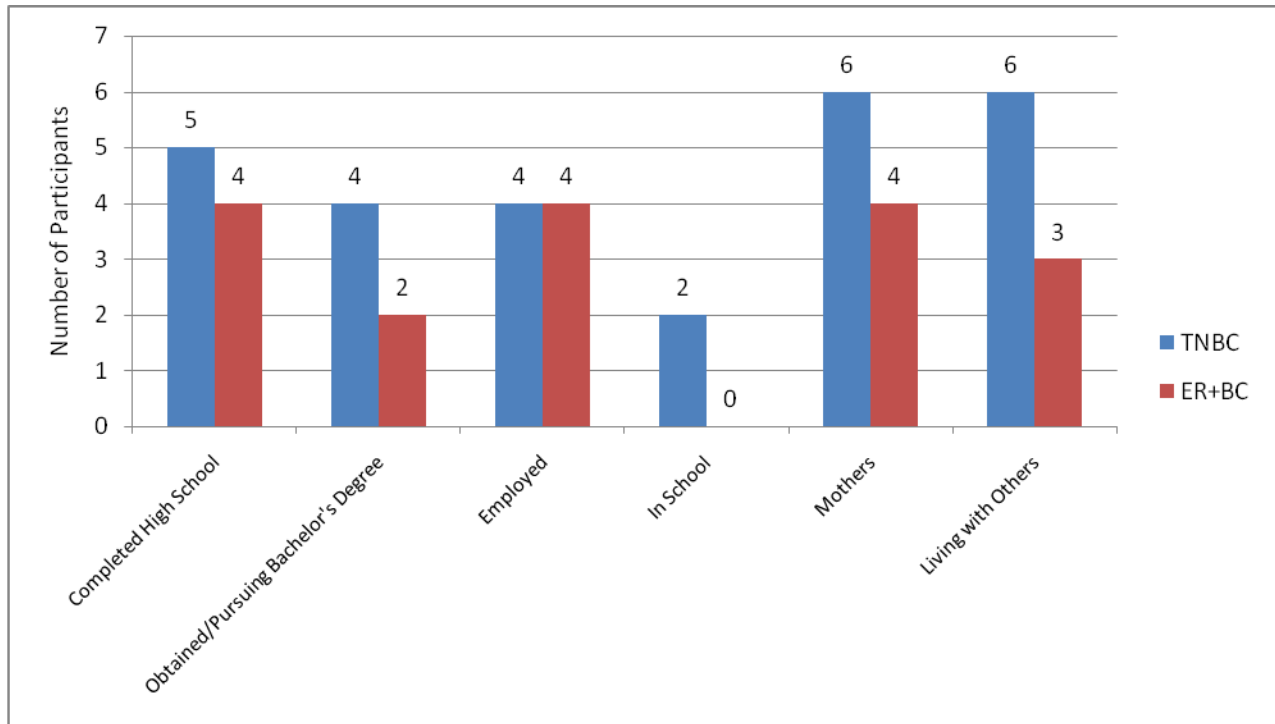


Figure 3. Descriptive Data from Questionnaire at Wave 1 Interview

In addition to the initial questionnaire given at the beginning of the interview process, data about participants' socioeconomic status throughout the life course were gathered through specific questions asked during the interviews. Included in the interview guide were questions about insurance status, employment issues, and financial struggles over time that allowed for open ended exploration. Insurance status and employment status were used as proxies for economic status. Of the women in the study group with TNBC, three of these women were on Medicaid, two had private insurance through their place of employment, and one was uninsured, but during the course of the study, was able to get coverage under her husband's insurance with the state. Two of the women on Medicaid were unemployed, and five of the six were struggling with significant poverty because of unemployment or their inability to work because of illness. For women with ER+BC, three were on Medicaid and three had private insurance. Three were

employed and voiced no significant concern regarding finances, one woman could be considered working class and experienced some financial strain, and two were struggling with severe poverty, homelessness, and unemployment. These questions were also asked retrospectively, in order to capture each participant's experiences of their social environmental throughout the life course.

### **Answering the Study Questions**

#### **Question 1 - Stressors and Strengths**

The first question posed in this study is: How does the biopsychosocial context in which young, African American women live inform how these women face a diagnosis of TNBC? This question is broken into three sub questions.

- a. Do young, African American women with TNBC experience any common stressors?
- b. What resources and strengths are employed by young, African American women with TNBC while facing the challenges associated with the disease?
- c. Do these stressors and strengths differ for women with TNBC as compared to those with ER+ BC?

**The burden of care throughout the life course for women with TNBC.** When comparing women with TNBC against women with ER+BC in this study, women with TNBC carry significant burdens of responsibility both at the time of interview and retrospectively, as they reflected on their histories. In general, women in the group with TNBC had more education, were more employed, and also had more responsibility to care for children, loved ones, and significant others at the time of their interviews. The women with TNBC discussed significant financial struggles as much as women with ER+BC, in other words, they were not

wealthier, and yet, they were also juggling more responsibilities during the time of interview than those who had ER+BC. This could be a reflection of their younger age, but, importantly as they reflected upon their personal histories, themes of self-sufficiency, caring for others, and carrying family burdens in isolation persisted throughout their pasts noticeably more than those women with ER+BC.

Women with TNBC were those women who identified as care-givers, babysitters, family rocks, and the ones who were responsible for holding the pieces together. In their own words, commenting about their roles in relation to other people throughout their lives, all of the women with TNBC in this study asserted that they have always been the source of strength and the ones who carry the bulk of responsibility. A few pertinent quotes demonstrate this persistent dynamic that was a through line for all participants in the study group with TNBC.

In relation to her role in the family, participant #TN\_11 states that she is the one who has always been “holding people together”; #TN\_1 is the person who has become, “used to taking care of people”; #TN\_10 stated, “I’m always the person that’s more concerned, and...I guess I worry a lot, I guess. The responsible one.”; #TN\_12 is the person who gets it done in her family and asserted, “It’s gotta be done, you might as well do it”. When talking about her role in the family, #TN\_9 stated, “...they use to me being the one that’s doing, always on the go you know, always that person that they go to.”; #TN\_6 asserts of the cancer experience, “...it’s like for the first time I’m going to be the patient. (pause) And not the caregiver.” These are just a few poignant examples of the history of care that these women have provided to others throughout their lives, which is unique from women with ER+BC. Although women with ER+BC certainly bear the brunt of much responsibility, especially given the recent diagnosis of breast cancer, this theme of constantly carrying the load throughout the life course was unique to those women with

TNBC. This theme of “carrying the burden” was found across all participants with TNBC and was seen consistently throughout all three waves of interviews for these participants.

The persistence and recurrence of this theme of carrying the burden and being the one responsible among the study group led the research team to examine closely the history of these women specifically to uncover the potential source of this responsibility over the course of additional interviews. The research team began to ask questions about the origin of this trend. Why is it that these women with TNBC uniquely hold these roles in their lives? Given our knowledge of the theory that informs this study, are there elements of these women’s’ histories that may have led to the need to live into this role?

**Inheritance of strength, mother mythology, and parental relationships.** One fascinating finding gleaned from the interview data is the theme around the family inheritance of strength in the African American, female tradition, and how this inheritance is passed from generation to generation among African American women. This imperative to be a strong woman was clearly demonstrated in the relationships between mothers and daughters for participants in this study. This was an interesting and complex dynamic that was both a strength and stressor in the lives of the participants. This theme was found in almost all of the women in the study, regardless of the subtype of breast cancer, and was primarily passed down from mother to daughter, throughout the generations. Most women in the study spoke of their mother or grandmother as the one in their lives who transmitted the importance of strength in the midst of struggle. The pressure to be a strong woman, not shed a tear, and continue fighting no matter the obstacles ahead, was at times a burden that seemed much too difficult for one woman to bear. This pressure to remain strong and never reveal weakness led to isolation and repression of difficult feelings that were forbidden from being spoken aloud. But it was also this mentality

that helped women to remain in treatment, to get up and go another day, and to continue living their lives.

One pertinent example of this dynamic was seen across interviews with participant #ER\_5. Recalling her mother's battle with cancer, participant #ER\_5 states, "my mother never dropped a tear about her having it. She never murmured nor complained about it. Never. Never. And I want to be the same way". She saw her mother exert unwavering strength in the face of cancer, and she wanted to embody this strength that she witnessed in her mother. For many women in the study, including #ER\_5, it was easy to speak about their relationships with their mothers in light of an inheritance of fortitude, power, and perseverance.

Ironically, this strength was often shrouded in a culture of silence, where it was forbidden to discuss the difficulty of cancer or to even talk about the importance of the history of breast cancer within the immediate family. Of this secrecy, participant #ER\_5 states, "... she had had it for like 4 years. And never said nothing to no one. No one...And all her sisters, see, died from cancer. Mmhm all of them died from cancer...and they were the same way. I think it is just in our genes you know not to tell (laughs). You know because her sisters didn't tell. You know and I'm like I guess it is just in us not to tell." Participant #ER\_5 followed the same model and refused to tell anyone in her life about her cancer except for her young daughter and one elder in her church. She chose to be "strong", which resulted in secrecy and silence about the diagnosis and treatment process. As a result, her young daughter then carried this burden of silence and sought to emulate her mother's strength in all things. The daughter, who was present during one of the interviews, states, "Sometimes I'm mad but I'll get through. I'm gonna be a strong person like my mom." This inheritance of silent strength is clearly passed from one generation to the next, which was abundantly clear in this example.

The strong, black woman/superwoman role has also been cited in the literature as both a stressor and a strength when coping with stress and illness (Woods-Giscombé, 2010). Woods-Giscombé (2010) asserts that this dynamic provides both benefits and liabilities, providing the drive to continue fighting, while increasing stress-related, poor health behaviors and putting strain on relationships. Other scholars assert that this dynamic enforces a distressing level of selflessness leading to the neglect of personal needs, and enforcing powerlessness (Beauboeuf-Lafontant, 2007).

Although the research team found this focus on strength demonstrated by the mother figure across both the study group and comparison group, there was a fundamental difference in how the position of the strong mother figure was realized in the lives of the participants in each group. For those women in the ER+BC group, their mothers held a position of reverence and flawlessness that could not be questioned, which tended to manifest in enmeshed relationship patterns. The respect and awe given from participants to their mothers in the ER+BC group was at times akin to reverence or worship. For #ER\_5, this was literally demonstrated in a shrine centered in her living room to her mother. The massive, plastic flower arrangement from her mother's coffin, who had passed away almost ten years prior, was the centerpiece of her coffee table and was a looming representation of the place of admiration that this participant had for her mother. In her eyes, her mother was everything that she wanted to be. Her mother was her world both before and after her death, and she and her mother spent countless hours together while she was alive. This is one pertinent example of how observation played a critical role in discovering this theme. It was critical to see how the participant's mother was still present in very physical ways in her life, and the testimony of the participant's daughter helped to solidify

the generational inheritance of female strength. This would not have been nearly as evident without the privilege of observation afforded by this in-home interview.

Similar patterns of reverence and/or enmeshment were seen among most of the women in the comparison group. Although not all saw their mothers as flawless, among those women with ER+BC, mothers were held in very high esteem and were intimately connected with every detail of the participants' lives. Reflecting on all of the things that her mother did for her while growing up, participant #ER\_3 states, "...mom was very supportive. She cooked breakfast, lunch, dinner. I mean, yeah, my mom was awesome. Breakfast, lunch, dinner, helped us with homework, I don't know how she did it." This was a mother who was extremely present during her youth, and continued to be present in her adult life, especially throughout the cancer experience. For the three women whose mothers were still alive in the comparison group, their mothers were all very involved in the treatment and decision making process of the participants, and two of the participants had their mothers move in with them during this time.

