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Treatment Decision Making in African American Women Diagnosed with Advanced Breast Cancer

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TREATMENT DECISION MAKING IN AFRICAN AMERICAN WOMEN
DIAGNOSED WITH ADVANCED BREAST CANCER

by

Dauphne Annette Sims

A Dissertation Submitted in
Partial Fulfillment for the
Requirements for the Degree of

Doctor of Philosophy

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May 2014

ABSTRACT
TREATMENT DECISION MAKING IN AFRICAN AMERICAN WOMEN
DIAGNOSED WITH ADVANCED BREAST CANCER

by

Dauphne Annette Sims

The University of Wisconsin-Milwaukee 2014
Under the Supervision of Professor Dr. Jennifer J. Doering

When diagnosed with breast cancer African American women have more advanced stage breast disease and encounter disparities throughout the cancer care continuum. The process of making treatment decisions can widen or narrow disparities in health outcomes. The decision making process in African American women may be influenced by several dynamics that influence how treatment decisions are made and have been previously unexplained. Guided by the conceptual framework of Cultural Capital, this grounded theory study explored the treatment decision making process of 12 African American women who were diagnosed with advanced (stages II-IV) breast cancer. The basic social process of *Fortitude in Treatment Decision Making* emerged from the data. *Fortitude* described an internal process that participants garnered to make treatment decisions and face the breast cancer journey. Utilizing *Fortitude*, participants described a treatment decision making process that included getting the diagnosis, communication with their physician, choosing a decisional pathway, and physician trust and/or mistrust that facilitated them in making treatment decisions.

This study provides nurses with a more thorough understanding of the decision making process in African American women facing advanced stage breast cancer.

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DEDICATION

This work is dedicated to my husband Marion Sims, III, my three beautiful daughters: Ronesia, Danielle, and Marian Annette, and my grandchildren both present and future. I also dedicate this work to all of the strong women who have influenced my life: my grandmothers, Carrie Elizabeth Joseph and Alberta Bell; my mother Melva Nanetta Bell and my aunt Ula Virginia (Sheila) Davis, whose journey with breast cancer was the impetus for my educational endeavor.

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Chapter One

The Problem

Decision making is a multifaceted phenomenon (Broadstock & Michie, 2000). There are many decisions that any woman would need to make once diagnosed with a life threatening disease. Yet, grasping what the decision making process is for African American women who are facing advanced breast cancer is complex. For example, African-American women are diagnosed at a later stage and therefore have more complex options to consider than their white counterparts (American Cancer Society [ACS], 2013). African-American women are more likely to die sooner (ACS, 2013), which means that poorly made treatment decisions have more dire consequences for African-American women's survival and quality of life. In addition, persistent health disparities make this process more daunting. A most important fact is that treatment decisions for African American women are not well understood. Therefore, the purpose of this study was to generate a substantive theory of the treatment decision making process of African American women who have been diagnosed with stage II to IV breast cancer.

The ability to make appropriate and informed decisions about breast cancer treatment can ultimately affect a woman's disease course, morbidity, and mortality (Hawley et al., 2007). A fundamental principle of decision making is autonomy and informed choice (O'Brien et al., 2008). In addition, patient involvement in medical decision-making refers to the ability and willingness of the patient to be an active participant in his or

her care (Gordon, 2002). A woman's ability to make informed decisions is imperative to her long term treatment outcomes with breast cancer (O'Brien et al., 2008). In the past, decision making was limited to clinical-decision making by health professionals (Broadstock & Michie, 2000). However, there has been a shift in the decision making paradigm where patient empowerment involves patient participation in their healthcare (Johnston Polacek, Ramos & Ferrer, 2007). For African American women, participation in breast cancer treatment decision making is linked to racial disparities throughout the cancer care continuum (Johnston, et al.; McVea, Minier, & Johnson Palensky, 2001; Shootman, Jeffe, Gillanders, & Aft, 2009).

The stage of disease at diagnosis is an important factor in the decision making process related to treatment in African American women. African American women present more often with late stage breast cancer disease (Adams et al., 2009; Short et al., 2009). This makes treatment decisions even more complex for all women (Halkett, 2007). The median survival after diagnosis of metastatic breast cancer, based on research by Chia et al. (2007) is around 24 months. Because of this short survival time frame women with advanced disease are likely to die sooner than later. Although there are several therapies for advanced breast cancer, decision making is especially complex in these cases due to the uncertainty of whether to further active treatment or to switch to supportive care (Sepucha, Ozanne, Partridge, & Moy, 2009). Smith (2008)

points out that “the right decisions are important to ensure that the patient achieves not just optimum survival but survival with as much a quality of life as possible” (p.51).

According to research findings, late-stage diagnosis in African American women is linked with a number of disparities including: inadequate access to care, lack of access to health information, and misconceptions about treatments (ACS, 2010). Most notably, African American women experience delays in receiving care once diagnosed with breast cancer (Ciamboone, 2006; Halpern, Chen, Marlow, & Ward, 2009; Onega, Duell, Shi, Demidenko, & Goodman, 2010) and they are less likely to receive standard treatment therapy than Caucasian women (Johnston Polacek et al., 2007; Shootmen et al., 2009).

Decision making in breast cancer comprises a series of steps or processes of decisions that need not be linear but reflect a woman’s preferences and values (Mohamed, Williams, Tamburrino, Wryobeck, & Carter, 2005). How this is done with African American women is not well understood. Yet, it is clear that there is a gap in the literature regarding how African American women engage in treatment decision making. Treatment decision making in African American women needs to be addressed from initial information needs to decisions regarding adjuvant therapies. It is important to consider the disparity in breast cancer death rates between African American women and all other ethnic groups. Filling this gap would help to reduce health disparities in mortality in

African American women as well promote quality of life for those women who ultimately choose palliative care. Therefore, it is imperative to explore the issues of decision making in African American women. The disparities surrounding treatment, specifically misconceptions and the lack of knowledge regarding appropriate treatment options (ACS, 2010), delays in treatment ((Ciamboone, 2006; Halpern, Chen, Marlow, & Ward, 2009; Onega, Duell, Shi, Demidenko, & Goodman, 2010), and the lack of empowerment perceived by African American women to participate in the decision making process are central to how late-stage disease is approached by the woman (Fagerlin et al., 2006; Hawley et al., 2009).

Purpose

Given that the purpose of this study was to generate a substantive theory of the treatment decision making process of African American women were diagnosed with stage II to IV breast cancer, it was imperative to gain understanding of their process of decision making. In addition, understanding the process of decision making in this group of women may aid health care providers to develop interventions and health care practices that may eventually reduce health disparities and promote quality of life for women and families facing this challenging illness. Moreover, a grounded theory will provide the insight into the complexities, types, and levels of decision making needed to address the immediate concerns of being diagnosed with advanced breast cancer.

Background and Significance

Phenomenon and Complexities of Decision Making

Decision making is a multifaceted process that includes decisional roles and preference, health care and patient communication styles, and information needs. Research performed by Ashing-Giwa et al. (2004) illustrated the challenges women (African American $n=5$; Asian American $n=5$; Caucasian $n=4$; and Latina $n=6$) experience managing with a breast cancer diagnosis including: lack of knowledge; medical issues such as insurance, cost and amount of time spent with physicians; cultural sensitivity of providers; language barriers; cultural factors related to beliefs about illness, gender role and family obligations. Fagerlin et al. (2006) point out that patient education is needed to ensure women of all ethnicities are able to make informed decisions regarding their care. Maly, Umezawa, Leake and Silliman (2004) stress that patient self-efficacy is a powerful predictor in how women participate in decision making with physicians, based on their work with women from all ethnicities.

Patient focused decisions involve patient autonomy and self-determination as part of the process (Broadstock & Michie, 2000). Denger et al. (1997) found, in their research, that a majority (66%) of Caucasian women wanted a substantial degree of involvement in making treatment decisions. Yet, there was a significant percent of the sample (34%) who wanted to delegate the decision making responsibility to their

physician. Moreover, other studies found similar results of a division between patient autonomy and the patients' desire for decisional involvement, with some patients choosing not to be active participants and assuming passive roles (Maly et al., 2004; Robinson & Thomson, 2001). Vogel, Helmes and Hasenburg (2008) found that newly diagnosed German breast cancer patients preferred the physician to make treatment decisions. Alternatively, Lantz et al. (2005) found that high satisfaction with decisional involvement was associated with higher levels of education and income, being married, and being white. Comparatively, minority women (African American and Latina) with low incomes were more likely to have low satisfaction or decisional regret with treatment decision making. Similarly, Hawley et al. (2007) found that the desire for treatment involvement varied according to the patient age, race, and/or educational status. Research by Hack, Denger, Watson, and Sinha (2006) showed that as Caucasian women progress along their breast cancer trajectory, they are inclined towards a more active and collaborative involvement in the care. However, the women who preferred a more passive role did so at the time immediately following surgery, around the time of adjuvant treatment planning, and follow-up. Hawley et al. (2009) linked race and decisional involvement and the role of others (spouse, family or friends) and found that African American women were least likely to indicate their spouse as important to their decision making. This is in direct contrast to research by Fowler (2006b) who

found that family and kinship ties are extremely important to African American women in decision making.

Illness and Decision Making

Classical theories of decision making presume that people have well expressed values and preferences that guide their decisions, (McCaul, Peters, Nelson, & Stefanek, 2005) and that people will make rational decisions (Betsch, Haberstroh, & Hohle, 2002). However, people confronting cancer are often in a state of information overload where they feel overwhelmed with information, options and choices (McCaul et al., 2005). Work by Vogel, Bengel, and Helmes (2008) show that many German women want a great amount of specific information concerning their illness and treatment. Conversely, Fagerlin et al. (2006) found that the majority of their participants did not have the level of knowledge commensurate with making an informed decision and that for the sample, African American women (24.2%) had less knowledge about their breast cancer treatment than white women (51.5%). Research by Hack, Denger and Dyck (1994) found Caucasian patients who were active in their decision making wanted more information and those who were passive in their decision making wanted minimal information.

Decision making is conceptualized differently depending on the discipline examining the concept. Behavior theorists discuss decision making as rational decisions that involve analytic decision making where decisional aids are utilized to help formulate solutions (Sepucha et al.,

2009). From another perspective, decision making, is thought to be problem based, where potential solutions are based on a person's available *routine*. Routine is defined as a set of prior behaviors or behavioral knowledge in which the person has learned a particular set of solutions (Betsch et al., 2002). This perspective views one's decision making as based on prior developed habits that allow people to implement decisions automatically. Furthermore, this type of decision making is not predicated on prior personal experience; instead, it can be learned by observation (Betsch et al.). Literature from a medical model perspective suggests that decision making involves including the patient in shared and informed decision making processes (Robinson & Thomas, 2001; Rimer, Briss, Zeller, Chan & Woolf, 2004; Whitney et al., 2008). Still other literature, from a systems perspective, describes decision making as an iterative process where one decision leads to another and decisions are revisited and changed based on the flow of information (Fowler, 2006a; Halkett, Arbon, Scutter & Borg, 2007).

Treatment Decision Making

The few studies that have examined treatment decision making in African American women have focused solely on early stage breast cancer (Hawley et al., 2007; Lackey, Gates & Brown, 2001; Maly, Umezawa, Ratliff, & Leake, 2006). Maly et al., found that older African American women often reported themselves as the primary decision maker. Conversely, these authors found that acculturated Latinas reported

family members were the final decision makers, more so than African American and Caucasian women. Only one study specifically researched the information needs of African American women with early breast cancer. These investigators found this group lacked the knowledge to make informed decisions (Fagerlin et al., 2006). However, research by Denger et al. (1997) regarding informational needs and decisional roles of women with breast cancer further clarified what informational needs may be lacking. The highest priority information needs for these Caucasian women were chances of cure and spread of the disease. Treatment options and family risk were in the next level of priority. The women cited adverse effects, home self-care, impact on family, and social activities in the medium level of priority. Finally the lowest priority cited was sexuality. Two investigators looked specifically at race and the mastectomy as a surgical treatment decision for women with early stage disease (Hawley et al, 2009; Katz et al., 2005). Information from the research by Katz et al. was illuminating because they found disparities with surgeons and their recommendations for breast conserving surgery (BCS). The surgeons in the study placed less emphasis on BCS when describing surgical options and making recommendations about surgery to African American women compared to Caucasian women. On the other hand Hawley et al. (2009) found that when minority women (African American and Latina) had greater patient involvement in decision making

this influenced their surgical decision making toward having a mastectomy.

