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Chemotherapy Adherence Decision Making in Early Stage Breast Cancer

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Chemotherapy Adherence Decision Making in Early Stage Breast Cancer

By

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An abstract of
A dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
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Abstract

Chemotherapy Adherence Decision Making in Early Stage Breast Cancer
By Jessica S. Holmes

Background: A survival disparity exists between African-American and Caucasian women with breast cancer. African-American women are more likely to die from breast cancer than Caucasian women despite having a lower incidence rate. Furthermore, African-American women are more likely to discontinue chemotherapy early, thus shortening their survival.

Purpose: The purpose of this study was to examine the variables that influence the decision to complete or discontinue chemotherapy in African American and Caucasian women; and, identify racial and contextual differences that may exist in this population. The Health Decision Model was used to frame the study where the roles of socio-demographic factors, social interaction factors, the cancer experience, breast cancer knowledge, and health beliefs were specifically examined to explore differences and relationships related to treatment decision making**.**

Sample and Design: The study recruited a convenience sample of 99 African-American and Caucasian women with early stage breast cancer. The measures and questionnaires employed for data collection were: Demographics Measure, Norbeck's Social Support Questionnaire, the Pargament Religious Coping Scale, the Comprehensive Breast Cancer Related Knowledge Scale, Memorial Symptom Assessment Scale Short Form, the Powe Fatalism Inventory, Center for Epidemiologic Studies- Depression and the Champion Health Belief Model Scale. The variable, days from diagnosis to treatment, was added as a proxy to adherence to treatment recommendations. Data analyses included univariate and bivariate analyses, multiple hierarchical regressions, and logistic regressions.

Results: Race was closely associated with many of the study's contextual factors. Additionally, education was found to be a significant predictor to many of the relationships explored within the model. Due to a largely adherent sample, predictors and differences to non-adherence could not be assessed. However, other findings revealed breast cancer knowledge and cancer fatalism predicted days from diagnosis to treatment.

Discussion: Knowledge and fatalistic views toward breast cancer were important predictors to the decision to start treatment. The predictors related to days from diagnosis to treatment have several clinical and policy-related implications. More research is needed in this area and to guide future intervention studies.

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Chapter I

INTRODUCTION

Statement of the Problem

According to the most recent statistics provided by the American Cancer Society, there are an estimated 230,480 new cases of breast cancer that occur each year with an estimated 57,650 deaths that occur in the United States (American Cancer Society, 2012). Breast cancer is the second leading cause of cancer death among women of all races, preceded only by lung cancer. However, with the promotion of early detection and advancement in treatment, breast cancer survival rates, within all races, are as high as 98% for localized disease (American Cancer Society, 2012).

Unfortunately, ethnic differences exist in the experience of African-American and Caucasian women diagnosed with breast cancer. Racial disparities in breast cancer survival rates exist across racial and ethnic groups. According to data from the Surveillance, Epidemiology, and End Results (SEER), the age adjusted incidence rates from 1975-2005 for Caucasian women was 128.6 cases per 100,000, 113.3 for African-American women, 97.2 among Hispanic women, and 58.0 in American Indian/Alaskan Natives (Ries, et al., 2007). Over the years, breast cancer incidence rates have decreased in Caucasian and African-American women. However, a bigger decline in incidence has been seen in Caucasian women with an average annual percent decrease of 3.2% from 2001-2005 versus only an annual 0.5% decrease in African-American women (Ries et al., 2007).

Greater improvements in survival and outcomes have been seen in Caucasian women than in African-American women. Although Caucasian women have the highest incidence of breast cancer, they also have high survival rates as well. The average five-year survival rate for localized breast cancer in Caucasian women is 99.3%, followed by African-American women with a survival rate of 92.6% for localized disease (American Cancer Society, 2012). In fact, Caucasian women have better survival rates at all stages of breast cancer diagnosis at 84.2%, 24.9%, 52% for regional, distant, and un-staged diagnosis, respectively (American Cancer Society, 2012). Yet, African-Americans experience significantly lower survival rates of 72.1%, 15%, and 45.2% respectively for regional, distant, and un-staged breast cancers. In addition, African-American women have a decreased likelihood of surviving five years after diagnosis at all stages of breast cancer when compared to Caucasian women (American Cancer Society, 2011). Early detection and improving treatment options have increased survival rates for breast cancer; however, African-American women have not benefited equally from the advancement of breast cancer care, as reflected in survival and mortality rates (American Cancer Society, 2012).

Many factors have been proposed to explain the widening mortality gap seen between African-American and Caucasian women with breast cancer. Factors that may explain disparities in breast cancer outcomes by race and ethnicity include more advanced stage at diagnosis, a lower proportion of hormone receptor positive tumors, differences in comorbidity, provider distrust, and a range of socioeconomic factors (Blackman & Masi, 2006; Shavers, Harlan, & Stevens, 2003; Ward, et al., 2004). Another important factor that contributes to the racial and ethnic survival disparity is

observed differences in the clinical management of breast cancer. Racial and ethnic disparities have been documented to persist in the use of the best evidenced-based treatments for breast cancer. Treatment disparities are evident in both treatment delay and chemotherapy adherence (Hershman, et al., 2003; Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999). Systematic review of observational studies of the influence of delay between screening, diagnosis, and treatment found that patients who delay treatment for three months or more had a 12% lower 5-year survival rate than those with shorter delays (mortality OR=1.47, 95% CI, 1.42-1.53) (Richards et al., 1999). Furthermore, a large study of 49,865 women gathered from SEER data from 1992-1999 showed that African-American women experienced the most diagnostic delay (median 29 days, $p<.001$) and the longest treatment delay (median 20 days, $p <.001$) with 11.2% experiencing combined clinical delay ($p<.001$) (Gorin, Heck, Cheng, & Smith, 2006). African-American race was a strong and consistent predictor of all forms of delay after controlling for age, comorbidities, marital status, place of residence, cancer stage, tumor characteristics, HMO status, cancer detection method, and poverty at census tract level (Gorin et al., 2006). Furthermore, Hershman and colleagues found African-American women were more likely than Caucasian women to terminate chemotherapy treatment prematurely and were two times more likely to die than Caucasian women (2005). Of the 344 women who completed all cycles of chemotherapy, 89% were alive 5 years after diagnosis and of the women who did not complete chemotherapy treatment, only 74% survived for 5 years ($p=.03$). In addition, of the ones who did not complete chemotherapy, only 81% of African-American women were alive 5 years after diagnosis versus 93% with 5-year survival in Caucasian women ($p=.03$) (Hershman et al., 2005).

Non-adherence to chemotherapy, including treatment delays from diagnosis to initiation of treatment, may contribute to survival differences in outcomes between racial groups.

Treatment decision-making is complex and is linked to patient outcomes so it is critical to examine the process that influences treatment decisions. The diagnosis of breast cancer is a very stressful event, requiring the woman to make multiple decisions about her care. The woman has to decide on multiple decisions such as when to seek help, selection of treatments that have varying risks and benefits, or the choice of inaction (Redelmeier, Rozin, & Kahneman, 1993). These decisions may or may not be consistent with the recommendations of the health care provider. Moreover, the role of treatment decision-making in contributing to breast cancer disparities in treatment is poorly understood. Adherence to treatment is multifaceted and no simple explanation for non-adherence exists. Because of race based differences observed in Caucasian and African-American women with breast cancer survival, adherence rates and the variables that effect treatment decision-making in both groups needs to be further elucidated through research.

Purpose

A thorough review of the literature did not reveal a prospective study devoted to describing or explaining the differences in variables influencing the decision to complete or not complete recommended intravenous chemotherapy treatment in African-American and Caucasian women with early stage breast cancer. However, this information is crucial for the development and testing of population specific interventions that have the potential for addressing disparities in breast cancer treatment adherence and survival rates between African Americans and Caucasians. Thus, the purpose of this study was to

examine the variables that influence the decision to complete or discontinue chemotherapy in African-American and Caucasian women and to identify racial and contextual differences that may exist in this population that may help explain racial differences. This study specifically examined the roles of socio-demographic factors (age, race, and access to care), social interaction factors (support mechanisms, i.e., social support and religious coping), cancer experience (chemotherapy side effects and depression), breast cancer knowledge, and health beliefs (perceived susceptibility, severity, motivation, benefits and barriers of the disease and cancer fatalism) in chemotherapy decisions**.**

Specific Aims

Aim 1: **To explore relationships among socio-demographic factors (race, age, access to care), social interaction factors (social support and religious coping), cancer experience (side effects and depression), breast cancer knowledge, and health beliefs (susceptibility, seriousness, benefits, barriers, motivation, and cancer fatalism).**

RQ 1: *What is the relationship among: (a) socio-demographic factors and breast cancer knowledge; (b) socio-demographic factors and social interaction factors; (c) socio-demographic factors and the cancer experience; (d) social interaction factors and the cancer experience; (e) social interaction factors and breast cancer knowledge; and (f) breast cancer knowledge and the cancer experience?*

RQ 2: *To what degree are socio-demographic factors, social interaction factors, breast cancer knowledge, and the cancer experience are related to specific health beliefs?*

Aim 2: To examine differences in adherence to chemotherapy between African-American and Caucasian women with early stage breast cancer in relation to socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs and to explore these factors as predictors of adherence to chemotherapy among women with early stage breast cancer.

RQ 3: *To what degree is race associated with differences in the adherence to chemotherapy in women with early stage breast cancer?*

RQ 4: *What socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs predict adherence to chemotherapy in African-American and Caucasian women with early stage breast cancer?*

Conceptual Framework

Overview of the Health Decision Model

The Health Decision Model (HDM) (Eraker, Becker, Strecher, & Kirscht, 1985; Eraker, Kirscht, & Becker, 1984) will provide the conceptual basis for the proposed study. There is a large body of literature that examines the degree to which a patient's health beliefs explain health related decisions. These beliefs have been the basis of many psychosocial models that attempt to explain and predict health behavior by examining the individual's beliefs and attitudes. For example, the Health Belief Model (HBM) (Becker, et al., 1977) is appealing and useful to a wide range of professionals concerned with predicting adherence to medical regimens, behavior modification, and preventative services. The HBM postulates that a health behavior (e.g. adherence) is determined by an individual's health beliefs, where their perceptions regarding susceptibility to the disease, severity of the disease, and the benefits and barriers to treatment are likely to be derived

or encountered result in a health behavior. However, the HBM has many practical and theoretical shortcomings such as the model's heavy reliance on beliefs that drive health behavior, its exclusion of other influencing factors, and issues related to the quantification of its concepts.

The HDM is a revised version of the HBM that incorporates strengths of the HBM and modifying factors of patient preferences to provide various predictors of adherence (Eraker et al., 1985; Eraker et al., 1984). The HDM is a unifying model of health decisions and resultant behavior where decisions analysis, behavioral decisions theory, and health beliefs are incorporated into the model. The HDM consists of the following six key interrelated components that predict the health decision to adherence: socio-demographic, social interaction, experience, knowledge, general and specific health beliefs, and patient preferences. The HDM also recognizes the importance of socio-demographic factors and social interactions that impact the disease experience and knowledge. These factors together interact with health beliefs and patient preferences which then predicts a health decision (Eraker et al., 1984). The model purports health beliefs effect behavior and behavior effects health beliefs.

Key Concepts and Propositions of the Health Decision Model

Conceptual descriptions of the variables used in the Health Decision Model (Eraker et al., 1985; Eraker et al., 1984) are as follows:

General Health Beliefs refer to patients' general attitudes and beliefs that contribute to their decisions about treatment regimens. These beliefs encompass general concerns in health related matters and the willingness to seek and accept health information. It also suggests that satisfaction with the patient-healthcare provider

interaction and other aspects of the medical encounter can influence general health beliefs and can impact health behavior. Authors of the model purport that patient satisfaction and open communication with his or her healthcare provider result in greater adherence to medical regimens (Eraker et al., 1984). These beliefs are also influenced by several extraneous factors such as culture, previous experiences, misinterpretation of information, and acceptance of non-medical references (Eraker et al., 1984). *Specific Health Beliefs* refer to the patients' perceptions regarding susceptibility to a specific disease, such as breast cancer, and severity of the disease, if contracted, and include benefits and barriers to undertaking a recommended action (Becker et al., 1977; Eraker et al., 1984). Specific health beliefs consist of four dimensions: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers. *Perceived severity* is an individual's perception or feelings concerning the seriousness of contracting an illness. Here, the individual weighs the medical and social consequences of leaving the condition untreated. *Perceived susceptibility* is the extent to which the individual believes he or she is prone to the health condition. The third dimension, *perceived benefits*, is where the individual considers the anticipated value of the recommended course of action or treatment approach. Here, the individual who shows an optimal level of perception of susceptibility and severity would not be expected to accept any recommended health action unless that action was perceived as feasible or beneficial. Lastly, *perceived barriers* are where the individual examines the costs involved in taking a particular action. An unconscious cost benefit analysis is thought to occur, where the individual weighs the benefits against perceptions of the health behavior being expensive, dangerous, or inconvenient and time consuming.

The incorporation of the *patient's preferences* can enhance adherence to healthcare providers' recommendations. The patient is involved in a decision analysis process where he or she weighs the benefits and risks in making a health decision (Eraker et al., 1984). A patient may be averse to taking a medication if he or she is doubtful of the therapeutic benefits of the drugs, but may be likely to accept risks to avoid inevitable adverse side effects. For example, a cancer patient may prefer to take a drug if it is certain that a therapeutic benefit will be obtained from the drug, such as extension of life, versus taking a drug that may not work at all (Donovan & Blake, 1992). The patient's decision process includes multiple risk aversions for gains and risk-seeking actions for loses during the decision making process. Trade-offs between benefits and risks are dynamic in nature and may change over time, either independently or as a result of previous decisions and experiences. The HDM acknowledges that individuals or patients make decisions about treatments, health behaviors, and lifestyle choices within the contexts of their beliefs and preferences.

The HDM includes the patient's lived *experiences*, which can have tremendous influence on health decision-making, and shape health behaviors (Eraker et al., 1984). The role of previous experiences is considered modified by health beliefs as well as experiences can modify health beliefs. These experiences are dynamic and constant and are continuously shaped by religious, cultural, historical, and aesthetic factors. The patient brings these experiences into the healthcare setting; they should be acknowledged as important influences to an individual's decisions regarding health behavior and treatments. One of the weaknesses of the HDM's parent model, the HBM, and other psychosocial models is ignorance of the patient's complexities and past experiences that

interact with their feeling and beliefs regarding illnesses and treatments (Becker et al., 1977). Additionally, past experiences with healthcare providers and the general medical environment shape how a patient thinks and feels about his or her illnesses and health and can impact behavior (Donovan & Blake, 1992).

A patient's *knowledge* about disease and treatments influences patient decisions. As purported by the model, a patient's health beliefs and preferences mold a patient's understanding and knowledge regarding his or her disease, diagnostic and therapeutic interventions (Eraker et al., 1984). Knowledge and understanding of their disease or treatment, frames the extent to which an individual will implement medical information and recommendations into his or her lifestyle. Non-adherence to medical treatment and regimens may be involuntary due to gaps in understanding the recommendations of the healthcare provider. The author of the HDM argues that patients with poor understanding of their regimens are at an increased risk for non-compliance (Eraker et al., 1984). Without proper understanding, patients cannot make a fair assessment of the risks and benefits of medical recommendations; this action can lead to behaviors that are not congruent with medical advice. The HDM purports a bi-directional relationship between health knowledge and experience. Past interactions and experiences with healthcare providers can influence knowledge. A collaborative and interactive patient-provider relationship impacts health knowledge (Mayeaux, et al., 1996). Healthcare providers that explain and assess patient understanding are more likely to have patients that adhere to medical advice (Trevino, Albright, Wright, & Cigarroa, 2005).

Social interaction factors such as social support and social networks can influence health behaviors such as adherence (Eraker et al., 1984). Family members, friends, work

associates, church members, and other members of an individual's social network can influence or motivate health behaviors. Socially supportive individuals can enhance supervision of the patient as well as assist and motivate adherence to medical regimens (Eraker et al., 1985; Eraker et al., 1984). Social support has influential impact and is beneficial to long-term treatment plans that require continuous actions on the part of the patient (Eraker et al., 1985; Eraker et al., 1984). A network of social support can also help a patient manage and cope with stressful health-related events and assist in behavioral modifications.

Socio-demographic variables such as race, education, income, age, and health insurance can serve as covariates to the HDM and can impact interrelationships purported in the model (Eraker et al., 1984). The extent of the model's proposed relationships can be impacted by socio-demographic factors and should be accounted for in behavioral models. Therefore, socio-demographic variables are purported to play a crucial role in health decisions.

Summary

In summary, the HDM serves as a popular framework to predict health decisions, such as adherence, by purporting relationships beginning with health decisions and including health beliefs, patient preferences, experience, knowledge, social interaction, and socio-demographic factors. Each component, except certain socio-demographic factors, is amenable to interventions to help increase adherence to medical regimens. The HDM provides the most appropriate and comprehensive framework to explore the predictors that best influence the decision to either continue or discontinue chemotherapy in women with breast cancer. For the purpose of this study, socio-demographic, social

interaction, knowledge, personal experience, and specific health beliefs will be measured as possible predictors of adherence to chemotherapy. These five factors have been identified in the literature as predictors of cancer treatment and general medical adherence in various populations. The HDM along with existing supportive empirical evidence will be used to predict the factors that best influence the treatment decisions among those who complete or discontinue chemotherapy (see Figure 1.1).

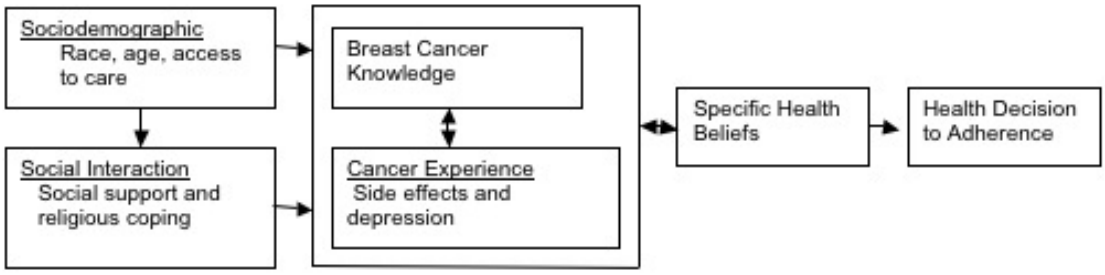

Figure 1.1: Factors That Influence Decision Making in Women with Breast Cancer as Adapted from the Health Decision Model (Eraker et al., 1984).

Relevance of Study

The decision to adhere to chemotherapy is an important factor that increases survival rates in women with breast cancer. Yet, virtually no study identifies the specific factors that influence the decision of women with early stage breast cancer to terminate or complete their recommended treatment. This study is consistent with the mission statement of the National Institutes of Health, National Institute of Nursing Research (NINR) to promote and improve the health of individuals, families, communities, and populations (National Institute of Nursing Research, 2011). The NINR supports research that encompasses health promotion, quality of life, and health disparities. This study is

consistent with the missions of the NINR as it seeks to build on the research needed for patients' decision making in order to promote optimal health outcomes and reduce health disparities seen in African-American women with breast cancer. In addition, an overarching goal of Healthy People 2010 was to eliminate health disparities, specifically racial differences seen in cancer survival (Healthy People 2010, 2008). This public health priority parallels this proposed study because African-American women may be more likely to die from breast cancer than Caucasian women because of their decision to terminate their recommended treatment early. The proposed study is significant because: 1) Research is lacking regarding why women with breast cancer adhere or do not adhere to their recommended breast cancer treatment regimen and how factors differ between African-American and Caucasian women; 2) Early termination of intravenous chemotherapy treatment is associated with decreased survival rates; 3) African-American women may be more likely to discontinue intravenous chemotherapy treatment early, which may contribute to the cancer disparity seen between African-American and Caucasian women. Research is warranted in this area to assess the nature and extent of early treatment termination or completion of recommended treatment among women with breast cancer and to identify possible factors that could affect this decision-making in women with breast cancer.

Summary

Although the prevalence of breast cancer for African-American women are lower (116.1 per 100,000) when compared to Caucasian women (125.4 per 100,000), the mortality rate is higher for African-American women at 32.4 per 100,000 versus 23.9 per 100,000 in Caucasian women (American Cancer Society, 2012). In fact, African-

American women are more likely to have higher mortality rates than Caucasian women, even when controlling for socioeconomic status, stage of diagnosis, tumor size, and access to care (American Cancer Society, 2012). The inferior survival outcomes observed in African-American women with breast cancer are well documented and is considered a public health priority (Bradley, Given, & Roberts, 2002). Although the reasons for this disparity are unclear, the results of a recent study suggest that African-American women are more likely to stop their intravenous chemotherapy treatment early, which shortens their survival (Hershman et al., 2005). Chemotherapy initiation is only the first step to improve survival rates; the woman must then complete therapy in order to receive full benefits of treatment. Women who do not complete their prescribed treatment have significantly decreased survival rates. This recognition is important because it suggests that breast cancer survival disparities can be decreased through clinical interventions that increase adherence to chemotherapy. Yet, there is no evidence that describes the factors that influence the decision to stop or continue intravenous chemotherapy treatment in women with breast cancer with early stage breast cancer and how these factors differ between races. This study was designed to examine the variables that influence the decision to complete or discontinue chemotherapy in African-American and Caucasian women, and identify racial and contextual differences that may exist in this population within the framework of the Health Decision Model (Eraker et al., 1985; Eraker et al., 1984).

Chapter II

BACKGROUND AND SIGNIFICANCE

This study focused on elucidating factors associated with treatment adherence in women with early stage breast cancer. More specifically, the study focused on explaining differences in variables influencing the decision to complete or not complete recommended intravenous chemotherapy treatment in African-American and Caucasian women with early stage breast cancer. The Health Decision Model (HDM) was the conceptual framework, which served as a basis for identifying key variables associated with treatment adherence. This chapter discusses prior research on the topic, particularly on key concepts from the HDM postulated to be associated with treatment adherence in African-American and Caucasian women diagnosed with breast cancer.

Defining Treatment Adherence

Adherence is described as the extent to which an individual's behavior coincides with medical health advice (Berg, Dischler, Wagner, Raia, & Palmer-Shevlin, 1993; Sabate, 2003). Traditionally, compliance was used to describe the degree in which a patient follows medical instructions. However, *compliance* and its definition imply a one-way relationship between patient and provider. The patient is a passive receiver of expert advice from his or her healthcare provider. The World Health Organization recommends healthcare providers to adopt the word "adherence" and its definition as follows:

> the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (p. 3, 2003).

It is important to note that adherence to healthcare regimens encompasses the patient's health related behavior that extends beyond taking prescribed medications to reach a therapeutic outcome. Therapeutic behaviors include actions such as seeking medical attention, filling prescriptions, taking medications appropriately, attending follow-up appointments, lifestyle modification such as diet and exercise, and executing self-management behaviors for chronic diseases (Sabate, 2003).

Today, adherence is commonly used to describe a collaborative and active relationship with the healthcare provider where the patient is involved in the treatment process. The main difference between adherence and compliance is the emphasis on the patient's willingness to accept medical recommendations. Adherence is facilitated by a relationship that highlights a partnership between the patient and in some cases his or her family, with the healthcare team. The healthcare provider considers the patient's abilities, beliefs, motivation, and barriers in relation to the plan of treatment. Adherence is contingent on an atmosphere of open communication that explores the patient's goals and an active discussion that explores therapeutic options, exchange of health information, regimen outcomes, and expectations and barriers to adherence.

Adherence to treatment regimens is a complex and multifaceted issue that is largely determined by the individual's intentional or unintentional choice to follow medical advice. Adherence can be separated into two distinct categories: intentional and unintentional non-adherence (Atkins & Fallowfield, 2006). Unintentional non-adherence

is the act of forgetting or misunderstanding the dose of the medication; whereas, intentional non-adherence is the deliberate decision to discontinue a medication. Intentional non-adherence is an active decision making process that is suggested to be a result of three factors: 1) lack of information about the advantages and disadvantages of the treatment; 2) the benefits of treatment are not obviously apparent; or 3) absence of the psychological adaptation required to see oneself in need of treatment (Atkins & Fallowfield, 2006). Intentional non-adherence is important in health care because it is a conscious act where the patient makes a decision about his or her treatment (Wroe, 2002). This decision can be a process with renegotiations when the patient weighs the perceived costs and benefits of treatment. The patient may then alter his or her treatment regimen to fit into a lifestyle that will offer the best quality of life. Since intentional non-adherence is a conscious phenomenon, it can be modified though intervention (Wroe, 2002). Therefore, this study focused on examining and exploring factors related to *intentional* non-adherence.