This type of relationship was very different than what was seen in the study group. Women with TNBC also spoke highly of the inheritance of strength passed down from their mothers, but this was done from a place of detachment and distance. Their mothers were strict, aloof, controlling, and/or absent from the home. These were not relationships of enmeshment, intimacy, or reverence, but were instead marked by withdraw, coldness, and sometimes even indifference. This is not to say that these were uncaring or bad mothers, but many of them had extenuating circumstances, such as extreme poverty, caring for an alcoholic spouse, needing to work long hours, or dealing with their own health issues that prevented them from being present and available to the participants during their childhood and into adulthood.



Additionally, none of the women in the group with TNBC had fathers who were present during their youth. Two fathers died at a young age (one from a violent murder witnessed by the participant), two were alcoholics, and two were altogether absent from the home. Although similar trends were found in the comparison group of women with ER+BC, (two had fathers who died at fairly young ages, two had fathers who were absent because of divorce, and one had an abusive and violent father), how mothers handled this absence was different in the lives of the women with TNBC. When speaking of their mothers' roles as it related to the absence of fathers, participants mentioned that this was a heavy burden for mothers to carry and parenting was difficult for these women. Because of these difficulties, it was obvious to these participants that their mothers were strong because they were able to make it through difficult times alone.

Growing up with an alcoholic father and experiencing the tragic death of her younger brother led participant #TN\_11 to keep her problems to herself over the years. When describing her relationship with her mom as she moves through cancer treatment, #TN\_11 states, "I really don't wanna put too much stress on her about myself...I mean, I'm ok and everything, but, even if I *wasn't*, I wouldn't tell her 'cause I feel like she has enough to go through with losing her youngest son... I know that she's going through a lot, so I really try my best not to really put any...extra, you know, on her or whatever. So... I don't really talk too much about the bad stuff." This type of distant relationship was typical of the mother/daughter relationships of those in the study group. Speaking of her tumultuous and distant relationship with her mom, #TN\_6 states, "I moved out, she was upset. I would see her at work, I would greet her, she'd cuss me out. In public, in front of everybody. It got to a point...I did this for a year. Mother's Day, I bought her some roses and flowers, she threw them in the trash right in front of me." Unfortunately, this relational difficulty was not a unique or isolated event for this participant, and

most participants in the study group had similar experiences with volatile, dependent, or distant mothers.

Although these relational differences between groups could potentially be seen through the lens of developmental transitions and age differences between groups, as younger women typically have more rocky relationships with parents, these relational differences went beyond traditional young adult angst and rebellion against authority figures. The significance of this finding links back to the previous section about the burden of care throughout the life course for women with TNBC and the impact of stressors on the body over the life course. It was made clear in these interviews that women with TNBC in this study have always carried the burden of care because this is what they had learned to do in their family of origin. It may be the case that this was a necessary role to assume in response to these experiences of poverty. For the women with TNBC in this study, neither of their parental figures were present in a tangible way while growing up, and even though they respected their mothers' strength, this was not a relationship of refuge or intimacy. This is a pattern that was noted throughout their entire lives. This pattern is compounded with poverty and tragedy that has been present throughout their entire lives, which will be explored in more detail in the next sections.

The burden of care assumed by these women as a result of parents who were impoverished and/or unavailable led to physical outcomes in their bodies. This is just one example of how the social environment may produce uncontrollable stress that interact with genes to produce changes consistent with TNBC and to impact health outcomes. From the time of childhood, women in the TNBC study group learned to make it on their own and carry the responsibility for themselves in the absence of parents who could carry these burdens for them. They were not able to rely on their mothers or fathers for support or to buffer the impact of

psychosocial stressors, and found it necessary to take on the responsibility alone. This dynamic references the etiology of TNBC, as seen in Figure 1. The social environment impacts breast cancer outcomes, and the impact of psychosocial stress throughout the life course is seen clearly in this group of women in these findings.

**Trauma history and the relational dynamic.** Nearly all of the participants in this study noted at least one significant, life-altering experience of trauma prior to the breast cancer diagnosis, if not repeated, prolonged trauma. These experiences ranged from rape, to witnessing physical abuse, to witnessing the murder of a loved one. Over the course of this study, extreme tragedy was shared during these interviews, and collecting these stories was often extremely disturbing and also tremendously moving for both participants and the research team. The privilege of coming alongside these women and sharing in this grief is important to note and many of the participants were able to open up for the first time in their lives about these traumatic events.

Unfortunately, the prevalence of exposure to traumatic events in this sample is consistent with the literature and was not surprising. Although these rates span a broad range depending on the definition and measurement of trauma, epidemiologists estimate that the rate of exposure to at least one traumatic event throughout the life course is between 51.2% to 89.6%, with non-whites being more likely to experience trauma in their lifetimes (Breslau et al., 1998; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). This sample was no exception, and the majority of women in this study quickly revealed such trauma when asked.

What was unique about the women with TNBC in this sample was the *type* of trauma experienced by these women. Of the women in the TNBC study group, all of those who had a significant trauma occur in their lives (five of the six) experienced a sudden and unexpected

death of a loved one, and most of these experiences of deaths were either violent events, multiple deaths within a short time frame, and/or were witnessed first-hand by the participants. In comparison, none of the women with ER+BC mentioned the death of a loved one as they were recalling traumatic events, with the exception of one woman who mentioned the death of her son shortly after childbirth due to complications. In addition to this loss of a child, two of the women in the comparison group were victims of rape, two witnessed rape or physical abuse, and one did not have a significant trauma event that came to mind.

Trauma cannot be ranked or placed on a hierarchy and the processing of and healing from such an event is unique to each individual. However, it is important to consider that different types of trauma may yield different psychosocial and physical outcomes. For example, Breslau et al., (1998) found that the trauma most often reported as the precipitating event among persons with PTSD (31% of all PTSD cases) was sudden, unexpected death of a loved one. This is extremely relevant as we think about this particular sample and the implications of experiencing this type of trauma. This finding may have broader implications as we consider this population of women with TNBC who have experienced sudden and unexpected loss. The significance of a sudden and unexpected loss in this group is realized amidst the backdrop of strained or distant mother/daughter relationships and absent fathers among those participants with TNBC, as seen above. The distance experienced in these relationships overlaid by the loss of fathers, brothers, and children in these cases inevitably impact the body, soul, and mind. With the strain of the central mother/daughter relationship compounded by the loss of significant family members or loved ones, often violently, it is easy to see how these women would feel the obligation to assume the roles of care-takers, responsibility carriers, and foundations for the rest of family. There was quite literally nobody else to do it. The strain of this role on the body over time in

combination with the healing from the traumatic experience of loss and the process of grief must be taken into consideration.

The other interesting ramification of such an experience may lie in how these women relate to others and how these dynamics impact their system of social support over time. This pattern of instability, impermanence, and volatility around the presence of those that are supposed to be closest to them has lasting impacts on the formation and maintenance of all significant relationships. When those relationships that are supposed to be the most reliable are absent, inconsistent, and lost unexpectedly and/or traumatically, it is natural to assume that such losses will impact how other key relationships and social networks are realized. This will be explored in more depth below.

**Spirituality and faith engagement.** All women enrolled in the study considered themselves spiritual. Without being prompted, most women identified as religious, and almost every participant talked about a “personal relationship with God” as being central to the way that they coped with cancer. All women in the study framed their faith within a Christian context and identified themselves as Christians. They all engaged in a personal prayer life to some extent and talked about the importance of faith in their lives. This was unanimous across both the study group and comparison group, which is a noteworthy finding, but also not surprising given the literature that supports the importance of faith among African American women during a cancer experience. As mentioned in the review of the literature in chapter 3, African American women are more likely than their Caucasian counterparts to say that they rely on comfort from God during the cancer experience and are more likely to find spirituality important across all phases of the cancer trajectory (Levine et al., 2007; Simon et al., 2007). Spirituality was a source of great strength for all women involved.

What is noteworthy in this study and contrary to the findings from the literature review is that over half of these women at the point of first interview did not actually attend a church or participate in a faith community at all. As opposed to attending church, women were much more likely to just pray on their own or watch preachers on television. They were notably disengaged from any tangible, spiritual community at the point of first interview. This dynamic was separate from the illness; these women had not attended church prior to their diagnosis and remained disconnected at the point of diagnosis and initial treatment. Further, comparatively, five women in the study group did not actively participate in church upon first interview, as compared to the comparison group where three women did not actively participate in church at the time of the first interview. More women in the study group with TNBC were disengaged from a spiritual community at the point of first interview, as compared to the participants in the comparison group. This disengagement from a spiritual community is an unexpected finding of this study, specifically in the study group of women with TNBC. The fact that so few of the participants were able to take refuge and find support in a spiritual community despite their strong sense of inner faith raised more questions in the minds of the research team, which caused examination of this dynamic in more depth about the reasons behind this disconnect despite the strong sense of inner faith.

Keri Day makes some pertinent observations about this dynamic in her book, *Unfinished Business*. In her commentary about African American women in the black church in the context of modern America, the author notes, "...some womanist scholars see the black church as deeply oppressive for poor black women...black churches have often been sites of oppression in which black women have practiced survival, not necessarily liberation" (Day, 2012, pg. 24-25). As opposed to finding freedom and support in the church, some poor black women, because of their

socioeconomic status and female gender, have actually experienced the church as a reinforcement of the oppression experienced in the world. These women have little place in these communities. They are not allowed to be active participants in the services because they are women, and are seen as charity cases because they are poor. As opposed to the church being a source of refuge and strength for poor, black women, especially those facing a major illness, the church can often be a place of pain and repression. Although it was difficult for the women in this study to explain the reason for disconnection from a spiritual community, the lack of involvement was often couched in feelings of guilt for not participating more. This is one explanation to explore as we seek to gain greater insight into the disconnect between private spirituality and engagement in spiritual community.

In light of the findings from Hamilton and Sandelowski (2004) mentioned in chapter 3 about the reported need for increased instrumental support in the form of prayers and religious practices for African American women facing a diagnosis breast cancer, the disconnect from those persons that may be able to provide this type of support is alarming, especially for those women in the study group who are most disconnected. In a group of highly spiritual women who are in need of spiritual support, this level of disconnection from a community is worrisome.

**Disconnect from surrounding community.** In addition to the disconnect from a spiritual community, women in this study were also isolated from their surrounding neighborhoods. Although many women in the study had people in their lives for whom they cared and who lived with them, there was little involvement in the neighborhood, community resources, or outside networks. Overall, women had little to say about their neighborhoods and communities, and the absence of information on this topic was telling and suggested a distinct detachment. Participant #TN\_9 states, “I don’t really talk with my neighbors because I’ve

always been the kind of person that I just dealt with my family. Because it's like so many different fluctuations of different neighbors that I don't want to get attached to them and then they leave." Participant #TN\_1 even hinted at the fact that the people in the neighborhood avoid her because of a fear of her cancer, "Yeah, some people don't come around. Yeah, some are fearful. Some send texts like I'm dead or dying. You know that is scary for them too... Sometimes I feel like I'm alienating myself for good reasons and sometimes it's just because people don't really don't want to accept my new circumstance."

This theme of isolation was persistent across both groups, but was more pronounced in women with TNBC, as their isolation from the community was amplified by their high level of responsibility. Participant #TN\_6 states, "... no matter what neighborhood I've lived in, I've never been a person to be outside very much...matter of fact, I don't really even know the neighborhood between school-work-school-work. In the middle [of the] year, usually I leave early in the morning and I come back at night. So...and it be like 12:00 when I'm coming in type thing." Women in the study group have limited engagement in the surrounding community, and one element of this is the necessity for them to work long hours, go to school, and care for others to the exclusion of connection to neighbors and friends.