Advanced Stage Breast Cancer

There is a gap in the literature regarding African American women with advanced stage breast cancer, specifically stages II to IV. There are numerous factors that are involved in making treatment decisions at this level: prior adjuvant therapy; hormone receptors; human epidermal growth factor receptor 2 (HER2) status; patient characteristics; response to prior chemotherapy; patient preference; re-biopsy and formal guidelines (Genetech, 2009). Research by Rosenzweig, Wiehagen, Brufsky, and Arnold (2009) explored how race and income status influence women's experiences with advanced breast cancer. They found that there were unique experiences for low-income African American women that implied greater physical and social distress and less understanding of illness and treatment goals. The women specifically verbalized a lack of knowledge regarding treatment efficacy and described some frustration in their attempts to find information regarding their health status and treatment goals.

Definition of Advanced Cancer

The American Joint Committee on Cancer (AJCC) has specific guidelines on how to stage breast cancer tumors. Staging is based on commonly understood knowledge about the way cancer develops and spreads (American Joint Committee on Cancer, 2014). Staging is based

on four main factors: a) location of the primary tumor a) tumor size c) lymph node involvement and d) the presence or absence of distant metastasis. The staging system is referred to as Tumor, Node and Metastasis (TNM) and goes from 0 to IV. It is also further delineated within each staging group (see Table 1). Advanced stage breast cancer is defined as stage IIB to IV (AJCC, 2014; Breastcancer.org, 2014; Genetech, 2009). Women with metastatic breast cancer are defined as having advanced staged breast cancer.

Table 1

Breast cancer staging

Stage of breast cancer	Staging Characteristics
Stage I	Tumor is no larger than 2 cm
Stage IIA	Tumor measure up to 2cm; no lymph node involvement; no distant metastasis
Stage IIB	Tumor is larger than 5 cm but has not spread to the axillary lymph nodes; Or tumor is larger than 2 cm but not larger than 5 cm; multiple lymph node metastasis;
Stage IIIA	Tumor is larger than 5 cm with multiple metastasis to the lymph nodes
Stage IIIB	Tumor may be any size with metastasis to the chest wall or has caused swelling or ulceration of the breast; multiple lymph node metastasis
Stage IIIC	A tumor of any size with multiple lymph node metastasis (above and below the clavicle; the tumor has not spread to distant parts of the body
Stage IV	A tumor of any size with multiple metastasis of lymph nodes and distant metastasis to the brain, lung, liver, and bone.

Patient-Physician Communication

Research about physician and patient communication has been well documented (Charles, Gafni, & Whelan, 2004; Maly, Stein, Umezawa, Leake, & Anglin, 2008; Nekhlyudov & Braddock, 2009). There was only one study that specifically looked at treatment decision making regarding patient physician communication in African American women ($N=39$; Royak-Schaler et al., 2008). These investigators found there were significant gaps in communication which can perpetuate misinformation. For example, 38 percent of the women were unaware of their stage of disease at diagnosis, 5 percent did not know which type of surgery they had undergone, and 31 percent never received either chemotherapy or radiation, even though it was indicated. Only 50 percent of women stated that their physician discussed treatment side effects with them. Finally, while 75 percent of the women reported that their primary source of information was their physician, they reported not receiving information on surveillance, symptoms after treatment and prevention of recurrence (Royak-Schaler et al., 2008). McVea et al. (2001) examined the patient physician relationship and low income women ($N=25$) with early stage breast cancer disease. They found that the patient physician relationship and the patient's emotional response to the diagnosis of cancer had a tremendous impact on the process of treatment decision making. Moreover, low income women did not perceive they had an opportunity for true informed decision making (McVea et al., 2001).

Breast Cancer Disparities

Barriers for African American women are reported in the literature throughout the breast cancer care continuum (Halpern et al., 2009; Johnston Polacek et al., 2007; Shootman et al., 2009). Among early stage breast cancer patients, Halpern et al. found that African American women ($N=1992$) were significantly more likely not to receive lymph node biopsy (LNB) than were Caucasian patients. Likewise, older patients ages 62 to 72 were more likely not to receive LNB than younger patients. At the other end of the continuum, Shootman et al., attempted to explain racial disparities in the development in metastases. These investigators found that African American women were more likely to be diagnosed with more advanced disease and with estrogen receptive (ER) negative and progesterone receptive (PR) negative breast cancers. In addition, African American women were more likely to develop metastases and be low-income than Caucasian women.

Additional barriers range from poor physician patient communication to disparities with age, income and disease state (McVea et al., 2001). In addition there are disparities in information sharing and coordination of follow up care plans (Royak-Schaler et al., 2008). Other barriers include incongruence with decisional roles and actual and preferred levels of involvement in decision making (Vogel, Helmes, et al., 2008; Hack et al., 2006). Some of the most important barriers are with treatment decision making especially with advanced breast cancer

disease (Sepucha et al., 2009). These investigators examined white women ($N=32$) with advanced breast cancer and assessed their decision making regarding using a decisional aid, decisional conflict, participation in decisions, and their treatment goals, experience and preferences. They found that the decisional aid was helpful. The women preferred a shared decision making style versus having the doctor make the decisions. However, ninety percent of the women felt that the main goal of treatment was to prolong life, given the lack of medical evidence for survival benefit (Sepucha et al., 2009).

Significance to Nursing Research

The way to begin to address the mortality issue in breast cancer with African American women is with nursing research. Nurses possess the training and skills to be able to design specific culturally competent research to facilitate knowledge development in this population of women. Nursing is the one common thread connecting the women throughout their journey with breast cancer from detection through survivorship. One way this is realized is through use of breast cancer “navigators” who are nurses who provide resources across time to help women manage the disease (Simon, 2013). In addition, oncology nurses play an integral role in advocating for breast cancer patients.

Part of the American Nurses Association six essential features of professional nursing is the provision of a caring relationship that facilitates health and healing (American Nurses Association [ANA], 2003).

In addition, nursing's application of scientific knowledge to the processes of diagnosis and treatment through the use of judgment and critical thinking is another essential need that is pertinent to this study's population of women (ANA, p.5). Nursing is at the forefront of fostering patient communication, providing support, and answering the questions that women have regarding breast cancer. In other words, nursing plays a key role in decision making. And, it is in this role that nursing needs to be better prepared and confident in assisting women making decisions about breast cancer care. The gaps in the literature on decision making in African American women with advanced breast cancer puts nurses in an ideal position to generate knowledge in this area.

Conceptual Framework

Cultural Capital

This study used the theoretical perspective of cultural capital to better understand the influence of culture, society, and economic factors on African American women and their decision making. The term cultural capital is broadly defined as people's symbolic and informational resources for action (Bourdieu, 1986). Those resources are forms of knowledge, operational skills, linguistic styles, values, norms, education, and advantages that a person has acquired through life long socialization (Abel, 2008). This sociologic framework by Bourdieu and Passeron facilitated the emergence of cultural capital as a conceptual tool for understanding social differentiation (Robbins, 2005).

Cultural capital can exist in three forms: in the embodied state (a form of long-lasting dispositions of the mind and body); in the objectified state, in the form of cultural goods (books, instruments, pictures etc.); and in the institutionalized state (educational degrees and professional titles; Bourdieu, 1986). It is expressed through habitus, a person's ways of acting, feeling, thinking and being which is shaped by one's past and present circumstances (Bourdieu, 1990). The equalities and/or inequalities of cultural capital are expressed in the social arena and milieu's (fields) in which people navigate on a daily basis (Bourdieu, 1986). Bourdieu (1990) defines 'field' as the social space in which interactions, transactions, and events occur. Given this definition, this theory creates a framework for how cultural practices contribute to social arenas and how these social spaces affect cultural practices and decisions. In terms of healthcare, class-related cultural resources interact with economic and social capital to form people's health decisions (Abel, 2008).

When applied to healthcare research, cultural capital can be used to define health relevant culture-based resources that are available to people to act in favor of their health (Abel, 2008). For example, cultural capital is linked to how African American women incorporate health knowledge as a resource for promoting their health (Abel, 2008). Linguistic capital, a form of embodied cultural capital, represents a means of communication and self-presentation acquired from one's

surrounding culture. This can play a significant role in how African American women communicate with healthcare providers.

There is a plethora of literature regarding the healthcare system in the United States and the inequalities in services, which includes the Institute of Medicine (2010) report on the disparities in healthcare. One of the disparities outlined in this report involves race and ethnicity. Therefore, it is important to explore the cultural perspectives of African American women and their decision making. The theoretical perspective of cultural capital will provide a context for understanding how cultural practices influence African American women's decision making in their social field(s) and within the field of the healthcare system.

Background and Use of a Cultural Capital Perspective

The French sociologist Pierre Bourdieu developed the concept of cultural capital in the 1960's to address the disparities in education of children from different social classes (Weininger & Lareau, 2007). Bourdieu posited that economic factors alone did not account for the difference, but that cultural habits and dispositions inherited from family were important as well (Bourdieu, 1986). Bourdieu maintained that culture shares many of the properties that are characteristic of economic capital, in that, cultural habits and dispositions comprise a resource capable of generating profits. Furthermore, he asserted that they can be transmitted from one generation to the next (Weininger & Lareau, 2003). Bourdieu's work used the notion that culture is directly implicated in

social inequality and that classes are differentiated from one another in terms of the overall volume of capital (economic plus cultural) controlled by individuals or families (Weininger & Lareau, 2007).

It is important to note that economic, social, and cultural capitals are interrelated fluid concepts that may help describe people's health through individual patterns of interactions; specifically the different forms of cultural capital can provide a context for understanding the differences in healthcare decisions, interactions, and treatment options. Shim (2010) defines a new concept called cultural health capital, based on Bourdieu work, which would help account for how patient provider interactions unfold in ways that may generate disparities in healthcare, specifically that while interaction styles might be non-purposeful, they are culturally-mediated and habitual. Similarly, Abel (2008) expresses the need for conceptualized cultural capital in healthcare research, particularly in relating cultural capital to healthcare inequalities based on the different forms as outlined by Bourdieu.

Cultural Capital and Decision Making in African American Women with Advanced Breast Cancer

This theory can be adapted to understanding decision making in African American women because the underlying theme of cultural inheritance (social and economic) is multifaceted and dynamic (Abel, 2008; Bourdieu, 1990). African American women may respond differently in healthcare situations based on their level of social or economic capital.

African American women who are limited in social capital may not interact fully with their healthcare provider and leave the encounter with unanswered questions, thus making uninformed decisions. In addition, this theory purports that capital can be obtained if a person is willing to work at it (Bourdieu, 1986). This proposition could provide a context to glean information on what cultural resources are needed to facilitate African American women in their decision making, which could inform future intervention development to reduce disparities. Moreover, this theory also could be utilized to explore the context of 'fields' in healthcare, specifically the use of power demonstrated by the healthcare provider and how this perceived use of power influences decision making. In addition, this theory could also assist in describing how the interaction within social fields involving family and friend's influence decision making and how decisions can evolve over time.

Research Questions

The research questions that guided this study were as follows:

1. How do African American women with advanced breast cancer describe their process of making decisions about treatment?
 - a. How do women participate in treatment decisions?
 - b. How is a woman's participation in their treatment decisions facilitated?
 - c. How is a woman's participation in their treatment decision hindered?

- d. How do women describe their patient-health care provider communication and interaction in relation to treatment decision making?
 - e. What additional resources do they utilize in making their treatment decision?
2. What factors of cultural capital do women utilize when making treatment decisions?
- a. What social supports do women utilize when making treatment decisions?
 - b. How do economic circumstances affect treatment decision making?
 - c. How do important cultural values or beliefs influence women when making treatment decisions?
 - d. How do cultural concerns influence their treatment decisions?

Chapter Summary

Breast cancer is the second most common cause of death in African American women. When diagnosed with breast cancer African American women have more advanced stage breast disease and encounter disparities throughout the cancer care continuum. The ability to make informed decisions about breast cancer treatment can ultimately affect a woman's disease trajectory and mortality. One way to address the increased mortality is explore the cultural aspects of treatment decision making of African American women.

Chapter Two

Review of Literature

This chapter will provide a comprehensive review of the breast cancer decision making literature. Breast cancer treatment research has provided new options for women making decisions regarding their breast cancer diagnosis. However, disparities in mortality continue for African American women for a myriad of reasons. The following literature review will examine:

- Health disparities in breast cancer, and
- Decision making processes

A summary of literature in each of these areas including identification of gaps in knowledge will be provided. In addition an overview and analysis of the pilot study conducted are provided.

Health Disparities in Breast Cancer

The disparities in health care for African American women are well documented (Halpern et al., 2009; Johnston Polacek et al., 2007; Shootman et al., 2009). There is compelling literature regarding disparities with African American women and breast cancer. The following areas that will be addressed are racial differences in tumor size and lymph nodes biopsy, diagnosis and treatment, the factors of race and insurance, and patient healthcare provider communication.