The Impact of Treatment Non-adherence

Due to conscious effort and opportunity for intervention, intentional non-adherence has been studied extensively in the literature. Poor adherence has been shown to be the cause of poor disease control among patients with chronic diseases, including cancer (DiMatteo, 2004a; DiMatteo, Giordani, Lepper, & Croghan, 2002; Heath, Singer, O'Shaughnessy, Montaner, & Hogg, 2002). All-cause hospitalization rates are highest among patients who have low medication adherence rates (Sokol, McGuigan, Verbrugge, & Epstein, 2005). It is estimated that 33 to 69 percent of all medication related hospital admissions are due to poor adherence rates (Kane & Shaya, 2008). In addition, non-

adherence bears high economic consequences; for example, it is estimated poor treatment adherence contributes to a 38% increase in health care costs for admissions. Patients who are non-adherent incur an estimated 12.5% increase in healthcare costs (Kane & Shaya, 2008). Overall, non-adherence is associated with an increase in healthcare costs across all services with an estimated $100 billion per annum spent on hospitalizations, disease deterioration, and death. Due to the high costs and poor health outcomes related to low adherence rates, the World Health Organization declares poor adherence to long-term regimens a critical issue with striking magnitude to population health (Sabate, 2003).

Adherence is a primary determinant of treatment effectiveness and optimum clinical benefit. Examples of these outcomes include decrease in healthcare costs; decrease disease exacerbations, crisis, or relapse and, increase in patient quality and preservation of life (Sabate, 2003). However, these benefits are not achievable if the patient does not adhere to medication or treatment. A meta-analysis of studies involving adherence to various treatments, regimens, and interventions for chronic illnesses showed adherence ranged from 5% to 100% and averaged about 75% in 569 empirical studies (DiMatteo et al., 2002). Adherence rates differed by disease where adherence to HIV antiviral medications was the highest at 88% and as low as 66% for medication adherence in patients with diabetes. DiMatteo also noted medical adherence rates averaged about 63% before 1980 and increased to 76% from 1980 and thereafter (2002). The increase in adherence rates is suggested to be attributed to the move from an authoritative laden provider-patient relationship to a relationship that acknowledges and includes the patient's autonomy and personal choices (DiMatteo et al., 2002).

Adherence to Intravenous Chemotherapy

Adherence to intravenous chemotherapy for breast cancer is significantly associated with improved outcomes (Bonadonna & Valagussa, 1981; Early Breast Cancer Trialist Collaborative Group, 2005). Intravenous chemotherapy, when indicated, offers survival and recurrence benefits in patients with primary breast cancer. However, even when faced with a potentially life-threatening illness such as breast cancer, it cannot be assumed that the patient will adhere to intravenous chemotherapy. A systematic review of 133 randomized trials showed highly significant reductions in annual rate of recurrence and death rates as a result of intravenous chemotherapy (Early Breast Cancer Trialist Collaborative Group, 1992). An overview of 18,000 women provided statistically definitive evidence that some form of chemotherapy can affect survival and recurrence with an odds reduction of 21% for recurrence and 11% for mortality. The effect of chemotherapy on annual death rates after five years was highly significant with a 28% reduction in recurrence rates and 16% reduction in mortality rates in the first five years (Early Breast Cancer Trialist Collaborative Group, 1992).

In order to receive maximum benefits from adjuvant treatment, patients must adhere to chemotherapy treatment regimens. Patients receiving less than 85% of total intravenous chemotherapy had a poorer clinical course than those receiving complete therapy. A significant reduction in the 5-year relapse free survival was seen in women with stage II breast cancer on intravenous chemotherapy who received less than 65% of the planned drug dose (Bonadonna & Valagussa, 1981). Yet, an early study found only 21% of the patients actually received more than 85% of the prescribed chemotherapy

dose and 34% of the patients received 66-84% of the prescribed dose and 45% received less than 65% of the dose prescribed (Lee, 1983).

Racial Differences in Chemotherapy Adherence

Racial differences exist in women who initiate and complete chemotherapy. For example, African-American women are more likely to be diagnosed and treated at a later stage of breast cancer than Caucasian women due to delays in the diagnosis and initiation of treatment (Gorin et al., 2006; Joslyn & West, 2000; Woodward, et al., 2006). However, the extent to which African-American women adhere to intravenous chemotherapy is inconsistent and largely understudied. One study found African-American women have an increased likelihood of an early treatment termination for intravenous chemotherapy. Only 68% of African-American women completed all prescribed cycles of adjuvant chemotherapy, compared to 76% of Caucasian patients (Hershman et al., 2005). In addition, women who did not complete their prescribed treatment had significantly decreased survival rates that were even lower if they were African-American. Non-adherence to breast cancer treatments and treatment delays have been purported to partially explain worse breast cancer outcomes in African-American women (Bickell, et al., 2006; Hershman et al., 2005). However, it is important to note these findings conflict with past studies where no significant differences between races were found to chemotherapy adherence rates (Andic, et al., 2010; Berger, Braverman, Sohn, & Morrow, 1988; Dobie, et al., 2006; Lebovits, et al., 1990). Due to inconsistencies in the relationship between race and chemotherapy adherence described in the literature, this area is in need of more research to establish the role race plays in chemotherapy adherence.

Contextual Factors Related to Adherence

Non-adherence is seen as a process of reasoned decision-making where the patient considers risks and benefits and aligns his or her beliefs with a behavior that will achieve his or her goals, preserve quality of life, and maintain personal autonomy (Donovan & Blake, 1992; Meyerowitz, Sparks, & Spears, 1979; Redelmeier et al., 1993; Revenson & Pranikoff, 2005). Since no adherence is believed to be the result of reasoned behavior, many studies attempt to explain variations and factors that influence the decision-making process (DiMatteo et al., 2002; Donovan & Blake, 1992; Dunbar-Jacob, Schlenk, Burke, & Matthews, 1998; Entwistle & Watt, 2006). The following sections are an extensive review of the healthcare literature concerning the role of various factors that may predict or influence adherence to cancer regimens. This review of literature was framed by the study's theoretical framework and the health decisions model as described earlier in chapter one. The factors that have been postulated to play a role in decision-making to chemotherapy adherence include socio-demographic factors, disease knowledge, social interactions, the disease experience, and health beliefs.

Socio-demographic Factors

Socio-demographic variables consist of race, age, and access to healthcare as predictors to adherence.

Race. The general adherence literature reveals race is frequently reported as a significant predictor of adherence to many long-term pharmacological regimens and chronic illnesses such as hypertension (DiMatteo, 2004a; Morris, et al., 2006). A search for studies that examined the relationship between race and chemotherapy adherence research in women with breast cancer is limited and offers inconsistent findings.

Research indicates that African-American women are more likely to be diagnosed and treated at a later stage of breast cancer than Caucasian women due to delays in the diagnosis and initiation of treatment (Gorin et al., 2006; Joslyn & West, 2000; Woodward et al., 2006). Patients who delay treatment have a 12% lower five-year survival rate (Richards et al., 1999). Evidence also reveals racial disparities exist in receipt of chemotherapy with African-American women are less likely to receive chemotherapy treatment when compared to their white counterparts after a diagnosis of a stage 1a or higher hormone receptor negative breast tumor (67% versus 78%; $P < .01$) (Bickell et al., 2006). A study with a small sample (n=28) and a rather homogenous (96% were black or Hispanic) sample found an overall adherence rate of 75% with aggressive multimodal therapy in locally advanced breast cancer (Berger et al., 1988). Another study of 51 participants with early stage breast cancer found non-adherent patients were of a significantly lower socioeconomic status, but the study did not report findings based on racial differences (Lebovits et al., 1990). However, Hershman et al found African-American women were more likely than Caucasian women to terminate intravenous chemotherapy treatment prematurely and were twice as likely to die as Caucasian women (2005). Only 68% of African-American patients, compared to 76% of Caucasian patients, completed all prescribed cycles of intravenous chemotherapy. Of the 270 Caucasian women in the study, 93% were still living 5 years after diagnosis, and of the 202 African-American women, 81% were living 5 years after diagnosis (Hershman et al., 2005). This study noted that it is the first study to find an association between early termination of chemotherapy and racial disparities in breast cancer outcomes. However,

more studies are needed to establish the relationship between race and chemotherapy adherence.

Age. The extent to which age is a predictor of adherence is unclear in the literature. Some studies report age to be individually associated with a greater effect on adherence and is a strong predictor of reported adherence in a population of chronic illnesses (Bardel, Wallander, & Svardsudd, 2007). Lower adherence rates were found in the younger populations with chronic illnesses versus higher adherence in the elderly population with chronic illness (Horne & Weinman, 1999). A possible explanation for this finding is older adults have a greater aversion to cost and increased readiness to seek medical care and less willing to "experiment" with their medication (Horne & Weinman, 1999). Conversely, adherence in the elderly can be compromised by a number of pre-existing medical conditions (Park, et al., 1999). When studying adherence rates in the elderly, the complexity of treatment regimens and the presence of co-morbidities must also be taken into account. As the complexity of treatment regimens increases, it becomes more difficult to incorporate recommended treatment into everyday life, which in turn has a negative effect on adherence rates. Medical conditions such as memory deficits and long and multiple treatments have been shown to be a barrier to adherence in the elderly (Griffith, 1990).

Age is a major risk factor for breast cancer. In the United States, the average age at diagnosis for breast cancer is 63 years old and most deaths from breast cancer occur in women older than 65 years old (American Cancer Society, 2012). Chemotherapy for elderly patients is a controversial issue in treatment for cancers (Desch, Hillner, Smith, & Retchin, 1993). Elderly patients are at an increased risk for chemotherapy toxicities such

as neutropenia, infection, mucositis, and cardiac toxicity (Repetto, 2003). These poor outcomes can impact the rate of adherence for elderly patients and can further aggravate poor outcomes. Empirical data show advancing age is significantly associated with longer delays in initiating chemotherapy treatment (Christman, Muss, Case, & Stanley, 1992; Grann, et al., 2006). A population study found women over the age of 75 years were less likely to receive or refuse chemotherapy for ovarian cancer (Cress, Malley, Leiserowitz, & Campleman, 2003). Several population studies found older age and an increase number of co-morbidities were correlated with adherence where women greater than the age of 50 years old had a significantly increased likelihood of an early termination in intravenous chemotherapy treatments (Hershman et al., 2005). Notably, non-adherence in the younger population is largely under examined in the literature. A recent study found that women of young age for breast cancer (i.e. those <40 years) were more likely to be non-adherent to oral hormonal chemotherapy (Hershman, et al., 2010). Young adults with breast cancer are a vulnerable group that faces medical, psychosocial, and economical challenges. Patients in this age range have the lowest health insurance, frequent delays in diagnosis, and low clinical trial accrual (Bleyer & Barr, 2009).

Access to care. Access to care consists of both physical access to treatment and financial access to treatment (i.e. health insurance). Physical access to care includes, but is not limited to the ability to have transportation to treatment centers. A lack of transportation is shown to be a barrier to adherence (Guidry, Aday, Zang, & Winn, 1997). Barriers such as distance to the treatment center, access to a car, and availability of someone to drive them to and from treatment centers can significantly impede starting and completing chemotherapy treatment (Guidry et al., 1997). In addition, financial

barriers such as insurance coverage delays or a lack of health insurance can impedes adherence to breast cancer screening and chemotherapy treatment (Duport, Ancelle-Park, Boussac-Zarebska, Uhry, & Bloch, 2008; Guidry, et al., 1996).

Access to care is also defined as having financial access to care and is most often influenced by socioeconomic status (Blacksher, 2008). Poor access to care has been linked to populations in lower socioeconomic status (SES) (Blacksher, 2008; Duport et al., 2008; Marmot, Friel, Bell, Houweling, & Taylor, 2008; Sabatino, et al., 2008), where SES has been shown to be associated with poorer survival outcomes in women with breast cancer (Fagerlin, et al., 2006; Franzini, Williams, Franklin, Singletary, & Theriault, 1997). Components of low SES such as low-income housing, low income, less educated, and lack of health insurance is associated with decreased adherence. People of low SES reported having more financial barriers to receiving care and greater difficulties navigating the managed care system than people of high SES (Rogowski, Freedman, Wickstrom, Adams, & Escarce, 2008).

There is extensive literature examining the role SES has on health, specifically breast cancer outcomes (Bradley et al., 2002). An early study (1981) of 900 women with breast cancer found the difference in survival between African-American and Caucasian women became insignificant when the comparison was adjusted for the distribution of socioeconomic status (p-value=.08) (Newman, et al., 2002). This finding suggests the observed differences in survival rates are largely due to distribution of socioeconomic status. Another more current study with a large population based sample (n=5719) found when controlling for race, age, marital status, and poverty level, African-American women did not have a statistically significant higher odds of dying from breast cancer

compared to Caucasian women (OR= 0.79, 95% confidence interval 0.57-1.09) (Bradley et al., 2002). This study showed that, regardless of race, low socioeconomic status is a risk factor for unfavorable breast cancer outcomes. On the contrary, a meta-analysis of 14 studies with a combined sample size of 10,001 African American and 42,473 Caucasian women evaluated the effects of socioeconomic status on mortality (Newman, et al., 2006). The meta-analysis found African-American race was a statistically independent predictor of breast cancer mortality even after adjusting for socioeconomic status. The analysis found the odds ratio for mortality in African-American women was 1.22 (95% confidence interval 1.13-1.30) when compared to Caucasian women (Newman et al., 2006). Therefore, research is still not clear if socioeconomic status is a significant variable that fully explains the negative outcomes seen in African-American women. Hence, it is difficult to draw steadfast conclusions about the role of SES onto breast cancer outcomes.

Despite the vast amount of literature examining the relationships between SES and breast cancer outcomes, relationships between adherence and SES are not extensively evaluated in oncology patients receiving chemotherapy treatments. Similar studies have shown low-income women were more likely to have poorer adherence rates to radiation therapy for ovarian cancer when compared to the national average (16% versus 63%). Low-income women were also more likely to discontinue or interrupt radiation therapy for nonmedical reasons (Formenti, et al., 1995). Another small self-report study found that SES was not related to oral chemotherapy adherence in women with breast cancer (Murthy, Bharia, & Sarin, 2002). However, this study was performed in India and these results may not apply to the United States.

A thorough review of the literature indicated that studies that connected SES and adherence to chemotherapy is largely limited. There is a growth of literature that examines the role race plays in predicting adherence to cancer therapy (Andic et al., 2010; Hershman et al., 2005; Hershman et al., 2010) but these studies fail to examine or adjust for socioeconomic status. Yet, it is important to note, that many factors that determine socioeconomic states are closely related to race. Minority groups make up a majority of the lower socioeconomic status in America, so it is hard to tease out the effects of poverty from the effects of race (Ingram, et al., 2003).

Social Interaction

Social interaction includes the woman's social mechanisms such as her formal and informal social networks and religious coping.

Social support. Social support is a multidimensional construct defined as the quantitative and qualitative aspects of a network of individuals that provide instrumental, emotional, and informational support to another individual (Bloom, 1982; Nausheen, Gidron, Peveler, & Moss-Morris, 2009). Social support has a positive effect on disease management and well-being (Bloom & Spiegel, 1984; DiMatteo, 2004a). Social support plays a central role in alleviating the impact of stress and facilitating coping in the presence of an illness (DiMatteo, 2004a). Bourjolly and Hirschman (2001) found social support was the most commonly used coping strategy for women with breast cancer. A network of support is shown to influence decisions about treatment and helps validate an individual's choices (Bloom, 1982). When faced with a new diagnosis such as breast cancer, a system of support can reduce the sense of isolation and ease the fear of uncertainties that accompany the diagnosis and treatment sequence (Bloom, 1982).

Emotional support is also beneficial in providing assurance and adjustment to the cancer diagnosis as well as to other types of chronic illness. A network of support offers the patient undergoing the diagnosis and treatment of breast cancer a means to feel accepted and reduces the feelings of isolation and loneliness and thus buffering the stress impact of the cancer experience (Bloom, 1982).

Social network impacts health behavior such as disease management and adherence to medications for chronic illnesses (DiMatteo, 2004a). Social support facilitates individuals to seek medical care and those with a larger support system have been found to be diagnosed earlier and have a better prognosis (DiMatteo, 2004a). Social support is instrumental to helping individuals adhere to treatment regimens; for example, a meta-analysis of 122 studies found practical support to bear the highest correlation with adherence. The risk for non-adherence was almost twice as high among patient who did not receive practical support as among those who did (DiMatteo, 2004b). In another example, the odds of adherence were almost twice as high (OR= 1.38) in adults who lived with others than in adults that lived alone. The results from DiMatteo's meta-analysis demonstrate the compelling link between social support and adherence, yet a majority of these links were drawn from the well-developed HIV, anti-hypertensive, and diabetes adherence literature (2004a). There is a gap in the literature that formally examines how social support affects adherence in the context of intravenous chemotherapy treatment.

The study's theoretical model purports several demographic variables may interact and influence the quality and quantity of an individual's network of social support. For example, there is an inverse relationship between age and social network

where social network declines as age increases (Pinquart & Duberstein, 2010). The support needs of the elderly are increased due to their growing number of co-morbidities thus increasing the elderly risk for insufficient sources of support (Goodwin, Hunt, & Samet, 1991; Pinquart & Duberstein, 2010). Ethnic differences also exist in the patterns of social network that may impact treatment decision-making to adherence. These differences in styles and sources of social support also have an impact on how a woman copes with the breast cancer diagnosis.

Coping. Coping with cancer requires help from others, where patients need a satisfying network of interpersonal relationships (Redelmeier et al., 1993; Revenson & Pranikoff, 2005). Coping is an important concept to decision-making where effective coping has been shown to be influential to treatment decisions and help individuals adhere to medical regimens (Revenson & Pranikoff, 2005). Bourjolly and Hirschman (2001) report seeking social support is the most commonly used coping strategy for African-American and Caucasian women with breast cancer. Socioeconomic variables such as race can influence a woman's coping sources and styles. Sources of social support differ between African-American and Caucasian women, where African-American women rely more heavily on God for support through the breast cancer experience and Caucasian women report relying more on their husband or partner for support (Bourjolly & Hirschman, 2001).

Caucasian women are more likely to report spouses, children, relatives, and friends as important sources for support and coping (Guidry et al., 1997). Particularly, spouses have been found to exert considerable influence on treatment decision-making and have a significant impact on adherence. In fact, DiMatteo's meta-analysis (2004)

found that married individuals were 1.38 times more likely to adhere to medical regimens than unmarried counterparts. Ideally, spouses can offer both practical (i.e. child care and transportation) and emotional support during acute and/or a chronic illnesses. Married women are more likely to be diagnosed with breast cancer at an earlier stage and are at a decreased risk of death when compared to unmarried women (Osborne, Ostir, Du, Peek, & Goodwin, 2005). It is suspected Caucasian women are more likely to report the social, physical, and emotional resources needed to cope with the breast cancer diagnosis than African-American women. Although, there are no studies that connect this claim, it is suspected better coping may influence the decision-making to treatment adherence in women with breast cancer.

Despite the most prevailing coping mechanism used by Caucasian and African-American women with breast cancer is social support, ethnic differences exist in the structure and function of their social support. African-American women are less likely to be married at the time of diagnosis of breast cancer and less likely to report support from their spouse as a coping strategy (Bourjolly & Hirschman, 2001; Osborne et al., 2005). Interestingly, married African-American women are even more likely to report God rather their spouse as a significant means of support (Bourjolly & Hirschman, 2001). Despite an emphasis on the extended family, African-American women are more likely to report a less supportive network of family and friends (Henderson, Gore, Davis, & Condon, 2003) and have smaller social networks than Caucasian women (Magai, Consedine, Adjei, Hershman, & Neugut, 2008). Conclusions from a meta-analysis of social support and adherence suggest that it is not the presence of family and friends but the quality of the relationships that have a greater impact on well-being and coping

(DiMatteo, 2004a). Studies further show that persons with few sources of support have a higher cancer death rate and this association is stronger for African-American women presenting with late stage disease. Given the evidence of the lack of quality support available to African-American women and the consequences of non-supportive social networks it is speculated that African-American women are more at risk for maladaptive coping which can impact treatment decision-making.

During a stressful breast cancer diagnosis, African-American women have an increased likelihood to draw from her social networks and have a strong reliance on a higher being as a coping strategy (Bourjolly & Hirschman, 2001). Religion and prayer play a vital role for African-American women coping with breast cancer (Henderson et al., 2003). Historically, church has played a significant role in the lives of African-Americans as a form of support system. Religion can be used a form of positive religious coping where satisfaction with the church and a spiritual connection with God or a higher being is linked to positive outcomes such as increased well-being and quality of life (Pargament, et al., 2000). Studies have shown religion and prayer provide African-American women with hope and the ability to live a positive life in the face of a breast cancer diagnosis (Henderson et al., 2003; Holt, Lukwago, & Kreuter, 2003; Simon, Crowther, & Higgerson, 2007). Furthermore, in regards to health, God is seen as a healer where prayer and faith can help alleviate or cure illnesses (Bourjolly & Hirschman, 2001). However, African-American women are reported to be more reluctant to discuss the use of religion out of fear of offending other individuals not of their faith (Bourjolly & Hirschman, 2001; Henderson et al., 2003). It is suspected the lack of recognition of faith can interfere with decision-making and can compromise attitudes towards treatment

adherence. Furthermore, African-American women with limited access to healthcare may have a greater reliance on God and religion for coping and as a means for healing. These attitudes may have a significant influence on decision-making in the context of adherence to chemotherapy. However, no study has directly examined how social interaction variables relate to adherence decision-making in a racially diverse group of women diagnosed with breast cancer. In addition, the extent to which African-American women with breast cancer rely on religion to a greater degree than Caucasian women is unknown (Bourjolly & Hirschman, 2001).

Breast Cancer Knowledge

A woman's knowledge of her breast cancer diagnosis has been associated with greater involvement in the decision-making process and better outcomes such as better functional and physical well-being, and greater patient satisfaction (Moyer & Salovey, 1998). Higher levels of knowledge about breast cancer have been shown to be associated with improved survival outcomes (Goodwin, Samet, & Hunt, 1996) where the women must rely on her knowledge of treatment options to make important decisions regarding her treatment (Chen, Diamant, Thind, & Maly, 2008). Patient knowledge increases understanding that enhances the ability to actively participate in the decision making process for medical care and disease management. A lack of knowledge about breast cancer and treatment is related to non-adherence to breast cancer screenings and oral cancer therapy (Loehrer, et al., 1991). A breast cancer diagnosis consists of an exchange of an overwhelming amount of information coupled with unfamiliar medical terms. Low levels of cancer knowledge may put an individual at risk of being less involved in treatment decision-making and the woman may not be aware of the benefits to treatment.

This in turn may put a woman at risk for making uninformed decisions about her cancer treatment.

Socio-demographic factors can influence the extent of breast cancer knowledge in women. Generally, younger women, Caucasian women and those with some college education are more knowledgeable about breast cancer risk factors, symptoms, detection methods, and treatments (Darrow, Schoenfeld, Cummings, Wilkes, & Madoff, 1987). African American women or women with less education are shown to be less likely to be knowledgeable about breast cancer treatment compared to Caucasian or more educated women, when controlling for age and stage of cancer (Fagerlin et al., 2006). Furthermore, low income and medically underserved women may be at risk for lower knowledge of breast cancer because of a lack of resources and lower educational levels with concomitantly lower health literacy, which could jeopardize appropriate treatment decision-making and survival outcomes (Chen et al., 2008). More research is needed to formally examine the relationships between lack of breast cancer knowledge and treatment decision making to chemotherapy adherence in an ethnically diverse group of women diagnosed with breast cancer.

Cancer Experience

The cancer experience includes treatment side effects and depression.

Side effects. Intravenous chemotherapy improves survival rates; however, not without adverse physical and emotional effects. Distressing physical symptoms can have a significant influence on long-term treatment decisions (Revenson & Pranikoff, 2005). Recommended chemotherapy treatment for breast cancer can be physically overwhelming to women and impacts quality of life (Payne, Medina, & Hampton, 2003).