Social stratification has further split the black community leaving many of the most marginalized women on the outskirts. Day states, "...many poor black women are not supported by their black communities to the extent that they were several decades ago...black communities have become more fragmented as economic stratification has intensified over the last few decades, contributing to a breakdown in a 'black communal consciousness'" (Day, 2012, page 25-26). This sense of isolation from both the spiritual community and surrounding black community was evident in the lives of the participants in this study, especially for those women



in the study group. Despite being around people constantly within their homes, especially in a care giving role, many of the women in this study had little support from others outside of their immediate families and relational responsibilities. The absence of involvement in the African American church community or neighborhood added to a history of unreliable or absent parental figures leaving women in the study group extremely isolated despite always having people around them.

**The importance of age.** Women enrolled in the study group were approximately 10.5 years younger on average than women who were enrolled in the comparison group, with two of the women in the study group being in their early 20s. This age difference that manifested in the first come, first served enrollment process is consistent with the literature about demographics of women with TNBC. TNBC is overrepresented among younger women and occurs at surprisingly young ages, especially among African American women (Bauer et al., 2007; Carey et al., 2006). This age difference was starkly evident in this sample, and some of the themes that surfaced in the interviews focused on the ramifications of this age difference in terms of the biopsychosocial stressors associated with such a diagnosis.

**Fertility, reproduction, and parenting.** Struggles specific to fertility, reproduction, and child rearing were unique to the study group of women with TNBC in this study. Although women from the comparison group faced treatment challenges that had implications for their female reproductive organs as they went through the experience of breast cancer, when asked during the interviews, all of the women in the comparison group were past the point in their lives where they wanted to conceive and raise children. These women already had older children or had decided not to have children. The women in the study group were presented with the fact that the aggressive chemo that they were undergoing had the potential to impact their ability to

have children in the future, and this was mentioned as a substantial struggle as they underwent treatment. Most of these women were given the choice to preserve their eggs in order to have options in the future in case they were unable to conceive, but the cost associated with such a procedure was an obstacle for many.

In reference to the cost of fertility treatment, participant #TN\_6 stated: "...I have a son. I don't have \$8,000 to give anybody to freeze eggs for me...you'd have to pay the \$4,000 up front...I haven't been working since the fifth. Where do I find \$4,000 to bring to you guys?" In reference to the experience of going through early menopause caused as a side effect of treatment, participant #TN\_10 stated, "...that was another thing that was traumatic for me, because my husband don't have any kids and we wanted kids together. And we were going to do artificial insemination..." Clearly this presents a significant challenge that impacts the rest of these young women's lives, which was unique as compared to older women who go through breast cancer treatment.

In addition to the future of their fertility, women in the study group had much younger children and were in the midst of parenting, often learning how to parent for the first time. Describing the moment when she found out about her breast cancer, participant #TN\_11 stated, "I have a six year old daughter so I was actually taking her to school...sometimes I kind of drop her off at the door and sometimes I walk her in, but um the doctor called me so I made sure I pulled over...but then my daughter was in the back seat and I didn't wanna like flip out too much in front of her and everything like that..." Learning how to cope while also fulfilling the parental role is a great challenge. The burden of breast cancer naturally has ramifications on the entire family, and the impact on small children for a young mother is difficult to navigate.

Overall, women with TNBC were faced with more aggressive surgical treatment decisions, which also affected their parenting choices. One woman with TNBC states, “I had my baby...June... of last year. And then I stopped breast feeding, um, probably around like August. And by November I found a lump in my right breast”. She had just become a mother for the first time, had finished breast feeding only months before, and was now preparing to undergo a radical double mastectomy preventing her from ever being able to breast feed again.

***Social and psychological development: Separation/individuation.*** Cancer as it impacts developmental milestones and stages of life is a critical piece to consider as we exam the social fabric of these young women. Two of the 6 women in the study group were forced back into dependence on their family of origin despite the attempt toward independence before the cancer experience. One of these young women had maintained her own apartment and was raising her child, but was forced to move back into her mother’s home due to her inability to pay the rent. Another had actively been working toward independence from her mother, but development toward this goal froze when she was diagnosed with cancer. Both of these women had contentious relationships with their mothers and were not pleased with the need to make this choice, but saw no other options.

When speaking about this dynamic around increased dependency on her mother and the associated financial struggles around loan repayment, #TN\_11 states, “I’m struggling with the, just the unemployment, so she really don’t ask me for anything, which I’m very thankful of, because it’s not enough...I definitely wanna get back to working, ‘cause I feel like she always worked too much...she’s still doing it and she has to pay off that debt too, and everything. So I wanna be able to help her and, you know, pay that off and get her to a sense where she can just work her regular shifts and she doesn’t have to, you know, have to put in so much overtime.”

The experience of this participant is increased dependence on a mother who is already overworked and financially struggling. In addition to be stuck at home and unable to move away from her mother as she had planned, there is also a feeling of guilt and dependency as she witnesses her mother take on extra hours to cover costs. In a previous interview #TN\_11 states, “I hate depending on people, so that’s...that’s...you know, it’s going to be hard because I won’t be able to come and go as I want to for awhile. But, I am hopeful for a speedy recovery, ‘cause I’m ready to get back to a sense of normalcy and see about working again and just pretty much just getting out of this house...” This participant now struggles significantly with having to rely on others while feeling the desire to become more independent.

These issues surface not just as a mild inconvenience, but are significant milestones along the trajectory of the maturation process. While most women similar in age to these young women are moving away from home, gaining independence, and establishing their own lives, these women are actually regressing back to a previous state of dependence in both their physical bodies (needing care during chemo and surgery, etc), but also regarding their financial independence, parenting ability, educational goals and professional development. The psychological and development impacts of cancer on their lives are significant. We cannot be sure of the life-long impacts of these developmental regressions, but over the course of the study, these setbacks were life altering and discussed often by participants.

***Productive engagement in society.*** Both of the women who were forced back into dependence on their mothers experienced marked disruptions in their college plans. Although they were initially enrolled in classes and actively pursuing bachelors’ degrees, they were forced to stopped taking classes and working toward their degrees, which caused uncertainty in their future involvement in a program of study. As we consider the unique impact that TNBC has on

the young, African American female population, we are left wondering about the long-term ramifications on society as these young women are taken out of the universities and colleges. Although initially able to pursue their educational goals and work toward obtaining degrees before the diagnosis, breast cancer becomes the single biggest barrier to continuing on this trajectory because of the multitude of complications that accompany such a diagnosis. These complications include, (1) physical limitations; simply becoming unable to commute to or attend classes because they are so ill, and also, (2) financial obstacles; paying medical bills and rent becomes the primary, consuming goal because they are no longer able to work therefore have no steady income to assist with meeting these needs. Paying for courses and course materials becomes a secondary priority, causing women to temporarily or permanently abandon their progress toward degrees.

When reflecting on the implications of having to take time away from school, participant #TN\_6 states, “I’m goin’ back to school in January. I don’t care...whatever in between it... and I’m just like, I’m not doin it...I mean school is more important than ummm, really, anything else because you can be street smart and business savy, but there is a lot of logistics and technical things that you kinda have to learn...” In this statement, the participant clearly identifies that school is one of the most important things to her. It is one of her primary goals in life, and she is determined to get back into class no matter what happens with her treatment.

Cancer also played a significant role in all of the women’s ability to work and engage productively with society in terms of their careers. Almost all of the women in the study group were significantly impacted in terms of their employment status. With the exception of the woman who was already unemployed at the beginning of the study, all of the women were forced to stop working or lost their jobs altogether due to their illnesses. One woman with

TNBC was forced to voluntarily surrender her job even though this was not what she wanted. “I had finished my chemo I had got a response from my job saying I had to voluntarily surrender...And then that’s what put so much pressure back on me...that was crushing”. Not only was she struggling financially and plunged into significant debt due to her inability to work, but this participant also lost a sense of self-worth from having been let go. She had taken a lot of pride in her career and was shocked and crushed to be suddenly fired from her position.

Participants in the comparison group did not experience such a severe impact on their work lives. Although some needed to take time off, none lost their jobs, and none had to stop work completely. This dynamic is mostly attributed to the severity and longevity of treatment necessary for those with TNBC as compared to those with ER+BC. The literature review revealed that financial concerns and job loss are indeed significant for all African American women facing breast cancer (Darby et al., 2009; Mujahid et al., 2010, 2011), but these findings reveal that women with TNBC may face even greater burden. Women with TNBC in this study faced much longer treatment trajectories, often undergoing extended chemo alongside a radical double mastectomy and then extensive reconstructive surgery. This is in comparison to women who needed lumpectomies and shorter rounds of chemo or radiation. The physical impact was less on women with ER+BC, which obviously impacted their ability to work and bring in an income.

***Feeling out of place.*** Women with cancer under the age of 50 represent the minority age group in breast cancer treatment, and women in the study group often relayed their struggles around feeling out of place because of their young ages. Sitting in the waiting room at the cancer center waiting for treatment left many of the participants feeling like outsiders, creating just one more hurdle in their road to recovery. Participant #TN\_11 states, “...everybody that’s there is

my mother's age or my grandmother's age and it just didn't seem like that was possible." The experience of a diagnosis of breast cancer is already a shock, but the additional burden of feeling unnaturally young in comparison to others in the room compounds the difficulty of the experience. Having breast cancer can be lonely, and yet, adding to this equation the unique age difference is an additional obstacle for many of these young women, increasing their feelings of loneliness. The women in the study group never mentioned knowing anyone else in their age group that was struggling with breast cancer, and they felt noticeably out of place. At a time in life when building friendships and establishing a sense of belonging is of utmost importance, the experience of breast cancer further separates young women from much needed peer groups. This dynamic is felt in very tangible ways as these young women wait at the cancer center and interact with others going through treatment. The women in this study realized their aloneness and were unable to connect with others who were having similar experiences. The impact of this separateness on development cannot be overlooked.

In addition to the relational dynamics of treatment at the cancer center, a few of these women also felt a marked separation from their peer groups because they were not being able to participate in the normal activities with their friends. This separation left these women feeling especially lonely and removed. As she continued to reflect on the experience of separation from the other women in the cancer center and then her peers, #TN\_11 states,

...just being younger, I feel like it just hit me different in the fact that some older women there are already established in their career, things like that. They've got more support from like a husband or something. It's like, I'm not at that point yet. So, I just wonder, you know, am I lacking in *that* area? And then my peers are all younger people, and like I said, they don't really *know* what's going on. Like I talk to 'em, but like, I don't know

how much they get it...Older people, they could have had like relatives or even their own friends or something. So they know a little bit more. But, in my age group, that's not really heard of.

The isolation experienced as a direct result of their cancer experience at an age where social networks and friend groups are of utmost importance is a significant barrier in the lives of those women who were young in this study, specifically those in the study group. Again, for women with TNBC, this points back to a history of isolation and loneliness in their family of origin, spiritual communities, and surrounding neighborhoods. Feeling out of place and isolated because of their young age is one more layer of the lifetime experience of loneliness felt by women in the study group.

*Youth seen as a strength in the recovery process.* Despite the many challenges associated with young age, youthfulness was both a curse and a blessing for some women in the study. That is to say that youth was seen as both a source of a stress and of strength. In one wave 3 interview, one of the youngest participants was reflecting back on the process and recalled that her young age was actually a benefit in terms of her recovery and ability to get back into her normal life. She states, "I said thank you Jesus I went through this at a young age because...if I was in my 30's it would have an even harder effect, but the fact that I am so young, I can bounce back." In terms of her psychological and physical ability to recover and return to baseline functioning, this participant actually counts her young age as a strength. This demonstrates the benefits of youth as it relates to the flexibility and strength of the body. Unfortunately, despite the sentiment that youth has given her strength, the prognostic factors associated with young age are not on this patient's side. Younger age has an adverse effect on overall prognosis, regardless of adjuvant/neoadjuvant treatment; in other words, young people



are more likely to die from TNBC than their older counterparts, despite their treatment regime (Baser et al., 2012; Liedtke et al., 2008). However, the psychological effects of feeling strong, able-bodied, and capable of recovery are indeed significant for this patient, and could be cultivated as a strength since she was able to return to baseline functioning quickly. It will be important for this patient to capitalize on this feeling of strength by following up regularly with routine checkups and constant communication with her oncologist, as opposed to distancing herself from the experience.