Disparities in Tumor Size and Lymph Nodes Biopsy

McBride et al. (2007) examined the biology of tumor size and stage of breast cancer along with the number of positive axillary lymph nodes and distant metastasis. Logistic regression models were developed for African American and white women diagnosed with stage I-III breast cancer. These women were identified through the Surveillance Epidemiology and End Results (SEER) program (African American women $n= 21,861$ and Caucasian women $n=234,313$). The SEER registry provided information regarding stage of disease; tumor grade, size and histology; lymph node status and overall survival of each patient.

The results showed African American women tumor sizes were significantly larger than Caucasian for women (2.5 cm versus 1.6). There were significantly more positive lymph nodes for African American women than for Caucasian women (4.3 vs 4.0). Across the range of tumor stages African American women had fewer stage I tumors (52.2%) than Caucasian women (65.9%) and African American women had significantly more stage II tumors than Caucasian women (40.4% vs 30.1%). In addition African American women had significantly more stage III tumors (7.4%) than Caucasian women (4.0%). They also found that tumor stage and race have a significant interaction with the mortality rate. There were racial disparities in survival rates between African American and Caucasian women: as stage at diagnosis increased, the racial disparity in survival also increased. Most importantly, African

American women had a 39 percent higher mortality rate than Caucasian women (McBride et al.).

Reeder-Hayes et al. (2011) evaluated the differences in the use of sentinel lymph node biopsy (SLNB) by age and race in Medicare patients with early breast cancer (stages I-II). Multivariable linear modeling was used to calculate the odds of receiving SLNB. Caucasian ($n=3574$) and African American ($n=300$) women who received breast conserving surgery including axillary staging with claims from 12 months before diagnosis to 24 months after diagnosis were identified through the SEER Medicare database. These investigators found in an unadjusted analysis across all years, African American women were half as likely as Caucasian women to receive SLNB ($OR .54$, 95% CI, 0.42-.069). In an adjusted analysis African American women were significantly less likely to receive SLNB than Caucasian patients ($OR=.65$, 95% CI, 0.57-0.87). Women enrolled in Medicaid had significantly lower odds of receiving the procedure ($OR=0.61$, 95% CI, 0.47-.078). Tumor characteristics were significantly associated with use of SLNB and overall women with lower risk tumor characteristics were more likely to receive SLNB. Specifically, that women with stage I or IIA tumors were more likely to have under SLNB than those with IIB tumors. The use of SLNB varied significantly by institution over time. Treatment at a cooperative group affiliated institution was associated with higher odds of receiving SLNB ($OR 2.31$, 95% CI, 1.50-

5.61). However, there was no significant interaction found between institutional characteristics and race.

Critique. These two articles highlight the disparities associated with lymph node biopsy with African American women being less likely than Caucasian women to have their lymph nodes removed, which is an important part of staging and diagnosis. One of the limitations noted of these studies was that there was no evaluation of the differences in treatment across the various stages of breast cancer. The aggressiveness of how these cancers were or were not treated has implications for mortality rates. However, these two studies confirm that lymph node removal and diagnosing is important especially for more advanced stages of breast cancer and tumor sizes. Another limitation noted was the small sample sizes (McBride et al., 2007; Reeder-Hayes, 2011) for African American women. The implication of race and institutional factors of affiliation with cooperative research groups and institutional policies that prevented performing lymph node biopsies were important considerations. The differences in how institutions treat breast cancer patients is an avenue of exploration regarding quality of care and outcomes. Neither groups of investigators looked at whether women made treatment decisions based on tumor sizes or lymph node biopsies. Finally, the finding that having Medicare does not seem to account for or explain the disparities in this area is an important finding.

Disparities in Diagnosis and Treatment

Williams et al. (2010) examined the factors associated with delays to diagnosis and treatment of breast cancer. Logistic regression, chi-square test, and Wilcoxon signed rank test, were used on a sample of African American women ($n=195$) and Caucasian women ($n=43$). This analysis was based on two data sets: Louisiana tumor registry (LTR) and Medical Center of Louisiana at New Orleans (MCLNO) electronic medical record extraction. The LTR contained statewide population based data on all newly diagnosed cancers. The MCLNO contained individual patient information (demographics, personal information, visits, patient history, laboratory, pathology and radiology results). Other criteria for the analysis were: Late stage disease, stages III-IV; Time from abnormality to diagnosis (the number of days from the date of the detection of the first abnormality to the date of the diagnosis); Time from diagnosis to initial treatment (the number of days from the date of the diagnosis to the date of the initiation of treatment); Date of Diagnosis (the date of initial diagnosis by a medical practitioner); and Treatment type (surgery, chemotherapy, radiation, other, and no treatment).

These investigators found that 31percent of the women from the MCLNO experienced delays in diagnosis that were greater than 60 days from clinical presentation with initial abnormality to diagnosis of breast cancer. African American race, stage, type of abnormality at presentation, and tumor size were all significantly associated with

diagnostic delays. In addition, these investigators found that African American race, early-stage classification, abnormality found by mammogram and decreasing tumor size were all risk factors for diagnostic delays. Although not statistically significant, Caucasian women experienced more treatment delays compared to African American women (20.9% versus 11.3%, $p=.089$). Finally, women experiencing treatment delays were significantly older than their counterparts not experiencing delays. For every 10 year increase in age, the odds of experiencing a treatment delay increased 1.6 times (OR 95% $CI=1.12-2.26$). A significant limitation of this study was the small sample size, which the authors acknowledge, along with the use of retrospective data from a single institution.

Gorin, Heck, Cheng and Smith (2006) examined delays in breast cancer diagnosis and treatment by racial/ethnic group. The purpose of the study was to describe time delays in the initial diagnosis and treatment of primary breast cancer of insured women using Medicare recipients. Racial/ethnic groups were compared in their diagnostic, treatment, and clinical delay ($N=49,865$). The women who had billing claims for diagnosis delay, treatment delay, and combined clinical delay (combined diagnostic and treatment delay) were identified through the SEER program. The racial groups were comprised of Caucasian ($n=43,627$) African American ($n=2982$) Asian/Pacific Islander ($n=1617$) and Hispanic ($n=1296$) women diagnosed with breast cancer within the

previous five years. Statistical analysis was conducted using chi-square and computer program PROC GLIMMIX to compare and analyze the associations between ethnic/racial groups. These investigators found African American women experienced the most diagnostic delay (median 29 days) with 22 percent experiencing delays for more than 2 months as compared to Caucasian women (18.3%) and Hispanic and Asian women (18%). In addition, African American women experienced the greatest amount of treatment delay (30.1%) as compared to Caucasian women (18.7%); Hispanic women (19.7%); and Asian/Pacific Islander women (21.7%). Eleven percent of African American women experienced combined clinical delay (2 month diagnosis delay and 1 month treatment delay) as compared to Caucasian (5.1%), Hispanic (6.5%), and Asian/Pacific Islander women (6.5%). In addition, this research found that while access to physicians were greater among African, Hispanic, and Asian/Pacific Islander women than among Caucasian women, more visits led to significantly increased diagnostic and combined clinical delay. These findings suggest that increased visits to healthcare providers were not sufficient enough to ensure timely use of diagnostic and treatment services.

Martinez et al. (2010) examined the use of radiation therapy in African American, Caucasian, Asian, and Hispanic women with advanced breast cancer. The SEER database was used to identify Caucasian, black, Hispanic and Asian patients with invasive breast cancer. The

sample included women who had stage III (≥ 10 metastatic lymph nodes) breast cancer ($n=12,653$). The majority of the patients were Caucasian (72%); Hispanic (10.4%); African American (10.3%); and Asian (7.3%). The patients were divided according to whether radiation therapy was given. Differences were compared among racial groups using analysis of variance for continuous variables and chi-square testing for categorical variables, proportions, and univariate logistic regression.

These investigators found disparities existed for African American women as compared to the other racial groups. African American women had the largest mean tumor size and were less likely to have radiation. Radiation therapy is a key component in the management of patients with advanced breast cancer. It is indicated for all patients undergoing breast conservation. Postmastectomy radiation therapy is the current standard for breast cancers with ≥ 4 axially lymph node metastases. Adherence to these guidelines is a marker for quality cancer care. These investigators identified that both African American and Hispanic women (45.8% and 48.6% respectively) were less likely to receive radiation therapy than Caucasian women (51.6%). Moreover, regardless of the racial/ethnic disparities, noted rates of radiation therapy were low for all populations with a range of 46 to 54 percent, but the reasons for this were unknown. However, researchers posited that clinicians were taking a nihilistic approach to patients and perhaps were assuming that they

had occult systemic disease and did not consider the need for radiation therapy (Martinez et al., 2010).

Critique. The above-mentioned research highlights disparities regarding diagnostic delays, age, and treatment. It highlights the importance of having the right treatment for the right type of breast cancer. These studies show a gap in the standards of treatment offered and that national treatment standards are an area for exploration. A couple of limitations that were noted were hormonal therapies were omitted in research by Gorin et al. (2006) and the specific reasons for the diagnostic delays are unknown for Williams et al. (2010). Also the issue of having access to diagnostic equipment is an important factor that needs to be explored further. The impact of treatment delays on age need further exploration. Finally, an exploration of the specific type of treatments offered to African American women when making their decisions is needed.

Breast Cancer Disparities and Health Insurance

Komenaka et al. (2010) researched race and breast cancer outcomes in the underinsured population. A retrospective review of medical records were used to draw comparisons between non-Hispanic Caucasian ($n=259$) and African American women ($n=315$) who were identified as being diagnosed with breast cancer utilizing a Cox proportional hazards regression analysis. Specific criteria for being considered underinsured were: a) if they did not have commercial

insurance or HMO coverage and b) if they had Medicare and Medicaid due to the limitations of coverage in these types of programs. The investigators found African American women were more likely to be unemployed, retired or disabled. African American women were more likely to have Medicaid or no insurance than non-Hispanic Caucasian women. African American women presented with more advanced clinical stage disease 52 percent had stage II-IV as compared to the non-Hispanic Caucasian women who had 41percent with these stages. Furthermore, African American women had a higher number of recurrence with distant metastases (70%) than their non-Hispanic Caucasian counterparts (49%). These investigators also found that late stage disease at diagnosis was the number one factor in the disparities in mortality between the two groups with proportionately more African American than non-Hispanic Caucasian women dying of breast cancer (18.6% vs 12.2%).

Similar research by DeSantis, Jemal and Ward (2010) compared African American women and Caucasian women diagnosed with invasive breast cancer stage III-IV. The researchers selected African American ($n=24,483$) and Caucasian women ($n=169,486$) ages 20-99 from the National Cancer Database. Logistic regression models were used to assess the associations between demographic characteristics and breast cancer prognostic factors. They compared age, race, insurance, education, stage of breast cancer, tumor size, and lymph node

involvement. They found that African American women were more likely to be younger, uninsured and live in zip codes where a large percentage of the population lacked a high school diploma. The breast tumors in the African American women were more likely to be larger, less differentiated, hormone receptor positive and have positive lymph nodes and metastasis. They found that adjustment for insurance and area-level educational attainment explained a substantial proportion of the African American –Caucasian difference in metastasis, tumor size and lymph node status. Being uninsured was strongly associated with not having regular mammography screenings which resulted in the diagnosis of more advanced tumors (DeSantis et al., 2010).

Critique. Research in this area provides strong evidence for increased tumor size, late diagnosis, and the potential for metastasis in African American women, over other ethnic groups, being directly related to mortality. Specifically, having insurance did not mediate differences between African American women and other ethnic groups. These investigators also linked zip codes and clustering of breast cancer patients in a geographical location to being underinsured. Limitations in the above studies are small sample sizes, the use of one institution, retrospective data (Komenaka et al., 2010) and not considering unknown comorbidities that affect breast cancer prognosis (DeSantis et al., 2010). The findings highlight exploration of being underinsured versus insured

and decision making, specifically, how personal finances affect treatment decision making.

Patient-Physician Communication

Patient physician communication is important to the process of decision making by African American women. The literature in this area highlights the disparity in communication between African American women and their healthcare providers (Royak-Schaler et al., 2008). Williams et al. (2008) explored communication and decision making with health care providers in African Americans living with cancer and their families. They utilized focus groups to identify and explore cultural perceptions, expectations, and desires as they related to quality of life (QOL). Thirty-three African American women participated with 21 of the other focus group members being caregivers of a family member with cancer.