Adverse side effects are the most common and established predictor to medical adherence to a myriad of chronic illnesses such as HIV, diabetes, and cancer (Heath et al., 2002). Several studies found side effects to be the most frequently reported reason for early discontinuation to women taking oral hormonal chemotherapy (Atkins & Fallowfield, 2006; Grunfeld, Hunter, Sikka, & Mittal, 2005; Lash, Fox, Westrup, Fink, & Silliman, 2006). Patients will alter their treatment to that not recommended by their healthcare provider to increase coping and to ameliorate symptoms (Heath et al., 2002). Depression, pain, fatigue, and hair loss are the most common distressing side effects experienced by women treated with intravenous treatment for breast cancer (Boehmke & Dickerson, 2005; Jacobsen, et al., 1999). These side effects threaten functioning, well being and quality of life (Arndt, Stegmaier, Ziegler, & Brenner, 2006; Badger, Braden, & Mishel, 2001; Boehmke & Dickerson, 2005; Jacobsen et al., 1999; Payne et al., 2003).

Breast cancer knowledge plays a role to the experience of side effects. Knowledge deficits impact how a woman diagnosed with breast cancer copes with symptoms from chemotherapy. Patients receiving little information about self-care tips reported more side effects during chemotherapy. Furthermore, patients that were provided with education about self-care behaviors used them earlier versus patients that were not provided this information (Schreier & Williams, 2011). Patients that were not provided with education about self-care behaviors to alleviate symptoms distress were more likely to experiment (i.e. eat less to alleviate vomiting) and rely on personal experiences and health beliefs to cope (Schreier & Williams, 2011). It is suspected knowledge deficits in regards to self-care to side effects increase symptom distress, thus impacting decision-making in the context of adherence.

Despite the large body of literature that establishes adverse side effects as a predictor to adherence in chronic illnesses, gaps in the literature still exist. Symptom distress and adherence have been examined extensively in women taking *oral* chemotherapy for breast cancer. Additionally, there is little literature that addresses the symptom experiences of African-American women and how the symptom experience may or may not differs with Caucasian women. For example, a small study found that African-American women are also less likely to seek treatment out of fear the side effects from cancer treatment will alter their body image and change their relationship with men (Payne et al., 2003). There is a large gap in the literature that examines relationships between symptom distress and adherence to intravenous chemotherapy. This area of research is largely un-navigated and is in need of research that explores relationships between side effects and adherence in women receiving intravenous chemotherapy.

Depression. It is noteworthy to describe in detail the role depression plays in the breast cancer experience and treatment adherence. Depression is the most common psychosocial side effect in women with breast cancer and poses a threat to well-being, functioning, quality of life, and survival (Reich, Lesur, & Perdrizet-Chevallier, 2008). A study of breast cancer patients found depressed women had a significantly decreased likelihood of survival (Groenvold, et al., 2007). It is predicted the decreased odds of survival in depressed cancer patients is related to adherence (Groenvold et al., 2007). Adherence is thought to be a mediator to the relationship between survival and depression due to depressed patients are less likely to be motivated to adhere to treatment regimens, which can affect mortality and morbidity. In fact, depression has been identified in several studies as a significant predictor to non-adherence to medical

treatments (Grunfeld et al., 2005; Heath et al., 2002; Lash et al., 2006). A meta-analysis of 12 studies that examined the influence of depression on adherence to medical treatments revealed a substantial relationship between depression and non-adherence with a statistically significant odds ratio of 3.03 (DiMatteo, Lepper, & Croghan, 2000). Thus, depressed patients are three times more likely to prematurely discontinue a treatment regimen than non-depressed patients.

It is predicted depression involves physiological, behavioral, and emotional interactions in the case of cancer (DiMatteo et al., 2000). For example, depression may contribute to poor adherence by making individuals more sensitive to treatment side effects (DiMatteo et al., 2000). A study of women with breast cancer found depressed women were more likely to report concomitant symptoms such as anxiety, fatigue, and difficulty concentrating. These women also perceived a greater number and more severe side effects than women who were not depressed (Badger, Braden, Mishel, & Longman, 2004). Increased symptom severity creates a slippery slope where patients become frustrated and more depressed and decrease the desire and ability to act upon treatment recommendations. Adherence to treatments then becomes futile where quality of life, health outcomes, and survival are ultimately compromised.

Depression impacts cognitive processes and affects patients' knowledge and understanding of their cancer treatment (Mystakidou, et al., 2005). A breast cancer diagnosis requires the patient to process and integrate a great deal of information about her diagnosis and treatment options. Emotional distress has been found to interfere with processing information accurately where forgetfulness of medical information is increased (Mystakidou et al., 2005). Increased forgetfulness coupled with a decreased

motivation to follow recommended treatments can influence the belief that adherence is not beneficial and not worth the trouble. Adherence to treatment requires patient motivation and beliefs that support behavior that is congruent with adherence (Mystakidou et al., 2005). However, depression undermines these beliefs and threatens motivation to adhere to treatment. Depression elicits pessimism and an avoidant style of coping, which leads to social isolation and decreases access to sources of social support (DiMatteo et al., 2000). Side effects, especially depression, compromise physical, emotional, and cognitive functioning and contribute to premature discontinuation of treatment and ultimately causing adverse outcomes (DiMatteo et al., 2000).

Cancer-Specific Health Beliefs

Patients make deliberate decisions about their health based on their beliefs about their illness and its treatment (Wroe, 2002). Health beliefs are important in influencing patients' attitudes toward their decision to cooperate with treatment regimens (Eraker et al., 1984). Health beliefs such as perceived susceptibility and perceived benefits have an impact on treatment decision-making and health behaviors. For example, African-American women believe several aspects of breast cancer are not in their control where God decides who develops breast cancer and who is cured from breast cancer (Barroso, et al., 2000). These health beliefs reflect a lack of control and self-efficacy to prevent, detect, or even help cure breast cancer. Furthermore, a study of 1,229 African-American and Caucasian women found women who report a low susceptibility or low likelihood to develop breast cancer were almost 3 times more likely (OR= 2.98, CI 1.51-5.30) to non-adherence to screening guidelines for mammography recommendations (Calvocoressi, et al., 2004). In addition, perceived benefits have an impact on an individual's behaviors.

If a woman views the benefits of getting screened early and being diagnosed at an early stage can increase chances of survival, adherence to mammography screenings is increased (Champion & Menon, 1997). In theory, the same health beliefs can have an impact on adherence to chemotherapy treatments despite the lack of evidence to support this claim.

There are racial differences related to the cancer specific health beliefs of breast cancer between African-American and Caucasian women. For example, African-American women are more likely than Caucasian women to have a fatalistic view of breast cancer where they are more likely to believe medical interventions will not make a difference in survivability (Lannin, Mathews, Mitchell, & Swanson, 2002; Powe, 1995a; Soler-Vila, Kasl, & Jones, 2005). Another cancer-specific health belief in African-American women is their lack of confidence in surgery as being therapeutic (Lannin et al., 2002; Loehrer et al., 1991). African American women believe cutting into cancer or exposing it to air will actually cause the cancer to spread (Lannin et al., 2002; Loehrer et al., 1991; Soler-Vila et al., 2005). Additionally, African-American women are more likely than Caucasian women to believe that the treatment to breast cancer is worse than the disease itself (Davis, Emerson, & Husaini, 2005). Lastly, African Americans are more likely than Caucasian women to believe alternative treatments such as herbs, medicines, or chiropractic are effective treatments for breast cancer versus medical interventions (Lannin et al., 2002; Loehrer et al., 1991).

Cancer-specific beliefs can predict adherence and survival rates as well (Soler-Vila et al., 2005). Solar-Villa et al. (2005) found that the belief of cancer incurability is significantly associated with survival in a cohort study of 423 African American and

Caucasian women diagnosed with breast cancer. Patients who believed that their cancer is curable experienced a better prognosis than their less optimistic counterparts (Soler-Vila et al., 2005). There is limited research on specific health beliefs African American women have about chemotherapy treatment and how this may relate to adherence to treatment, but it is predicted in this study that health beliefs and cancer specific perceptions are related to adherence to chemotherapy treatment.

Summary

This chapter presented an extensive review of the literature in regards to factors related to adherence decision-making and interrelationships that were found to exist between socio-demographic variables, social interaction factors, breast cancer knowledge, the cancer experience, and specific health beliefs. The study's theoretical framework provide a guide to explore how these variables may play a role in predicting adherence in women with early stage breast cancer. This review of literature revealed many gaps in the literature that specifically assessed the nature and extent of the relationship among the study's proposed variables and chemotherapy adherence. Due to gaps and inconsistencies in the literature, the proposed study aims to describe the factors that influence the decision to stop or continue intravenous chemotherapy treatment in women with breast cancer with early stage breast cancer and how these factors differ between races.

Chapter III

BREAST CANCER: A FEMINIST PERSPECTIVE

The integrity of modern medical science rests on a reputation that scientific knowledge derives from scientifically sound research and rigorous (and ethical) clinical experimentation. Scientists claim biomedicine is a value-free discipline that is led by objectivity and statistical computations. However, a close examination of the biomedical field reveals a science that is greatly influenced by outside forces and often reflects the social and political atmosphere of its time. This chapter aims to present a unique perspective to the study of women and breast cancer. A feminist lens will be used to examine how ideological discourses in social environments construct the meaning of breast cancer and women's health. Sexism and racism that is pervasive in science will be uncovered and dissected to reveal the power structures that are involved in how women experience breast cancer.

History of Women's Health

Historically, the standards of medicine are derived from standards established by white males. Early clinical studies commonly studied the experiences of white men and used their experiences as a reference point to establish medical standards and practices. Up to the 1980's, women, minorities, and children were virtually invisible to researchers and clinicians, which reinforced a social hierarchy that placed white men at the center of focus (Epstein, 2007). The exclusion of these populations was a reflection of gender and race relations of that time. As early as the 13th and 14th centuries, women's health was pathologized and was viewed as an inherently unhealthy and inferior deviation from the

male norm (Green, 2008). Scientists set out to explore the experiences of men and very seldom explored those of women and dealt with issues in women's health with a "hands off" attitude. When scientists did examine the bodies of women, they were interested in her sexual traits- feminine beauty, shape and size of the lips, size and shape of her breasts, size and shape of clitorises, sexual desire, fertility, and her pelvis (Green, 2008; Schiebinger, 1993). Male involvement in women's health rarely extended beyond intervening in cases of menstrual difficulties, a few uterine conditions, and in few cases of difficult child birth (Green, 2008). Essentially, the health of women was centered on her reproductive organs. Ultimately, the size, shape, and position of the pelvis emerged as the universal measurement of womanliness (Schiebinger, 1993). For example, Monica Green highlighted the works of an early textbook, *Treatments for Women,* which described several sexist treatments and remedies for diseases inflicting women such as

> for pain after birth, inserting a long digression… on how the uterus delights in holding and retaining the foetus, mourning when it looses it…[and] based on its anatomy, the uterus is so desirous of intercourse (2008, p. 83).

These early works reveal how women were viewed as subordinate and sexualized bodies, which dictated how medicine examined women. These views of women continued throughout the 18th and 19th and better parts of the 20th centuries, where men remained the cornerstone for human anatomy (Schiebinger, 1993). The standardization of the male body privileged the male body over the female body. This male bias overshadowed the health of women and forced women into an invisible population.

Modern Medicine and Women

Modern medicine eventually evolved into a science that based its standards of care on scientific proof and evidence based practice. Modern medicine based its practices from findings collected from rigorous clinical trials. Clinical trials became the standard for medical research and drug development. Scientists argued clinical trials offer unbiased and statistically supported data that can universally applied to the general population (Epstein, 2007). However, a closer examination reveals clinical trials were also influenced by a political agenda that introduced a problematic bias in the foundation of medicine. The evolution of clinical trials and human experimentation led to many reforms and government protocols to ensure human subjects were ethically protected and not placed at undue risk of harm. Under this new regime, certain populations were deemed vulnerable to undue harm and were placed under protection. This led to certain 'at-risk" populations (i.e. institutionalized persons, children, and the poor) to be omitted or underrepresented in clinical trials. These new reforms inadvertently introduced problems into the new generation of biomedicine. Vulnerable populations, such as women, were once again found to be unaccounted for in the new standard of measurement and standardization of medicine (Epstein, 2007).

Disguised as a means to protect women and children, the Food and Drug Administration (FDA) formally instituted a rule that pushed women into a medically invisible population. A report, *General Considerations for the Clinical Evaluation of Drugs,* released by the FDA in 1977 explicitly stated women of childbearing age should be excluded from clinical trials. Women of childbearing age were defined as premenopausal women that have the potential of becoming pregnant. This definition

included women that were on oral, injectable, or mechanical contraception, single women, and even married women whose husband has been "vasectomized." However, the FDA did permit female prisoners the opportunity to participate in clinical trials due to the likelihood of pregnancy was non-existent in this population. Lastly, the FDA issued report recommended women in mental institutions to be omitted from clinical trials due to their risk of becoming pregnant as well (The Food and Drug Administration, 1977). Essentially, women were denied inclusion from research due to the unpredictability of their hormones and risk of pregnancy. Excluding women from research also excludes women from receiving the same benefits that may have emerged from; thus jeopardizing the state of women's health.

The politics of inclusion molds scientific knowledge and practice. For example, the results from the famous Framingham Study are still used today to guide the assessment of risk factors for developing heart disease (Gordon, Castelli, Hjortland, Kannel, & Dawber, 1977). The prospective study started in 1948 and continued for 50 years and studied a homogenous community in Boston. The study essentially consisted of thousands of white, mid-age, and middle-class males and virtually no blacks, Asians, low-income individuals, and women. Data from the study had a profound impact on the development of a standard tool using blood pressure, cholesterol, physical activity, smoking, and body mass index to assess the risk for developing heart disease. Due to the lack of representation of women in the study, researchers fail to see that heart disease has a different manifestation in women. It is now evident that heart disease in women follows a different disease progression than seen in men (Milner, et al., 1999; Wenger, 2002). Women tend to develop heart disease later in life. In addition, symptoms of heart disease

typically present itself differently in women where women seldom experience the classic crushing chest pain commonly seen in men. Women experience more silent symptoms such as nausea, shoulder tension, and dyspnea (Milner et al., 1999; Wenger, 2002). Research that examines heart disease, cancers of non-reproductive organs, and diabetes in women are largely ignored and under-researched. The lack of attention to issues that affect women have subjected women to late and misguided treatment as in the case of heart disease in women. The lack of representation of women in the Framingham study demonstrates subtle gender biases that impact women's health. The lack of women in research put women at risk for poorer health outcomes such as under-diagnosis or missed diagnoses (Fosket, 2000).

As clinical research becomes more scientifically grounded and more central to modern medicine, it is important to analyze who gets studied and who gets ignored. However, Steven Epstein (2007) writes that the "inclusion and difference paradigm" may cause more harm than benefit. It creates profiling and reinforces the historical notion of difference versus equality (Epstein, 2007). Yet, it is apparent that male bias operates as in implicit element in scientific schools of thought. These complexities are relevant and significant to the quality of women's life. The following section will transition to specifically examine the breast cancer experience of women while using the same feminist lens. This will uncover that breast cancer is not just a biological disease that impacts women but also a disease that is entrenched with political and social values.

The Construction of Breast Cancer

Healthy, non-diseased breasts are iconic of female sexuality and have long been the center of attention and infatuation with the woman's body. Not just deposits of fatty

tissue, ducts, and glands, breasts are indicators of the current political atmosphere and greatly influenced by political and social forces. Historically, breasts have been seen as the 'crown jewels of femininity- ornaments of sexuality' (Yalom, 1997). The view of breasts is based on the culture and politics of the environment in which the owner of the breast lives. Across different cultures, breasts do not take on the same sexualized meaning that it has in the West. Non-Western cultures have their own infatuations- small feet in China, the nape of the neck in Japan, and buttocks in Africa (Yalom, 1997). The historical perspective of the breast has been taken hold by the Western imagination, as the representation of breasts evolved from nourishment, motherhood, sexual, and commercialization.

The contextual meaning of breasts is not stagnant and has changed over time. In early pre-agricultural time, the image of maternal breasts was idealized for its epitome of femininity. Breasts in its maternal function were seen as a source of nourishment and life (Yalom, 1997). Breast milk represented life or death for an infant and was the corner stone for humankind to continue. The desexualized breast was worthy of reverence due to its ability to deter death through lactation. The turn of the Renaissance marked a turn in knowledge and ways of thinking (Yalom, 1997). Breasts evolved into an object to be desired that brought idealized pleasure instead of life and nourishment. Breasts became eroticized and their sexual meaning eventually overshadowed the maternal and domestic meaning. The male point of view eroticized, "sexualized and commoditized for the male gaze and masculine consumptions …and conceptualized in terms of reproductive potential" (Saywell, Henderson, & Beattie, 2000, p. 39).

Maureen Casamayou states, “breast politics have emanated from a wide spectrum of governmental, economic, religious, and healthcare sources- all traditionally male dominated institutions, not known for putting women’s interests at the top of their priorities” (2001, p. 44). Breasts have long been placed on a sexual pedestal. With the emergence of breast cancer, it is no surprise that Western society will not let this disease kill its women or most importantly, her breasts. Disease is socially constructed and socially maintained (Fosket, 2000). Breast cancer crosses medical realms and enters social realms where culture, economic, symbolic, and gendered constructs frames the many cultural and social meanings of cancer. Breast cancer has always been around and affecting the lives of millions of women, but the attention to breast cancer evolved due to its connections with the changing social and political climates. Breasts were seen as a powerful symbol of femininity and female identity tied in with female sexuality. For many decades, breast cancer was associated with fear and shame due to cancer’s life threatening mutilation to the breasts. The “male engendered breast vaunting” culture also added to the emotional pain of losing a breast cancer (Casamayou, 2001, p. 45). This view began to slowly change over the decades. The 1960s feminist revolution, the increased health consciousness of the 1980s, and the legacy of the feminist movement in the l980s helped diminish the taboos related to discussing breast cancer openly and the doors to activism and media representation were opened (Casamayou, 2001).

Breast cancer is not the number one killer of women (this position belongs to heart disease) nor is it the number two killer of women (this belongs to lung cancer) in the United States. Breast cancer is the third leading cause of death of women in the United States. Yet, breast cancer is one of the most researched, well funded, highly

advocated, and commercialized disease that affects women (Casamayou, 2001). The breast cancer campaign is the most visible and successful public health campaign that secures millions of dollars in funding annually (Casamayou, 2001). Breast cancer's highly visible media and commercial representation is a reflection of Western society's infatuation with the breast. The breast cancer movement is a campaign that is concerned with saving the breast instead of saving the woman. Breast cancer is seen as a grotesque disease because the disease threatens and mutilates the breasts. Cancerous breasts threaten the idealized femininity and erotication of the woman's body. This viewpoint is especially reflected in the over-sexualized and fetishized imagery and narratives of breasts presented in the public and private sectors, as well as mainstream culture (Saywell et al., 2000).

The breast cancer awareness campaign is the most visible and successful public health campaign that secures millions of dollars in funding annually (Casamayou, 2001). The use of unprecedented resources, such as countless charities, publicity, and the very successful pink ribbon campaign, has been used in the war against breast cancer. Breast cancer research soon became a multi-billion dollar industry. The National Cancer Institute (NCI) spent $81 million in breast cancer research in 1991 compared to $65 million for lung cancer (Breast Cancer Action Group, 2009). By 2007, the NCI funneled almost five times more the 1991 level where $572.4 million was used for breast cancer research while the National Institutes of Health (NIH) spent an additional $705 million in the same year (Breast Cancer Action Group, 2009). The Susan G. Komen for the Cure Foundation reported investing nearly $1 billion in breast cancer since its founding in 1980 and $270 million in total revenues in 2010 (Susan G. Komen for the Cure, 2012).

Interestingly, only 15% of this revenue went to promoting breast cancer screening efforts and 7% went towards funding treatment in uninsured women with breast cancer.

The commercial sector also saw a window of opportunity to capitalize on the breast cancer movement as well. When a corporation wants to signal their product is woman friendly, they usually strategically place a pink ribbon on the product and claim a portion (usually an unnamed amount) will be donated to breast cancer research. Additionally, breast cancer is presented as a "sexy" disease where the media focuses a disproportionate representation of young women's bodies. Breast cancer is commonly diagnosed in post-menopausal women. However, younger and "youthful" sufferers of breast cancer represent many images of breast cancer. The media attempts to save the desirability of the breast by covering breast cancer in terms of its sexual potential. Saywell et al explains, "because it occurs in that iconic lump of flesh- both erotic and maternal- [breast cancer] brings the sexism in women's health issues to the surface (2000, p. 44). It seems the breast cancer movement that empowered women a decade ago was replaced with a pink ribbon culture that focuses on a female identity that is defined by breasts. No organization would even dare try to make any of the other disease, i.e. heart disease or lung cancer, into a "sexy disease."

The infatuation with breast continues into the doctor's office, as millions of couples decide whether or not to surgically remove a woman's breast in hope to cut out the cancer. While on the surface, giving up one's breast in order to increase one's survival rate seems like a logical plan, yet millions of women have difficulty undergoing life-saving mastectomy. When a woman decides to give up her breast, masking her surgery with prosthesis or undergoing major reconstructive surgery is expected and

commonplace. This suggests a woman's self-worth is connected to her breasts; a woman without her breasts seems to be less of a woman. Essentially, the breast cancer awareness campaign went from saving the woman to saving the breasts.

Audre Lorde carried multiple identities- black, lesbian, feminist, and warrior poet- and was the voice for women with breast cancer in her autobiography, *The Cancer Journals* (1997). In *The Cancer Journals*, Lorde broke the silence surrounding breast cancer and voiced her pain, grief, and fear related to her own diagnosis (1997). Lorde describes a woman's breasts as the index to which society values women and "as decoration and externally defined sex objects" (1997, p. 62). The heteronormitve standard of beauty enforces the use of breast prostheses to hide and normalize the woman's post-mastectomy (one-breasted) body. However, after her mastectomy, Lorde refused to wear her breast prosthesis and accepted her one-breasted body despite being viewed by society as distorted and disfigured. She argues breast prostheses silence the woman and keep the post-mastectomy woman "in a position of perpetual and secret insufficiency, infantilized and dependent for her identity upon an external definition by appearance" (1997, p. 59). Lorde urges one-breasted women to break the silence and invisibility and become visible to each other and come to terms with their own loss and pain and to reclaim their self-image. After the mastectomy, silencing a woman during her physical and emotional recovery can have two negative effects: (i) women are denied the chance to come to terms with her new body where her body will remain alien to her, masked with prosthesis. She mourns the loss of her breast in secrecy and forced into silence and invisibility; and (ii) it forces women to narrowly think the biggest concern post-recovery is to conceal her scar and to normalize her outward appearances (Lorde, 1997). This

concern ignores the bigger necessity for "nutritional vigilance and psychic armament that can help prevent recurrence (Lorde, 1997, p. 59). Every woman should view her breast as a sign of victory where only her breast was removed and not her femininity or identity. She is not less of a woman but, in fact, a warrior where her scar resulting for the mastectomy should be seen as an honorable wound (Lorde, 1997).

The Other Body: Analysis of Black Women's Bodies

It is evident sexism is laced in our society where sexist ideology found a way to frame the field of biomedicine. Western society is built on a system of hierarchies where certain groups are viewed as either superior or inferior. Women are not the only group that has been historically oppressed. Minorities, specifically African Americans, endured a long history of overt and covert societal racism. Racism permeated society and found its way to impact politics, economics, the judicial system, and the "value-free" hard sciences. Being female in Western society presents itself with unique biases and complexities of power structures. Being African American in this society also presents itself with separate and distinct biases and complexities of power structures. When sexism and racism collides, the intersection creates a third space that is attached with another set of unique experiences and biases. A look into the health of African American women reveals profound evidence of how the product of racism and sexism is pervasive in the fields of medicine.