### **Question 2: The Illness Trajectory**

The second study question posed in this study is: What is the trajectory of the illness experience for young, African American women with TNBC as compared to women with ER+BC? There are myriad changes that the research team saw over time that are noteworthy among all participants in this study. One of the great strengths of this study is that the research team was able to follow participants throughout the course of their diagnosis and treatment, increasing engagement and gaining insight into change that occurred over time. This longitudinal design yielded a rich window of insight that would otherwise not be accessible with a single interview.

**Physical changes and the treatment trajectory.** For obvious reasons, women with TNBC experienced longer periods of treatment and more extensive medical interventions. Five of the six participants with TNBC had double mastectomies and then a full course of chemotherapy (or had suggested that this would be the course of treatment before dropping from the study, in the case of participant #TN\_12). This was then followed by radiation and reconstructive surgery. Although women in the study group were often nearing the end of treatment at the time of their last interview, most were not fully done. At the point of diagnosis

of TNBC, women have an extremely long road ahead of them, which often lasts upwards of one year.

This trajectory is compared to women with ER+BC who tend to experience shorter treatment lengths that are less extensive and less invasive. Only one woman in the ER+BC comparison group had a double mastectomy, and this medical intervention reflected her choice to be very aggressive in treating the cancer, which was not necessarily the standard course of treatment for a woman with her stage and subtype of cancer. Four of these women had lumpectomies and one had a single mastectomy. Because treatment was often less extensive, the research team found that participants in the comparison group were often fully recovered at the time of their final interviews and had a little more space to reflect upon the experience after being away from it for some time. The literature consistently identifies physical challenges associated with breast cancer as a significant burden for African American women with breast cancer more so than for white women (Bowen et al., 2007; Rao et al., 2008), and the present findings indicate that physical challenges are even greater for African American women with TNBC.

Women in both groups struggled to find meaning as they were forced to deal with the radical changes happening in and to their bodies. For many, this brought about a crisis of identity, especially as these women worked through issues of femininity and sexuality. As a ramification of more severe and invasive treatment, women with TNBC expressed greater struggle with their identities as they re-defined who they were as women after their breasts were removed in surgery, their hair had fallen out due to chemotherapy and in the case of some, they had gone through early menopause, halting their normal female processes. When these natural, physical associations with womanhood were removed, it becomes difficult to find identity in

gender, and this issue was pervasive and difficult for these women in the study group. One woman in the study group (#TN\_10) stated poignantly, "... you feel less of a woman. Because I've got the scars and I've got the breast cancer, but then the coloration of the skin –you don't feel beautiful –you feel less attractive. And I know it's the physical –the outside physical part of it, but it toys with your emotions until you start to feel down". These experiences were especially pertinent for women with TNBC going through extensive, aggressive treatment. Perhaps this is just a result of the treatment regime rather than the subtype, but taking into consideration identity is a critical piece of the puzzle as we try to frame the experience of TNBC for women, since they face such aggressive treatment regimes.

Across both groups, there was relatively strong treatment adherence with a couple of notable exceptions. Participant #ER\_5 knew about her diagnosis for many months and specifically chose not to get surgery despite doctors' strong recommendations because she believed that she felt the lump getting smaller and God was healing her. Despite her reservations, she ended up starting chemo by the end of our interviews, and was willing to consider surgery if it was still needed after the chemotherapy. Many of the women talked about how they considered dropping out of treatment, although none actually did. In terms of reconstruction surgery, of those women who had mastectomies, only one woman chose not to get reconstruction. Participant #ER\_7 had a single mastectomy and chose not to go through the reconstruction process as she felt it was not that important to her overall health. Participant #TN\_1 had extreme pressure to not get reconstruction from her mother and was even ostracized from the family for choosing to do so, but she ultimately ended up choosing to get reconstruction despite the strain that this put on her relationships. As she reflected on her decision, #TN\_1 states, "...in the back of your mind [you hear] your mom saying 'oh don't do that, and oh don't

go through that, just let it [go]’, but no...” Ultimately, #TN\_1 decided to cut her mother out of her life because she was such a negative influence on her treatment decisions. “That’s why when you were here last I said I had to just cut [her out]...I had to, like I said, shut some things off because I had to stay focused.” Clearly, this decision was a point of internal struggle as this participant went against her mother’s wishes and broke relationship with her mother in order to have reconstruction. This is another primary example of the relatively more tumultuous relationships between mothers and women in the study group with TNBC, this time specifically around the exertion of control over treatment decisions. This situation was extremely difficult for #TN\_1, and we spent a lot of time in the interview talking about the difficult relational dynamics as they specifically dealt with her decision to have reconstruction. Her mother viewed this choice as unnecessary and even gauche since her sister, who had also had breast cancer and a double mastectomy, could not afford reconstruction and went without.

**Changes in social support.** Having greater social support seems imperative when accounting for the numerous expectations and responsibilities on these women’s shoulders, but the research team found that these networks were not in place for women in the study group. Although none of the women with TNBC lived alone and most were often surrounded by people in their daily living situations, the individuals in the participants’ lives were more likely to be people who needed something from them (care as a dependent child, financial support as an elderly parent, etc.). In other words, as noted above, these women were often engaged in caregiving, rather than care receiving, and deeply involved in relationships marked by giving support rather than receiving support. These women embodied the experience of feeling lonely in a crowd, and though were often surrounded by people, felt extreme isolation. Although she lived with her mother, daughter, and occasionally her older brother, #TN\_11 was never able to

lean on these relationships for support. She reflects on her relationship and ability to talk with her mother and states,

... I'm ok and everything, but, even if I *wasn't*, I wouldn't tell her...Because I feel like she has enough to go through with losing her youngest son, and then finding out this about her daughter. So, I know that she's going through a lot, so I really try my best not to really put any...extra, you know, on her or whatever. So...yeah. I kinda, I don't really talk too much about the bad stuff with her or whatever, 'cause I don't want her worrying about it.

Even though she lives in the same household, she is unable to come to her mom and share openly about her struggles. She feels the need to care for her mother instead who is grieving the death of a child and working three jobs to pay the bills. This dynamic was difficult to define, and the research team found the need to distinguish having a close support network with whom women were able to share openly from just having people around them.

Social support can be defined in numerous ways, but for the purposes of this study, the research team used the three types of social support identified in the literature review mentioned in chapter 3 to provide insight into the dynamics of social support in these women's lives. We used the term "robust" to characterize support systems that had the potential to provide a combination of instrumental, emotional, and informational support, as identified in the literature (Bourjolly & Hirschman, 2001; Hamilton & Sandelowski, 2004).

As the team began to explore the intricacies of the social support networks of the women in the study, the team began to identify two distinct dynamics at play, which were best visualized on a grid. This grid was not created with the intent to quantify the data or place women in categories that were not malleable, but rather, the hope was to map these ideas to provide visual

clarity and to demonstrate the differences between being around people as compared to receiving support. These grids also helped to map any changes in the support network over time. In the grid below, “access to a robust support system” was defined as the presence of people in the immediate environment who were accessible and who could provide a combination of instrumental, emotional, and/or informational support. This included family members, friends at work, people in their congregations, or any other individuals who were available to them on a consistent basis. To meet criteria for this box, people in the support system needed to be adults and able to consent to mutual relationship.

Regardless of immediate access to a robust support system, the decision to actively seek out, pursue, and participate in supportive relationships was a different dynamic altogether. There were situations where support networks were available to provide one or a combination of different types of support, but the participant had chosen for one reason or another to not engage in this network. Examples of this were when the benefits of instrumental or informational support to be gained were outweighed by the costs of accepting this support due to broken relationships, abusive histories, or harmful relational dynamics. In the example of participant #TN\_1, this participant had to back away from her family even though taking on the obligations of treatment associated with the cancer experience was overwhelming.

People don't understand...so I had to back from the family a little bit to focus. Like I said it is a lot in a day's time to have to deal with I'm keeping my appointments, my medical records, this and that. And family can, being there –can overwhelm you to where it's just not healthy. From what I had to do is I had to step back.

It was in this participant's best interest to remove herself from these relationships for the time being because they were causing more stress than support. On the other hand, there were

participants who did not have access to a consistent network of support within their immediate family or work environment, and yet, they actively sought out this support through reaching out to support groups, participating in churches, or becoming engaged in the community.

Figure 4 and Figure 5 below show the placement of participants in regard to these two dynamics at the point of first interview, and then at the last interview, after they had progressed through the cancer treatment regime. As demonstrated below, all women with TNBC except for participant #TN\_9 at first landed in both negative categories, at once not having access to a robust support system, while also not indicating that they were making strides to obtain a support system or engage in mutually supportive relationships by identifying and pursuing outside resources. This is interesting considering the information above that none of these women lived alone but also consistent with their experiences of isolation and burden carrying uncovered in the data. These women are highly responsible and not living alone, but the relationships in their lives did not classify as “robust” because these relationships were marked by one-sided care giving or they were simply a product of co-habitation. Women with ER+BC tended to actively seek out and engage in social support more by reaching out to colleagues at work, seeking out online support through Facebook, or engaging in faith communities.

Access to a Robust Social Support System:	Yes	No
Active Attempts at Finding and/or Engaging a Social Support System:		
Yes	ER_2    ER_8 ER_3    TN_9	ER_4
No		TN_1    TN_10 ER_5    TN_11 TN_6    TN_12 ER_7

Figure 4. Grid of the Dynamics of Social Support for all Participants – Wave 1

In Figure 5, we see clearly how some of the participants in the study changed over time in regard to their support system. From the point of first interview to the third interview, there was marked progression in some participants. A few key stories will help to fill out the shifts that we have mapped below. Although some women stayed in the same quadrant, there were numerous changes. Notable, most of these changes occurred in the women with TNBC.



Access to a Robust Social Support System:	Yes	No
Active Attempts at Finding and/or Engaging a Social Support System:		
Yes	ER_3    TN_9 ER_8 (at wave 2)	TN_1 ER_4
No	ER_2    TN_10 TN_6	ER_5    TN_11 ER_7 <del>TN_12</del>

Figure 5. Grid of the Dynamics of Social Support for all Participants – Wave 3

Participant #TN\_1 was struggling with significant depression upon first interview. Although she had some family in town and was living with her spouse and child, she did not have access to these individuals, and was simultaneously actively making decisions to keep these individuals on the periphery of her life during this time of diagnosis and treatment, especially in regard to the tension with her mother over the decision to have reconstructive surgery. When speaking about her relationships with her husband and with her son, she states, “I’m here recuperating, he has to go out and do all the activities with my son...we aren’t physically separated, we still feel separated”. She is cohabitating with her husband at this point, and is in relationship with her son insofar as she provides care for him and coordinates his after school activities. Additionally, while her social support network is not robust, she is also actively making decisions to stay disconnected from her family. “Because don’t nobody understand how [or] what you’re going through. Then you don’t want to build bad relations. People don’t

understand when you're sick...so I had to back from the family a little bit to focus" and "the best thing I can do for myself right now is to just kind of shut down ...because I don't know what to do right now at this point." Although this participant's support system is not robust, she had the opportunity to reach out to those individuals in her life with whom she could potentially develop relationship, but she had actively chosen to push away and "shut down". She is isolated because she does not have a robust support system to reach out to, but she is also isolated because she is choosing not to pursue other outlets for support but to instead shut people out of the experience.