The investigators utilized grounded theory and found the following themes: 1) Effective communication where the participants stressed that a fundamental part of effective communication was the establishing of a relationship with which the physician and other healthcare providers sought to “know and understand” the patient and family as individuals. In addition, in knowing the individual patient, the physician/healthcare provider should communicate with them based on that knowledge. Lastly, the “knowing” of the patient was also the foundation for effective decision making. 2) Decision making with one of themes being having a

sense of control. The participants felt that the physicians/healthcare provider role was to clearly outline available options and then to respect the decision making ability and choices of the patient and their family. Secondly, not all patients have the capacity to be self-advocates and participants expressed concern for vulnerable populations. Lastly, individuals who were older, poorer, and had low levels of formal education were at particular risk. The participants felt it very important that vulnerable populations “need to know that they have a choice” (Williams et al., p.1223).

Maly et al. (2008) studied the differences of physician communication and patient empowerment in older women with breast cancer. A cross sectional sample of Latina ($n=99$), African American ($n=66$), and Caucasian women ($n=92$) over the age of 55 and who were recently diagnosed with stage I or higher breast cancer were recruited. The participants were interviewed either by telephone or in-person. In addition, the participants completed a supplemental self-administered questionnaire regarding physician communication. The researchers utilized a confirmatory factor analysis to assess three hypotheses: 1) There would be racial/ethnic disparities in older women’s QOL and breast cancer treatment; 2) Patient empowerment through physician communication, as reported by patients would predict better QOL and receipt of breast conserving surgery (BCS) and: 3) Relationships among race/ethnicity and the outcomes of QOL and BCS would be mediated by

physician and system level factors (physician communication and perceived racism) and patient cognitive factors (self-efficacy, knowledge, and coping).

Inspection of the results showed African American women reported good QOL whereas Latinas reported worse QOL. African American and Latina women received BCS less often compared with Caucasians. Greater patient perception of interactive information giving and shared treatment decision-making by physicians correlated with increased QOL and receipt of BCS. Compared with Caucasians, African Americans expressed substantial mistrust of the health care system and Latina reported somewhat less mistrust. In addition medical mistrust also predicted decreased feelings of self-efficacy in interacting with physicians, thus reducing both QOL and the likelihood of receiving BCS. African American race was significantly and negatively ($r = -.14$, $p < .001$) associated with physician emotional support and breast cancer knowledge. Latina ethnicity was significantly and negatively ($r = -.32$, $p < .001$) related to both breast conserving surgery and quality of life. Greater patient perception of interactive information giving and shared treatment decision making by physicians correlated with increased quality of life.

Critique. The above research supports the need for more exploration into communication patterns of physicians and the need for information gathering of women with breast cancer. The research also

highlights issues with physician trust, communication, and quality of life which has implications for follow up and survivorship. Both of these studies specifically addressed decision making and information needs. The use of grounded theory to examine communication was noted in the Williams et al. (2008) study. Limitations noted for both studies were the small sample sizes and use of nonrandom sample and potential bias (Williams et al., 2008) and variance in the definitions of effective communication. This research lends insight into the exploration of the specific informational needs of African American women at the point of diagnosed with breast cancer.

African American Women and the Decision Making Process

Decision making is a multifaceted phenomenon (Broadstock & Michie, 2000). A review of the literature reveals decision making theories and frameworks from medical to organizational disciplines. Yet, grasping what decision making is for African American women who are facing a challenging illness is complex. There are many decisions that any woman would need to make once diagnosed with a life threatening disease. Some of the seminal work by Hack et al. (1994) who examined decisional control and illness information and Biloudeau and Denger (1996) and Denger et al. (1997) who examined decision roles, preferences, and involvement for Caucasian women laid the ground work for other research into decision making and breast cancer illness. The following

literature will describe research regarding decision making and breast cancer.

Decisional Roles and Preferences

Katz et al. (2005) examined the relationship between patient involvement in decision making and the type of surgical treatment chosen. Women were chosen by random sampling with the Surveillance, Epidemiology and End Results (SEER) database, who had invasive breast cancer, stages 0-II and were classified as being post-surgical. Seventy-seven percent of the women eligible for the study completed a written survey ($n=2,382$). If the written survey was not returned, the remaining participants were called and completed an abbreviated telephone survey ($n=1844$). The authors developed instruments to specifically measure independent variables of patient involvement in surgical decision making and clinical factors (i.e. cancer stage, medical comorbidities, and clinical contradictions to BCS or mastectomy) and utilized logistic regression to determine the type of surgical treatment received. Study results showed racial differences between numbers of surgeons seen, number of office visits, timing of decision, and surgical recommendation. African American women visited more surgeons, had more visits before surgery and were less likely to have made the surgical decision during the first consultation. In addition, African American women reported receiving less information about breast conserving surgery. Surgeon decision control was strongly associated with receipt of breast conserving surgery

for Caucasian women; this association was less evident for African American women. In fact, African American women were more likely to have received mastectomy compared with other ethnic groups when the decision was perceived to have been made by the surgeon.

Hawley et al. (2009) evaluated the association between patient decision involvement and surgery received in an ethnically diverse population of Latina, African American and Caucasian patients. Secondly, they evaluated patients' attitudes about surgery and the role of family and friends in surgical treatment choices. Women were recruited using a SEER registry by random sampling with a sample size of ($n=1651$): Latina ($n=395$), African American ($n=448$) and Caucasian patients ($n=808$). This study was designed to stratify race with women who had early stage breast cancer 0-II. Written survey instrumentation was used (96.5%) with follow up telephone surveying (3.5%) for those who did not return the written survey. The authors used the framework of health care utilization. The patient survey assessing the initial surgery the patient received was based on a pilot study utilizing this framework. Patient involvement was measured using the control preferences scale developed by Denger et al. (1997). The control preference scale asks respondents to rate their actual involvement in medical decision on a 5-point scale (Hawley et al.). Latina patients were further categorized by low-acculturation and high-acculturation by utilizing the short acculturation scale by Hispanics developed by Marin et al. (1987). Patient

attitudes regarding surgery were assessed by asking the patient to indicate the importance of issues related to cancer recurrences, radiation, and body image. ANOVA was used to evaluate racial and ethnic differences in age at diagnosis. Logistic regression models were constructed to examine the odds of having a mastectomy as the initial surgical treatment.

The results showed the majority of women reported shared surgical treatment decision making. All women reported concerns that recurrences were important in their treatment decision making. However, African American women indicated that this issue was quite or very important more often than the other groups. In addition, African American women and high-acculturated Latina patients reported that body image concerns were quite or very important in their treatment decisions. Most women reported having a family member or friend present during surgical consultation. However, African American women were least likely to report having been accompanied. Moreover, African American women were the least likely to indicate that their spouse was very important in decision making. In regards to decision involvement and initial mastectomy, most of the women who initially received mastectomies were greatest among women who reported a patient-based decision compared with those who reported a shared or surgeon-based decision. Women who reported that concerns about recurrence and radiation were very important in their decision making received

mastectomy significantly more often than women for whom concerns about these issues were of little importance. Conversely, those who were quite or very concerned about body image were less likely to receive initial mastectomy compared with those who were not very or moderately concerned.

Critique. Findings from these studies are important because they involved three key factors; patient perception, patient involvement, and treatment choices in surgical decisions. They provide information on various ethnic groups (African American, Caucasian, and Latina) and how these women preferred to participate in treatment decision making. These studies provided information on the specific types of decision making and informational needs of women with early stage breast cancer. In addition, Hawley et al. (2009) specifically studied how women rated their decision making, the role of their significant others in their decision making, and support in their surgery consultations. A strength of the Katz (2005) study was that it illustrated how physicians presented the information to their breast cancer patients. Some physicians only presented one option, while others were careful to lay out all of the alternatives. A strength of these studies is the use of the SEER registries because they are population-based registries that would potentially yield a sample that is generally representative of the population in that geographical area. Another strength of these studies is that they began to

tease out what other factors influence patient involvement and patient attitudes and the role of others in the patient's decision making process. Limitations of these studies include not addressing the time frame involved in decision making nor evaluating the physician's involvement in decision making. Lastly, neither study examined women with advanced stage breast cancer.

Perceptions and Experiences of Treatment Decision Making

Wenzel and Shaha (2008) explored women's perceptions of and experiences with breast cancer treatment decision making in Managed Care Organizations (MCO) to ascertain if any limitations were imposed on treatment options. Utilizing phenomenology, women (Caucasian $n=9$; African American $n=4$; and Asian Pacifica Islander, $n=1$) were interviewed who were enrolled in a MCO from their initial treatment decisions (6-8 weeks) through any decisions made regarding chemotherapy and/or radiation (1 year or longer). The results showed how participants reported preferring to defer treatment decisions to their provider and relied on advice and recommendations from family or friends, especially from previous cancer survivors. In addition, women related that some decisions were dictated by the cost of premiums and provider choice. These women wanted the MCO to offer more choices in their treatment facilities and retain trusted cancer providers. Some women expressed concerns about the difficulties of being accepted by another health plan should their spouse change jobs.

Halkett et al. (2007) sought to understand the phenomenon of how women made decisions when diagnosed with early stage breast cancer. This study was different from other decision making studies, in that the investigators explored the experiences of making these decisions, rather than the decisions themselves. The authors interview 18 South Australian women who had completed treatment, and were guided by a hermeneutic phenomenological design. The investigators found that during their experience with early breast cancer, women found they needed to make many decisions, including: Who they would talk to; which provider or providers they would consult; what treatment they would receive; how they would communicate with healthcare professionals; how active they would be in their treatment choices; whether to seek a second opinion; how to react to their diagnosis; what meaning they would allocate to breast cancer; and how breast cancer would change their lives. The themes identified were: *Being challenged* where the experience of making decisions began when the women suspected they had cancer and decided to go for a mammogram; *Getting ready*, when the women received the diagnosis, they attempted to get into a state of readiness; *Surviving*, where the experiences of making decisions was characterized by the need to survive; *Sharing the challenge*, where the women did not experience the challenge of breast cancer and making their decisions alone; and *Interrogating the future*

where the phenomenon of making decisions was a continuous experiences because of the ongoing effect on their lives.

Lally (2009) explored the pretreatment thoughts and behaviors of women newly diagnosed with breast cancer regarding their surgical treatment decision making experiences. The investigator utilized a grounded theory methodology. Lally interviewed 18 women with stage 0-II breast cancer who had either: 1) Undergone surgical consultation with one of four general surgeons or a surgical oncologist; or 2) Had been presented with surgical options but had not undergone surgical treatment. Inspection of the results showed the pretreatment period was characterized by the following themes: a) Information processing where overall the women felt that information about breast cancer was important, plentiful and readily available and that their needs were met; b) Contemplating options, this involved making the choice between lumpectomy or mastectomy with or without breast reconstructions; and c) Interacting with others, with the women experiencing multiple interactions with healthcare providers and family and friends who affected their decision making. In addition, the investigator found that women did not share their preferences with their surgeons and that surgeons did not make treatment recommendations. In fact, treatment options were contemplated and preferences formed often before the initial surgical consultation.

Critique. The above research demonstrates how important communication and timing are in the decision making process. Specifically, how allowing time for contemplation and the availability of choices are key factors in decision making. This research also highlighted how women demonstrated trust in their providers by utilizing a passive decision style. Most importantly, this research highlights how facilitating women's decision making early in the process when they are making critical choices is key to their smooth transition from a health state to an illness state. A strength of this research was that it provided alternate descriptions for informed and shared decision makings, where informed decision making involved information gleaned from sources other than the physician. A limitation of the Halkett et al. (2007) study was that it did not look at who supported the women in their decision making. Another limitation noted was in the Wenzel and Shaha (2008) study where the specific stage of breast cancer nor the effects of cost containment on treatment decision making were assessed.

Decision Making and Social Processes

Fowler (2006a) sought to describe the social process used by African American women in making decisions regarding mammography screening. Fowler used grounded theory methodology to interview 30 African American women of diverse socioeconomic backgrounds. Results showed that the women's decisions were associated with five social processes: 1) Acknowledging prior experiences with healthcare providers

and systems where assertiveness skills and prior positive experiences with healthcare providers accounted for prior success in navigating healthcare systems; 2) Reporting fears and fatalistic beliefs and related treatment, where participants pondered the negative effects of breast cancer but realized the benefits of adherence to breast health recommendations; 3) Valuing the opinions of significant others, where all participants identified with influential women in the media promoting empowerment for African American women; 4) Relying on religious beliefs and supports, where this group of women used the bible or religious scriptures metaphorically to affirm or reaffirm positive role-model images of strong and powerful women when confirming decision-making about mammography screening; and 5) Caregiving responsibilities of significant others, where caregiving was necessary for the protection and social interactions of future generations.

Critique. This investigation was important because it linked culture and social ties to screening practices. Although, the investigator looked only at how mammography screening decision making was employed, some of the themes could be extracted for future exploration with women diagnosed with breast cancer. The strength of this investigation highlights how social support plays an important role in decision making with African American women. Another strength of this investigation is that it highlights the need of establishing credibility in the African American community. A limitation noted was the sample

consisted of religious women which views might differ from non-religious women.