Historically, the desired bodies were those of white European women. Women of African descent did not fit the definition of femininity, beauty, and purity. Black women's bodies were seen as inferior, animalistic and subhuman and were forced to perform hard labor next to black men (Schiebinger, 1993). Historians suggest by the 19th

century conceptions of inferiority and racial difference became entrenched in medical practice and led to human experimentation on slaves (Epstein, 2007). An infamous case that displays the poignant exploitation and complete disregard to black women's bodies is the gynecological experimentations performed on slave women by Dr. J. Marion Sims. Dr. Sims, the "father of gynecology," experimented and perfected a revolutionary surgical procedure to treat vesico-vaginal fistula (Sartin, 2004). Dr. Sims performed about 30 surgeries on unconsenting and powerless black women. Despite the availability of anesthesia at this time, Dr. Sims performed all his surgeries on black women without the use of any anesthesia. It was believed at that time the "subhuman" characteristics of slaves caused them to not feel pain. The societal organization of power, control, and complete disregard of black women's bodies is quite evident in this example.

The bodies of black women were viewed as a perversion to sexuality and believed to embody promiscuity (Schiebinger, 1993). Europeans fantasized of the sexual and fecund African women where African women were often sold as prostitutes or concubines. Another glaring example of the hyper-sexualization and exploitation of black women is the legends of Sara Baartman, pejoratively known as the Hottentot Venus. Sara Baartman spent years in Europe displayed, where her "alluring and primitive" body attracted on-lookers by the hundreds to peer at the "paradoxical freak of race and sexuality" (Crais & Scully, 2009). Sara Baartman was a reflection of Western imagery of black women and their sexuality- "a primitive woman with extremely large buttocks… and remarkable sexual organs" (Crais & Scully, 2009, p. 2). The "Hottentot Venus" was the symbol of Western perceptions of black women: sexual, primitive, and inferior. A French professor, set out to examine Baartman's body, provided a report in

great detail and length that justified her body was more ape than human and was the representation of another sub-species of humans (Schiebinger, 1993). Another memoir of Baartman provided nine of the sixteen pages describing her breasts, genitalia, and buttocks (Schiebinger, 1993). The societal perception of black women is evident of how race, gender, and sexuality are reflected in the scientific community.

The Other Breasts: Breast Cancer and Black Women

European women were often depicted with supple and firm breast, desired and cherished in the European culture. However, the breast of African women did not hold the same meaning. African women were depicted in European literature with exaggerated sagging and pendulous breasts (Schiebinger, 1993). Sagging breasts in European culture were a sign of old age, undesirability, witchcraft, savagery, and impurity (Schiebinger, 1993). The breasts of African women were depicted to be nothing that was desirable or valued. The effects of mistreatment and disrespect of black bodies and breasts still linger today and manifest as racial disparities. As described in the previous chapters, African-American women are disproportionately more likely to die from breast cancer when compared to their white counterparts. The documentation of this phenomenon sparked a plethora of research studies that aimed to identify the underlying factors that explain the widening mortality gap between African-American and Caucasian women diagnosed with breast cancer. However, no study in scientific literature fully answers the question to the survival and mortality disparity observed between African-American and Caucasian women. In fact, more questions than answers are created. Despite millions and perhaps billions of dollars pumped into breast cancer research, why do African-American breasts not benefit from the movement? Why are the

breasts of African American women placed in a space of the "other"? Are the historical effects of racism and sexism still active and persistent in African-American women? These unanswered questions are a reflection of the value Western society places on African-American women and their bodies. Black breasts occupy a space of "other" and are seen not desirable and valued enough to be saved from the threat of breast cancer.

Women's Bodies and Healthcare

The previous sections introduced and dissected how gender and race bias is built into healthcare and in the context of breast cancer. The gendered, racial, and medicalized view of women's experiences assumes proprietorship over women's lives and bodies. Women bodies are socially constructed as subordinate objects that are open to be alienated, shaped, maintained, and interpreted by society. Laura Potts eloquently argues

> "medical objectification of women's bodies is particularly worrisome, because it takes place in the context of a sexist society, which already objectifies women by reducing them to their bodies…and body parts…and then reduces those bodies to their sexual or reproductive functions under patriarchy" (2000, p. 19).

The deconstruction of women's bodies has a profound impact on women's experiences and these experiences are relevant and significant in the sustainability of women's health.

The field of medicine is a powerful institution that is regarded as a protector and restorer of health and life (Sherwin, 1992). A close examination of the field of medicine with a feminist lens reveals areas of science that show patterns of bias, discrimination, hegemony, and patriarchy. A feminist perspective asks the necessary questions like who matters and who gets ignored. Additionally, a feminist analysis allows for the examination of the intersectionality. The experiences of women are shaped by

intersections of gender, race, class, and age. For example, black women uniquely encounter social issues such as poverty, violence, reproductive concerns, lack of education, and susceptibility to disease (Collins, 2000). These intersections of oppression factor into the lives of women and their experiences cannot be captured wholly by looking at these dimensions separately. Deconstructing the medical field allows for a better and more holistic understanding of how gender and race play a role and interacts in medicine and the broader healthcare system. This perspective will be employed in the proposed study to explore how these subtle but problematic complexities of bias and sexism intersects with the healthcare encounter and shapes the woman's experiences in the medical setting.

Traditionally, when a woman enters into a medical office, political and societal norms will dictate how her medical encounter will ensue. Unbeknownst to the woman, her decision-making, her course of treatment, and her road to a cure is greatly influenced by outside societal forces. A noteworthy point is that women are more likely to encounter the healthcare field, either as a patient, a care giver for children, family member, or the elderly, or as a child bearer (Sherwin, 1992). Additionally, the medical field is still generally a male-dominated science. The medical profession claims it is moving from a paternalistic patient-healthcare provider relationship to a more collaborative relationship that involves their patients. However, the patient-healthcare provider encounter is still influenced by the traditional paternalistic norm. Paternalism in healthcare revolves around the locus of control in decision-making. Theories of decision-making rest on the premises that individuals make rational decisions in his or hers best interests (Janis & Mann, 1977; Lipshitz & Strauss, 1997). However, during a stressful situation, like a

diagnosis of breast cancer, a woman may not be capable to make decisions in her own best interests (Sherwin, 1992). Paternalism refers to the practice of healthcare providers making decisions on behalf of their patients (Sherwin, 1992). Due to the healthcare provider's superior knowledge and best intentions for his or her patients, it is considered justified for the healthcare provider to make authoritative decisions in the best interests of his or her patients. This is problematic because the breast cancer patient, a woman, and the healthcare provider, more likely than not male, enter into a power struggle that is reflective of society's oppressive status of women. Women who are diagnosed with breast cancer are expected to follow their healthcare provider's precise orders to be slashed (lumpectomy or mastectomy), burned (radiation), and/or poisoned (chemotherapy). Because patients, like women, are expected to submit to the directions and recommendations of their provider, women who do not follow through with any of the healthcare provider's recommendations are labeled as defiant or in medical terms, non-compliant, to medical recommendations.

Another area that is problematic in the medical encounter is the sterile expectations of the woman and her decision-making. Patients, in this case, women are expected to detach themselves from their cultural, social, political, and economical experiences and enter into the exam room sterile from any outside influences. This is certainly a distortion of a more complex reality. Before and after a breast cancer diagnosis, the woman's perception of the breast cancer experience is imbued with multilayered and unique experiences in which the disease is understood. Breast cancer is seen as purely a biomedical entity but breast cancer is profoundly constructed with social and cultural sources (Braidotti, 1994; Sherwin, 1992). Women draw from these

embodied experiences and other knowledge sources when constructing their own knowledge and understanding of the disease. The biomedical model fails to recognize how women's bodies are meaningful entities that are attached with lived and personal experiences that take part in social relationships and cultural meanings (Sherwin, 1992). These embodied meaning influence decision-making in women and shapes medical encounters. The breast cancer experience starts with a detection or screening for suspicious lumps. In order for women to be diagnosed, it starts with the woman's embodied knowledge of herself and she must sense that something is wrong. The discovery of a lump releases many emotions that are continuously constructed and molded throughout the woman's life. These emotions and experiences are carried into the medical encounter. However, traditional biomedical framework fails to teach healthcare providers how to connect to the woman and the embodied knowledge that she carries with her (Sherwin, 1992). Conflicts can then arise.

Women are not monolithic but rather are complex with overlapping identities and interconnectedness between physical, symbolic, and sociological structures (Braidotti, 1994). Embodied theories recognize women in relation to their bodies and their bodies in relation to society. Subjective experiences determined by multilayer variables of class, race, age, culture, and sexual preferences and attitudes that interact and intersect to create a unique embodied experience (Braidotti, 1994). Meaning from the woman's childhood, sexuality, health beliefs, and social relationships, and her breasts can have a significant impact on her decision-making. Women draw on these experiences and feelings when making decisions about their bodies. However, women's own constructions of their embodied illness may not be taken seriously in the medical encounter; healthcare

providers expect women to detach themselves and engage in a professional and distant interaction with one-sided transference of information and medical advice (Sherwin, 1992). This encounter is mechanical and passive and commanded by the healthcare provider. The best medical encounters are when the interaction between the healthcare provider and patient moves from a professional transaction to a personal interaction (Lende & Lachiondo, 2009).

It is important to acknowledge that a woman's construction of her embodied illness may clash or not fit in the biomedical model. Women may take the information and knowledge she gained from the medical encounter and try to make sense of it with her personal understandings and judgments of medicine. If these two dynamics do not line up with each other, it is suspected that the woman may: (i) ignore her embodied self and put aside her personal feelings and experiences and follow the healthcare provider's orders; (ii) self advocate and attempt to collaborate with the healthcare provider and mold her experiences with medical advice into a collaborative understanding; or (iii) ignore medical advice and rely only on her understanding of breast cancer. The third phenomenon is problematic in medicine because it can lead to the woman deciding to forgo treatment that may help in curing breast cancer. However, understanding how a woman's decisions are influenced and constructed sheds light to multifaceted phenomena tied to treatment decision-making.

Summary

This chapter's aim was to introduce a feminist perspective in the analysis of women and breast cancer. The theories and content presented here will be used to help examine and perhaps explain how social, cultural, and racial factors can influence a

woman's decision-making to adhering to treatment recommendations and how race can moderate the decision-making process. A deeper understanding of how women define illness and how society defines women's illness can provide a more holistic analysis of the study's research findings.

Chapter IV

RESEARCH DESIGN AND METHODOLOGY

Overview of the Study

This chapter describes the research design and methodology of the proposed study. The study sought to identify factors that influence the decision-making of African-American and Caucasian women with early stage breast cancer to adhere to recommended chemotherapy treatment or to prematurely discontinue treatment. The major predictor variables that were selected based on the Health Decision Model (HDM) (Eraker et al., 1984) that were propagated to influence the decision to continue or discontinue chemotherapy in a sample of African-American and Caucasian women with early stage breast cancer included: socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs. Racial and contextual differences also were explored within the sample of women in the study.

Research funding to support the study was obtained from the National Institutes of Health, National Institute of Nursing Research via a National Research Service Award (Grant No. F31-011414-02), as well as an American Cancer Society Doctoral Degree Scholarship in Cancer Nursing, and a Sigma Theta Tau International (Alpha Epsilon Chapter) Research Award.

Research Design

A prospective exploratory design was used to test relationships among socio-demographic factors (race, age, access to care), social interaction factors (social support and religious coping), breast cancer knowledge, the cancer experience (side effects and

depression) and health beliefs (specific health beliefs and cancer fatalism) and the decision to adhere or discontinue chemotherapy treatment. Data collection was conducted prospectively at two time points: 1) at enrollment into the study and initiation of chemotherapy treatment (time point 1), and, 2) at the end of the recommended duration of chemotherapy treatment (time point 2).

Power Analysis and Sample Size Calculation

Power Analysis and Sample Size (PASS) statistical software was used for sample size calculation (Hintze, 2000). Since the most statistically complex analysis that was used in this study was multiple regression analysis, sample size was calculated using this statistical procedure. It was calculated that a sample size of 120 was needed to achieve 80% power to detect a small effect size or a R-Squared of 0.10 attributed to 6 independent variable(s) using an F-Test with a significance level (alpha) of 0.05000 (the variables tested were adjusted for an additional 3 independent variable(s) with an R-Squared of 0.10). However, a preliminary analysis of the data revealed a rather homogeneous sample in regards to adherence. A dominantly adherent group lacked the variation needed to compare differences between those who continued or discontinued chemotherapy. The preliminary analysis revealed a sample size of n=90 would produce an effect size of .299 while a sample of n=120 would produce an effect size of .258. Due to the small variation between the effect size of a sample of 90 participants and 120 participants coupled with the extended time it was taking to recruit patients, it was decided to end recruiting efforts at n=99 participants.

Research Sample and Setting

The target population for this study was Caucasian and-African American women initially diagnosed with early stage breast cancer. Early stage breast cancer was defined as having a primary diagnosis of Stage I, II, or IIIa breast cancer. Recruitment sites that serve low, middle, and/or high socioeconomic populations were targeted to ensure the availability of a heterogeneous sample. The sample was recruited from the Grady Health System and the Emory University Winship Cancer Institute, both located in Atlanta, Georgia.

The Grady Health System (GHS) is a comprehensive health services delivery system in Metro-Atlanta that advocates providing quality, cost-effective, and customer-focused health care to residents of metropolitan Atlanta and citizens of the State of Georgia. The demographic profile of GHS are middle age to older adults (58% above age 60), 85% less than $10,000 income per year, 59% less than high school education, 50% Medicare, 19% Medicaid, and 23% uninsured. GHS gave the researcher adequate access to the minority oncology population as well as members of low socioeconomic and uninsured populations. The Winship Cancer Institute (WCI) is an interdisciplinary clinical cancer treatment center that is devoted entirely to the care of patients with cancer. This recruitment site gave adequate access to middle-class and upper class individuals from various racial backgrounds (Caucasian and African American).

A sample of 99 African-American and Caucasian women were used to explore relationships and to examine adherence rates between the two groups and to predict significant variables that best influenced the decision to adhere to chemotherapy treatment or discontinue chemotherapy. Of the 99 participants who signed informed

consent, one patient's breast cancer diagnosis was restaged to advanced cancer and no longer met study eligibility and was dismissed from the study. Two patients withdrew from the study- one patient withdrew from the study due to moving her care to a different state and another patient withdrew due to becoming very ill. A total of ten patients were lost to follow up and did not return the questionnaires for time point two. Therefore, a total of 13 participants were lost to follow up or withdrew from the study, giving the study an 87% retention rate. The sample included 51 African-American women whose ages ranged between 26 and 76 years and 48 Caucasian women whose ages ranged between 29 and 86 years. Sample characteristics are presented in Table 4.1.

Using Chi-square analysis, differences were observed between African-American and Caucasian women in the study. Appendix A consists of a table of descriptive differences between Africa-American and Caucasian women in the sample. African-American women reported lower income (χ^2= 13.061, p= .000), less educated (χ^2= 4.501, p= .027), less likely to report private health insurance (χ^2= 19.060, p= .000) than Caucasian women. There was no significant difference in access to reliable transportation between African-American and Caucasian women in the study (χ^2= 2.022, p= .122). African-American women significantly reported to being single or not married at entry into study (χ^2= 28.310, p= .000). Furthermore, African-American women more frequently reported her spouse or partner was unemployed, when compared to Caucasian women in the sample (χ^2= 31.449, p= .000). There was no difference in living arrangements between the two groups, were both groups reported to living with at least one family member (χ^2= 27.475, p= .102). Overall, the sample demonstrated similar characteristics.

Table 4.1 *Characteristics of the Sample*

Characteristic (n/%)	Total Sample (N=99)	Caucasian (n=48)	African American (n=51)
Age			
45 or younger	35 (35.4%)	18 (51.4%)	17 (48.6%)
46-55 years old	28 (28.3%)	11 (39.3%)	17 (60.7%)
56 years and older	36 (36.4%)	19 (52.8%)	17 (47.2%)
Mean	51.83	52.75	50.96
Total household income[a]			
< $10,000	17 (17.9%)	5 (5.3%)	12 (12.6%)
$10,000- $19,999	8 (8.4%)	3 (3.2%)	5 (5.3%)
$20,000- $29,999	12 (12.6%)	3 (3.2%)	9 (9.5%)
$30,000- $39,999	5 (5.3%)	0 (0%)	5 (5.3%)
$40,000- $49,999	3 (3.2%)	2 (2.1%)	1 (1.1%)
$50,000- $59,999	3 (3.2%)	2 (2.1%)	1 (1.1%)
$60,000- $69,999	7 (7.4%)	3 (3.2%)	4 (4.2%)
$70,000- $79,999	6 (6.3%)	4 (4.2%)	2 (2.1%)
$80,000- $89,999	10 (10.5%)	6 (6.3%)	4 (4.2%)
$90,000- $99,999	4 (4.2%)	1 (1.1%)	3 (3.2%)
$100,000 or more	20 (21.1%)	17 (17.9%)	3 (3.2%)
Highest level of education			
<12th grade	3 (3%)	2 (2%)	1 (1%)
12th grade	16 (16.2%)	4 (4%)	12 (12.2%)
Vocational/ trade school	10 (10.1%)	6 (6.1%)	4 (4%)
>1 of junior college	12 (12.1%)	2 (2%)	10 (10.1%)
Associate's degree	7 (7.1%)	4 (4%)	3 (3%)
Baccalaureate degree	30 (30.3%)	19 (19.2%)	11 (11.1%)
Master's degree	19 (19.2%)	9 (9.1%)	10 (10.1%)
Doctorate/ Law degree	2 (2%)	2 (2%)	0 (0%)
Marital status			
Now married	46 (46.5%)	35 (35.4%)	11 (11.1%)
Domestic partner	1 (1%)	1 (1%)	0 (0%)
Single/ never married	22 (22.2%)	4 (4%)	18 (18.2%)
Divorced	19 (19.2%)	7 (7.1%)	12 (12.1%)
Separated	2 (2%)	0 (0%)	2 (2%)
Widowed	9 (9.1%)	1 (1%)	8 (8.1%)

Table 4.1 cont'd *Characteristics of the sample*

Characteristic (n/%)	Total Sample (N=99)	Caucasian/white (n=48)	African American/ black (n=51)
Spouse or partner employed			
Not applicable	47 (47.5%)	10 (10.1%)	37 (37.4%)
Yes	36 (36.4%)	30 (30.3%)	6 (6.1%)
No	16 (16.2%)	8 (8.1%)	8 (8.1%)
Living arrangements			
Lives alone	23 (23.2%)	8 (8.1%)	15 (15.2%)
Lives with spouse	40 (40.4%)	30 (30.3%)	10 (10.1%)
Lives with domestic partner	5 (5.1%)	3 (3%)	2 (2%)
Lives with children	19 (19.2%)	1 (1%)	18 (18.2%)
Lives with family member	12 (12.2%)	6 (6.1%)	6 (6.1%)
Employment status			
Unemployed	25 (25.3%)	11 (11.1%)	14 (14.1%)
Full-time	32 (32.3%)	17 (17.2%)	15 (15.2%)
Part-time	11 (11.1%)	8 (8.1%)	3 (3%)
Retired	13 (13.1%)	9 (9.1%)	4 (4%)
Medical leave/ disability	18 (18.2%)	3 (3%)	15 (15.2%)
Type of health insurance[b]			
None	3 (3.1%)	1 (1%)	2 (2.1%)
Private	53 (54.6%)	36 (37.1%)	17 (17.5%)
Medicare	2 (2.1%)	1 (1%)	1 (1%)
Medicaid	26 (26.8%)	3 (3.1%)	23 (23.7%)
Combination	13 (13.4%)	6 (6.2%)	7 (7.2%)

Note. [a]*4 missing cases*
[b]*1 missing case*

Recruitment of the Sample

Active recruitment was used to recruit the study's sample. A collaborative relationship with the recruitment site's healthcare team was used to help identify eligible patients. Medical chart review was also used to identify potentially eligible participants. Once potential patients were identified, the physician or nurse practitioner asked the patient during an office visit if she was willing to hear information about the study. Eligible participants who were willing to learn more about the study had the study explained in detail by the researcher and were asked for voluntary participation into the study.

Sample Inclusion/Exclusion Criteria

Inclusion criteria for participation in the study were: 1) self-reported African-American/black or Caucasian/white woman; 2) diagnosed with early stage (I, II, or IIIa) breast cancer; 3) completed two or less chemotherapy treatments; 4) able to read, write, and speak English; 5) initial and primary diagnosis of breast cancer documented in the medical charts; 6) an intravenous non-hormonal chemotherapy regimen 7) provides voluntary consent to participate in the study; and 8) over the age of 21 years. Exclusion criteria for the study were 1) advanced stage breast cancer (stage IIIb or IV); 2) chart documented of a major mental disorder; 3) unable to read or write English.

Rationales for the Selected Population

African-American and Caucasian women were the population of interest in this study because the literature provides conflicting reports regarding adherence to chemotherapy regimens for the two populations (Andic et al., 2010; Hershman et al., 2005). In addition, differences in survival between African-American and Caucasian

women with breast cancer warrant research to help elucidate the reasons behind the disparity (Siegel, Naishadham, & Jemal, 2012). Therefore, the aim of this study was to confirm or disconfirm racial differences in chemotherapy adherence and analyze predictors to the decision to continue or discontinue chemotherapy. Men were excluded from the study because of the infrequent diagnosis of breast cancer in males. Children were not eligible for the study because of the rare occurrence of breast cancer in children. The frequency, amount, and type of chemotherapy treatment are different for early and advanced stage breast cancer; these facts can potentially cause a difference in the decision-making process in women with a terminal diagnosis. Thus, the study only included women with a diagnosis of early stage breast cancer as documented in their medical charts. All participants were requested to read and speak English in order to read, comprehend, and complete the questionnaires. Women treated with hormonal and self-administered oral chemotherapy were excluded because those treatments produce different costs and benefits to patients and may produce different predictors to treatment adherence. The study excluded women with mental disorders, in order to control for the risk of harm to the participant who does not properly understand the study or their recommended treatment.

Recruitment Strategy

African Americans are largely underrepresented in clinical research due to poor recruitment and retention of this population so special effort was made to ensure adequate representation of African Americans in the sample (Dennis & Neese, 2000; Gorelick, Harris, Burnett, & Bonecutter, 1998). Barriers to recruitment and retention include distrust of researchers due to historical human experimentation of this population.

Specifically, this group is seen as a vulnerable population due to the historical injustices that put African Americans at an increased risk for harm and exploitation (Aday, 2001). In light of this information, the following plan was used for the inclusion, recruitment, and retention of African-American women in the proposed study:

1. The study had targeted goals for recruitment and conducted monthly assessments of the recruiting progress.
2. All potential participants were informed about the study on an individualized basis with ample time to discuss the consent process and time commitment.
3. All study materials were assessed and revised for cultural sensitivity as well as appropriate reading level and ease of understanding.
4. Participants were asked to provide feedback on any issues or problems they had regarding culturally sensitive matters during the study and at the conclusion of the study.
5. Participants were provided the PI's contact phone numbers and were encouraged to ask any questions that might arise during the study or after its conclusion.
6. The only cost for participants in this study was time where the amount of time required for this study was no more than one hour per contact.

Methodology

Operational Definitions

The following methods were used to measure the study variables:

1. ***Socio-demographic factors***: Variables that specify background characteristics of an individual such as gender, race, age, education, marital status, religious affiliation, and employment. Socio-demographic

characteristics were measured in this study by a demographic questionnaire compiled by the investigator. Socio-demographic variables which were used as predictors of decision adherence in this study were:

a. *Race*: A formal system of classification commonly based on a combination of physical features, ethnic or cultural background characteristics. Race was self-reported on the demographic questionnaire.

b. *Age*: A quantitative measure of an individual's longevity in number years lived after birth. Age was measured by calculating the number of years lived based on the date of birth specified on the demographic questionnaire.

c. *Access to care*: An individual's physical ability to interface with and obtain healthcare resources, such as transportation to gain access to healthcare or financial ability to gain access to healthcare, such as type of health insurance. Financial access to healthcare can serve as a proxy of socioeconomic status, where persons can be placed into social strata, e.g., lower, working, or middle class based on health insurance coverage. Within this study subjects with no health insurance coverage or who had Medicaid were categorized as lower class; those with insurance coverage were categorized as working/middle class.