But the position of #TN\_1 begins to change and this change becomes evident during her last interview. After voicing her struggle with significant depression and realizing that she has hit an emotional "rock bottom", she realizes the need to reach out for help, and decides to go to counseling and participate in a support group. This brings significant change in her life, and causes noteworthy growth. Participant #TN\_1 states, "...this therapist just really has helped assist me through all of this. I mean...tremendously there's not nothing I can't call or you know sometimes you go through a lot of this and you don't know how to express it to someone else, but they are very in tuned and... able to give me you know things that can help me through it". In finding her therapist, #TN\_1 has found an outlet and a source of emotional support that she previously did not have. This required her to reach out and seek support, which required great courage. She also finds a support group and decides to begin attending church, which is life altering for her and tremendously helps to alleviate the depression she was experiencing at the beginning of her cancer journey. Although her immediate access to a robust support system has not changed, she is actively making choices to seek out sources of support, which may ultimately result in the development of a robust support system over time.

As another example of change over time, participant #TN\_10 at the time of the first interview was actively being stalked by an ex-boyfriend and had moved numerous times to escape him. She felt unsafe all of the time and was attempting to hide from him, limiting her ability to engage in social activities. Her network was extremely small, and although she was living with her new boyfriend, they had only been dating a few months and he was quite distant. She was unable to work due to her physical status and she had no spiritual community.

This is contrasted with the second and third interviews. Between interviews, she had experienced a radical, internal spiritual awakening, had been re-baptized, and was actively attending her home church multiple times per week. Her church community had grown exponentially and she was regularly receiving visitors from the church and calls expressing support and care. As opposed to never going to church and hiding in her home from a dangerous ex-boyfriend, at the second interview, she was attending church every week for spiritual growth:

... I got baptized again... Yes I got baptized [since] the last time I talked to you. I got baptized again... And something was just telling me this is just a new beginning for you to start over. Do it again and just do it right this time. So when I'm sitting in church and just sitting in the pew I just stood up and I joined church; I joined the church all over again. And I'd never been baptized by any other church but that church.

Despite this new access to a support system, participant #TN\_10 remained distant and aloof from specific relationships in the church, and by the third interview, she had transferred her allegiance. During the last interviews, she states,

I just want something more now. I'm thinking about going back to my old church that I was at before I went back to my home church. Um, they did more with uh healing hands, the gift of discerning spirits, um helping you to learn your spiritual gift. So I went to that

church this past Sunday and I told ‘em I won’t be at church this Sunday to usher but I’m just going to pay a visit to a church that I once went to.

This spiritual transition brought about significant growth in her personal life, but she remained disconnected in some ways and emotionally removed from others in the community.

On the contrary, women with ER+BC in the study did not experience as much growth in this area of their lives and in fact, the research team even noted a regression in terms of the social support network for one participant. Rather than growing from the experience of breast cancer in regard to their system of social support, the experience of breast cancer resulted in isolation and depression. In Figure 4, it is clear that #ER\_2 begins with both a robust social network and also demonstrates a strong ability to reach out and engage mutually with this network; however, at the last interview, #ER\_2 expressed significant isolation, was tearful throughout the interview, and stated that she was experiencing what her doctor was describing as PTSD. When asked whether or not she still had people with whom she could open up, she stated, “I used to. I don’t so much anymore just because it’s over, so then I kinda’ feel like I’m beating a dead horse and I don’t want to be that person who...some people get drunk off the attention they get when they are sick, and so I don’t want to be like...ok well the cancer’s gone, but I’m still bringing it up all the time.” As opposed to when she was first diagnosed, #ER\_2 now feels cut off from her friendship network and unable to reach out to them for the comfort that she needs. The experience of cancer has caused significant emotional turmoil, and yet, because of the time that has elapsed from the point of her original diagnosis, she no longer feels able to reach out to her support network, even though they are available to her.

**Post-traumatic growth.** As mentioned above, women in the study group noted the most positive change over time in regard to both their spiritual engagement and their social support

networks. Although this group is more isolated in general, women with TNBC demonstrated enormous capacity for growth and change as they faced this traumatic event in their lives.

Almost every woman with TNBC in the study experienced some kind of positive change in their lives after the experience of breast cancer, which was evident during the final interview.

Participant # TN\_1 reflects on this feeling of determination and says, “I must live. And I guess this proves to me that I don’t think I could just sit down and die. And you know you hear about people that just take off and they feel so helpless. I’m the total opposite.” This participant proceeds to seek out counseling and begins attending a support group where she meets women with whom she is able to relate. Demonstrated in Figures 4 and 5 above, the capacity for growth in terms of social structure was profound. Though under extreme stress and pressure, these women were able to grow as they sought out the resources and support that they needed in a time of need. As opposed to recoiling and dwelling in a situation of isolation, women with TNBC in this study demonstrated amazing resiliency and an ability to tap into needed resources. It is clear that the women with TNBC in this study have tremendous capacity for survival, resiliency, and growth.

Additionally in terms of engagement with a spiritual community, we saw significant change in the study group over time in terms of their engagement with a faith community as these women moved through their cancer journey. Comparatively, more women with ER+ breast cancer attended church than those who have TNBC at the point of first interview, but the research team saw more change in the study group in this regard. Two of the women in the study group actually began attending church during the time that they were going through treatment and were able to engage with a spiritual community in ways that they had not previously been able.

As mentioned above, participant #TN\_10 was actually re-baptized and was able to re-commit her life to her spiritual practices during the time of this study. Despite expressing significant depression at the point of first interview, she gradually demonstrated growth in her spiritual life and become more engaged with her faith community at each point of contact. During her wave two interview, she discussed the experience of a miraculous healing of the breast cancer that she attributes to a divine intervention from God. After completing her chemo treatment, the doctors were unable to locate the tumor during her ultrasound and #TN\_10 states that this was because God miraculously intervened in her life. The entire journey through cancer led her to a place of deeper spiritual realization and a stronger connection with God. The research team did not see similar growth in the comparison group. In fact, one woman who was actively attending church at the wave one interview had noted a decline in attendance and was no longer able to make services as often as she had at the point of first contact.

Posttraumatic growth related to the cancer experience, specifically around spiritual renewal, is not uncommon among cancer survivors (Denney, Aten, & Leavell, 2011; Morrill, Brewer, & O'Neill, 2008). The interesting part about this finding in the data is the difference seen between the study group and comparison group when evaluating this type of growth. The research team postulated that this ability to adapt was a reflection of the study group's exposure to and ability to acclimate to difficult and traumatic circumstances while growing up. In the face of an extreme lack of support from parental figures and exposure to loss and grief, these women learned to make it work and seek out what they needed in order to continue going. In the face of trauma and difficulty, these were the women who were survivors based on their own grit. These were not the women who turned to addictions or bad habits to survive even though they witnessed those around them engaging in these behaviors. Instead, they were the ones who

carried the burden, found resources, and adapted. As she lived out this determination to live, participant #TN\_1 states,

... I've met some amazing women that have uh conquered this thing and those are the kind of women that really are kind of you could sit down and have a true conversation about... Those go getters that say you can do this and it is tough right now but you can do this. There's one in my support group. One is my neighbor. And let's see she works in and out of town a lot, but she experienced it at a real young age and she said that you look good and I'm like oh I'm coming back! (laughs)

This pattern of fortitude becomes evident in how women in the study group cope with and address this life threatening disease. They seek support, go to church, find counseling, and do what they need to do in order to make it through.

This was evident in how women with TNBC tended to face their cancer. Women with TNBC drew on their strength and found what they needed to get through it alone. There was no need to depend on others emotionally, since this had proven unreliable, but these women were able to identify the resources that they needed to get through this difficult period, as they had done through numerous trials in their lives. These women were specifically skilled at surviving, and instinctually knew what they needed to get through. They showed up at their appointments, reached out to counselors, went to church, found child care, found new jobs after getting laid off, and were extremely resilient in the face of hardship.

### **Question 3: Building a Conceptual Framework**

The third and final research question of this study asks: How do we conceptually frame the disease experience for young, African American women with TNBC?, which calls for a synthesis of the new findings from the data as they relate to relevant theory and background

literature. Although difficult to distill all of this information into a concise model, it is critical to begin this process in order to lay a foundation for future work. It is helpful to first see a concise summary of the findings from the data in working toward a synthesized conceptual framework.

As unique from women with ER+BC, women with TNBC in this study demonstrated the following stressors and strengths, drawn from their unique histories and upbringing:

- Burden carriers throughout the life course
- Inheritance of strength from mothers
- Distant/strained relationships with mothers
- Absent fathers
- Experienced sudden, unexpected deaths of loved ones (at times through violence)
- Limited engagement in a spiritual community (at beginning of the study)
- Limited engagement in neighborhood/community
- Young age at time of diagnosis

As a result of cancer, women with TNBC experienced many things that were unique from women with ER+BC over the course of the treatment trajectory:

- More aggressive/prolonged treatment regimes
- Greater struggle with female identity
- Changes in social support system – often positive shifts
- A capacity for posttraumatic growth

As discussed in chapter 5, many of these findings are consistent with the literature, but many were unexpected or enhanced the literature reviewed in chapter 3 in new ways. Since there are no studies to date that enumerate the unique psychosocial experiences of women with



TNBC, this information supplements the literature on African American women with breast cancer, and begins to fill the gaps in our knowledge about those elements that are unique to women with TNBC (see chapter 2, Figure 2).

Of the many theories and theoretical orientations that inform how we understand health disparities, there are three that are central to a comprehensive understanding of the biopsychosocial issues present for women with TNBC as study question 3 is answered and a conceptual framework is built. These three key theories or theoretical orientations were discussed briefly in chapter 2: Intersectionality Theory, the concept of allostatic load as a theoretical orientation to understanding health disparities, and Social Action Theory. These theoretical approaches provide a lens through which we can view and begin to understanding the phenomena of TNBC and provide insight into how best to understand the disease experience for young African American women with TNBC. They work together and inform one another, while laying a foundation from which to view the data.

These three theories were chosen specifically because they broaden the lens through which health outcomes have traditionally been viewed. In chapter 2, it was made clear that individual level theories are rendered grossly inadequate when we look at this specific population of young, African American women facing a diagnosis of TNBC. This is because understanding this subtype of breast cancer necessarily involves looking beyond just individual coping and behavior to larger community and population level variables. Those theories that focus solely on the individual fail to capture the interlocking psychosocial systems at work in the lives of these underserved women and neglect to incorporate the impact of epigenetic factors. Given the impact of the social environment on health outcomes, individual level theories are inadequate in addressing societal and population level issues that lead to TNBC. Therefore, the

three theories articulated below and used in building a conceptual framework are those theories that move beyond just the individual and incorporate the impact of larger systemic issues.

**Intersectionality Theory.** As mentioned in chapter 2, Intersectionality Theory is a meta-theory that helps to describe and explain the socio-political dynamics of oppression manifested in health disparities. Intersectionality Theory posits that an individual exists within the context of many overlapping systems of oppression and that all of these overlapping systems inform the individual's life experiences and sense of self (Murphy et al., 2009). Patricia Hill Collins opened up the understanding of oppression and set the foundations for Intersectionality Theory when she described the Matrix of Oppression. Within this matrix, we see the multiple identities that inform positions of power within society. These locations, either within the culturally dominant or culturally subordinate groups, guide our experiences and positions of influence. Intersectionality Theory uses this framework as an understanding of how overlapping systems of oppression affect identity in a unique and holistic way. The following table demonstrates the culturally dominant and culturally subordinate positions in our society. Each individual falls in a unique place on this matrix, as the various layers of identity intersect.