The Utility of the Cultural Capital Conceptual Model

Integrating Bourdieu's theory with the culture aspects of African American women and breast cancer treatment decision making will aid in outlining cultural resources, the obtainment of these resources, and how these resources can help African American women navigate the health care system. This theoretical perspective was important because it helped to frame an explanation for the differences in why African American women are dying more so than any other ethnic group.

The basic tenets of this theory are how one utilizes existing cultural resources (cultural norms and values, social, and economic supports), how to profit from these resources, and how to accumulate more resources. Most importantly, these tenets provide a structured argument for functioning in the social world (Bourdieu, 1986). So for African American women to be able to take a cultural inventory and assess what cultural resources they do and do not possess, gives them the opportunity to fully utilize their resources or improve upon any deficiencies. This is a problem based theory where action is required (Abel, 2008). So, where they see inequality they can take action or tap into their resources to change their circumstance. One way Bourdieu elaborates on for changing and gaining cultural resources is through education (Bourdieu, 1986). By obtaining more knowledge (e.g. college

education) a person can improve upon their cultural, social, and economic resources. This in turn, provides people with more assets in which to navigate their world. This is extremely important for African American women who face health care disparities. By tapping into one's cultural capital, a woman can begin to educate herself, improve upon her linguistic skills, be aware of her social position field, and feel more empowered to be a participant in her healthcare.

Chapter Summary

How African American women with advanced breast cancer make treatment decisions remains unknown. This literature review illustrates many examples of health disparities and known areas of decision making that attempt to ferret out these processes. The disparities presented in this literature review show how African American have limited access to care when it comes to delays in diagnosis and treatment. In addition, most of the studies did not assess if the women being studied had regular healthcare providers. Furthermore, geographically the lack of access to care is focused on rural areas. However, the limits in access to care in urban areas is not understood for this population and is an area for exploration.

This literature review details specific disparities with radiation treatment as an option. Therefore specific treatment options need to be explored with this population. Also, this literature review revealed another major area of disparities involving patient-healthcare provider

communication and the barriers that exist within this relationship. What it did not reveal was a definition for effective communication and the level of trust that is needed for women making treatment decisions. Finally, there was a specific conceptual gap noted because there has been no research that utilized Bourdieu's cultural capital theory with decision making in African American women diagnosed with advanced breast cancer. This theory has the potential to provide a cultural framework for understanding the decisional needs of African American women.

There were a few studies that specifically focus on breast cancer and decision making. However, there was several methodological gaps noted with these studies that are outlined as follows:

- 1) While the sampling of these studies made attempts at diversity, the sampling focused on women with early stage breast cancer and the sampling numbers for African American women were usually small with the majority number of women being Caucasian;

- 2) There was limited information on cultural ties and social norm processes for women with advanced cancer;

- 3) The literature review highlighted significant financial barriers for women getting treatment for breast cancer, however, barriers for women with advanced breast cancer remain unknown;

4) Specific measurements of who supported the women and their level of involvement was alluded to (Katz, 2005; Hawley et al., 2009) but needs further exploration for women with advanced breast cancer;

5) There was limited information regarding timing of decisions in the abovementioned research. Yet, the pressure of timing in decision making was a theme found in the pilot study by Sims (2009);

6) The impact of patient-physician communication on decision making is well documented. However, the impact of this relationship in treatment decision making needs to be explored;

7) Many of the studies were retrospective reviews or chart studies. However, there was a caveat in the study by Lally (2011) which included a prospective review utilizing grounded theory and this type of study would be optimal for women with advanced breast cancer to capture decision making over time; and lastly,

8) There were no studies that examined the treatment decision making process from diagnosis through follow-up.

This literature reveals the need to study the concept of how African American women with advanced breast cancer make their treatment decisions in the context of their everyday lives. This study will focus on the identified knowledge gaps through an investigation using grounded theory methodology to capture the processes utilized by this group of women. To this end, a substantive theory will be generated regarding treatment decision making.

Chapter Three Methods

Design

Being diagnosed with advanced breast cancer involves complex decisions that require a simultaneous need for disease knowledge (Broadstock & Michie, 2000; Fagerlin et al., 2006). A grounded theory methodology allowed an exploration of the decision making processes of African American women as they address their disease trajectory with various treatment modalities. In this chapter an overview of grounded theory, protections of human rights, instrumentation, data collection procedures, analysis, and establishing rigor are provided.

Overview of Grounded Theory

The grounded theory method was developed by Glaser and Strauss (1967). Grounded theory methods involves an inductive process using a constant comparative method. The goal of this method is to develop a theory that describes the process of social interactions that characterize a particular experience (Ayres, 2007). This method identifies a basic social process that emerges over time as data are coded through several levels of abstraction. It involves data collection with the generation of hypotheses and categories through open, selective, and theoretical coding, and theoretical memos (Glaser, 1978). Glaser explains “this process generates theory that fits the real world, works in prediction and explanations, is relevant to the people concerned and is readily modifiable” (p.142). Most importantly, grounded theory provides nursing

with a viable means of generating theory grounded in the realities of everyday clinical practice (Elliott & Lazenbatt, 2005).

Pilot Study Findings

A pilot study was conducted by the investigator utilizing grounded theory to explore informed decision making in African American women ($N=6$) diagnosed with breast cancer to answer these questions:

1. How do African American women describe their decision making about detection screening practices, diagnosis and treatment of their breast cancer? 2. What information is needed to facilitate African American women's decision making? Sample characteristics were as follows: The average age at diagnosis was 53 years. The initial diagnosis of breast cancer for two of the women has been within the past year and they are currently undergoing chemotherapy and/or radiation. The initial diagnosis for the remaining women ranged from 2-6 years. There was one woman who has had breast cancer twice in the same breast, with three years between reoccurrences. Four of the women are employed and two are retired.

Preliminary analysis utilized a structured interview guide to facilitate the inquiry and found several themes: levels of decision making, decision making styles, decisional autonomy, factors that assist with decision making, and informal decisional processes. This pilot study emphasized the complexity of decision making including the varying sources of information the women had to process and sort through, the

navigation of the medical system with coordinating two or more physicians and treatment options, and time, where decisions needed to be made rapidly, as an essential factors. Most importantly, this pilot study demonstrated that variations in stage and treatment decisions were an important factor. Treatment decision making in woman with stage I versus a stage III breast cancer were vastly different.

Analysis

Undertaking the pilot study assisted the investigator with understanding cultural issues in interviewing techniques and the need to establish credibility with participants effectively before delving into sensitive information. In addition, information gleaned from this pilot study showed that this inquiry was too broad in its scope and needed to be more focused on women with advanced breast cancer for the dissertation study. Lastly, the investigator learned how to apply to the Institutional Review Board (IRB) for human protection and organize research documents and data.

Protection of Human Subjects

Approval to conduct this study was granted by the IRB from the University of Wisconsin-Milwaukee (UWM) and Swedish American Hospital Treatment Center, Rockford, Illinois (see Appendix A). Each participant signed a consent form (see Appendix B) and agreed to be audio-taped. The investigator explained to each participant how their anonymity would be ensured. Participants were allowed to pick a

pseudonym and the investigator referred to them by this pseudonym throughout the audio-taped interview. Other procedures to ensure anonymity included keeping audio files and transcriptions on a personal password protected computer, destroying the file that links the participants name with their pseudonym, and erasing all digital and audio files at completion of the study.

Sample

This study included a purposive sample of 12 African American women diagnosed with stage II to IV breast cancer living in or near Rockford, Illinois. Participants were recruited from a large regional cancer treatment center. African American women were recruited who met the following inclusion criteria: 1) Over the age of 30, 2) Able to understand, speak, and write English, 3) Had no cognitive impairments (Alzheimers, Dementia, etc.), 4) Diagnosed with stage II, III, or IV breast cancer, 5) Had an initial diagnosis of breast cancer within the past 4 years, and 6) Were currently or had previous been in treatment for breast cancer. Employing theoretical sampling, an initial sample of nine women were interviewed, and sampling continued beyond data saturation to interview three additional women to ensure complete data saturation.

Setting

The participants were recruited from a large regional cancer treatment center. This treatment center serves a large multi-county area and offers several treatment therapies along with clinical trials. A staff

research nurse coordinated the recruitment based on the inclusion criteria provided. This coordinator handed out flyers (see Appendix C) and spoke with participants who expressed interest in the study. These participants were asked to provide their contact information. Then, an email was sent to the investigator with the participants contact information and an interview was set up at a convenient time. All 12 interviews were conducted in the participants' homes.

Instrumentation

A semi-structured interview guide was developed to interview the research participants (see Appendix D). An interview guide matrix was developed to ensure all the research questions were addressed (see Appendix E). In addition, to capture any clustering of breast cancer by geographical area, a demographic information sheet was developed (see Appendix F).

Procedures

All of the interviews were digitally recorded and transcribed verbatim by a transcriptionist. Each interview lasted approximately 60 to 90 minutes. After each interview field notes were written to include recording the geographical location, neighborhood and home setting, reflections about the participant and/or interview process. The demographic sheet was filled out by each participant after the interview was complete and the audio taped stopped. This allowed participants to ask questions clarifying information on the demographic form without

providing identifying information. At the end of the interview the participants were given a \$20.00 visa gift card in appreciation for their participation. The possibility of a second interview was built into the consent form and was explained to the participants as either being either another in-person visit or telephone call. Nine of the participants were called to clarify information and/or reflect on themes to see if this captured their experiences.

Analysis

Open coding was initiated immediately once the interview transcription was complete. The constant comparative process was initiated with the first interview and continued throughout the analytic process (Glaser, 1992). The coding was organized with N-Vivo 10. This iterative process continued until theoretical saturation was achieved (Glaser, 1978). Theoretical memos were generated, and data reduction (selective coding) was performed looking at the frequency of the codes to decide which codes were representative of the emerging theory (Glaser, 1978; 1992). Beyond selective coding, theoretical coding resulted in the development of core categories from which the basic social process of the grounded theory emerged (Glaser, 1978; 1992). Theoretical coding involved utilizing modeling to visualize and show relationships embedded in the data (Glaser, 1978). As data analysis progressed the semi-structure interview guide was revised to capture the emerging theory (see

Appendix G). Approval to use the revised interview guide was obtained through an IRB amendment.

Establishing Rigor

Establishing that the findings of a qualitative research study are rigorous is critical for dissemination of the research and advancement of sound science. One way to guarantee rigor is to include procedures that establish the credibility of the analysis throughout the research process. Glaser and Strauss (1967) related four properties in establishing trustworthiness and credibility: fitness- where the categories within the theory must directly related to the data; work- where the theory should have an explanatory power and be able to interpret what is taking place within the context of the theory; relevance-where the theory is relevant because the researcher allows the core problems and processes to emerge from the data rather than attempting to impose a preconceived theory on to the area of study; modifiability-where given that the social or clinical world is constantly changing, the theory must be adaptable and modifiable.

Rogers and Cowles (1993) discuss the research audit trail and how important documentation is to any rigorous qualitative study. It is necessary to maintain accurate and comprehensive notes related to the contextual background of data, the impetus and rational for all methodological decisions, identifying the evolution of the findings and the researchers' particular orientation to the data are essential to ensure

rigor (Rogers & Cowles). Finally, Lincoln and Guba (1985) outline four criteria for trustworthiness for qualitative research: credibility, transferability, dependability and confirmability. These criteria were used to establish rigor in this study.

Credibility

Credibility refers to confidence in the truth of the data and their interpretations (Lincoln & Guba, 1985; Polit & Beck, 2008). Lincoln and Guba (1985) suggest five activities that make more credible findings. These include prolonged engagement, observation and triangulation (sources, methods and investigators), peer debriefing, negative case analysis, referential adequacy, and member checks. Credibility in this study was established with periodic meetings with the major professor to discuss emerging concepts, issues, and concerns as well as provide updates to recruitment, data collection, and analysis.

Dependability

Dependability refers to the research process by examining the methodological and analytic decision trails created by the investigators during the course of the study. Systematically documenting the rationale, outcome, and evaluation of all actions related to data collection, sampling, analysis, and dissemination (Hall & Stevens, 1991). Dependability is how stable and reliable is the data over time and conditions (Polit & Beck, 2008). Dependability can be established by overlap methods, stepwise replication, and inquiry audit (Lincoln, &

Guba, 1985). Dependability in this study was established by using the constant comparative method, keeping theoretical memos, and coding reports that could be exported from N-Vivo to a spreadsheet to trace the investigator's decisions throughout the analysis.