2. ***Social interaction***: The support mechanisms available during the woman's diagnosis of breast cancer. Social mechanisms include social support and religious coping.
    a. *Social support*: A satisfying network of interpersonal relationships. Social support was measured by Norbeck's Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981).
    b. *Religious coping*: The ability to adapt to a life-changing event through the belief in a higher being as measured by the Pargament Religious Coping Scale (RCOPE) (Pargament et al., 2000).
        i. *Positive religious coping*: A secure relationship with God that promotes positive health outcomes such as increased well-being and quality of life as measured by RCOPE's spiritual support, benevolent religious reframing, collaborative religious coping, and congretional support subscales.
        ii. *Negative religious coping*: Discontent or a tenuous relationship with God that can decline health as measured by RCOPE's spiritual discontent, punitive religious reframing, self-directing religious coping, and congregational discontent.
3. ***Breast cancer knowledge***: A person's understanding of information relevant to the breast cancer diagnosis, including the risks, treatment options, and side effects that encompass the disease. This variable was measured by the Comprehensive Breast Cancer Related Knowledge Test (Stager, 1993).

4. ***Cancer experience***: A person's encounter with the side effects of treatment and depressive symptoms a woman experiences during treatment for breast cancer as indicated.
    a. *Side effects:* The unpleasant symptoms that women experience during the recommended treatment as measured by the Memorial Symptom Assessment Scale Short Form (MSAS-SF) (Chang, Hwang, Feuerman, Kasimis, & Thaler, 2000).
    b. *Depression*: A dull or drab mood, which includes feelings of sadness, melancholy, and lowered energy and self-regard. Depression was measured by the Center for Epidemiologic Studies Depression (CES-D) Scale (Hann, Winter, & Jacobsen, 1999).
5. ***Cancer related health beliefs***: The beliefs and perceptions a woman holds about the breast cancer experience including cancer fatalism, as measured by the Powe Cancer Fatalism Inventory (Powe, 1995a); and, five concepts of the Health Belief Model: perceived susceptibility, perceived seriousness, perceived benefit, perceived barriers, and motivation, as measured by the Champion Health Belief Model Scale (Champion, 1984).
    a. *Cancer fatalism:* The belief that cancer is incurable and death is inevitable.
    b. *Perceived seriousness:* An individual's perception or feelings concerning the severity of contracting an illness.
    c. *Perceived susceptibility:* The extent to which the individual believes he or she is prone to the health condition.

d. *Perceived benefit*: The anticipated value of the recommended course of action or treatment approach.

e. *Perceived barriers*: A person's assessment of the costs involved in taking a particular action or treatment.

f. *Motivation*: A set of beliefs that spur a person to take or not take a particular action or treatment focused toward attaining good health.

6. ***Health Decision to Adherence***: The choice to either stop treatment early or complete the course of treatment once recommended intravenous chemotherapy treatment has started, as measured by medical chart review.

   a. *Adherence*: Completing at least 85% or more of the prescribed chemotherapy as measured by amount of scheduled appointments divided by the amount of appointments that were attended.

   b. *Non-adherence*: Completing at less than 85% of the prescribed chemotherapy as measured by the amount of scheduled appointments divided by the amount of appointments that were attended.

7. ***Days from diagnosis to treatment***: a proxy for adherence to treatment recommendation; measured by the number of days from diagnosis of breast cancer to the initiation of cancer treatment as documented in the woman's medical charts.

8. ***Early stage breast cancer***: An initial and primary diagnosis of Stage I, II, or IIIa breast cancer as indicated in the woman's medical chart.

Measurement Instruments

The measurement instruments used in the study consisted of a collection of questionnaires, which were used to collect data to address the research aims of the study. This section describes each questionnaire.

Demographic Questionnaire

A demographic questionnaire was compiled by the principal investigator to collect demographic information from each subject inclusive of the socio-demographic variables utilized in the study. The questionnaire measured demographic information such as age, race, education, combined household income, living arrangements, employment, stage of disease at diagnosis, type of health insurance, and usual transportation to appointments. Race, age, and date of birth were self-reported variables. A copy of the demographic questionnaire is included in Appendix B.

Norbeck's Social Support Questionnaire (NSSQ)

The Norbeck's Social Support Questionnaire (NSSQ) (Norbeck et al., 1981) was utilized to measure the perceived social support of the participants. This instrument measures the types (affect, affirmation, and aid) and sources of social support through a 6-item and 3-situation specific item questionnaire using a 5-point rating scale from 0 (not at all) to 4 (a great deal). The questionnaire asks each respondent to list the first names or initials of those she considers a part of her support system. The respondent is then asked to answer nine questions regarding functional properties (e.g. emotional and tangible support, stability of relationship, and frequency of contact) for each of the listed support network members.

Because the NSSQ is not a summative-type instrument, Pearson correlations among the items and subscales were calculated to test internal consistency reliability (Norbeck et al., 1981). Each of the two items for each subscale was highly correlated: Affect, .97; Affirmation, .96; and Aid, .89. The test-retest correlations were Affect, .89; Affirmation, .88; and Aid, .86. Validity of the NSSQ was tested in relation to concurrent and construct validity, and the response bias of social desirability, which was ruled out (Norbeck, Lindsey, & Carrieri, 1983). Concurrent validity was tested with the Social Support Questionnaire (SSQ), developed by Cohen and Lazarus (Cohen & Lazarus, 1977). The affirmation and affect scale of the NSSQ was moderately associated with the SSQ measure of informational support (r=.33) and emotional support (r=.51), respectively (Norbeck et al., 1983). Construct validity was assessed using the Fundamental Interpersonal Relations Orientation (FIRO-B) measure (Schutz, 1977). Construct validity was demonstrated by significant associations between FIRO-B's need for inclusion and affection scales to NSSQ's functional subscales (r= .18 to .27) and to most of the NSSQ's network scales (r= .17 to .23) (Norbeck et al., 1983).

Pargament Religious Coping Scale (RCOPE)

The Pargament Religious Coping Scale or known as the RCOPE (Pargament et al., 2000) measures the range of religious coping strategies. This instrument is a 63-item questionnaire that measures both helpful and harmful religious coping methods. Respondents are asked to reflect on the role religion played as a form of coping during a specified event such as chemotherapy sessions for women in this study. Each respondent is asked to answer each question on the extent to which there is agreement with each statement using a Likert scale of 1 (not at all) to 4 (a great deal). Positive religious

coping subscales (e.g. spiritual support, benevolent religious reframing, collaborative religious coping, congregational support) ranges from 3 to 12 and the overall positive religious coping scale ranges from 36 (low) to 144 (high). Questions that constituted the negative religious coping subscales (e.g. spiritual discontent, punitive religious reframing, self directing religious coping, congregational discontent) ranges from 3 to 12 where the overall negative religious coping score ranges from 27 (low) to 108 (high). If the respondent is not religious, he or she is asked to substitute "religion" with "spirituality" and "God" with a "higher being or force" or to simply mark "not at all" if neither applied.

Factor analysis largely validated the conceptualization and the construction of the subscales and provided evidence of high internal consistency and incremental validity. All but three subscales (Reappraisal of God's Power, Marking Religious Boundaries, and Interpersonal Religious Discontent) had alphas of .65 or greater, and seven subscales had alphas of .80 or greater for internal consistency subscales, confirming generally high reliability estimates (Pargament et al., 2000). Cronbach's alpha levels (>0.75) calculated for the RCOPE is acceptable. The root mean square error of approximation of the 16 factors revealed a good fit of the final model (RMSEA= .046) (Pargament et al., 2000). The RCOPE has performed well in predicting physical and psychological adjustment to life crises when compared to a measure of Global Religiosity in other studies (Koenig, Pargament, & Nielsen, 1998; Pargament, Smith, Koenig, & Perez, 1998).

Comprehensive Breast Cancer Related Knowledge Scale

Health knowledge of breast cancer was measured by the Comprehensive Breast Cancer Related Knowledge Scale (Stager, 1993). This scale is a 20-question true-false

scale consisting of two subscales (general knowledge and curability) that assesses the knowledge or risk factors for breast cancer, symptoms of breast cancer, side effects of treatment, treatment efficacy, and methods of treatment. Correct answers were summed to produce a score that ranged from 0 to 12 for the general knowledge subscale and 0 to 8 for the curability subscale and an overall score ranging from 0 to 20.

Content validity was supported utilizing four experts in the field of oncology. Issues and concerns with any of the measurement's items expressed by the content expert was addressed with each item (Stager, 1993). After content validity was established, pilot testing of the instrument with a convenience sample of 20 women was performed. The pilot testing established readability, clarity, and time to complete the questionnaire (McCance, Mooney, Smith, & Field, 1990). The internal consistency reliability for the post-tested general knowledge subscale was 0.60 and for the curability subscale was 0.62, which is acceptable. The overall alpha coefficient was 0.71 (Stager, 1993).

Memorial Symptom Assessment Scale Short-Form (MSAS-SF)

The Memorial Symptom Assessment Scale Short Form (MSAS-SF) (Chang et al., 2000) was used to measure the participant's symptoms experienced during chemotherapy treatments. The MSAS-SF is an abbreviated version of the Memorial Symptom Assessment Scale developed to provide multidimensional information about common symptoms experienced in oncology populations. The MSAS-SF instrument captures 28 prevalent symptoms of cancer therapies and assesses the patient's rated severity, frequency, and distress associated with the symptoms. The respondent is asked to mark the experiences they experienced during chemotherapy and then rate how bothersome or

distressful the symptom was. Distress is rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much).

Psychometric properties of the scale consisted of a Cronbach's alpha coefficient that ranged from 0.80-0.87 for each subset of symptoms. The one day test-retest coefficient ranged from 0.86 to 0.94 and the one week test-retest ranged from 0.40-0.84 (Chang et al., 2000). The MSAS-SF subscales were assessed against the subscales of the Functional Assessment Cancer Therapy (FACT-G) (Cella, et al., 1993) to determine criterion validity. Correlation coefficients between the MSAS-SF and FACT-G subscales ranged from -.74 to -.68 (Chang et al., 2000).

Center for Epidemiologic Studies-Depression (CES-D)

Depression was measured by the Center for Epidemiologic Studies-Depression Scale (CES-D) (Hann et al., 1999). This instrument is a 20-item, self-report scale designed to survey six components of depression: depressed mood; feelings of guilt and worthlessness; feelings of helplessness and hopelessness; psychomotor retardation; loss of appetite; and sleep disturbance. Rated on a 4-point scale (0 = rarely or none at all; 3= most or all of the time), respondents indicate how often within the last week they experienced each symptom. The scores for the 20 items are added and result in an overall score that ranges from 0 to 60. It is important to note, the CES-D is not a diagnostic tool and is only a measure of depressive symptomology where a score equals or is greater than 16 is indicative of positive symptomology over the past week. Respondents who indicated high scores on the CES-D had their primary care provider notified for further evaluation.

Construct validity was evaluated in sample of women diagnosed with breast cancer by comparing the CES-D with the Profile of Mood State Fatigue Scale (POMS-F) (McNair, Lorr, & Droppleman, 1981), the State version of the State–Trait Anxiety Inventory (STAI-S) (Spielberger, 2005), and the Mental Health Summary Scale from the Short-Form 36 Health Survey (SF-36 Vitality scale) (Ware, Kosinski, & Keller, 1994). Scores on the CES-D were expected to be positively correlated with the POMS-F and STAI-S and inversely related with the SF-36 Vitality scale. Construct validity was demonstrated by moderate to high correlations with measures of the POMS (r= 0.66), STAI (r= 0.77), and the SF-36 Vitality scale (r= -0.65) (Hann et al., 1999). The CES-D was found to have good internal consistency with alpha coefficients >0.85 in a group of women with breast cancer as well as adequate test-retest reliability (Hann et al., 1999).

Champion's Health Belief Model Scale

The Champion's Health Belief Model Scale (CHBMS) (Champion, 1984) measures five concepts of the Health Belief Model: perceived susceptibility, perceived seriousness, perceived benefit, perceived barriers, and motivation. Each respondent is asked to rate how much she agrees or disagrees with each statement using a 5-point Likert scale of 1 (strongly disagree) to 5 (strongly disagree). The instrument subscales assess beliefs related to susceptibility to breast cancer before diagnosis, seriousness of her breast cancer diagnosis, benefits of chemotherapy treatments, suspected barriers to chemotherapy treatments, and motivation for good health.

The test-retest correlations ranged from 0.47 to 0.86 (Champion, 1984). Factor analysis of the measure revealed statistical evidence for the independence of constructs. Principal components factor analysis for all items ranged from 0.36 to 0.75. Internal

consistency of the factors ranged from 0.36 to 0.78. Cronbach's alpha reliability coefficients for subscales ranged from 0.80 to 0.93 (Champion, 1984). A multiple regression analysis of the subscales revealed a multiple R of 0.51 with 26% of variance accounted for in the model, which also demonstrates construct validity (Champion, 1984).

Powe Fatalism Inventory (PFI)

The Powe Fatalism Inventory (PFI) (Powe, 1995a) was used to measure the fatalistic belief that death is inevitable with breast cancer. Items address fear, predetermination, pessimism, and inevitability of death through 15 "yes" or "no" questions. "Yes" responses are summated to produce a PFI score. Scores ranging from 0 to 8 denote low fatalism attitudes and scores of 9 to 15 denote high fatalism.

In a sample of African-American women, the PFI has a reported internal consistency reliability ranging from 0.84 to 0.87 (Powe, 1995a). Validity and factor analysis of the PFI is acceptable (Powe, 1995a). Factor analysis resulted in all items loading on one factor. Fourteen of the items revealed Eigen values > 0.30. The coefficient alpha for internal consistency reliability was 0.87.

Adherence Measurement

A medical chart review was used to measure adherence. A patient's missed appointment due to no show, cancellation, or refusal was documented in her medical records. Measure for adherence was based on a cut-off point of 85%, which was calculated by dividing the number of prescribed chemotherapy sessions, by the number of appointments attended. Adherence was dichotomized as a "yes" or "no" variable where patients that attended 85% or more of their chemotherapy sessions were considered

adherent (“yes”) and those completing <85% were considered non-adherent (“no”). Due to a fairly adherent sample, a second measure of adherence was added to the study. Adherence was examined as a continuous variable where percentage rates of adherence were explored in the study’s sample. In addition, days from diagnosis to treatment were added to explore rapidity of adherence to treatment recommendations.

Data Collection and Procedures

Approval from the Institutional Review Board (IRB) of Emory University, Winship Cancer Institute’s Clinical Translational Research Committee, and Grady Healthy System’s Research Oversight Committee was granted for the study. Once the study was approved to recruit participants at each respective site, several meetings were held to introduce the principal investigator (PI) and the study to the healthcare teams at GHS and WCI. The physician or nurse practitioner identified all patients on their schedule who had been newly diagnosed with breast cancer and were recommended intravenous chemotherapy. The PI met potentially eligible participants at the patient’s next office visit. Potential participants were given an overview of the study and invited to participate. Participants who did not meet the criteria were thanked for their time and excluded from the study.

All data for the study were collected through questionnaires administered by the PI. All data collected were kept confidential in a secure location. To help alleviate the possible burden of completing several questionnaires, data collection consisted of two time points: time point one (T1), at enrollment, and time point two (T2), at the end of the participant’s chemotherapy sessions. Upon enrollment in the study or at the initiation of intravenous chemotherapy (T1), four questionnaires were administered: 1) Demographics

measure; 2) CES-D; 3) PFI; and 4) Champion's Health Belief Model Scale. The timing of administration of these questionnaires was considered as the appropriate baseline information each participant. The PFI and Champion's Health Belief Model Scale were used to determine attitudes, beliefs, and feelings about breast cancer that existed at initiation of the chemotherapy treatment regimen that might predict the participant's decision to adhere or discontinue chemotherapy. Depression scores also were obtained at baseline. It was estimated to take one minute to complete each question for each questionnaire so the estimated time to complete the questionnaires at T1 was 35 minutes. Additionally, the average time of an intravenous chemotherapy session was about three hours. The participants took this time during their chemotherapy sessions to complete the questionnaires. Once T1 questionnaires were completed, the woman was thanked for her time and was told she would be seen again at the end of her chemotherapy treatment to administer T2 questionnaires.

The duration of recommended chemotherapy for early breast cancer varied between women, ranging from one to six months. The second time point was at the end of the prescribed intravenous chemotherapy therapy (T2) and the following five questionnaires were administered: 1) RCOPE; 2) MSAS-SF; 3) CES-D; 4) Norbeck's Social Support Questionnaire; and 5) the Breast Cancer Related Knowledge Measure. Estimated time to complete the questionnaires at T2 was 25 minutes. The RCOPE was administered at T2 to capture social support that the participant used throughout the entire (before and during) chemotherapy regimen. The MSAS-SF was used to identify symptoms the woman experienced during chemotherapy treatment. The CES-D was used at this time point to capture depression that may have occurred during chemotherapy.

The knowledge measure was administered at T2 to measure the amount of knowledge the participant acquired during her chemotherapy experience. The woman's adherence to chemotherapy was assessed at the second time point via a medical chart review. At the completion of the study, the participant was given a $10 gift card to a local grocery store for appreciation of time and contribution to the study. Contact of the participant was approved by IRB, so if the PI was unable to meet the participant at the end of her chemotherapy treatments, the participant was contacted and asked permission to mail the last set of questionnaires along with her gift card. The participants were provided a self-addressed and postage paid envelope to send questionnaires back to the principal investigator.

During the study, efforts were taken to ensure the patient's convenience and to respect her time. Efforts included giving participants ample time to voluntarily complete the questionnaires at each time point. The participant was also given the opportunity to take the questionnaires home and return or send back the questionnaires upon completion. If the participant decided to take the questionnaires home, the study participant was advised the questionnaires must be filled out by the patient and not by a family member in order to protect the reliability of the data. A stamped envelope was provided for return mail. In addition, IRB permission was obtained to call the participant if the questionnaires were not returned by a pre-specified date. To avoid coercion, the participant was contacted once by phone with a friendly reminder.

Protection of Human Subjects

The following information relates to both research sites. Standardized procedures and protocols were established to minimize risks, including risks to confidentiality. In

compliance with human subjects and the Health Insurance Portability and Accountability Act (HIPPA) procedures, potential participants were given an explanation in detail about the study's purpose, what participation entailed, rights to confidentiality, time commitment, risks and benefits involved, and contact information. Participants were informed that participation was strictly voluntary and participants could withdraw from the study at any time without consequences to themselves, their families, or their medical care. Once this information was reviewed, the participant was asked if she was interested in participating in the study. If she agreed and before any data collection was gathered, informed consent was obtained. A copy of the "Informed Consent to be a Research Subject" form is included in Appendix C. All data was obtained specifically for research purposes. Participants were advised that any information obtained from the questionnaires is kept confidential and that their names or initials were not associated with the data. All research data was kept secured in locked cabinets, coded with no identifying information. Only the PI had access to these files.

A HIPPA authorization form was provided and signed by the participants. A copy of the HIPPA authorization form is included in Appendix D. The HIPPA form highlighted the participant's rights regarding her medical information. The participant was advised that her medical information would be kept confidential and would not be used for any other purpose outside the parameters of the research study. The participant was given information on how to revoke authorization to their medical information at any time during the research study. To further reduce the risks of breeched confidentiality the following strategies were used: 1) coded data using unique identification codes; 2) stored names separate from identification codes; 3) informed consent forms kept separate from

the data; 4) all data kept were secured in locked files at Emory University; and 5) only the PI had access to the data. All computer databases were password protected. After completion of the study, all data were stored according to Emory University's regulations and guidelines. Lastly, all participants were told that any publications resulting from the study would not name or describe in an identifiable way any individual participant. Although not a clinical trial, this study adhered to the procedures to ensure the quality of the data and the safety of the participants. The study was governed by the policies and procedures of Emory University's Institutional Review Board and was considered low risk to participants. The PI insured the informed consent process was conducted appropriately and written informed consent occurred prior to any data collection or study procedures. Only eligible participants were enrolled based on the eligibility criteria and the PI was trained and certified for human subjects' research. No adverse event occurred that required reporting to the IRB as in line with protocol.

Potential Risks and Benefits

The potential risks for the study were very minimal since participants were only required to complete questionnaires. The inconvenience of time required completing the questionnaires constituted minimal risk. Another potential risk was the possibility that participants would experience emotional distress when completing questionnaires about their treatment experience. If this occurred during the study, the participant was advised to stop and resume the portion of the study at a later time or withdraw from the study, if the emotional risk was very distressing. However, this risk did not occur during the study. There were no other known financial, legal, or social risks to the participants in the proposed study.

There were no known benefits to the participants other than the possibility of providing them with a sense of contributing to increased understanding of the science of chemotherapy adherence in women with breast cancer. It was anticipated that the study would provide needed information about predictors of decision-making and chemotherapy treatment adherence. Information gained from this study could lead to the development of interventions and studies promoting adherence to chemotherapy and ultimately improve health outcomes, such as increased survival rates.

Data Analysis

Data analysis was guided by the specific aims and their related research questions, which were framed by the study's theoretical model adapted from the Health Decisions Model. Data analysis examined the variables that influenced the decision to complete or discontinue chemotherapy in African-American and Caucasian women and aimed to identify racial differences that may exist in these two populations. The study also specifically examined relationships among socio-demographic factors (i.e. age, race, and access to care), social interaction factors (support mechanisms, i.e., social support and religious coping), cancer experience (i.e. chemotherapy side effects and depression), breast cancer knowledge, and health beliefs (i.e. perceived susceptibility, severity, seriousness, barriers, and benefits and motivation and cancer fatalism) in chemotherapy decisions.

The Statistical Package for the Social Sciences 19.0 (SPSS Inc., 2011) was employed for data analysis. Double entry and double-checking were performed to decrease data entry errors. Data analyses consisted of descriptive statistics, correlations, and regression coefficients to support the study's theoretical model. Descriptive statistics

such as means, frequencies, and standard deviations were employed to examine the sample's demographic data. A significance level of 0.05 was selected as the statistical criterion for testing all aims and their associated hypotheses and research questions. Data analyses to address each aim and research question included:

Aim 1: **To explore relationships among socio-demographic factors (race, age, access to care), social interaction factors (social support and religious coping), cancer experience (side effects and depression), breast cancer knowledge, and health beliefs (susceptibility, seriousness, benefits, barriers, motivation, and cancer fatalism).**

RQ 1: *What is the relationship among: (a) socio-demographic factors and breast cancer knowledge; (b) socio-demographic factors and social interaction factors; (c) socio-demographic factors and the cancer experience; (d) social interaction factors and the cancer experience; (e) social interaction factors and breast cancer knowledge; and (f) breast cancer knowledge and the cancer experience?*

Aim 1 and RQ 1 were approached using univariate analyses to explore descriptive statistics of the sample's socio-demographic characteristics. Pearson's correlations were used to examine relationships among socio-demographic factors (race, age, and access to care). Multiple regressions using hierarchal stepwise procedure were used to identify predictors of breast cancer knowledge, social interaction factors, and the cancer experience. Significance was set at p-value < .05. Due to the bidirectional relationship purported by the model, the relationship between breast cancer knowledge and cancer experience was examined using Pearson's correlations or Spearman's Rho. Significant relationships were determined at p-value < .05.

RQ 2: *To what degree are socio-demographic factors, social interaction factors, breast cancer knowledge, and the cancer experience are related to specific health beliefs?*

Research question 2 was answered by entering the significant predictors revealed in research question 1 into the model to predict specific health beliefs (susceptibility, seriousness, benefits, barriers, motivation, and cancer fatalism).

Aim 2: To examine differences in adherence to chemotherapy between African-American and Caucasian women with early stage breast cancer in relation to socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs and to explore these factors as predictors of adherence to chemotherapy among women with early stage breast cancer.

RQ 3: *To what degree is race associated with differences in the adherence to chemotherapy in women with early stage breast cancer?*

Aim 2 and RQ 3 were addressed by examining adherence rates between African-American and Caucasian women. Differences in adherence to chemotherapy treatment between African-American and Caucasian women with breast cancer could not be addressed because the sample was 90% adherent.

RQ 4: *What socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs predict adherence to chemotherapy in African-American and Caucasian women with early stage breast cancer?*

Predictors of adherence to chemotherapy could not be determined to answer RQ 4 because the sample was 90% adherent.