	Culturally Dominant	Culturally Subordinate
Gender	Male	Female
Race	Caucasian	Minority
Ability	Able Bodied	Disabled/III
Socioeconomic Status	Wealthy	Poor
Education	Well Educated	Under Educated
Sexual Orientation	Straight	Gay

*Table 1. Matrix of Oppression*

Additionally, it is clear that our socio-political positions within this framework guide our experience of health and disease. Those who fall into many culturally dominant categories have access to resources, support, power, and information that positively impact health outcomes. This dynamic is clearly at play in those women who have TNBC. Most women with the TNBC diagnosis fall into many of the culturally subordinate positions, which affect both etiology of the disease as well as disease outcomes. When disempowered in society, these women not only face higher rates of disease, but also have less access to care and needed resources to impact disease outcomes. These power dynamics impact relationship structures, job and career opportunities, and neighborhood dynamics, among a host of other psychosocial issues. This theoretical foundation is the stage on which the TNBC drama unfolds. Although this foundation for understanding health disparities is not exclusive to women with TNBC, the unique position in this matrix for each person and the ramifications of this position on the way that these women

were raised and learned to interact with the world is important to consider as one critical, foundational piece of the puzzle.

**Allostatic load, a theoretical orientation.** Given their position of disempowerment in our culture, young, African American women have many negative health outcomes including worst breast cancer outcomes. Viewing these dynamics in light of allostatic load as one key theoretical orientation helps to unpack the psychological and biological processes that result in negative cancer outcomes. In the face of chronic stressors over time, these natural processes of the body build-up, leading to what is known as “allostatic load”, which is an unhealthy accumulation of stress in the body (Goldstein & McEwen, 2002; Bruce McEwen & Lasley, 2003). This leads to system burnout and flattened cortisol responses, ultimately resulting in disease. Allostatic load is often measured using salivary cortisol, adrenaline, and various other biomarkers, although all of the biomarkers important to measuring allostatic load have not yet been identified. This theoretical conception of bodily stress reactions, which has gained a lot of traction in scientific communities, is critical as we begin to gain insight into how TNBC occurs. When the body experiences multiple, chronic stressors over time, it is unable to adaptively process stress and develops aggressive breast tumors.

This dynamic is especially relevant given the socio-political position of women who are at risk of and who are diagnosed with TNBC. Given the position of disempowerment in society, and the host of psychosocial stressors that accompany these positions, it is only natural that these women would have significant allostatic load. As seen in chapter 5, women with TNBC in this study are those to whom the burden of care has always fallen. In the absence of parental figures who were able to be present and relieve this load, these women bore the sole responsibility of these burdens for themselves and for their families. Exposure to such extreme stressors over

time and the accumulation of stress responses in the body becomes a critical piece in understanding these dynamics.

**Social Action Theory.** Once the socio-political environment in which disease occurs is understood, and the biological processes are clarified, we can begin to better contextualize behavioral theories that might impact breast cancer outcomes among this group. It should first be stated though that changing health behavior without first understanding this context of oppression in which disease occurs is futile and even cruel for women who are oppressed.

Within the context of this theoretical framework, Social Action Theory (SAT) helps to inform the discussion as it is one of the few behavioral theories that describe mechanisms and strategies for change as opposed to just describing behavioral processes. Additionally, unique to SAT is the understanding that activating behavioral change takes place only within the context of social ties and community engagement. This is applicable to women with TNBC, as we have seen that this piece of their lives is often missing. There is limited engagement in the surrounding community, despite the importance of this social structure to health outcomes.

SAT posits three phases of behavioral change related to improved health. These include 1) identification of the habit or behavior that needs to be altered, 2) assessing resources and mechanisms for change, which include social ties, and 3) engaging the community for change. This theory will be informative as women with TNBC attempt to overcome the psychosocial barriers that prevent participation in adequate follow-up care, stress reduction, emotional and mental health care, and adherence to treatment. SAT targets specific behaviors, identifies resources, and engages the community in attempting to alter elements of the environment that do not support healthful behaviors.

## **Synthesizing the Theory and Data**

Below is a theoretical model that begins to synthesize and explain the phenomena of TNBC based on the findings from the present study and the existing knowledge discussed in the preceding chapters. This model does not necessarily demonstrate causal links (although these have been demonstrated in previous studies), but instead demonstrates the relationships between theories, ideas, and data found in this study, showing visually how these are linked.

The outside, peripheral rectangles theoretically frame the ideas in the model using the three theories discussed above. These rectangles represent the underlying theory upon which the other concepts rest. These are the building blocks that inform what was observed in the data.

The first box in the model accounts for the socio-political placement of the individual within our culture using the Matrix of Oppression as a framework. Although the relevance of the Matrix of Oppression spans breast cancer subtypes, the position of women with TNBC uniquely plants them in a vulnerable position giving way to other vulnerabilities that are linked to poor health outcomes. In other words, because these women are poor, African American, female, and young, they are uniquely positioned to experience other social environmental stressors that their white, wealthy counterparts may never experience. This position places them in a position of vulnerability in our culture, which is a critical piece to understanding the holistic lives of women with TNBC.

These overlapping systems of oppression then set the stage for difficult and strained parental relationships, exposure to violence, trauma, loss, and grief compounded by silence, and social isolation. The socio-political placement of these individuals in society, compounded with both the experience of psychosocial stressors and lack of social support as a buffer impact the body's acquisition of allostatic load over time. As the social environment of these women

become increasingly stressful, there are physiological and biological reactions in the body. The acquisition of allostatic load then impacts health outcomes such as the occurrence and severity of breast cancer.

The combined effects of all of these processes affect motivation and ability to engage in adherence behavior. Given the lack of social support, SAT asserts that worse health outcomes are then associated with isolation and disengagement from the community. The data from this study demonstrates that these women with TNBC are indeed uniquely isolated from others, which impacts their ability to engage in healthy behaviors.

All of these elements combined, leading to the TNBC diagnosis, position these women in a place of vulnerability. These women with a diagnosis of TNBC then face unique challenges after diagnosis, as discussed above, including young age, aggressive treatment regimes, struggles with their female identity, etc. which compound with already existing challenges of engagement in the community. The following model summarizes these thoughts into a model that is useful for understanding this unique group of underserved women.

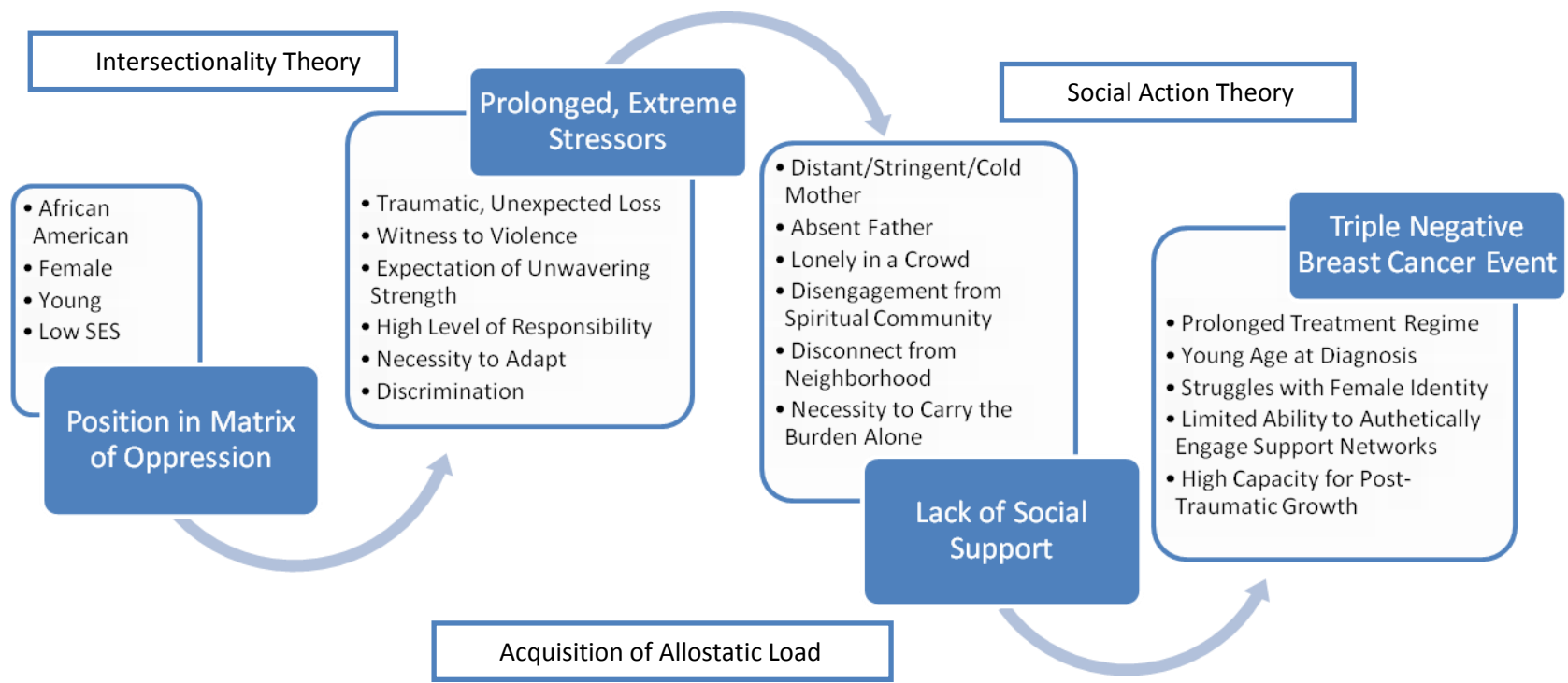


Figure 6. An Integrative Model to Inform our Understanding of the Disease Experience for Young, African American Women with Triple Negative Breast Cancer



This model begins to lay a foundation for how to understand and work with women with a diagnosis of TNBC. This is a holistic model, demonstrating the multitude of elements that come into play when conceptualizing care for these women. One of the central points of this model is that women with TNBC face unique challenges, unlike other women, but also, have an arsenal of adaptive strengths. An important conclusion from this model is the importance of understanding that the social environment cannot be separated from how we understand gene expression changes and malignant cell growth. This model assists in demonstrating how these elements are linked and cannot be separated from one another. In summary, a holistic, multi-level approach to understanding the disease experience is necessary in order to fully address the challenges and engage the strengths of women diagnosed with TNBC.

## **Chapter Six - Implications and Next Steps:**

### **Social Workers Responding**

#### **Study Strengths and Limitations**

Before delving into the implications of this study, it is first important to acknowledge its strengths and limitations, which demands a note about the evaluation of qualitative research. Qualitative research requires the use of specific criteria as evaluative standards, which are necessarily different than those used in quantitative research. These standards of quality help to uphold the legitimacy of the findings, while recognizing that qualitative research must be evaluated differently than quantitative research. Although there are many approaches to understanding evaluative standards in qualitative research, Lincoln and Guba (1985) articulate helpful terminology and standards that assist in understanding these differences. These authors propose the use of *credibility*, *transferability*, *auditability*, and *confirmability* as direct alternatives to the use of internal validity, external validity (or generalizability), reliability, and objectivity in quantitative research, which are not applicable to qualitative methods. These evaluative methods were applied to the findings of this study once it was complete by the research team as a method of reflection on external standards. Additionally, the strategies for rigor used in this study and the intricate involvement of the research team in all steps of data collection and analyses, which are outlined in chapter 4, were employed during the study to ensure that it was rigorous (Padgett, 2008). To the best of our ability, the research team attempted to stay true to the data and adequately reflect the truth of the participants' stories. This framework and terminology specific to understanding qualitative research helps to guide our understanding of the limitations.