Confirmability

Confirmability refers to objectivity and the potential for congruence between two or more independent people about the data's accuracy (Polit & Beck, 2008). Essentially, this process establishes that the data represents the information the participants provided. Confirmability is established by an audit trail (Lincoln & Guba, 1985). This investigator maintained an audit trail throughout data analysis. Detailed field notes and observations were kept along with theoretical memos. A doctorally prepared nurse familiar with qualitative approaches was utilized to perform an audit trail. All study data were submitted to the auditor including: Transcripts, field notes, theoretical memos, open and selective coding reports, along with theoretical models (see Appendix H for the auditor's conclusions).

Transferability

Transferability refers to how generalizable and applicable are the findings to other settings or groups (Polit & Beck, 2008). It is the responsibility of the researcher to provide "a thick description to enable someone interested in making a transfer to reach a conclusion about whether transfer can be a possibility" (Lincoln & Guba, 1985, p.315). In

addition, Lincoln and Guba point out “that it is the naturalist responsibility to provide the data base that makes transferability judgments possible” (p.316). Transferability occurred by providing a thick description of the substantive theory from use of the constant comparative methods, theoretical memoing, and audit trail. The reader of the grounded theory evaluates transferability.

Chapter Summary

This chapter outlined the grounded theory methodology and study processes that were utilized to conduct this research. Sampling, data collection, management, and procedures, along with the protection of human rights were described. Finally, the procedures used to establish rigor were provided.

Chapter Four Results

Chapter Four presents the results obtained from interviews of 12 African American women diagnosed with advanced breast cancer. The purpose of this study was to generate a substantive theory of the treatment decision making process of African American women who have been diagnosed with stage II to IV breast cancer. The research questions for this study were:

1. How do African American women with advanced breast cancer describe their process of making decisions about treatment?
 - a. How do women participate in treatment decisions?
 - b. How is a woman's participation in their treatment decisions facilitated?
 - c. How is a woman's participation in their treatment decision hindered?
 - d. How do women describe their patient-health care provider communication and interaction in relation to treatment decision making?
 - e. What additional resources do they utilize in making their treatment decision?
2. What factors of cultural capital do women utilize when making treatment decisions?
 - a. What social supports do women utilize when making treatment decisions?

- b. How do economic circumstances affect treatment decision making?
- c. How do important cultural values or beliefs influence women when making treatment decisions?
- d. How do cultural concerns influence their treatment decisions?

The first section of this chapter will summarize the sample characteristics of the study group and provide an individual synopsis of each participant. The second section will provide the grounded theory of treatment decision making derived from the data. Finally, the last section will discuss how the grounded theory addresses each research question.

Sample Characteristics

The inclusion criteria for the study were: 1) age 30 or older; 2) diagnosed with stage II-IV breast cancer in the past 4 years; 3) starting treatment, actually receiving treatment, or have been in treatment; 4) able to understand and speak English; 5) report no known cognitive impairments. A total of 12 participants were recruited for this study. The participants' range in age was 32 to 78 years ($M=55$ years, $SD, 13.9$). Five of the participants were married (45%); four were single (36%); and three were divorced (25%). The participants reported diverse household incomes with the majority of participants (78%) reporting less than \$40,000.00 annually (see Table 2). The geographical areas where the participants lived were reported to assess any clustering of illness. The majority of the participants (58%) lived in urban areas toward the center

of town. The other 40 percent of participants lived in suburban areas. Five participants (41%) reported having Medicare; three (25%) reported Medicaid; three (25%) reported having both Medicare and Medicaid; and two participants (16%) reported having Blue Cross/Blue Shield Insurance. The participant's educational levels varied with a majority of participants report having a high school diploma or some college education. Two of the participants report having college degrees (see Table 2).

Table 2

Participant Demographics

Demographic	Age (Range)	Mean(SD)	Number (% of sample)
Total N=12	32-78	55(13.9)	
Educational Level			
<HS Diploma			2(16%)
HS Diploma			4(33%)
Some College			4(33%)
College Degree			2(16%)
Marital Status			
Single			4 (33%)
Married			5 (41%)
Divorced			3 (25%)
Geographical area (zip code)			
61101			4 (33%)
61102			3 (25%)
61104			1 (8%)
61108			1 (8%)
61109			1 (8%)
61111			1 (8%)
61112			1 (8%)
Type of Medical Coverage			
Medicare			5 (41%)
Medicaid			3 (25%)
Medicare and Medicaid			3 (25%)
Commercial (Blue Cross/Blue Shield)			2 (16%)
Annual Household Income			
<\$20,000			4 (33%)
\$21,000-40,000			5 (41%)
\$41,000-60,000			1 (8%)
\$61,000-80,000			1 (8%)
\$ 81,000-100,000			1 (8%)

Seven of the participants were diagnosed between one to three years before the interview. With five of the participants reporting being diagnosed within the past 9 months (see Table 3). For treatment, participants reported a variety and combination of treatment experiences. Six participants (50%) reported receiving chemotherapy and radiation; four (33%) report receiving chemotherapy only; one participant (8%) reported receiving radiation only; two participants (16%) report receiving adjuvant hormone therapy; and three participants (25%) reported being in various clinical trials.

Table 3

Treatment Demographics

Diagnosed	Number (percent of sample)
9 months ago	5 (41%)
1 year ago -3 years ago	7 (58%)
Type of Treatments	
Chemotherapy	4 (33%)
Radiation	1 (8%)
Chemotherapy and Radiation	6 (50%)
Other (Hormone and Adjuvant)	7 (58%)
Clinical Trials	3 (25%)

Participant Synopses

A synopsis of each participant's interview was created to locate each participant within their everyday context. Each participant was assigned a number at the time she was recruited into study to protect

her identity. A pseudonym was chosen for each participant for the purpose of reporting these findings.

Interview with Participant 01: “Diana”

Diana is a 54 year old married woman who was diagnosed nine months ago and had a mastectomy for stage II breast cancer. She is married; living with her husband in a single family home. She has one adult stepdaughter and parents that are very supportive. She reported feeling that she was misdiagnosed. She was told she had stage one breast cancer by one physician. However, she was called back, by the same physician, to the office seven months later and told that she needed to start chemotherapy and radiation. She was concerned and sought out a second opinion with a new physician. Two months ago her new physician told her that she should have had chemotherapy and possible radiation within the first three months because of her tumor size. In fact, she should have been treated for a stage II diagnosis. However, her window of opportunity for treatment was lost. She currently is taking Tamoxifen daily for five years. She works, has insurance, and reports not having any trouble paying for her medication.

Interview with Participant 02: “Teresa”

Teresa is a 50 year old single woman who was diagnosed one year ago and had a lumpectomy for a stage III breast cancer. She lives in a single family home with her adult sons and boyfriend. She describes a supportive family consisting of her sons, sister, and boyfriend. Her sister

attends all of her physician appointments with her. Teresa appeared very uncomfortable in her surroundings during the interview. Her home was chaotic. The television volume was loud and there were a lot of young people running in and out of her home. She complained of excruciating pain in the breast where she had the lumpectomy that was unresolved with medication. She feels her physician is indifferent to her pain issues and does not respond to her when she tells him about how much her breast hurt. Her treatment consisted of approximately one year of chemotherapy. She is currently taking Anastrozole daily for five years. She reports that she has Medicaid and does not have any money concerns, yet she thinks having Medicaid is the reason why she cannot get any treatment for her pain.

Interview with Participant 03: “Anna”

Anna is a 60 year old married woman who was diagnosed two years ago and had a lumpectomy for stage II breast cancer. She lives with her husband in a single family home. She has two supportive adult daughters and a sister. Her sister comes every day to clean and cook for her. Anna also has Multiple Sclerosis (MS) and has mobility issues related to this disease. Her husband is there to support her navigating the steps in their home. She has strong spiritual beliefs and feels that her spirituality is a part of her treatment. She had chemotherapy and radiation for several months. She is currently taking Leuprolide daily for five years. She reports having no problems paying for her medication now

that she has Medicare. When she worked she had Blue Cross insurance. However, when she was diagnosed with breast cancer and could no longer work she had to pay for Consolidated Omnibus Budget Reconciliation Act (COBRA) to continue her insurance coverage. Due to the exorbitant cost she terminated her Blue Cross coverage. Her money concerns were prevalent at that time because she had to pay \$3,000 per month for her MS medication. Because the chemotherapy put her MS in remission and she now has Medicare, she no longer has any money concerns regarding her medication.

Interview with Participant 04: “Crystal”

Crystal is a 34 year old single woman who was diagnosed nine months ago and had bilateral mastectomies for stage III breast cancer. Crystal lives with her three daughters in a duplex apartment complex. She has limited family who live in the nearby area. Her three young daughters, ages 8-16, are supportive in cleaning the house and cooking. However, they are unable to drive and do errands for her. Yet Crystal describes being independent and does not want the help of her extended family. Her grandmother and other family members come to visit from a large city two hours away, but Crystal feels smothered by their care and concern. She takes being a role model for her daughters very seriously. She believes in relying on self. She is enrolled in college and has high expectations for the future. She would rather struggle through any obstacles in her life than ask for help. She has a difficult time trusting

others. At one point her physician told her to quit college. She refused because she did not trust what the physicians told her about being around large groups of people when going through chemotherapy. She eventually was hospitalized with shingles for two months due to her compromised immune system. She had chemotherapy for six months before surgery and will be completing radiation. Crystal is an entrepreneur. She has a hair salon and babysitting service in her home and speaks freely about the other businesses she would like to start. She reports having Medicaid and no money concerns.

Interview with Participant 05: “Lynn”

Lynn is a 68 year old married woman who was diagnosed two years ago and had a mastectomy for stage III-IV breast cancer. She lives with her husband in a single family home. She speaks of the love and care her husband gives to her since being diagnosed. She has a supportive extended family that is involved in her care. Hanging in her living room is a framed poster that was signed by several family members. This poster was given to her after going through surgery and chemotherapy and is a symbol of love to her. She shared how she is the oldest living family member and therefore the matriarch of the family. She is the holder of all history, wisdom, and knowledge for the family and takes her family responsibility seriously. Lynn is able to speak about her cancer with humor and humility. She is spiritual and frames much of her experiences with information from the Bible. Even though she had eight

lymph nodes removed that were positive for cancer, she was told by her physician that she did not need chemotherapy or radiation. She is currently taking Tamoxifen for five years. She reports having Medicare and Medicaid and no problem paying for her medication.

Interview with Participant 06: “Maya”

Maya is a 69 year old divorced woman who was diagnosed one year ago and had a mastectomy for stage II breast cancer. She lives alone in a single family home. Her support system consisted of three adult sons along with four adult nieces and a sister who are all nurses. Her nieces and sister were all supportive of Maya by taking turns coming to town to accompany her to her treatments. Her sons were very supportive by taking her to church and shaving their heads when she lost her hair. Maya is fiercely independent. She talks about when she was married, how her husband did not like to travel, so she would travel with her young sons alone. She feels that waiting is unnecessary. If you want to do something or go somewhere, you should make a plan and follow it. She has an adult niece who is a breast cancer survivor and she is adamant about only following the advice her niece provides regarding treatment decisions. Her treatment consisted of chemotherapy and radiation once weekly for three months. She does not take any other medications for her cancer but has regular follow up visits with her physician. Maya currently works approximately four to six hours a day

driving a bus for disabled children. She reports having Medicare with no money concerns.

Interview with Participant 07: “Maria”

Maria is a 56 year old married woman who was diagnosed nine months ago and had a lumpectomy for a stage III breast cancer. She lives with her husband in a single family home. She has an adult son and a cousin, who is a breast cancer survivor, who are supportive. Maria feels that she was misdiagnosed by her surgeon. She was told that she had stage one breast cancer, yet when she went to the oncologist, she read her report that documented she had stage III breast cancer. She found out about the different diagnosis after the surgeon told her a lumpectomy is best for a stage one breast cancer. She feels that she made an erroneous decision based on faulty information. She also is extremely angry that she was told over the phone by the radiologist that she had breast cancer. At the time she was informed of her breast cancer she was told to contact a particular surgeon. However, this surgeon was not forthcoming with her about the removal of several lymph nodes nor the advanced stage of her breast cancer. She feels that she did not receive proper treatment because of her race and the fact that she did not have insurance. Her niece who survived breast cancer, played a pivotal role in helping her to navigate the healthcare system in finding an oncologist. Her treatment consisted of chemotherapy three times per week for six months and daily radiation for seven weeks. She is currently taking

Tamoxifen for five years. She has significant money concerns because she and her husband were laid off at the time of her diagnosis. Even though she has a bachelor's degree in social work she is unable to work due to her diagnosis. However, she was able to get some financial help from other agencies. Currently, she has Blue Cross insurance through her husband's job and has applied for disability. She reports having money concerns because of her past medical bills.