Other Findings

Preliminary analysis of the data determined that the sample was largely adherent; therefore, the outcome variable days from diagnosis to treatment was used as a proxy for adherence to treatment recommendations. Prior evidence found African-American women were more likely to delay treatment where women who delayed treatment had a 12% lower five-year survival rate (Richards et al., 1999). The current study found once a woman started chemotherapy, she completed treatment as recommended by her healthcare providers. However, some women experienced considerably more days from diagnosis to treatment than other women who started and underwent treatment recommendations.

Limitations

The design of the study had some limitations. The convenience sample of participants who presented at the two recruitment sites may not reflect the general population. This selection bias can potentially affect the external validity of the results and generalizability of the findings. However, it was not feasible for the proposed study to use random selection due to the costs and extensive resources needed to sample from the general population of women with early stage breast cancer. The study only examined predictors between two populations, i.e., Caucasian and African-American women, and did not address ethnic diversity. Therefore, results regarding predictors of the decision to adhere or discontinue chemotherapy cannot be generalized outside these two racial groups, or to women with late stage breast cancer. A threat to reliability of the findings is introduced due to the sensitive nature of adherence. However, it is assumed

the participants of the study answered truthfully and honestly on the administered questionnaires.

Summary

A predictive prospective study design was utilized to explore relationships among socio-demographic factors, social interaction factors, breast cancer knowledge, the cancer experience, and specific health beliefs to the decision to adhere or discontinue chemotherapy. The study recruited 99 African-American and Caucasian women diagnosed with early stage breast cancer from two cancer centers located in the Atlanta, Georgia metropolitan area. Once participants provided informed consent, they were administered questionnaires at two time points during their chemotherapy. The questionnaires addressed demographic information, health beliefs, cancer fatalism, health beliefs, social support, religious coping, side effects, breast cancer knowledge, and depression. Various methods of statistical analyses (e.g. multiple regressions, independent t-tests, Chi-square, and Pearson's correlations) were employed to test relationships and the extent to which socio-demographic factors, social interaction, breast cancer knowledge, the breast cancer experience, and specific health beliefs predicted days from diagnosis to treatment. The results of the study are presented in the next Chapter.

Chapter V

RESULTS

The following sections present the results of the data analyses for each aim and research question. The goal of each aim and research question is to confirm hypothesized relationships or disconfirm relationships purported in the study's theoretical model (see figure 5.1). In addition, relationships among socio-demographic factors (age, race, and access to care), social interaction factors (social support and religious coping), cancer experience (chemotherapy side effects and depression), breast cancer knowledge, and specific health beliefs (perceived susceptibility, seriousness, benefits, barriers, motivation and cancer fatalism) were examined. The extent to which these factors predicted days from diagnosis to treatment was also examined.

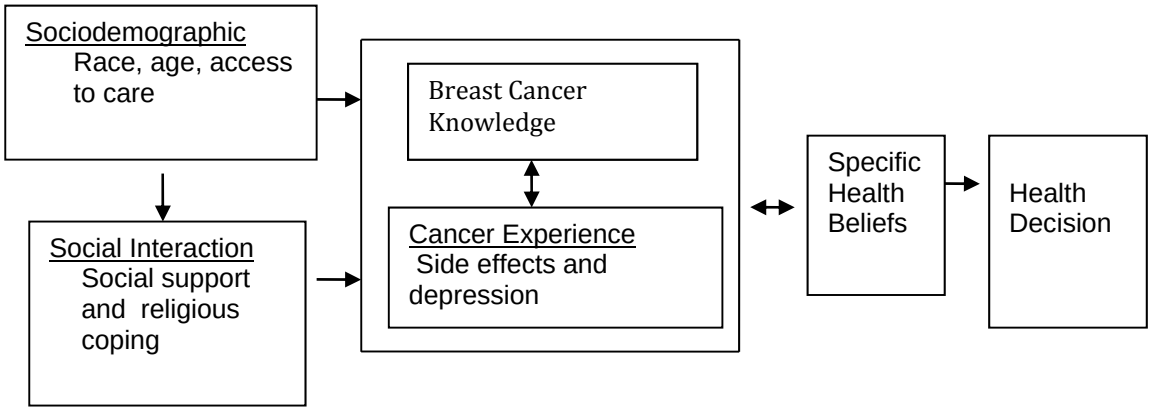

Figure 5.1 Theoretical Model: Factors that influence decision making in women with breast cancer as adapted from the Health Decision Model.

Aim 1

To explore relationships among socio-demographic factors (race, age, access to care), social interaction factors (social support and religious coping), cancer experience (side effects and depression), breast cancer knowledge, and health beliefs (susceptibility, seriousness, benefits, barriers, motivation, and cancer fatalism).

Associated Research Questions:

RQ 1: *What is the relationship among: (a) socio-demographic factors and breast cancer knowledge; (b) socio-demographic factors and social interaction factors; (c) socio-demographic factors and the cancer experience; (d) social interaction factors and the cancer experience; (e) social interaction factors and breast cancer knowledge; and (f) breast cancer knowledge and the cancer experience?*

Bivariate relationships between socio-demographic variables were explored to determine significantly correlated variables to enter in the regression model. Table 5.1 displays a Pearson's correlation matrix and associated p-values between socio-demographic factors. Race was found to be significantly correlated with income (r= -.371, p= .000), marital status (r= .535, p= .000), education (r= -.213, p= .034), and health insurance (r= -.443, p=.000). These variables were entered into the first block in all multiple regression models using hierarchical stepwise procedure. Race was entered in the second block of the regression model.

Socio-demographic Factors and Breast Cancer Knowledge

Separate hierarchical multiple regression analysis was conducted to test for significant socio-demographic predictors to breast cancer knowledge and its subscales (general knowledge and curability knowledge). As described above, significant

correlates to race (i.e. income, marital status, education, and health insurance) were entered into the first block and race was entered into the second block using hierarchical stepwise procedure. Results of the multiple regression analyses using hierarchical stepwise procedure are presented in Table 5.2.

Education, income, and race predicted overall breast cancer knowledge (F= 8.786, p= .000) in the final model. In step 1, education accounted for 13.6% of the model's variance; in step 2, the addition of income accounted for 4.5% of the variance; and in step 3, race added 2.17% of variability to the overall model (overall R^2= 21.7%). The standardized beta coefficients of education (β= .263, p= .010) revealed a positive relationship to breast cancer knowledge. As education increased, overall breast cancer knowledge increased as well. Race (reference group = African American) had a negative relationship with overall breast cancer knowledge (β= -.203, p= .041). That is, African-American women in the study were less knowledgeable about overall breast cancer knowledge. Income was not a significant predictor in the model; however, there was a tendency for knowledge to increase as income increased (β= .160, p= .137).

Education and marital status predicted general breast cancer knowledge (F= 11.583, p= .000). The variability in education and marital status was 22.9%. The final model for general breast cancer knowledge revealed that individuals who had higher levels of education were more knowledgeable about general breast cancer (β= .354, p= .001). Additionally, those who were not married were less knowledgeable about general breast cancer information (β= -.281, p= .006).

The data on curability breast cancer knowledge did not meet the assumption of normality for linear regression analysis. Therefore, scores from the curability of breast

cancer knowledge subscale were dichotomized into low breast cancer knowledge (less than 75% correct) and high breast cancer knowledge (75% correct or higher). Using the same covariate entry criteria described above, logistic regression analysis was performed using hierarchal forward stepwise procedures. Results of the logistic regression analysis using hierarchical forward stepwise procedure are presented in Table 5.3. Income was the independent predictor of curability breast cancer knowledge in the final model. According to the Hosmer and Lemeshow test, the model fit well (.717). The Cox and Snell R^2 was 0.70 and the Nagerlkerke R^2 was 0.122. Those with higher incomes were more knowledgeable about the curability of breast cancer (β= .216, p= .028).

Table 5.1 *Pearson's Correlations Between Socio-demographic Factors*

		1	2	3	4	5	6	7	8
1. Age	R	--							
	Sig.								
	N								
2. Race	R	-.079	--						
	Sig.	.436							
	N	99							
3. Income	R	.035	-.371**	--					
	Sig.	.735	**.000**						
	N	95	95						
4. Marital status	R	.003	.535**	-.455**	--				
	Sig.	.973	**.000**	**.000**					
	N	99	99	95					
5. Education	R	.014	-.213*	.304**	-.153	1			
	Sig.	.891	**.034**	**.003**	.130				
	N	99	99	95	99				
6. Employment	R	-.229*	-.169	.439**	-.106	.075	--		
	Sig.	**.023**	.094	**.000**	.299	.458			
	N	99	99	95	99	99			
7. Health insurance	R	.072	-.443**	.664**	-.341**	.309**	.376**	--	
	Sig.	.486	**.000**	**.000**	**.001**	**.002**	.000		
	N	97	97	93	97	97	97		
8. Transportation	R	.106	-.143	.327**	-.238*	.171	.202*	.298**	--
	Sig.	.294	.158	**.001**	**.017**	.090	**.045**	**.003**	
	N	99	99	95	99	99	99	97	

*Correlation is significant at the 0.05 level (2-tailed) **Correlation is significant at the 0.01 level (2-tailed)

Table 5.2 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Socio-demographic Factors Predicting Breast Cancer Knowledge (N=83)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Overall Knowledge[a]				
Step 1				
Constant	13.096	.723		
Education	.399	.102	.369	.000
Step 2				
Constant	13.048	.707		
Education	.291	.110	.269	.010
Income	.132	.057	.236	.023
Step 3				
Constant	13.779	.780		
Education	.285	.108	.263	**.010**
Income	.089	.060	.160	.137
Race	-.844	.408	-.203	**.041**
General Knowledge[b]				
Step 1				
Constant	6.411	.583		.000
Education	.309	.082	.389	.000
Step 2				
Constant	7.258	.636		
Education	.282	.080	.354	**.001**
Marital status	-.257	.092	-.281	**.006**

Note. Significant p-values in final model are bolded.
a. R^2= .136 for Step 1; ΔR^2= .045 for Step 2; ΔR^2= .035 for Step 3.
b. R^2= .389 for Step 1; ΔR^2= .045 for Step 2; ΔR^2= .078.
c. R^2= .127 for Step 1

Table 5.3 *Summary of Logistic Regression Analysis (Hierarchal Forward Stepwise Procedure) for Socio-demographic Factors Predicting Curability Breast Cancer Knowledge (N=80)*

Predictors	B	SE	Wald	Adjusted OR	p-value
Constant	.623	.522	4.854	1.865	.233
Income	.216	.098	1.423	1.241	**.028**

Note: R^2 (Cox and Snell)= .070; Nagelkerke R^2= .122

Socio-demographic Factors and Social Interaction

Using the same hierarchical stepwise methods described above, socio-demographic variables were entered into a linear regression model to test the predictability of the various socio-demographic variables to social interaction factors (social support and religious coping) (Table 5.4 and 5.5). Separate models were used to test social support (total network properties) and the individual dimensions of social support: emotional support, aid support, functional support. The final regression model revealed education as an independent predictor of total network properties (F= 4.195, p= .044). However, education only explained 5.2% of the variability in the final model. The model revealed that individuals with higher levels of education reported greater overall social support (i.e. total network properties) (β= .227, p= .044).

Education and marital status were predictive of emotional support (F= 5.798, p=.005), aid support (F= 6.188, p= .003), and functional support (F= 5.755, p= .005) in the respective models. Individuals with higher levels of educations reported greater emotional support (β= .264, p= .021), aid support (β= .253, p= .021), and functional

support (β= .249, p= .024). Whereas, participants who were married reported more emotional support (β= -.221, p= .044), aid support (β= -.246, p= .024), and functional support (β= -.238, p= .031) available.

Income predicted negative religious coping in the final model (F= 5.926, p= .017). Individuals with lower incomes reported more negative religious coping (β= -.269, p= .017). Positive religious coping was predicted by health insurance in the final model (F= 11.660, p= .001). Individuals who were not covered by private insurance reported less positive religious coping (β= -.365, p= .001).

Table 5.4 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Socio-demographic Factors Predicting Social Support (N=81)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Total Network Properties[a]				
Step 1				
Constant	52.301	13.003		
Education	3.760	1.836	.227	**.044**
Emotional Support[b]				
Step 1				
Constant	57.882	37.067		
Education	13.947	5.234	.291	.009
Step 2				
Constant	98.069			
Education	12.647	41.276	.264	**.017**
Marital status	-12.210	5.958	-.221	**.044**
Aid Support[c]				
Step 1				
Constant	29.936	15.425		
Education	5.652	2.178	.284	.006
Step 2				
Constant	48.541	17.063		
Education	5.051	2.136	.253	**.021**
Marital status	-5.653	2.463	-.246	**.024**
Functional Support[d]				
Step 1				
Constant	96.007	52.099		
Education	18.585	7.356	.278	.014
Step 2				
Constant	156.193	57.779		
Education	16.639	7.233	.249	**.024**
Marital status	-18.286	8.340	-.238	**.031**

Note. Significant p-values in final model are bolded.
a. R^2= .052 for Step 1.
b. R^2= .084 for Step 1; ΔR^2= .048 for Step 2.
c. R^2= .080 for Step 1; ΔR^2= .060 for Step 2.
d. R^2= .077 for Step 1; ΔR^2= .056 for Step 2.

Table 5.5 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Socio-demographic Factors Predicting Coping (N=78)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Negative Religious Coping[a]				
Step 1				
Constant	42.655	1.941		
Income	-.658	.270	-.269	**.017**
Positive Religious Coping[b]				
Step 1				
Constant	112.912	5.413		
Health insurance	-22.213	6.505	-.365	**.001**

Note. Significant p-values in final model are bolded.
a. R^2= .072 for Step 1.
b. R^2= .133 for Step 1.

Socio-demographic Factors and Cancer Experience

Income was the independent predictor of symptom frequency (F= 12.076, p=. 001), symptom severity (F= 9.783, p= .003), and depression at T1 (F= 5.533, p= .021) in separate final models. Results of the multiple regression analyses of socio-demographic predictors of cancer experience are presented in Table 5.6. Individuals with lower incomes reported more symptoms (β= -.372, p= .001) and higher symptom severity (β= -.340, p= .003). Income was also predictive of higher symptomology for depression at T1 (β= -.241, p= .021) but not at T2. Education predicted symptomology for depression at T2 (F= 5.868, p= .018) but not at T1. In the final model those with lower levels of education reported higher symptomology for depression at the end of chemotherapy (β= -.266, p= .018). None of the socio-demographic factors predicted change in depression scores.

Table 5.6 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Socio-demographic Factors Predicting Cancer Experience (N=77)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Symptom Frequency[a]				
Step 1				
Constant	17.199	1.222		
Income	-.530	.167	-.372	**.001**
Symptom Severity[b]				
Step 1				
Constant	43.889	3.745		
Income	-1.601	.512	-.340	**.003**
CES-D T1[c]				
Step 1				
Constant	15.849	1.851		
Income	-.610	.259	-.241	**.021**
CES-D T2[d]				
Step 1				
Constant	23.154	4.079		
Education	-1.393	.575	-.266	**.018**

Note. Significant p-values in final model are bolded.
a. R^2= .139 for Step 1.
b. R^2= .115 for Step 1.
c. R^2= .058 for Step 1.
d. R^2= .071 for Step 1.

Social Interaction and Cancer Experience

To predict cancer experience factors (symptom frequency, symptom severity, symptomology for depression at T1 and T2, and the change in depression scores), income, education, marital status, and health insurance were entered into the first block of the regression model using hierarchical stepwise methods. Race was entered into the second block followed by social support factors (total network properties, emotional, aid, and functional support) in the subsequent block to predict the dependent variable. None of the social support factors entered the final model to explain symptom frequency, symptom severity, or symptomology for depression at T1 or T2.

The same procedures were performed to test religious coping as a predictor to cancer experience factors. The only significant model in the analyses was negative religious coping and education, which predicted symptomology for depression at T2 ($F= 6.141$, $p= .003$). The model revealed that as negative religious coping increased, symptomology for depression at T2 increased as well ($\beta= .277$, $p= .015$; see Table 5.7). Education was not a significant predictor in the final model.

Table 5.7 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Coping Predicting Cancer Experience (N=77)*

	Unstandardized		Standardized	
	B	SE	B	P-value
CES-D T2[a]				
Step 1				
Constant	22.976	4.155		
Education	-1.385	.584	-.264	.020
Step 2				
Constant	9.111	6.845		
Education	-1.049	.580	-.200	.075
Negative Religious Coping	.298	.119	.277	**.015**

Note. Significant p-values in final model are bolded.
a. R^2= .070 for Step 1; ΔR^2= .073 for Step 2.

Social Interaction and Breast Cancer Knowledge

Social support variables and religious coping variables were tested for their predictability of breast cancer knowledge (Table 5.8). Using the same variables described above in blocks 1 and 2, social support and its subscales were entered into block 3, and religious coping variables were entered into block 4 using hierarchical stepwise procedures. None of the social support variables entered the final model as predictors to general breast cancer knowledge. However, emotional support and income were predictors of overall breast cancer knowledge (F= 8.649, p= .000). Participants with increased emotional support were more knowledgeable about breast cancer (β=.238, p= .029) than participants with less emotional support. Income was not a significant predictor in this model.

Using the same covariate entry criteria described above, logistic regression analysis was performed using hierarchal forward stepwise procedures to test the predictability of social interaction factors to curability breast cancer knowledge (Table

5.9). Marital status and negative religious coping were predictors of curability breast cancer knowledge. According to the Hosmer and Lemeshow test, the model was a reasonable fit (.499). The Cox and Snell R^2 was 0.149 and the Nagerlkerke R^2 was 0.287. The model revealed those with low negative religious coping were more knowledgeable about the curability of breast cancer (β= -.079, p= .027). Marital status was not a significant predictor in the final model.

Table 5.8 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Social Interaction Factors Predicting Breast Cancer Knowledge (N=77)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Overall Knowledge[a]				
Step 1				
Constant	14.696	.428		
Income	.196	.059	.361	.001
Step 2				
Constant	14.051	.508		
Income	.169	.058	.312	**.005**
Emotional Support	.005	.002	.238	**.029**

Note. Significant p-values in final model are bolded.
a. R^2= .130 for Step 1; ΔR^2= .054 for Step 2.
b. R^2= .144 for Step 1; ΔR^2= .077 for Step 2.

Table 5.9 *Summary of Logistic Regression Analysis (Hierarchal Forward Stepwise Procedure) for Social Interaction Factors Predicting Curability Breast Cancer Knowledge (N=75)*

Predictors	B	SE	Wald	Adjusted OR	p-value
Constant	2.014	1.110	3.291		.004
Marital Status	.216	.098	1.423	7.493	.070
Negative Religious Coping	-.079	.036	4.888	.924	**.027**

Note: R^2 (Cox and Snell)= .149; Nagelkerke R^2= .287

Breast Cancer Knowledge and Cancer Experience

Due to the bi-directional relationship between breast cancer knowledge and the cancer experience purported by the conceptual model, Pearson's correlations and Spearman's Rho were used to examine significant correlations between the two factors (Table 5.10). Pearson's correlations did not reveal any significant relationships among breast cancer knowledge and its subscales and the cancer experience (side effects and depression). Due to the distribution of the curability knowledge data, relationships were examined using Spearman's Rho, which revealed no significant correlations between curability knowledge and the cancer experience factors. Additionally, partial correlations were performed controlling for race, income, education, marital status, and health insurance and revealed no significant correlations.

Table 5.10 *Relationships between the Cancer Experience Factors and Breast Cancer Knowledge*

Variables	Overall knowledge[a,b]	General knowledge[a,b]	Curability knowledge[c]
Symptom frequency	.039	.071	-.169
Symptom severity	-.043	.008	-.093
CES-D T1	.018	.110	-.193
CES-D T2	.009	.191	-.209
Change in CES-D	-.007	.091	-.022

Note. No significant correlations
a. Controlled for race, income, education, marital status, and health insurance
b. Pearson's correlations
c. Spearman's Rho correlation

RQ 2: *To what degree is socio-demographic factors, social interaction factors, breast cancer knowledge, and the cancer experience are related to specific health beliefs?*

This question was answered by employing multiple regression models and inputting independent variables using a hierarchical stepwise method. Income, education, marital status, and health insurance were inputted into block 1, race was inputted into block 2, non-socio-demographic predictors that were significant in research question 1 (negative religious coping and emotional support) were inputted into block 3 and significant correlations between the respective health beliefs were inputted into block 4 using stepwise methods. See Table 5.11 for the Pearson's correlation matrix among health beliefs and socio-demographic factors, social interaction factors, breast cancer knowledge, and cancer experience. Table 5.12 presents the significant results of the multiple regression analyses using hierarchical stepwise procedures.

To predict beliefs regarding susceptibility to breast cancer, the multiple regression model was specified as described above. No socio-demographic factors, social interaction factors, breast cancer knowledge, and cancer experience were significantly related to beliefs about susceptibility to breast cancer. Additionally, none of these variables were predictors of breast cancer susceptibility. To predict beliefs about the seriousness of breast cancer, blocks 1-3 were set up as previously described and the following significant correlates to seriousness were entered into block 4: age, curability, symptom frequency, symptom severity, depression at T1 and T2. The final regression model found age, negative religious coping, depression at T1, and symptom frequency as predictors of beliefs about seriousness of breast cancer ($F= 9.821$, $p= .000$). These four independent variables explained 36.3% of the model's variability. Although age was not

a significant predictor, the model revealed that as age increased, beliefs about the seriousness of breast cancer decreased (β= -.143, p=.158). Younger participants believed breast cancer was a more serious disease. The model also showed that participants with high negative religious coping viewed breast cancer as a serious disease (β= .303, p= .002). Participants who experienced more symptoms (β= .236, p= .031) or had increased symptomology for depression at T2 (β= .260, p=.017) viewed breast cancer as a serious disease.

No correlations were added to block 4 of the regression model to predict beliefs regarding treatment benefits. The benefits of breast cancer treatments were predicted by negative religious coping in the final model (F= 13.924, p= .000). Participants with high negative religious coping believed breast cancer treatments were beneficial to their health (β= .398, p= .001).

Age, depression at T1, and change in depression were correlated to beliefs about barriers to breast cancer treatments and were added to block 4 of the regression model. The final model revealed depression at T1 was an independent predictor of beliefs about barriers to breast cancer treatments (F= 11.985, p= .001). Increasing symptomology for depression at T1 predicted beliefs regarding barriers to chemotherapy (β= .378, p= .001). Participants who had high symptomology for depression at the beginning of chemotherapy were more likely to believe that concerns regarding chemotherapy must be overcome.

To predict motivation, the following significant correlations were entered into the 4th block of the model: education, aid support, curability and overall knowledge, and depression at T1. Education was the independent predictor of motivation in the final

model. Participants with higher education reported greater motivation to maintaining their health (β= .288, p= .013).

Emotional, aid, and functional support, curability knowledge, and depression at T1 were correlated to cancer fatalism and were entered into block 4 of the regression model using hierarchical stepwise methods. The final model revealed emotional support, negative religious coping, depression at T1 and curability knowledge as predictors to fatalistic beliefs about breast cancer (F= 7.132, p= .000). Individuals with high fatalistic beliefs about breast cancer reported greater emotional support (β= .334, p= .002). Negative religious coping was not a significant predictor in the final model. Participants who experienced increased depression symptomology at T1 had higher fatalistic beliefs toward breast cancer (β= .319, p= .003). In addition, participants who were less knowledgeable about the curability of breast cancer had higher fatalistic views about breast cancer (β= -.293, p= .012).