It is obvious that the sample size for this study is small and it would be inaccurate to generalize to all African American women with TNBC. Although sample size can be considered a limitation, especially in quantitative research as it limits the breadth of the study, the design of this study was strategic and intentional, and therefore, the small sample size is one of the great strengths of this study and this study demonstrates high *transferability*. Although broad generalizations to all women cannot be made from these findings, this study is one of the first of its kind to understand, in depth, the lives of young African American women with TNBC, which significantly contributes to our knowledge of this population. This knowledge is transferable to other studies and can be built upon in future research.

One limitation of the small sample size is this study's ability to compare differences between the study group and comparison group. The research team felt as if they achieved a significant level of depth with each participant and also noted repetition across cases as seen in the NVivo coding analysis. Despite this fact, it is true that the differences found between groups could be attributed to chance because the sample size is small. This limitation is duly noted; however, given the research questions stated at the beginning of the study, these findings were important because they were the first to bring to light the specific experience of women with TNBC as they differed from other African American women with breast cancer. The comparison group provided a point of reference to begin to uncover unique experiences for women with TNBC. The findings based on the comparison between groups were informative because they provided a foundation from which to explore these emerging themes in a larger sample.

Specifically, the comparison group brought to light the finding about the very significant age difference between the two groups, which is also mirrored in data from other studies. From

this comparison, the research team was able to clearly demonstrate the stage of life differences experienced between the two groups, and articulate the different concerns and contexts in which breast cancer is experienced for women with TNBC as compared to women with ER+BC. Women with TNBC specially discuss their experience of being young with breast cancer, attending school while going through treatment, and raising young children in the midst of illness. This was unique to the group with TNBC and important when researchers and clinicians seek to understand and assist women with TNBC. As mentioned in the findings section, this difference is specific and distinct, and would not have been found had it not been for this design that included the comparison group as a critical piece of the study. Additionally, this finding has significant implications for clinicians who work with young women with TNBC. As preliminary examples, support and assistance specific to stage of life could be provided through cancer care providers and social workers at this very crucial time. Perhaps considering simple applications of this knowledge would be helpful for these women; examples might include tuition assistance programs, provision of childcare, and counseling related to coping with intimate relationships while going through cancer treatment could be important for this group of women.

Additionally, the comparison of these two groups is essential in exploring the impact of the social environment on health outcomes, specifically as it relates to women with TNBC. Exploring the differences in these women's early lives, relational histories, and experiences of poverty throughout the life course is essential in parsing out the theoretical foundations of this study that clearly demonstrate the impact of the social environment on breast cancer outcomes. This comparison is crucial as researchers attempt to understand the impact of the social environment on the body. Clearly, this comparison requires more exploration and further

inquiry, and future research could potentially sample more women in each group while removing the longitudinal component of this research design to confirm these findings in a broader context.

Limitations to transferability include the fact that the findings from this study are both time and location specific. The data were collected in a specific area, in a city with a complicated and unique history, especially around racial dynamics, poverty, and segregation. Although this does not negate the findings, it is important to keep this in mind as we think about application. The history of segregation and racism and the ongoing racial divide in the city of St. Louis is unique and these dynamics are relevant as we think about these findings. The findings must be placed in context.

Additionally, the Siteman Cancer Center is one of the premier cancer centers of its kind. It holds the prestigious Comprehensive Cancer Center designation from the National Cancer Institute and is one of only 21 institutions to hold membership in the National Comprehensive Cancer Network. Across the entire sample, women in this study were exceptionally pleased with their care and had overwhelmingly positive things to say about their treatment and the people who were assigned to their cases. When asked about their experiences at the Siteman Cancer Center, women were overwhelmingly positive and complimentary. This is wonderful, and should also be taken into consideration when looking at the results as they apply to others. Women who receive care at Siteman may represent a unique group of women who have access to quality of care not typically provided to all women, as not everyone has the privilege to access services such as these. Perhaps the physical and emotional complications associated with TNBC are even more pronounced at other cancer centers that lack the resources and connections of Siteman. The differences in care received could be explored in future studies.

Another limitation is the inability of this study to compare results across racial differences. It was beyond the scope of this study to compare women in the study with their white or Hispanic counterparts, but a potential future level of inquiry might explore how these findings apply to young, white or young, Hispanic women with TNBC. The focus of this study was specifically on the African American experience and was only able to examine differences based on *subtype* of breast cancer, but an equally interesting comparison could take place based on *racial* differences, which could add to our understanding.

### **Impact of Interviews on Participants**

Another consideration when looking at the outcomes of this study is the impact of interviews themselves as an impactful experience for participants. A few women mentioned the importance of this study as a significant event that assisted them in coping with the difficulty of the diagnosis and treatment. One participant stated, "...one of the things, I just hope every woman would take the opportunity to do these interviews...Because so many women be afraid to talk about it. And it's like, don't be afraid because if you be quiet and don't say anything that person that really needs to hear this may just decide not to do the treatment, you know, and that's like, I couldn't keep quiet." It was a beneficial experience and impacted their treatment decisions. Many of the women in both the study group and comparison group felt heard and were able to share openly. The impact that the study had on their cancer journey is a question worthy of exploration but was kept constant across both groups, which should not impact the contrast of the study group to the comparison group.

### **Implications**

The findings from this study are numerous and have implications for theory, policy, research, and practice as these relate to the triple-negative experience. As the research team was

able to unpack some of the psychosocial needs along with the inherent strengths of women with TNBC, it was apparent that there was a gap in terms of how women with TNBC are understood and cared for holistically by the medical system and mental health professionals across the life course. It is impossible to hear these stories of strength and struggle without experiencing a sense of urgency about the needs that remain unaddressed. But it is also clear that addressing these needs will not be simple or clear cut. Implications for understanding the larger issues at hand and the requisite responses include action on multiple levels.

**Broadening our understanding: Expanding our theoretical orientations.** One of the clear outcomes of this study was the move toward broadening the theoretical lens from which we understand and work with women at risk for and/or diagnosed with TNBC. This applies specifically to how we understand women with TNBC, the impact of their adverse experiences over the life course, and how TNBC impacts them given their young age. One of the significant aims of this study was to begin to provide an integrated model where we are able to move beyond individual level theories in increase our understanding of women with TNBC. One of the major findings in the review of relevant theory in chapter 2 is that existing, individual-level theories alone are inadequate in providing a complete framework for understanding women with TNBC. Individual level theories that focus only on personal behavior or stress and coping are reductionistic as we begin to understand these women in a broader context, specifically, understanding how the social environment impacts health outcomes. The implications of Figure 6, the emerging theoretical model, on how social workers understand the theoretical landscape for women with TNBC are significant in that the model begins to weave together theories that can ultimately provide a broader, more comprehensive approach to understanding the theoretical underpinnings of the occurrence and treatment of TNBC. By tying together Intersectionality

Theory, the implications of the acquisition of allostatic load over time, and the importance of Social Action Theory, policy makers, researchers, and clinicians alike are able to gain a better perspective on the multifaceted issues facing women with TNBC in order to intervene in ways that are more appropriate and effective.

**Calling attention to sexism, racism, and classism: Implications for health policy.**

Interlocking systems of oppression such as sexism, racism, and classism compromise the health of women and minorities across the globe by preventing equality in access to care and affecting the quality of care received, specifically among diseases, like TNBC, linked to the social environment. These dynamics are often ignored in health policy initiatives. African American women often bear the brunt of these interlocking systems of oppression, resulting in disparate health outcomes especially for diseases such as breast cancer. This dynamic is clearly seen in the lives of the women with TNBC in this study as the implications of their experiences of poverty and discrimination throughout the life course impact both the occurrence of breast cancer, but also how the disease is faced and walked through post diagnosis. It is important to consider that these women face a very aggressive form of breast cancer at a unique time of life as compared to other women, which means that breast cancer co-occurs with the experiences of other significant life burdens such as establishing their careers, attending college, and raising children. Many clinicians do not recognize the unique challenges associated with an early diagnosis of breast cancer and are ill-equipped to provide supports appropriate to these needs. Farmer (1999) asserts that such inequalities are the very reason that people fall ill, and that illness is the natural result of the violation of social and economic rights. Structural violence is the term that is used to describe the violence inflicted on individuals through unjust political, economic, and social systems (P. E. Farmer, Nizeye, Stulac, & Keshavjee, 2006). These unjust



structures that inflict injury and illness on individuals, especially those who are members of minority groups, demand more than just a cursory acknowledgment. In terms of health care policy and health reform, underserved populations such as African American women with TNBC need to become a priority.

Social workers involved in policy work are ethically obligated to address these issues in hopes of equaling the playing field in terms of accessing care and improving quality of care. A number of concrete steps could address these issues. Such ideas as increasing access to health insurance through supporting health reform legislation, improving educational efforts about health issues among underserved populations, and allocating funds to grass-roots organizations that provide community health care, such as low-income, neighborhood health clinics, could begin to address some of these issues. These are just a few examples of policy improvements that would have significant impact. Social workers should be among the primary leaders working on this front.

**Implications for future research.** Given the limitations mentioned at the beginning of this chapter, further research should be conducted that is able to build on these preliminary findings. Now that key stressors and strengths have been identified, the trajectory of the illness experience has been explored, and a framework for understanding this population has been laid, future research can explore and confirm these findings with women with TNBC in different cities and settings in an attempt to confirm and expand upon the data presented here.

Other examples of future research to be conducted include research that is intimately connected with the community through participatory action approaches. Methods such as the use of focus groups, photo-voice, and partnering with community leaders and stake-holders can help researchers to better understand the most pressing needs and concerns of African American

women with aggressive, triple-negative disease while simultaneously mobilizing these women to impact their communities. Priority should be placed on facilitating ways in which women are able to be heard and tell their own stories, articulating their most common concerns, questions, and needs. The telling of these stories should be coupled with empowerment to act and speak out to those in authority who have the ability to change social structures. Research that promotes action and engagement with the community is one vital approach to improving understanding and working toward change.

Future intervention research could also explore specific psychosocial interventions that seek to address and minimize this burden of care carried in isolation by women with TNBC. Intervention research could focus on finding strategies that help women to decrease isolation, connect with others, and engage in their communities, while providing support in maintaining their responsibilities. Providing specific strategies for women with these histories to learn to connect and build community could be explored. Providing opportunities for cohesiveness with others and decreasing the experience of isolation might be one key element to explore in this approach to intervention research.

**Implications for practice: Prevention, assessment, and intervention.** As clinicians critically consider the findings of this research, this study will have significant implications for practitioners in three areas of clinical practice. These three areas include implications for prevention of TNBC, assessment of women who are at risk for or who are going through initial diagnosis of TNBC, and finally, psychosocial interventions for women who are walking through the experience of TNBC. These implications are relevant to a multitude of health professions, specifically social work, and call for a multidisciplinary approach, where clinicians work

together to pool their expertise in an attempt to intervene with these women in a way that is holistic and addresses the underlying disparities present in this underserved group of women.

***Prevention.*** As seen in the Integrative Model proposed in Figure 6, a full understanding of women facing TNBC requires that we broaden the theoretical lens to include neighborhood, community, and societal-level approaches to understanding these issues. By framing the beginning of the model with Intersectionality Theory, it becomes apparent that systems of socio-political oppression inform the disease experience throughout the life course, and the larger community and society are critical as we consider the impact of these forms of oppression on the body over time. As we think about prevention of TNBC in this light, action at a larger level becomes imperative as we consider the best ways to potentially prevent the wear and tear on bodies caused by these outside stressors.