Interview with Participant 08: "Amy"

Amy is a 32 year old single woman who was diagnosed two years ago and had a lumpectomy for stage III breast cancer. She lives in an apartment with her teenage daughter. She has a very large supportive family that consists of her sister, brother, and 13 aunts and uncles. Amy's mother died in childbirth and her baby brother died one week later, both from rare heart diseases, when she was eight years old. She was raised by her grandmother and aunts and uncles. Her brother and sister supported her by coming over and cooking for her daughter and taking Amy to her treatments. They provided comfort by giving her massages after her chemotherapy. Her aunts would come over to pray for her and clean her house. Her daughter helped her mother as much as she could while learning to be self-sufficient by getting herself ready for school. Because of Amy's age and advanced breast cancer she had to have chemotherapy for two years. Amy recalled the intense fatigue, where she would sleep for 24 hours. There were times when all she could

do was watch a movie with her daughter. She recounts her extreme fear of everything. She was afraid of the needles, MRI machines, ultrasound machines, the intravenous medications, etc. She just had no frame of reference for the events that were happening in her life. In addition to the two years of chemotherapy she had radiation daily for several months. She is currently taking Tamoxifen for five years. She reports having Medicaid and no money concerns.

Interview with Participant 09: “Joy”

Joy is a 66 year old married woman who was diagnosed 3 years ago and had a mastectomy for stage III breast cancer. She lives with her husband in a single family home. She has three adult sons and one adult daughter who are supportive. Joy and her husband are pastors of churches for three different locations. They have a large church family that supports them yet they have many responsibilities due to their occupations. Joy is intensely spiritual and believes in a divine order predestined by God. After Joy was diagnosed with breast cancer her husband had a stroke. Therefore, she had to arrange for her treatments and a caretaker for her husband. She was told to have a lumpectomy for her breast cancer by one physician, however when she went for her second opinion she was told to have a mastectomy. She choose to have the lumpectomy because the first physician had a ‘machine’ in his office and she felt that made him more thorough. She felt that was what God wanted her to do. After having treatment she was told her cancer was not

responding and she would now need a mastectomy. While recovering from her mastectomy Joy became ill and had four major surgeries to correct several intestinal hernias and to remove her ovaries. She is currently going through chemotherapy for a second time.

Joy reports having Medicare and outlines several financial concerns stemming from the co-payments required by Medicare. With having so many appointments and each requiring a co-payment she was unable to keep up with the payments. When she had insurance, most of her treatments were covered and the amounts she was required to pay were manageable. However, having Medicare as a primary payor source is problematic, because Medicare does not pay for a large portion of her treatments. She spoke about all of the Medicare rules and legalese as being hard to understand. She currently has several bills in collection and this is worrisome to her. With her and her husband being sick, she feels a tremendous amount of pressure due the lack of money.

Interview with Participant 10: “Celine”

Celine is a 47 year old divorced woman who was diagnosed 16 months ago and had bilateral mastectomies for stage III breast cancer. She lives in an upstairs apartment with her children, one adult daughter, a 18 year old daughter, a 12 year old daughter, a six year old son, and an infant grandson. Her oldest daughter supports her mother by running errands, cooking, and cleaning for the younger children. She also has a supportive brother and mother. Her mother supports her by taking care

of her younger children when she is ill. Celine describes a toxic relationship with her sons' father who did not approve of her decision to have bilateral mastectomies. He became abusive when she was going through treatment and now she and her children are on the run from him. Although she has a legal document in the form of a restraining order, she is fearful that he will find her. She has moved several times in the past few months. During one of these moves she fell through a porch and broke her ankle. Now she has mobility problems and is not able to move around as much as she would like. She has chronic pain issues from her reconstructive breast surgeries and recent injury. Celine feels that she has been disrespected and ignored by her doctors. She feels that there is systematic racism built into the healthcare system that leaves her feeling powerless.

Celine's initial treatment was a lumpectomy and chemotherapy. She was told she was not responding to treatment and that her cancer was spreading. She was then scheduled to have 31 weeks of chemotherapy, however she only completed 29 weeks of chemotherapy before having surgery for her bilateral mastectomies and bilateral breast reconstructions. She is currently enrolled in a clinical trial and finishing the remaining weeks of her chemotherapy. Celine worked in the healthcare system for many years and now that she cannot work she describes having a significant reduction in her income. She reports having Medicare and Medicaid and problems paying for her medication.

She is upset that she cannot support her children in the way that she used to. She plans to create some income by becoming an entrepreneur and starting a business that she can operate from her home.

Interview with Participant 11: “Kara”

Kara is a 49 year old divorced woman who was diagnosed two years ago and had a mastectomy for stage III-IV breast cancer. She lives with her boyfriend in a single family home. Her support system consisted of her boyfriend and two sisters. Her sisters supported her by taking her to appointments. Her boyfriend was supportive by cooking and cleaning the house while she was going through treatment. She also had three adult nieces who took her to her physician and treatment appointments. Kara feels confident in her knowledge about breast cancer. She had a lot of experience taking care of her mother who died of breast cancer. When it came to treatment advice she only trusted her sisters and God. She had chemotherapy for nine months and currently is taking Aromasin for five years. Kara reports having Medicare and Medicaid and no money concerns; she is able to pay for her medications.

Interview with participant 12: “Elise”

Elise is a 78 year old divorced woman who was diagnosed eight months ago and had a lumpectomy for a stage II breast cancer. She lives alone in an assisted living facility. She has a sister and two adult nieces who are very supportive. Her nieces are both social workers and support her by taking her to her treatment and physician visits. Her sister

supports her by visiting, providing advice, and morale support. Elise is extremely proud of her education and experiences in life. She has always been independent and worked until she retired as a Dean in the school of sociology. She is an advocate of education and research. She and her nieces researched all of the possibilities for treatment before making an informed decision. Her treatment consisted of chemotherapy once a week for ten weeks to shrink her tumor before having surgery. She had a lumpectomy two months ago and has recently begun radiation. She is scheduled to have radiation five days a week for 3 weeks. She is currently on a clinical trial. Elise reports that she has Medicare and Blue Cross/Blue Shield insurance and no money concerns.

Explication of the Grounded Theory

The grounded theory for the treatment decision making process of African American women diagnosed with advanced breast cancer, consists of eight core categories: *Diagnosis*, *Physician communication*, *Physician Trust*, *Physician Mistrust*, *Autonomous and Shared Decision Making*, *Paternalistic Decision Making*, *Fortitude*, and *Treatment Decisions* (see Figure 1). The *Diagnosis* is the procedure and methods utilized to find the evidence of breast cancer. This begins and drives the process of treatment decision making. *Physician communication* describes the informational manner and style employed by the physician(s) to deliver the diagnosis. This essential component lead to whether or not the women describe *Physician trust* or *Physician mistrust*. These categories

influence how participants chose one of two decision making pathways: the *Autonomous and Shared Decision Making* pathway or the *Paternalistic Decision Making* pathway. The first pathway, *Autonomous and Shared Decision Making* describes the physician-patient relationship in which the communication is two-way. The information exchange is a dialogue, options are given, and decisions are patient driven. There are four subcategories that influence *Autonomous and Shared Decision Making*: *Family Support*, *Additional Information*, *Connections with Past Breast Cancer Survivor's*, and *Spirituality*. The second pathway, *Paternalistic Decision Making* describes the physician-patient relationship in which the communication is one way. The information is provided, there may or may not be a dialogue, options may or may not be given, and the decisions are physician driven. The one core category that influenced *Paternalistic Decision Making*: was *Physician Trust*. *Fortitude* describes how the women internalize and process the information, which allows them to build mental strategies to face treatment decisions. It is the linchpin that connects all types of decision making and is integral to how the women proceed with their decisions. *Women's Treatment Decisions* are the outcomes of the decision making process and are directly related to the potential success of the women's treatment.

Each major concept and its related subcategories will now be discussed in turn. Data excerpts will be provided to demonstrate the relationships within the grounded theory. Each excerpt will be label by

the participant pseudonym and identification number to facilitate the reader's evaluation of dependability, transferability and confirmability.

Fortitude in Treatment Decision Making

Fortitude was the basic social process that emerged from this grounded theory. This was the internal process that the participants needed in order to face the diagnosis and make the necessary decisions for their treatments. *Fortitude* is the first concept discussed, because *Fortitude* undergirds the grounded theory. *Fortitude* is defined in the dictionary as the strength of mind that enables a person to encounter danger or bear pain or adversity with courage (Merriam-Webster, 2012). *Fortitude* was a constant theme with all the participants and was evident in how they forged toward their treatment decisions thus their treatment.

"You can't just give up cause they say you got cancer. Baby, you gotta keep on keeping on. It's got to come from within cause the doctors are just a tool of God. The doctor don't have the final say" (Lynn, 05,393-395).

"I'm going, you know what, everything happens for a reason. I said, okay I am going to go through it" (Anna, 03,67-68).

Tenacity is also a synonym of fortitude and it sums up the women's collective movement towards making their treatment decisions.

"Two things, you have to force yourself to get up and do something. You just can't lay there..... The tenacity to hold on to life..... Live again" (Joy,09,324-325;336-337).

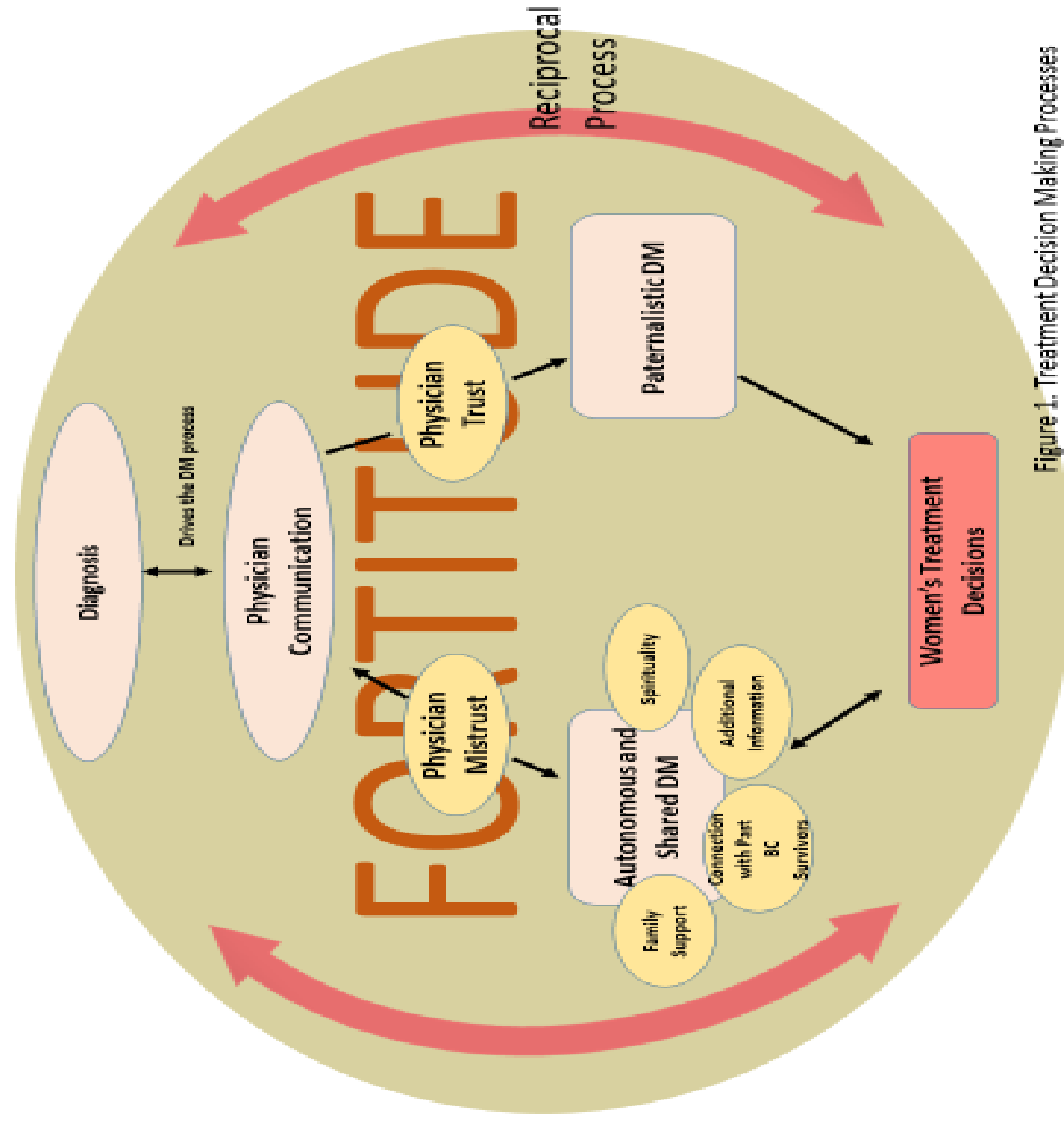


Figure 1. Treatment Decision Making Processes

Determination, strength, and grit are all synonyms of Fortitude and characterize to how the women rationalize their emotional journey in the decision making process. The participants were determined in their treatment plan.