Table 5.11 *Pearson's Correlation Matrix: Health beliefs and Contextual Factors*

Socio-demographic Factors		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Susceptibility	R	--	.080	.050	.069	.039	-.065	-.006	-.057	-.097	-.023	-.127	.022
	Sig.		.437	.628	.504	.706	.526	.951	.577	.357	.822	.215	.834
	N		97	97	97	96	96	97	97	93	97	97	95
2. Seriousness	R		--	.059	.659**	-.027	.269**	-.251*	.051	-.137	-.013	-.148	.021
	Sig.			.564	**.000**	.796	**.008**	**.013**	.617	.187	.901	.145	.839
	N			98	98	97	97	98	98	94	98	98	96
3. Benefits	R			--	-.086	.011	-.063	.066	-.002	-.048	.044	.046	.019
	Sig.				.401	.915	.541	.519	.982	.646	.664	.656	.856
	N				98	97	97	98	98	94	98	98	96
4. Barriers	R				--	-.072	.221*	-.207*	-.048	-.142	-.012	-.052	-.041
	Sig.					.482	**.030**	**.041**	.637	.173	.910	.609	.692
	N					97	97	98	98	94	98	98	96
5. Motivation	R					--	-.136	.045	-.075	.197	-.009	.344**	.364**
	Sig.						.188	.662	.468	.059	.930	**.001**	**.000**
	N						96	97	97	93	97	97	95
6. Cancer fatalism	R						--	-.033	.105	-.114	.063	-.159	-.158
	Sig.							.746	.307	.278	.537	.120	.127
	N							97	97	93	97	97	95
7. Age	R							--	-.012	.025	.035	-.036	.034
	Sig.								.904	.811	.729	.722	.740
	N								99	95	99	99	97

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
8. Race	R								--	-.371**	.535**	-.213*	-.443**
	Sig.									**.000**	**.000**	**.034**	**.000**
	N									95	99	99	97
9. Income	R									--	-.455**	.304**	.664**
	Sig.										**.000**	**.003**	**.000**
	N										95	95	93
10. Marital status	R										--	-.153	-.341**
	Sig.											.130	**.001**
	N											99	97
11. Education	R											--	.309**
	Sig.												**.002**
	N												97
12. Health insurance	R												--
	Sig.												
	N												

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

Social Interaction Factors		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Susceptibility	R	--	.080	.050	.069	.039	-.065	-.122	-.132	-.112	-.097	.098	.109
	Sig.		.437	.628	.504	.706	.526	.282	.245	.330	.394	.386	.331
	N		97	97	97	96	96	80	79	78	80	81	81
2. Seriousness	R		--	.059	.659**	-.027	.269**	.010	-.026	.001	.019	.079	.394**
	Sig.			.564	**.000**	.796	**.008**	.933	.821	.991	.869	.479	**.000**
	N			98	98	97	97	81	80	79	81	82	82
3. Benefits	R			--	-.086	.011	-.063	-.144	-.153	-.163	-.145	-.007	.378**
	Sig.				.401	.915	.541	.199	.175	.152	.197	.952	**.000**
	N				98	97	97	81	80	79	81	82	82
4. Barriers	R				--	-.072	.221*	.011	-.042	-.016	-.003	-.047	.126
	Sig.					.482	**.030**	.919	.714	.887	.980	.676	.260
	N					97	97	81	80	79	81	82	82
5. Motivation	R					--	-.136	.212	.249*	.201	.212	.138	-.047
	Sig.						.188	.059	**.027**	.078	.058	.219	.675
	N						96	80	79	78	80	81	81
6. Cancer fatalism	R						--	.227*	.230*	.232*	.213	.172	.183
	Sig.							**.043**	**.042**	**.041**	.058	.125	.103
	N							80	79	78	80	81	81

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
7. Emotional support	R							--	.914**	.993**	.984**	.001	-.102
	Sig.								**.000**	**.000**	**.000**	.990	.369
	N								79	79	80	79	79
8. Total aid	R								--	.956**	.914**	.095	-.103
	Sig.									**.000**	**.000**	.407	.372
	N									79	80	78	78
9. Total functional support	R									--	.981**	.050	-.106
	Sig.										**.000**	.663	.360
	N										79	77	77
10. Total network properties	R										--	.017	-.089
	Sig.											.881	.435
	N											79	79
11. Positive religious coping score	R											--	.384**
	Sig.												**.000**
	N												82
12. Negative religious score	R												--
	Sig.												
	N												

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

Breast Cancer Knowledge		1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Susceptibility	R	--	.080	.050	.069	.039	-.065	.113	-.072	.039
	Sig.		.437	.628	.504	.706	.526	.313	.519	.727
	N		97	97	97	96	96	82	82	82
2. Seriousness	R		--	.059	.659**	-.027	.269**	.020	-.268*	-.108
	Sig.			.564	**.000**	.796	**.008**	.854	**.014**	.329
	N			98	98	97	97	83	83	83
3. Benefits	R			--	-.086	.011	-.063	-.148	-.110	-.161
	Sig.				.401	.915	.541	.181	.320	.145
	N				98	97	97	83	83	83
4. Barriers	R				--	-.072	.221*	.081	-.088	.016
	Sig.					.482	**.030**	.468	.428	.888
	N					97	97	83	83	83
5. Motivation	R					--	-.136	.194	.232*	.236*
	Sig.						.188	.082	**.036**	**.033**
	N						96	82	82	82

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

		1.	2.	3.	4.	5.	6.	7.	8.	9.
6. Cancer fatalism	R						--	-.042	-.333**	-.179
	Sig.							.705	**.002**	.108
	N							82	82	82
7. General knowledge score	R							--	.509**	.913**
	Sig.								**.000**	**.000**
	N								83	83
8. Curability knowledge score	R								--	.813**
	Sig.									**.000**
	N									83
9. Overall knowledge score	R									--
	Sig.									
	R									

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

Cancer Experience		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Susceptibility	R	--	.080	.050	.069	.039	-.065	-.059	-.053	.169	.115	-.034
	Sig.		.437	.628	.504	.706	.526	.605	.639	.097	.302	.766
	N		97	97	97	96	96	80	80	97	82	81
2. Seriousness	R		--	.059	.659**	-.027	.269**	.369**	.389**	.435**	.359**	-.021
	Sig.			.564	**.000**	.796	**.008**	**.001**	**.000**	**.000**	**.001**	.851
	N			98	98	97	97	81	81	98	83	82
3. Benefits	R			--	-.086	.011	-.063	-.155	-.195	.102	.126	.112
	Sig.				.401	.915	.541	.168	.081	.316	.255	.318
	N				98	97	97	81	81	98	83	82
4. Barriers	R				--	-.072	.221*	.205	.213	.425**	.028	-.301**
	Sig.					.482	**.030**	.066	.056	**.000**	.800	**.006**
	N					97	97	81	81	98	83	82
5. Motivation	R					--	-.136	-.168	-.191	-.306**	-.109	.182
	Sig.						.188	.136	.090	**.002**	.330	.103
	N						96	80	80	97	82	82
6. Cancer fatalism	R						--	.285*	.210	.279**	.184	-.037
	Sig.							**.010**	.062	**.006**	.097	.740
	N							80	80	97	82	81

**Correlation is significant at the 0.01 level (2-tailed) *Correlation is significant at the 0.05 level (2-tailed).

Table 5.11 cont'd *Pearson's Correlation matrix: Health beliefs and Contextual Factors*

		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
7. Symptom frequency	R							--	.838**	.403**	.487**	.109
	Sig.								**.000**	**.000**	**.000**	.338
	N								81	81	80	79
8. Symptom severity	R								--	.491**	.578**	.118
	Sig.									**.000**	**.000**	.301
	N									81	80	79
9. Depression score at T1	R									--	.504**	-.440**
	Sig.										**.000**	**.000**
	N										83	82
10. Depression score at T2	R										--	.561**
	Sig.											**.000**
	N											82
11. Change in depression scores	R											--
	Sig.											
	N											

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).

Table 5.12 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Contextual Factors Predicting Health Beliefs (N= 73)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Seriousness[a]				
Step 1				
Constant	41.670	5.389		
Age	-.240	.103	-.264	.023
Step 2				
Constant	23.944	7.308		
Age	-.181	.098	-.200	.069
Negative religious coping	.379	.113	.362	.001
Step 3				
Constant	21.553	6.817		
Age	-.129	.091	-.191	.061
Negative religious coping	.317	.106	.303	.004
Depression at T1	.381	.108	.353	.001
Step 4				
Constant	14.430	7.382		
Age	-.129	.091	-.143	.158
Negative religious coping	.336	.104	.321	**.002**
Depression at T1	.281	.115	.260	**.017**
Symptom frequency	.389	.176	.236	**.031**
Benefits[b]				
Step 1				
Constant	16.054	1.110		
Negative Religious Coping	.104	.028	.398	**.000**
Barriers[c]				
Step 1				
Constant	17.049	.952		
Depression at T1	.223	.065	.378	**.001**

Note. Significant p-values in final model are bolded.
a. R^2= .070 for Step 1; ΔR^2= .127 for Step 2; ΔR^2= .121 for Step 3; ΔR^2= .045 for Step 4.
b. R^2= .158 for Step 1.
c. R^2= .143 for Step 1.

Table 5.12 cont'd *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Contextual Factors Predicting Health Beliefs (N=73)*

	Unstandardized		Standardized	p-value
	B	SE	B	
Motivation[d]				
Step 1				
Constant	25.649	2.350		
Education	.835	.327	.288	.013
Fatalism[e]				
Step 1				
Constant	2.527	.618		
Emotional support	.007	.003	.233	.046
Step 2				
Constant	-.339	1.450		
Emotional support	.008	.003	.259	.024
Negative religious coping	.071	.033	.244	.033
Step 3				
Constant	-1.142	1.389		
Emotional support	.009	.003	.295	.007
Negative religious coping	.057	.031	.198	.069
Depression at T1	.100	.032	.339	.002
Step 4				
Constant	6.091	3.108		
Emotional support	.010	.003	.334	**.002**
Negative religious coping	.023	.033	.081	.475
Depression at T1	.094	.030	.319	**.003**
Curability knowledge	-.821	.318	-.293	**.012**

Note. Significant p-values in final model are bolded.
d. R^2= .083 for Step 1.
e. R^2= .054 for Step 1; ΔR^2= .059 for Step 2; ΔR^2= .111 for Step 3; ΔR^2= .068 for Step 4.

Aim 2

Aim 1 found several significant relationships among the conceptual variables, which were supported by the study's theoretical model. Aim 2 sought to examine differences in adherence to chemotherapy between African-American and Caucasian women with early stage breast cancer in relation to socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs and to explore these factors as predictors of adherence to chemotherapy among women with early stage breast cancer

RQ 3: *To what degree is race associated with differences in the adherence to chemotherapy in women with early stage breast cancer?*

RQ 4: *What socio-demographic factors, social interaction factors, cancer experience, breast cancer knowledge, and health beliefs predict adherence to chemotherapy in African-American and Caucasian women with early stage breast cancer?*

Ninety percent (n= 84) of the sample were adherent to their chemotherapy regimen and 10% (n= 9) of the sample discontinued chemotherapy prior to completion. For the 44 Caucasian participants, 42 (87.5%) were adherent and 2 (4.3%) were non-adherent. For the 49 African-America participants, 42 (82.4%) were adherent and 7 (13.7%) were non-adherent. Due to the predominately adherent sample, the data was highly skewed and did not meet assumptions for the intended statistical analysis. Specifically, statistical analysis could not be conducted to determine racial differences in adherence rates and predictors to the decision to discontinue chemotherapy.

Other Findings

Due to the fact the sample was largely adherent, the variable, days from diagnosis to treatment, was used as a proxy for adherence to treatment recommendations. The number of days from diagnosis to treatment in the overall sample ranged from 7 to 564 days. The participant who delayed treatment >500 days did not return to start chemotherapy and was omitted from the analysis. The mean days from diagnosis to treatment was 59.69 days and delays ranged from 44 to 74 days. The median days to treatment was 42 days and ranged from 35 to 48 days. The median number of days to treatment for Caucasian women was 33 days and ranged from 27.74 to 38.26 days. The median number of days to treatment for African-American women was 47 days and ranged from 41.06 to 52.94 days. Linear regression modeling was employed with the following covariates: socio-demographic factors, social interaction factors, breast cancer knowledge, cancer experience, and health beliefs to explore predictors of days from diagnosis to treatment using hierarchical stepwise methods.

Pearson's correlations were first employed to examine significant relationships between the study's contextual factors and days to treatment. Race (r=.231, p= **.**024), health insurance (r= -.318, p= .002), overall breast cancer knowledge (r= -.358, p= .001), symptom severity (r= .271, p= .016), motivation (r= -.221, p= .033), and cancer fatalism (r= .247, p= .017) were correlated with days to treatment (Table 5.13). In the multiple regression model, income, education, marital status, and health insurance were inputted in block 1, race was inputted in block 2, and only significant correlations were inputted in block 3 using stepwise methods. Table 5.14 displays the multiple regression models of factors that predicted days from diagnosis to treatment using hierarchal stepwise

procedures. The final model revealed emotional support, general knowledge, and cancer fatalism as predictors of days from diagnosis to treatment ($F= 7.557$, $p= .000$). Emotional support was not a significant predictor in the model. According to the model, those who were less knowledgeable about breast cancer experienced more days from diagnosis to treatment ($\beta= -.352$, $p= .002$). Participants with higher fatalistic views about breast cancer were more likely to experience more days from diagnosis to treatment ($\beta= .253$, $p= .019$).

Table 5.13 *Pearson's Correlations Between Days to Treatment and Conceptual Factors*[a]

		1.	2.	3.	4.	5.	6.	7.	8.
1. Days from diagnosis to treatment	R	--	.231*	-.318**	.247*	-.358**	-.221*	.269*	-.419**
	Sig.		**.024**	**.002**	**.017**	**.001**	**.033**	**.016**	**.000**
	N		95	93	93	82	93	80	94
2. Race	R		--	-.443**	.105	-.305**	-.075	.179	-.127
	Sig.			.000	.307	.005	.468	.110	.218
	N			97	97	83	97	81	96
3. Health insurance	R			--	-.158	.211	.364**	-.276*	.524**
	Sig.				.127	.059	.000	.014	.000
	N				95	81	95	79	94
4. Cancer fatalism	R				--	-.042	-.136	.210	-.208*
	Sig.					.705	.188	.062	.045
	N					82	96	80	94
5. General knowledge score	R					--	.194	-.113	.284**
	Sig.						.082	.319	.010
	N						82	80	82
6. HBM-motivation	R						--	-.191	.371**
	Sig.							.090	.000
	N							80	94
7. Symptom severity	R							--	-.387**
	Sig.								.000
	N								80
8. 100% adherent vs. <100% adherent	R								--
	Sig.								
	N								

Note. a. Only significant correlations (bolded) to days to treatment displayed
*Correlation is significant at the 0.05 level (2-tailed). **Correlation is significant at the 0.01 level (2-tailed).

Table 5.14 *Summary of Multiple Regression Analyses (Hierarchal Stepwise Procedure) for Contextual Factors Predicting Days to Treatment (N=73)*

	Unstandardized		Standardized	
	B	SE	B	P-value
Step 1				
Constant	113.770	24.540		
Education	-8.858	3.410	-.293	.011
Step 2				
Constant	196.032	36.784		
Emotional support	-5.256	3.477	-.174	.135
General knowledge	-12.488	4.312	-.333	.005
Step 3				
Constant	174.941	36.671		
Emotional support	-3.957	3.409	-.131	.250
General knowledge	-13.217	4.185	-.352	**.002**
Fatalism	5.094	2.119	.253	**.019**

Note. a. R^2= .086 for Step 1; ΔR^2= .097 for Step 2; ΔR^2= .062 for Step 3. Significant p-values in final model are bolded.

Summary

This chapter described relationships among socio-demographic factors (age, race, and access to care), social interaction factors (social support and religious coping), cancer experience (chemotherapy side effects and depression), breast cancer knowledge, and specific health beliefs (perceived susceptibility, seriousness, benefits, barriers, motivation and cancer fatalism). Several of the study's conceptual factors were found to be associated with each other, as suggested by the conceptual model. Due to a largely adherent sample, factors that influenced the decision to discontinue chemotherapy could not be statistically analyzed. Therefore, the outcome variable, days from diagnosis to treatment, was added as a proxy to adherence to treatment recommendations. General knowledge and cancer fatalism were found to be significant predictors of days from diagnosis to treatment.

Chapter VI

DISCUSSION AND CONCLUSIONS

Adherence to treatment is a multifaceted phenomenon and depends on many factors where no simple explanation for non-adherence exists. Based on the Health Decisions Model and a review of the literature, socio-demographic factors, disease knowledge, social interactions, cancer experience and health beliefs were examined to determine the extent of their relationships to decision making to chemotherapy adherence. This prospective study attempted to analyze differences and relationships within the study's conceptual framework that influenced the decision to discontinue recommended intravenous chemotherapy treatment in African-American and Caucasian women with early stage breast cancer. The study sample was largely adherent; therefore, days from diagnosis to treatment was used as a proxy for the decision to initiate treatment.

Summary of Findings

Research question 1

1. Race was closely associated with education, income, health insurance, and marital status.
2. Higher levels of education predicted increased knowledge to overall breast cancer and its subscale, general breast cancer knowledge. Those with higher incomes were more knowledgeable about the curability of breast cancer.

3. Higher levels of education predicted functional support and aid support. Individuals with private health insurance reported higher positive religious coping. Individuals with low incomes reported higher negative religious coping.
4. Individuals with high negative religious coping were more likely to be depressed at T2.
5. Individuals with lower incomes experienced more symptoms, increased symptom severity, and increased symptomology for depression at T1. Individuals with lower levels of education were more likely to be depressed at T2.
6. Individuals with more emotional support were more knowledgeable about breast cancer. Individuals with low negative religious coping were more knowledgeable about the curability of breast cancer

Research question 2

7. Younger individuals viewed breast cancer as a serious disease. Those with low negative religious coping scores also viewed breast cancer as a serious disease. Individuals with increased symptomology for depression at T1 and experienced increased symptom severity also viewed breast cancer as a more serious disease.
8. Individuals with high negative religious coping viewed chemotherapy treatment as beneficial.
9. Individuals who were more depressed at the start of chemotherapy were more likely to believe they had to overcome many obstacles to make it to chemotherapy treatments.
10. More educated individuals were more motivated about health maintenance.

11. Individuals with lower emotional support had more fatalistic beliefs about breast cancer. Individuals who were depressed at the start of chemotherapy also had a higher fatalistic view about breast cancer. Individuals with lower knowledge about the curability of breast cancer had higher fatalistic views about breast cancer.

Research questions 3 and 4

12. Due to a largely adherent sample, racial differences in non-adherence rates could not be examined. Additionally, predictors to the decision to discontinue chemotherapy could not be evaluated.

Other findings

13. Lower educated individuals experienced more days from diagnosis to treatment. Along the same line, individuals who were less knowledgeable about breast cancer experienced more delays to treatment. Individuals who had high fatalistic beliefs about breast cancer delayed treatment longer, as well.

Discussion of Findings

Unfortunately, this study could not confirm or disconfirm racial differences in rates of non-adherence to recommended chemotherapy regimens. Because of the high rates of chemotherapy adherence in the study's sample, predictors to the decision to discontinue chemotherapy could not be evaluated. It is possible this study recruited motivated individuals who were more likely to adhere. This study found that time to *starting* treatment after diagnosis was an interesting phenomenon that was explored further. The exploration of the outcome variable, days from diagnosis to treatment

(delays to treatment), as a proxy for adherence to treatment recommendations, revealed meaningful outcomes.

Participants who were less knowledgeable about breast cancer or did not completely understand breast cancer treatment were more likely to delay starting treatment. This is an important predictor due to the fact breast cancer knowledge can be modified at the clinical setting through teaching strategies employed by healthcare providers to ensure adequate understanding of breast cancer and its treatments. Increasing knowledge can help dispel myths and false beliefs about breast cancer and breast cancer treatment and can empower a woman to start treatment sooner. Further interventional studies are needed in this area to examine the impact of increasing one's understanding to breast cancer has on delays to treatment and chemotherapy adherence.

Participants who were less educated experienced more delays to treatment. Although formal education levels cannot be modified in the clinical setting, education levels can be used to help identify patients who may be vulnerable to treatment delays. Education was closely related to breast cancer knowledge. Therefore, this finding further supports the importance to assess for knowledge and understanding of breast cancer in the clinical setting. Once a woman is diagnosed with breast cancer, it is important to intervene at this point to ensure a woman understands her diagnosis, what treatment entails, and the risks and benefits of each treatment option. This can potentially decrease delays to treatment and later improve breast cancer outcomes.

Participants with a fatalistic view of breast cancer experienced longer delays from diagnosis to treatment. These individuals may view breast cancer as a death sentence where initiating chemotherapy treatment may not be worth their while. These individuals

may feel powerless to face breast cancer and believe they must overcome insurmountable odds to treat and cure breast cancer. Furthermore, low knowledge or understanding of treatments related to the curability of breast cancer was correlated with a fatalistic view towards breast cancer. Other studies have shown cancer fatalism is most evident in those with lower education or knowledge about the disease (Powe, 1995a; Powe & Finnie, 2003). A study examining cancer fatalism and colorectal screening found individuals who exhibited lower knowledge about colorectal cancer and to screening had a more fatalistic view of cancer, which was associated with delays to appropriate colorectal screening (Powe, 1995b). A breast cancer diagnosis requires the patient to process and integrate a great deal of information about her diagnosis and treatment options, therefore breast cancer knowledge is key where it can potentially lessen fatalistic views about breast cancer and decrease treatment delays. For example, a study found that patients who believed their cancer is curable experienced a better prognosis than their less optimistic counterparts (Soler-Vila et al., 2005).

Noteworthy Relationships within the Model

Although health insurance did not enter the final model as a predictor to delays to treatment, health insurance was closely correlated to delays in treatment. Inadequate access to healthcare (i.e. health insurance) served as a barrier to initiating treatment for breast cancer after diagnosis. Participants who were not covered by private insurance were more likely to experience more days from diagnosis to treatment. In addition, it is important to note, race was strongly correlated with health insurance. African-American women were less likely to be covered by private health insurance, thus increasing their risk of experiencing more days from diagnosis to treatment. Additionally, several studies

found health insurance predicts breast cancer outcomes; patients who are uninsured or covered by Medicare or Medicaid are less likely to be screened with mammography, more likely to delay treatment and be diagnosed at more advanced stage of breast cancer, and have decreased survival rates (Ayanian, Kohler, Abe, & Epstein, 1993; Bradley et al., 2002; Roetzheim, et al., 2000). The role health insurance has on access to treatment has important policy implication, which will be discussed in detail later in the chapter.

Participants who believed breast cancer was a serious or hopeless disease may also believe chemotherapy is too time consuming and interfered with personal activities. Additionally, those who viewed breast cancer as a serious disease experienced more symptoms and increased symptom severity. The fear of breast cancer may potentiate the symptom experience; however, no other study has reported similar findings to help support this connection. Younger participants also viewed breast cancer as a very serious disease. This finding is explained by a study that found younger women diagnosed with breast cancer experienced poorer psychological adjustment and outcomes (Siegal, Gluhoski, & Gorey, 1999). Younger women experienced more difficulties coping with an untimely diagnosis and experienced uncertainty about the future (Siegal et al., 1999). Although not predictive in the model, curability knowledge was correlated to seriousness. Thus, participants who understood the treatments related to curing breast cancer viewed breast cancer as a less serious disease suggesting knowledge about breast cancer can lessen fears surrounding the diagnosis.

Participants with a baccalaureate's degree or higher were more motivated to maintaining their health. This reflects prior knowledge that more educated individuals tend to live healthier lifestyles (Ross & Wu, 1995). Additionally, participants with

private insurance were more motivated towards health maintenance. This motivation may be partially explained by having access to healthcare. Increased knowledge about breast cancer can help a woman with breast cancer feel empowered, which is reflected in the relationship between knowledge and motivation.

Negative religious coping predicted breast cancer knowledge and beneficial beliefs about treatment. Participants who viewed chemotherapy as beneficial or were more knowledgeable about the curability of breast cancer had high negative religious coping scores. This finding is cautiously interpreted but it is suspected participants with negative religious coping are more externally controlled. Participants with high religious coping may view the fate of breast cancer is not in their hands but in the hands of others, such as a higher being. Thus, negative religious coping, in this case, is not a maladaptive strategy but can be used as a strategy for self-growth during stressful times.

Education was predictive of emotional support and the receipt of aid support in this study. It is suspected participants with higher levels of education have more access to resources that provide a means of support during the stressful diagnosis of breast cancer. Information can be used as a type of support; whereas, information about the diagnosis and treatment options can heighten satisfaction with treatment and reduce physiological, psychological, and behavioral stress (Bloom, 1982).

Participants who started chemotherapy with high symptomology for depression (T1) believed many barriers would be encountered during treatment where many things must be sacrificed in order to make it to chemotherapy. Although depression was not a predictor to treatment delays, depression is related to other breast cancer experiences such as decreased use of mammography (Bogner & Wittink, 2004). Furthermore,

depression can impact cognitive processes and have an effect on patients' knowledge and understanding of their cancer treatment (Mystakidou et al., 2005). Emotional distress has been found to interfere with processing information accurately where forgetfulness of medical information is increased (Mystakidou et al., 2005). The relationship between depression and beliefs in barriers support the need for assessment and screening for depression at diagnosis and throughout the breast cancer treatment experience to optimize breast cancer outcomes.