To our knowledge, no established interventions aimed at prevention of breast cancer target the amelioration of health disparities at the neighborhood and community levels. Interventions that move beyond the individual to include the context in which the individual lives, works, and socializes have the potential to be highly effective given the impact of environmental factors on etiology specifically around the triple-negative disease. Designing interventions that incorporate these factors is the next step on this agenda as the relevance of the surrounding community is being demonstrated.

Although extremely preliminary, it is helpful to think creatively about what such an approach might look like. The current study outlines a framework for understanding this population of women with TNBC and articulates the need to provide holistic care for women with TNBC and preventative measures used by clinicians in the health care field need to think outside of traditional approaches to incorporate these elements. As one example of a creative

approach to holistic intervention, a potential intervention might utilize a transdisciplinary health care team, centrally located in settlement houses embedded within low-income, African American communities. This new model of care would incorporate multiple professions and disciplines, and would extend the realm of prevention and intervention by including comprehensive psychosocial care for women before they are ever diagnosed with TNBC. These teams based in settlement house could work hand in hand with local clinics, such as Planned Parenthood, and other providers of health care to low-income recipients. In this model of prevention, holistic, psychosocial care would be provided by all team members who might meet bi-weekly to discuss and case plan for each patient who would be considered high risk for TNBC among other diseases associated with poverty. These teams could be led by a social worker and could also include a nurse practitioner, a pastoral/spiritual care person, a psychologist, and a music therapist, among other key players relevant to the patient's unique psychosocial concerns seen in the conceptual framework (see Figure 6).

As stated above, these teams would be based in settlement houses within low-income communities, and would be intimately tied to the surrounding neighborhood in which the patients live in order to begin to address the isolation that exists among these groups of women. Multiple programs of support could be offered through these centers (such as parenting programs, emergency childcare, prayer groups, trauma counseling, and GED classes), and access to these services would be provided through the team as deemed necessary by a comprehensive assessment. This approach would provide an interdisciplinary, multi-level method of assisting women with accessing services, addressing the barriers posed by systematic oppression, and receiving psychosocial care on multiple-levels specifically relevant to the stressors and strengths that they experience. Such a model of holistic care before TNBC is ever diagnosed could

potentially help to buffer the effects of stress, provide a safe space for women, and build a support network for women who are at risk. This would also help with education about breast health and could provide access to early screening for those at risk.

Although perhaps grandiose, this example is given to demonstrate the need to incorporate multiple levels of prevention into the plan of care for women who are at risk for TNBC. As we work together to improve health outcomes for these women, part of this process will involve exposing and addressing barriers to care that are present due to dynamics of power and control in our culture and communities, which necessitate a multi-level approach that takes into account the interaction of genes with the social environment. The presence of these settlement houses in the communities and the relationships built because of the work of the team members could theoretically help to improve neighborhoods and drive down crime rates and isolation, resulting in healthier neighborhoods overall. Using the conceptual framework outlined in this study as a guide, intervention should address multiple levels of the social environment.

***Assessment.*** In addition to innovative prevention methods that involve the creation of safe spaces in neighborhoods where integrated care is provided throughout the life course for those at risk, when patients present in breast cancer centers and clinics for possible diagnosis, comprehensive assessment tools can also be employed to provide information about the complete person who is seeking care. Often patients are filtered in and out of breast clinics and mammography centers without the medical teams comprising a full understanding of the needs of the individual. Although great attention may be given to the mammography and physical health screening, rarely are women asked about their mental health, spiritual health, emotional well-being, sources of support, or involvement with their local community. Women are often

compartmentalized, but this study reveals the importance of understanding that addressing physical health alone limits the clinician's ability to appreciate and treat the whole person.

Based on the findings from this study outlined in Figure 6, a comprehensive assessment of a woman being screened for breast cancer and at risk for TNBC might include a measure of stress, a social support survey, a screening of financial concerns, and a trauma measure. This assessment tool would need to be brief and easy to complete in a waiting room, but could also provide a quick snapshot of any psychosocial concerns that may call for more thorough investigation. Early assessment could set the stage for comprehensive care that addresses the whole person. As demonstrated in this study, TNBC is linked to larger systemic factors that impact the body over time. Exploring these issues early in the diagnostic process would help to provide a better window into the issues at hand and would ultimately lead to a more complete plan of care for women diagnosed with TNBC.

***Intervention.*** Although many interventions exist for women facing a diagnosis of breast cancer in general, few address the needs of minority populations or the psychosocial concerns of African American women with breast cancer that were highlighted in chapter 3. Furthermore there are no interventions that exist that specifically target women diagnosed with TNBC. Of the interventions that have demonstrated success among minority populations with breast cancer, such as the patient navigation models (Wells et al., 2008), issues such as inadequate research, limited reach outside of the health care system, and uncertainty of long-term sustainability threaten to undermine the progress made, and none address the specific needs of women with TNBC that were identified in this study. Given the findings of this study, two models of intervention post diagnosis of TNBC may be worthy of exploration.

Regarding the psychosocial concerns articulated by women in this study, the need for a targeted psychosocial support intervention may be important to explore. As one such example to from which to glean, Spiegel and colleagues (1989; 2007) created a psychosocial intervention in which they tested the effectiveness of a supportive group therapy approach not just on psychological, emotional, and social outcomes, but also on breast cancer survival. Supportive Expressive Group Therapy is a group psychotherapeutic model where treatment is provided weekly over the course of a year, and patients are encouraged to build relationships, confront problems, and find enhanced meaning in their lives. This treatment is designed to specifically address existential issues and encourage open dialogue about taboo subjects such as mortality and loss. In addition to a significant reduction in distress and improvements in emotion regulation for those undergoing this treatment (Classen et al., 2001; Spiegel et al., 2007), the original study also found a significant increase in survival for the intervention group (Spiegel, 1989). Although a recent attempt to replicate this study by Spiegel and colleagues found no significant overall effect of treatment in a group of 125 women with confirmed metastatic or locally recurrent breast cancer (Spiegel et al., 2007), there was a significant increase in survival for women with ER negative breast tumors, suggesting a need for research that examines effectiveness among subtypes of women with breast cancer. This is specifically relevant to this group of women with TNBC, as their tumors are ER negative.

This intervention is critical to note because it points to the importance of designing interventions that address the whole person. Perhaps improving the overall psychosocial wellbeing of women with TNBC would also have an impact on their breast cancer survival outcomes, as seen with Spiegel's intervention. In Spiegel and colleagues' sample in the aforementioned intervention (2007), 92.2% of participants in the experimental group were white

women, with a mean education of 16.1 years and only 21.9% of the treatment group earned less than \$39,999 per year. A new intervention that specifically incorporates technique similar to those used in SEGT, but also addresses psychosocial issues relevant to this population with TNBC based on the findings from this study, would be one approach to intervention that would be worthy of exploration given the positive results from Spiegel's study. It would be necessary to design an intervention that specifically targets the needs highlighted in Figure 6, and then tests the model on a sample of women that is representative and includes minority women. Particular attention should be paid to trauma and loss, and issues of attachment associated with parental relationships as two potential elements to explore for this new intervention.

A second approach to intervention for women with TNBC would be based on increasing these women's connection to their neighborhood and access to available resources in an integrated way. A neighborhood support coordinator (NSC) intervention is a proposed model of intervention that is designed to work with women in the context of their communities and based on the model of downward causation seen in Figure 1 (Gehlert, Small, & Bollinger, 2011). The NSC has some of the features of a patient navigator mentioned above, such that the central goal is to help women overcome systemic barriers, but there are two critical differences. First, rather than being clinic based, this intervention focuses on engaging the women in the neighborhood and community in which they live in order to increase support. Secondly, the NSC helps the women to navigate overlapping systems rather than limiting the scope to the health care system only. This provides a more comprehensive approach to care rather than limiting it to the health care setting. An intervention such as this would allow for greater connection within the community and care that is more integrated. In this way, the issues raised in Figure 6 could be addressed in a multitude of ways. The NSC could assist women with TNBC to navigate not only



the health care system, but also address their financial concerns, career and educational concerns, and assist with finding options for childcare among other needs.

*The role of social workers.* Social workers play a critical role in each of these areas where implications for clinical practice are called for. Social workers are uniquely positioned to implement holistic care throughout the life course, as they are distinctively trained to understand the person within the context of their social environment. In prevention approaches, social workers could be the central point of contact in these neighborhood-based settlement houses, pulling the other disciplines together, leading team meetings, and coordinating care. Their role in this setting is essential in providing continuity and cohesiveness. In breast clinics, social workers would be essential in administering new assessments and following up on issues that may require additional attention. For post-diagnostic interventions for women with TNBC, social workers could be the ones running the psychotherapeutic support groups and would be the ones filling the role of neighborhood support coordinators. Their intervention skills would be essential in providing quality, comprehensive care throughout the illness trajectory for women at risk for and diagnosed with TNBC.

The findings of this study regarding the importance of understanding the impact of the social environment on the physical body imply that the role of the social worker on breast cancer teams is invaluable in that the social worker is specifically trained to understand these dynamics. Because of the person-in-environment focus, social workers are able to assist other professions in understanding the importance of these population and societal level factors at play. New social workers who are being trained in health care need to have, as part of their curriculum, these lines clearly drawn. This person in environment approach extends beyond just mental and emotional implications, and includes the physical body as well. For social work training, this should be

clearly articulated and expanded upon so that this connection is clearly understood and taken into clinical practice.

### **Moving Forward**

The fields of social work and of health care in general are at the very beginning of their journey to address breast cancer disparities in African American women. This is the tip of the iceberg in many ways, and much remains unknown about this population of women, specifically those with the triple-negative diagnosis. According to our Code of Ethics, “The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty” (National Association of Social Workers, 1996, p. 1). As social workers, it is not only important, but also part of our ethical responsibility to address disparities such as these. By broadening our theoretical orientation to such problems, understanding and educating health care workers about the variation in breast cancer subtypes, increasing our knowledge of the multifaceted, contextual lives of African American women with a triple-negative diagnosis, and striving to improve interventions by increasing appropriateness and relevance, we can begin to address these issues. It is also imperative that social workers begin to reach across disciplines to join hands with other disciplines, as addressing these issues requires the expertise of multiple fields of inquiry. The steps outlined here are just a few ideas to be explored in future research that will move us toward improving the lives of underserved women who are facing TNBC.

*On a Personal Note...*

*"The light shines in the darkness, and the darkness has not overcome it." John 1:5*

*I would be remiss if I did not take this opportunity to comment on the impact that this study has had on my life personally and on the lives of my research assistants. During the course of this study, I heard stories of repeated and violent rape, stories of the deaths of multiple children, stories of murder, stories of tremendous fear induced by stalkers, stories of lost causes, and stories of broken relationships. I held their hands as women in this study talked about regrets and I passed tissues as they grieved the loss of loved ones. I was inundated with tragedy and at times, the research team and I found these stories too difficult to bear.*

*But these stories of trauma were juxtaposed with stories about great joy and triumph, stories about the ability to grow in faith and live with a greater hope, and stories about enduring in the midst of struggle. These were women who loved fiercely and gave generously. These were women who were valiant in the face of tragedy. These were women who survived to tell. For this, I am grateful. For this, I am changed.*

*As I tried to remain objective and maintain the role of rigorous researcher, it would be a lie to say that my heart was not simultaneously moved as I heard these stories of struggle and triumph, tragedy and growth, loss and rebirth. These stories were often dark, and we all struggled under the weight that we bore as we came alongside these women to help carry their burdens for a time. But in the midst of darkness, there is always light. I could write a thousand pages and not fully capture this experience or do justice to all of the things that I heard. But it is my hope that in the midst of great darkness that is ever-present in this world, this small study somehow brings light to the lives of these women and to the lives of all who hear their stories.*

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