Symptom frequency and symptom severity were strongly associated with depression. Participants with high symptomology for depression experienced increased symptom frequency and severity. Additionally, depression and the symptom experience can influence health beliefs about breast cancer. Depression and concurrent adverse symptoms can impact a woman's decision to start chemotherapy. Again, this finding supports the importance of screening for depression in women diagnosed with breast cancer. The proper management of depression can potentially prevent adverse symptoms and may increase likelihood to adhere to recommended treatment recommendations.

The study found low-income participants experienced more symptoms and higher symptom severity. It is suspected individuals with low incomes lack the access to medications or resources needed to alleviate chemotherapy related symptoms. Non-private health insurance was correlated to symptom severity and frequency, which again may be attributed to a lack of access to medications and resources. Additionally, factors closely tied to race, such as income, education, insurance, and transportation were significantly correlated with symptom severity and frequency. Research that examines the symptom experiences of African-American women during chemotherapy and how

these differences may or may not differ from Caucasian women is very limited. However, this study provides preliminary evidence that African-American women have different symptom experiences than Caucasian women. African-American women, on average, experienced more symptoms than Caucasian women during treatment. The most commonly reported symptoms in African-American women were hair loss, fatigue, and changes in the way food tastes. Race was not associated with symptom severity; however, African-American women had a higher mean score for symptom severity.

Complex interrelationships among education, knowledge, and depression emerged in the study. A participant with lower levels of education, which is related to breast cancer knowledge, was predictive of depression at T2. Additionally, negative religious coping was predictive of depression at T2. This association leads credibility to the fact decrease knowledge about breast cancer puts a patient at risk for inadequate coping and depression possibly due to the lack of information needed to understand and properly cope with her diagnosis. A lack of understanding of breast cancer can lead to maladaptive coping, which can potentiate depression. Furthermore, depression impacts health beliefs, where individuals with depression had more fatalistic views towards breast cancer, which is a significant predictor to treatment delays. More studies are needed to further examine the interrelationships among knowledge, depression, beliefs and adherence to treatment recommendations; these studies can spearhead interventional studies in the future to decrease treatment delay.

Feminist Perspective of Findings

Biomedical frameworks fail to connect the lived and embodied meanings women attach to their bodies and fail to recognize how these experiences play a role in making

health-related decisions. Findings from this study demonstrate many socio-cultural factors play a role in treatment decision making such as socioeconomic status, health beliefs, and knowledge and understanding of the disease. These factors can contribute to the active decision to both seek and complete chemotherapy treatments. Additionally, healthcare providers must recognize the embodied meanings a woman attach to her body, including her breasts, and acknowledge that these meanings play a role in the decision making process. The way a woman defines her breasts is influenced by personal, cultural, political, social, and historical entities. In the healthcare setting, it is expected for the woman to freely give over her meaning-loaded body to a setting, person, or treatment regimen. Therefore, it is essential for healthcare providers to create an environment that allows women to express what cancer treatments mean to them and their bodies. This approach facilitates a patient centered relationship where the healthcare provider incorporates both personal experiences and the study's findings to promote optimum treatment decisions.

Study Conclusions

Several relationships purported by the study's conceptual model were supported by the study's findings. Socio-demographic factors were found to influence breast cancer knowledge, social interaction factors, the cancer experience, and health beliefs. In addition, the study's findings revealed relationships between health beliefs and the study's conceptual factors. However, social interaction factors were not strongly associated with the cancer experience, as propositioned by the model. Breast cancer knowledge and the cancer experience did not reveal a strong relationship, as well. Unfortunately, the data could not test the model as a whole for predictors to the decision

to discontinue chemotherapy. However, an examination of days from diagnosis to treatment as a proxy for adherence to treatment recommendations revealed findings that have important clinical, research, and political implications.

Implications for Clinical Practice

Treatment delays have been linked to poorer survival (Gorin et al., 2006; Hershman et al., 2005; Hershman et al., 2003). The study's findings suggest it is important to acknowledge the decision making process for adherence starts at the diagnosis of breast cancer. It is important to intervene at this point to potentially decrease treatment delay and maximize breast cancer outcomes. Vigorous follow up with patients can lessen delays and can play a role in improving adequate follow-up to treatment. Furthermore, knowledge was a very important predictor to many of the relationships explored in the study, where higher levels of breast cancer knowledge influenced social support, coping, the cancer experience, health beliefs, and delays in treatment. A woman's knowledge and understanding of her breast cancer diagnosis is associated with a greater involvement in the decision-making process and better outcomes, such as better functional and physical well-being (Chen et al., 2008; Fagerlin et al., 2006). The study's findings suggest women relied on their knowledge of breast cancer to make important decisions regarding their treatment. Patient knowledge increases understanding and enhances the ability to actively participate in the decision making process for medical care and disease management. Informed decision-making and improvements in how treatment information is communicated is essential in the healthcare setting. The patient-healthcare provider relationship is critical for assessing the patient's knowledge and the extent to which she understands breast cancer and its associated treatment. Information

that flows in both directions and is repeated increases patient engagement, cooperation, and knowledge to breast cancer. Collaborative patient care and targeted education strategies have the potential to promote quality decision-making.

It is important to recognize the impact depression has on treatment decision-making. Depression compromises physical, emotional, and cognitive functioning, which contributes to ineffective coping, proper cognitive processing of information, maladaptive health beliefs, and finally delays to starting treatment. The proper assessment and treatment of depression can improve clinical outcomes and can help women cope with the breast cancer experience and improve quality treatment decision-making.

Implications for Research

Further research is needed in this area to closely examine the decision making process that occurs in the vulnerable time period from diagnosis to treatment. Additionally, more research is needed to examine how treatment related variables, not explored in this study, can impact or confound the findings in this study. For example, if a patient receives surgery or chemotherapy first, can have an impact on the woman's decision making process and should be explored in future studies. The impact of interaction terms within the study's variables should also be examined for its influence on treatment decision making. Future studies should expand on this study where a larger study is conducted that specifically examines the relationship between decision making and adherence to treatment recommendations.

Future research dedicated to this topic is necessary and essential to designing intervention studies to enhance treatment decision-making. This study presents

preliminary findings on several avenues where researchers and clinicians can intervene to improve treatment decision making to adherence to treatment recommendations. Intervention studies are needed to provide evidence of strategies that are effective at decreasing delays to treatment and what strategies provide the most beneficial breast cancer outcomes. Additionally, research that explores strategies to increasing knowledge and understanding of breast cancer can increase a woman's ability to actively participate in treatment decision making.

Implications for Policy

This study has several policy implications to improve the time between diagnosis and cancer treatment. Access to care in the form of health insurance was correlated to treatment delays, which has several implications on the structural level. Systematic interventions can improve the delivery of healthcare, where policies can be implemented to allow equal access to healthcare and treatment. Additionally, hospital level policies should promote practices that enhance patient's knowledge and facilitate patients to have active roles in the diagnosis and treatment process.

Policies that aim to de-fragmentize healthcare delivery can improve continuity of care and decrease significant delays to treatment. Complexities of the health care systems and multiple barriers can impede optimum care and impact health outcomes. Hospitals and healthcare centers should implement policies that aim to provide services to women with breast cancer to ensure positive outcomes. Promoting culturally sensitive healthcare providers can enhance patient relationships and promote trust and empowerment that can help improve and ensure positive health outcomes. Policies that implement nurse navigators to provide individualized, interpersonal, and comprehensive

assessments of each individual's projected educational needs and treatment goals. Nurse navigators can provide assistance to patients with communication, transportation, financial, administrative, and emotional barriers to care.

Women who lack resources, such as African-American women who are more likely to be poor, are more likely to come across systematic, financial, emotional, psychosocial, and transportation barriers that can impede treatment adherence and increase the chances of system failures. Successful implementation of policies that strive to lessen the days from diagnosis to treatment can improve health outcomes in women with breast cancer, specifically African-American women since prior studies revealed African-American women are more likely to delay treatment.

Strengths of the Study

Previous studies used large national databases to assess adherence rates between racial groups. The use of large national databases present with limitations such as the difficulty to control for extraneous factors or determine specific predictors to treatment decision making. The prospective design of this study allowed predictors to starting chemotherapy to be examined, which is also vulnerable period for treatment decision-making. Prior studies examined and defined treatment delay as the time from which a woman finds an abnormality to the time she seeks medical attention. This study is unique where it examined the time period between diagnosis and initiating treatment. Additionally, this study identified predictors to starting chemotherapy that can be potentially modified with interventions at the clinical setting. This data can be used in future research such as intervention studies that promote quality treatment decision making and ultimately help improve survival rates. Since prior studies found African-

American women with breast cancer are more likely to delay treatment (Hershman et al., 2003), this information can be used to decrease delays to treatment in this vulnerable population. The study can be used as a spearhead to subsequent studies and intervention studies that can help close the disparity gap.

Limitations of the Study

The limitations should be noted in this study. First, the study's sample was generally an adherent sample, which is clinically advantageous, but statistically problematic when exploring relationships and differences to chemotherapy non-adherence between groups. This study was unable to answer what influences a women to discontinue chemotherapy and unable to confirm racial differences in this sample. In addition, this sample included a convenience sample with an extensive inclusion and exclusion criteria, thus findings cannot be generalized to the general populations. Additionally, this study only included women with early stage breast cancer. The decision making process for breast cancer that is still curable is suspected to be different from more advanced breast cancer. Important to note, African-American women are more likely to present with late stage breast cancer, so this study omitted a subpopulation of African-American women with late stage breast cancer. African-American women are also a heterogeneous population with several subpopulations that is tied with unique beliefs and cultural practices, so the study's findings should cautiously be applied to the general African-American population. Despite these limitations, the strengths of this study and the potential implications of the study's findings outweigh its limitations.

Summary

In conclusion, although this study was unable to examine all of its research questions, this study was able to provide information and advance the knowledge base of the decision making process related to starting chemotherapy in women with early stage breast cancer. Knowledge and fatalistic views toward breast cancer were important predictors to treatment decision making and allow for opportunities for intervention to improve the treatment experience. The study produced fruitful results that can guide future research that improves health outcomes in women with breast cancer.

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Appendix A

Descriptive Differences between African-American and Caucasian Women

Descriptive differences between African-American and Caucasian women

Characteristic (n/%)	Caucasian/white (n=48)	African American/ black (n=51)	p-value
Age (mean (*SD*); years)[a]	52.75 (12.18)	50.96 (10.56)	.355
Total household income[b]			
< $50,000	13 (28.3%)	32 (65.3%)	**.000**
$50,000 or more	33 (71.7)	5 (34.7%)	
Highest level of education[b]			
<Associate's degree	18 (37.5%)	30 (58.8%)	**.027**
Baccalaureate's degree or higher	30 (62.5%)	21 (41.2%)	
Marital status[b]			
Now married	36 (75%)	11 (21.6%)	**.000**
Single	12 (25%)	40 (78.4%)	
Spouse or partner employed[b]			
Yes	30 (62.5%)	6 (11.8%)	**.000**
No	8 (16.7%%)	8 (15.7%)	
Living arrangements[b]			
Lives alone	8 (19%)	15 (33.3%)	.102
Lives with other	34 (81%)	30 (66.7%)	
Employment status[b]			
Unemployed	23 (47.9%)	33 (64.7%)	.069
Employed	25 (52.1%)	18 (35.3%)	
Type of health insurance[b]			
None	5 (10.6%)	26 (52%)	**.000**
Private	42 (89.4%)	24 (48%)	
Reliable transportation[b]			
Yes	42 (87.5%)	39 (76.5%)	.122
No	6 (12.5%)	12 (23.5%)	

Note. *Significant findings (p<.05) are bolded.*

a. *Independent t-test*

b. *Chi- square test*

Appendix B

Demographic Questionnaire

Demographic and Personal Information Form

Age _____ Date of birth _____

1. What race or ethnicity do you consider yourself?
    a. African American or Black
    b. Caucasian or White
    c. Hispanic or Latino
    d. Other

2. What is your total household income?
    a. Less than $10,000
    b. $10,000- $19,999
    c. $20,000- $29,999
    d. $30,000- $39,999
    e. $40,000- $49,999
    f. $50,000- $59,999
    g. $60,000- $69,999
    h. $70,000- $79,999
    i. $80,000- $89,999
    j. $90,000- $99,999
    k. $100,000 or more

3. What is your marital status?
    a. Now married
    b. Domestic partner
    c. Single/ Never married
    d. Divorced
    e. Separated
    f. Widowed

4. What are your living arrangements?
    a. Live alone
    b. Live with spouse
    c. Live with domestic partner
    d. Live with children

5. What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received.
    a. 6^{th} grade or less
    b. 7^{th} to 9^{th} grade
    c. 10^{th} -11^{th} grade
    d. 12^{th} grade
    e. Vocational or trade school diploma
    f. At least 1 year of junior college
    h. Associate's degree
    i. Baccalaureate degree
    j. Master's degree
    k. Doctorate or law degree

6. What is your current employment status?
    a. Full time
    b. Part time
    c. Retired
    d. Medical leave/ disability
    e. Unemployed

7. What is your occupation?
    a. Professional/ executive business
    b. Manager/ Administration
    c. Clerical. Sales
    d. Skilled labor
    e. Semi-skilled labor
    f. Unskilled labor
    g. Not applicable

8. Is your spouse or partner currently employed?
    a. Yes
    b. No
    c. Not applicable

9. What type of health insurance do you have?
    a. Private
    b. Medicare
    c. Medicaid
    d. None
    e. Other_____

10. What stage of breast cancer were you diagnosed at?

11. Do you have reliable transportation to and from the hospital?
    a. Yes, all the time
    b. Yes, some of the time
    c. No reliable transportation

Appendix C

Consent to be a Research Subject Form

Emory University School of Nursing
Consent to be a Research Subject

Title: Chemotherapy Adherence Decision Making In Early Stage Breast Cancer

Principal Investigator: Jessica Holmes, RN, BSN

Sponsor's Name: National Institute of Nursing Research, National Institutes of Health

Introduction/ Purpose
You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.** The decision to join or not join the research study will not cause you to lose any medical benefits. If you decide not to take part in this study, your doctor will continue to treat you.

- Please carefully read this form or have it read to you
- Please listen to the study doctor or study staff explain the study to you
- Please ask questions about anything that is not clear
- Feel free to take home an unsigned copy of this form and take your time to think about it and talk it over with family or friends

If you agree to join this research study, you will receive a copy of this consent form with your signature and the date, to keep. Do not sign this consent form unless you have had a chance to ask questions and get answers that make sense to you. Nothing in this form can make you give up any legal rights. By signing this form you will not give up any legal rights.

The purpose of this study is to understand the decisions a woman diagnosed with early stage breast cancer makes during her prescribed chemotherapy treatment. The researcher is interested what influence a woman's decision to attend her chemotherapy sessions and how these decisions and influences compare between African American and Caucasian women. A total of 120 women will be recruited into the study. Participants must be 21 years or older to consent to participate in the study.

Procedures
About 60 African and American women and 60 Caucasian women (120 African American and Caucasian women total) who are being seen at the Winship Cancer Center, Grady Hospital, or Emory Midtown (Crawford Long Hospital) and newly diagnosed with early stage breast cancer (stage I, II, or IIIa) will be asked to participate in the study. The study will be conducted by Jessica Holmes, a doctoral student at Emory University's School of Nursing. After the study has been explained to you by the investigator or research assistant, and eligibility to participate in the study has been met, your consent will be obtained. Arrangements will be made to fill out questionnaires at two time points. You will be asked to answer questions about your race, age, access to care, your support systems, coping, chemotherapy side effects, depression, knowledge about breast cancer,

and beliefs about breast cancer. The first time point will be at enrollment and at the beginning of your chemotherapy treatment. The second time point will be at the end of your prescribed chemotherapy treatment. If you become too tired or are unable to complete any of the questionnaires, arrangements can be made to complete the surveys at a later time. It is estimated the entire study (including both time points) should take about 60 minutes of your time.

Risks

Risks to participants are expected to be minimal. Although you may experience emotional stress when answering the questions; however, the questionnaires are commonly used in research and an emotional response are rare. If you become too tired, the questions will be continued at an agreed upon time. If you become disturbed with any of the questions in the interview, your health care provider will be notified, or you can ask the questions to be stopped.

We will give you emergency care if you are injured by this research. However, Grady Health System has not set aside funds to pay for this care or to compensate you if a mishap occurs. If you believe you have been injured by this research, you should contact the Principal Investigator, Jessica Holmes, RN, BSN at 202-213-1840 or by email, jholme3@emory.edu

Benefits

This study is not designed to benefit you directly.

Payment for Participation

Participants will receive a $10 gas or gift card at the completion of the study. Participants who withdraw early from the study will receive a pro-rated gift card of $5 after completion of the first set of questionnaires.

Confidentiality

The investigator will keep all information about the participants private. However, certain offices and people other than the researchers may look at your medical charts and study records. Government agencies, Emory or Grady employees overseeing proper study conduct may look at your study records. Study sponsors may also look at your study records. These offices include the Office for Human Research Protections, the sponsor(s), the Emory Institutional Review Board, the Emory Office of Research Compliance, the Office for Clinical Research, and the Grady Research Oversight Committee. Emory and Grady will keep any research records we produce private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Study records can be opened by court order or produced in response to a subpoena or a request for production of documents unless a Certificate of Confidentiality is in place for this study.

Costs
There are no costs to the participants.

Withdrawal from the Study
Your participation is completely voluntary and you have the right to refuse to be in this study. in fact, you can stop at anytime after giving your consent. This decision will not affect in any way your current or future medical care or any other benefits to which are otherwise entitled.

Questions
If you have any questions about this study please feel free to contact the Principal Investigator, Jessica Holmes, at 678-615-2847 or 202-213-1840, or jholme3@emory.edu.

If you have questions about your rights as a research subject or if you have questions, concerns, or complaints about the research, you may contact the Emory University Institutional Review Board at 404-712-0720, 1-877-503-9797, or e-mail to irb@emory.edu.

If you are a patient at Grady Hospital, please call Dr. Curtis Lewis, Senior Vice President for Grady Health System Medical Affairs at (404) 616-4261.

Consent
I have read this consent form (or it has been read to me). All my questions about the study and my part in it have been answered. I freely consent to be in this research study.

By signing this consent form, I have not given up any of my legal rights.

_____
Name of Subject

_____ _____
Signature of Subject Date

_____ _____
Signature of Legally Authorized Representative (when applicable) Date

_____
Authority of Legally Authorized Representative or Relationship to Subject
(when applicable)

_____ _____
Signature of Person Conducting Informed Consent Discussion Date

Appendix D

The HIPPA Authorization Form

Emory University School of Nursing Research Subject HIPAA Authorization to Use or Disclose Health Information that Identifies You for a Research Study

Name of Study: Chemotherapy Adherence Decision Making In Early Stage Breast Cancer
Study Number:_____
Name of Principal Investigator: Jessica Holmes, RN, BSN
Subject Name:_____

The privacy of your health information is important to us. In protecting your health information that identifies you, we will follow all requirements of the Health Insurance Portability and Accountability Act ("HIPAA" for short) that apply. This form will let you know how we will use any health information that you give us for this study that identifies you. :

Please read this form carefully and if you agree with it, sign it at the end.

Research Study: You are being asked to volunteer to participate in a research study. You are being asked to participate in this study because you self identify as an African American or Caucasian woman diagnosed with early stage breast cancer (stage I, II, IIIa). The purpose of this study is to examine the variables that influence the decision to complete or discontinue chemotherapy in African American and Caucasian women; and, identify racial and contextual differences that may exist in this population. Your willingness to participate in this study will assist in developing a better understanding of the decisions women make during their chemotherapy treatment and what factors best influence these decisions. You will be asked to complete survey questions. The entire amount of time needed to complete the study questions will be about 60 minutes. The lead researcher for this study is a doctoral student in the Nursing School at Emory University. This study will be conducted as part of the requirements for her work towards completing the requirements for a doctoral degree.

People That Will Use or Disclose Your Health Information that Identifies You and Purpose of Use/Disclosure:
The following people and groups will use and disclose your health information in connection with the study. In this form, all of these people and groups are called the "Information Users":

The principal investigator, Jessica Holmes, RN, BSN, and her research staff and people and organizations that she uses to help her conduct the Research Study will use and disclose your health information to do this work. National Institute of Nursing Research, National Institutes of Health is/are the sponsor(s) of this Research. The sponsor(s) and all other people and organizations that the sponsor(s) retain(s) to help it conduct and oversee the Research Study may use and disclose your health information to make sure that the research is being done correctly and to collect and analyze the results of the research.

There are a number of University persons/units, government agencies and other individuals and organizations that may use and disclose your health information to make sure that the Research Study is being conducted correctly and safely, and to monitor and regulate the research or public health issues. These people and organizations include the following: the Emory University Institutional Review Board; Grady's Oversight Research Committee; the Emory University Office for Clinical Research; the Emory University Office of Research Compliance; research monitors and reviewers; data safety monitoring boards; any government agencies who regulate the research including the Office of Human Subjects Research Protections, and public health agencies.

By signing this document you agree to allow any of these Information Users to use or disclose your health information that identifies you in order to conduct the Research Study, or to monitor or regulate research. In addition, we will comply with any laws that require us to disclose your health information, such as laws that require us to report child abuse or elder abuse. We also will comply with legal requests, or orders that that require us to disclose your health information, such as subpoenas or court orders. Finally, we may share your health information with a public health authority that the law authorizes to collect or receive such information for the purpose of preventing or controlling disease, injury or disability and/or conducting public health surveillance, investigations or interventions.

Description of Health Information that Identifies You that Will be Used or Disclosed
The Information Users may use or disclose the following health information about you: medical diagnosis, chemotherapy treatments, appointment times, study results, and answers to survey questions.

Revoking Your Authorization:
You do not have to sign this Authorization. In addition, if you sign this Authorization, later, you may change your mind at any time and revoke (take back) this Authorization. If you want to revoke this Authorization you must write to:

Jessica Holmes, RN, BSN
Emory University Nell Hodgson School of Nursing
1520 Clifton Road, NE
Suite 353
Atlanta, GA 30322-4207

If you revoke your Authorization, the researchers will not collect any more health information that identifies you, but they may use or disclose identifiable information that you already gave them in order to notify any of the other Information Users that you have taken back your authorization; to maintain the integrity or reliability of the Research Study; and to comply with any law that they are required to obey.

Other Items You Should Know:
HIPAA only applies to people or organizations that are health care providers, health care payers or healthcare clearinghouses. HIPAA may not apply to all Information Users. If HIPAA doesn't apply to an Information User, then that User doesn't have to follow HIPAA requirements when it uses or discloses your health information..
You do not have to sign this authorization form, but if you do not, you may not participate in the Research Study or receive research-related treatment. You may still receive non-research related treatment.
We will put a copy of your signed informed consent form for the Research Study and your signed HIPAA Authorization form into any medical record that you may have with Emory Healthcare facilities. Laboratory and medical procedure results received from Emory Healthcare facilities may also be placed in any medical record that you have with Emory Healthcare facilities.

If your identifying information is removed from your health information, then the information that remains will not be subject to this authorization or covered by HIPAA, and it may be used or disclosed to other persons or organizations, and/or for other purposes.

Expiration Date: The Researchers will add your PHI to a database that they are compiling for research purposes. There is no data or event after which your authorization will expire and your PHI will no longer be used for this purpose.

As a study participant, if you any questions regarding the study, you may call Ms. Jessica Holmes, the study's Principal Investigator at (202) 213-1840 or (678) 615-2847 or by email at jholme3@emory.edu. If you have any questions regarding your rights as a study subject, you may call the Emory University Institutional Review Board at 404-712-0720 or 1-877-503-9797 or by email at irb@emory.edu.

A copy of this authorization form will be given to you.

_____
Signature of Study Subject OR Subject's Legal Authorized Representative
Date _____ Time_____

_____
Printed Name of Study Subject OR Subject's Legally Authorized Representative

If Representative, Relationship to Study Subject: _____

_____
Signature of Person Obtaining Authorization

_____ _____
Date Time