“You’ve got to be there for yourself, you know? I think I did pretty good because you know sometimes they say, are you sure you want to do this?” (Lynn, 05,324-326).

“Now that I know, the sickness is already here, but I am doing my best to deal with it, and keep going, and keep Christ in my life every day” (Anna, 03.264-266).

Strength was evident with this participant who reported how....*she just knew that she had inner strength because of her daughter and because of her sister, and just for herself. She is a very strong person and she did not want cancer to beat her, and so she wasn’t going to let it win. (Amy, 08,191-193).*

Having that mental toughness or grit resonated with the participants.

“You’re going to suffer some hard knocks. You have to be a fighter, and I’ve been fighting – fighting – because I’m determined that I’m not going to let this beat me” (Celine, 10, 181-183).

“I got tired and I was always tired a lot, but I never let it get me down. I was tired but I would get up” (Maya, 06,280-281).

“...the Lord don’t make no mistakes, and I’m still here, so I got a purpose” (Maria, 07, 308).

“First of all, I come from a family where we don’t quit..... And I was determined that I would not be in the wrong hospital and have a wrong team. If it didn’t work, I would go tell them” (Elise, 12,540;572-574).

The Diagnosis

To understand the context of *Fortitude* and its importance, one must look at the total process that drives the decision making process

that emerged from the data. Hearing the *Diagnosis* for the first time was the beginning.

“It was a tumor. I always did a self-breast exam. It started off as a little knot. But instead of me going straight to the doctor, I waited until it got bigger. I waited a couple months and it got bigger. That’s when I went to the doctor and had an ultrasound and that’s when they saw the big mass in there” (Amy, 08,2-5).

“I went in for the mammogram. They said they saw something and I need to come in and get rechecked. So, I went in and got rechecked. I had the second mammogram and that’s when they said they really did see something. So I went in for the initial needle biopsy. The next day he called and told me over the phone that I had breast cancer” (Maria, 07,3-7).

For some participants it confirmed what they already suspected.

“I knew I had it. They didn’t know I had it, but I knew I had it” (Celine,10, 295).

“What they said was like it was fast growing, but I think I caught it kind of fast before I had a mammogram. But I had went in the bathroom, you know how you feel yourself off and on, and I felt something and I went and got a mammogram” (Maya, 06,3-6).

Going through the initial testing and subsequent biopsy was experienced by all the participants. Most times the mammogram and/or ultrasound along with the biopsy was completed in the same day.

“I had an appointment downstairs to have my mammogram. My whole day from 10 o’clock until after 4 o’clock that day it was like from one case to the other, they did the mammogram, and then they did the ultrasound and of course the radiologist checked it and she came back in and they said they wanted an ultrasound to check it and then they shared with me that the terminology as far as with the long needle to get a sample of the tissue, a biopsy, they put like a block on it so it would not hurt, but it did hurt” (Joy, 09,4-9).

For others there were a few days between the testing and biopsy.

“I felt a lump so I went to the doctor. I went and got a mammogram and then a biopsy. Once I got the biopsy, that’s when all of us went into a room and they told me” (Crystal, 04, 3-6).

The next steps were confirming the *Diagnosis* and staging their disease.

The American Joint Committee on Cancer (AJCC) sets guidelines for staging tumors (NIH; ACS, 2013). The disease staging involves (TNM) which indicates: the size of the tumor, the amount of lymph nodes positive for cancer, and any metastasis (NIH; ACS). The participants were asked if they knew the stage of their breast cancer. Most of them did.

“It was stage 2. When he went in and removed a cyst from my left breast and found it was cancerous, he took out 2 of my lymph nodes and one had cancer in it also, and he had to go back in and remove the rest of my lymph nodes” (Anna, 03,12-15).

“Well, they said the options but they said this one in the third or fourth stage or whatever it’s called” (Kara, 11,32).

“He told me it was between stage 3 and 4” (Lynn, 05, 8).

For some the diagnosis was not so clear. One participant explains:

Not at first, but eventually mainly after the surgery is when I found out exactly what stage I was in for sure. They were guesstimating... Yea, the doctor who performed the surgery said to him that’s what it could be, but to be for sure he would need to see the exact size of the tumor” (Diana, 01, 6-10).

The information sharing and exchange is a critical element with *Diagnosis*. Once the diagnosis is confirmed this process changes from static (listening) to dynamic, in that the participants now have to act

upon this information. Communication with the physician(s) is paramount.

Communication

When the participants are going through *Diagnosis*, they try to grasp what is being said to them. The amount of information is so overwhelming that some of the participants could not comprehend all the information.

“The communication was good. It was just, finding out I had cancer, everything else was just blah, blah, blah, blah, blah, blah” (Crystal, 04,15-16).

“So when I found out, I called Dr., and first they were talking about a lumpectomy, and blah, blah blah, and all this stuff” (Celine, 10, 13-15).

To glean information about the communication exchange between the physician and healthcare team the participants were asked: “Describe your feelings about your communication with your health care provider.”

“I felt that he was very knowledgeable with what he was doing. I felt comfortable with it” (Lynn, 05,14-15).

“They were very very helpful in communicating with me. Every test result, everything that they got, they gave it to me, even though I didn’t know what I was reading, but they would explain to me and everything” (Crystal, 04,103-105).

Some of the participants’ describe communication interactions that were not positive. One participant felt she was not heard by her physician:

“My doctor – I feel like my doctor do for me what he wants. I feel like he doesn’t take what I’m saying into consideration at all. I mean, he’ll listen to me, but then he’ll say, ‘Ok, we have to do this because I think this is

better for you,’ or, ‘You shouldn’t be in that much pain.’ You don’t know how I feel, because you’re not me!” (Celine, 10,70-73).

One participant felt she was not told the severity of her disease:

“He didn’t tell me at this it was a stage 3. I found out it was stage 3 when I read a report from Dr..... to Social Security. That’s when I found out it was stage 3” (Maria, 07,74-75).

Another participant was upset and confused by the differing opinions on how to treat her breast cancer. Her initial physician said that she did not need any treatment but months later called her up and said that she needed chemotherapy and radiation. She saw a second doctor who confirmed that she should have had chemotherapy and radiation but the opportunity for that treatment was no longer an option.

“I got a little angry with my oncologist because after my surgery he said I didn’t need any treatment, no radiation, no chemo, because it was so small. Every couple of months I would go back for a checkup. A couple months ago he flipped the script on me and said I needed chemo, and I got angry, and I’m like what? So I got scared” (Diana, 01, 42-47).

She goes on to describe her visit with the second physician:

“I asked for a second opinion. She told me that she feels the reason why he flipped on me was because of the size of the tumor.... But the only sad part is too much time had passed” (Diana, 01,52-56).

Aspects of Trust

The communication interaction with the physician and healthcare team facilitated whether or not the participants’ trusted or mistrusted their physicians. These concepts were the lens through which participants viewed and responded in their decision making. These

physicians were not the participant's primary care physicians. Therefore, these physicians were new referrals for the participants and there was not time to establish a relationship before learning they had a breast cancer diagnosis.

Physician Trust

One outcome of communication with the physician was *Physician Trust*. Participants described trusting that their physicians knew what they were doing. When the participants were asked *"Tell me about how much you trust your healthcare providers?"*

One participant gave a percentage:

"100%. It was Dr. N.... that was with me and Dr. A.... is the one who did my radiation after I went through the chemo. They are the ones that I depend on" (Anna, 03, 50-53).

Other participants described the same type of complete trust:

"I guess I trust his opinion to a fault..... he was the one that was telling me, 'I'm going to make sure you have all the help you need, and I'm going to make sure everything's ok,' and that kind of thing. That's what he told me" (Celine, 10, 139-140).

".....it was just all new to me, but they were really open. They would call my phone and talk to me, and doctors would come in and see me. They were good. I could talk to them" (Amy, 08, 79-81).

On the other hand, Physician mistrust was just as prevalent with some the participants and influenced their decision making.

Physician Mistrust

The participants were asked *"How much they trusted the physician?"*

"In the beginning I didn't because they were all new doctors, so I took the paper work they gave me to my doctor that I have been going to regularly"

and let her look over it before I consented to the treatment” (Crystal, 04,38-40).

One participants’ trust was so violated that she did not question what she knew was a mistake in her diagnosis, ergo her treatment decisions.

The participant was asked:

“Did you ever call Dr. S... back and confirm and say I think this is a bit much for stage 1. Did you ever confront her for an explanation?”

“No, because the first person was wrong, and at least with the book as I was reading I could decipher and determine what was applying to me and what wasn’t” (Maria, 07,113-114).

One participant only trusted the physician when her family was present.

“I trusted them more when my sister was there with me” (Kara, 11,109).

Therefore, as the participants assimilated information they described their decision making pathway. However, these decisions were based on the initial information provided, and once more information became known some decisions could not be altered (for instances surgery decisions, whether or not the participants had a lumpectomy or mastectomy), because some of the additional information was received only after an irreversible surgery. This information led to the types of decisional pathways that were chosen by the participants and their influencing factors.

Decisional Pathways

Paternalistic Decision Making

With *Paternalistic Decision Making* encounters are described in terms of participants’ preference and/or reliance on the physician to

make their treatment decisions. When participants were asked “Who made the decision about whether or not you would have treatment?” Six of the participants describe *Paternalistic Decision Making*.

“To tell you the truth, the way the doctors explained it to me, they laid a plan out for me. They said this is what you need to do, so I just said okay” (Amy, 08,50-53).

“What happened was, Dr..... who did the surgery got in touch with Dr. and she was the one that set everything up. My breast did not have to be removed. They just removed a cyst that was there. A month later I started chemo” (Anna, 03, 57-60).

“He told me that I would need to have treatment and I just wanted to do whatever it took just so I could be with my kids” (Celine, 10, 191-192).

“Dr C.... because of his thoroughness, and the nurse practitioner. He explained everything, the size of it, and that I had to have radiation And I had chemo after that” (Joy, 09,90-93)

Thus, *Physician trust* directly influenced this decisional pathway.

While *Paternalistic Decision Making* was what six of the participants described, the remaining six participants described making their own decisions and being more involved in the process of treatment decision making.

Autonomous/Shared Decision Making and Influencing Factors

There were several factors that influenced this type of decision making. These factors are described by the participants in tandem with their Autonomous and shared treatment decisions: *Additional Information, Family support, Connections with past breast cancer survivors, and Spirituality*. The participants who described *Autonomous*

and Shared decision making did so with confidence and conviction. The participants describe that they were in control of their decision making.

“I told them to remove the breast” (Kara, 11,35).

“I primarily made that decision... at that time my brother had passed away and I was getting ready to go to Arkansas. So between that and the fact that something had to be done, I made my own decision” (Maria, 07,31;55-57).

“Ultimately it was really up to me what I wanted to have done” (Teresa, 02,41-42).

Additional information. Some of the participants sought understanding and utilized *Additional Information* to gather information about their disease:

“I made the decision on my own.....Once I got the literature from the internet and then meeting with the doctors and I made it because it is my body” (Crystal, 04,69-70).

“I wasn’t prepared to have a mastectomy but after I talked to my doctor and I did some reading.... I didn’t want to have a lumpectomy in January and have to go back and have a ... you know, so I said, well, I don’t use it anymore, so whatever. So, here I am.” (Lynn. 05,42-46).

Family support. *Family support* was described by all of the participants in this study however, when it came to *Autonomous and Shared decision making*, what the participants families thought was as or more important than what their physician thought.

“And then they did ask me then after a while– because I had talked to my sister and then they said, ‘well you should just probably go on and have the breast removed’ (Kara, 11,35-36).

“My niece went with me, so we was in there talking to the doctor together. To me it didn’t really matter, you know I wanted it off cause I didn’t want it to come back or nothing” (Maya, 06,32-34).

The participants were asked *“Who helped make your treatment decisions?”*, two women responded:

“My sister and my doctor, and my son” (Teresa, 02, 53).

I follow what my niece tell me. “They told me what kind of treatment I needed so I went on and got the chemo and the radiation” (Maya,06,128;26-28).

One participant describes a *Shared decision making* process with her family and healthcare team:

“I had good input from my family and from me viewing the material.... Initially my plan was to have the chemo first, and then the surgery and then back to what I’m doing now.... So the second time they came back they came back with a lot more stuff. You know, things in writing, all that kind of stuff. So the three of us had things to look at, we could raise questions” (Elise, 12,142;206-207).

Connections with past breast cancer survivors. Having a Connection with past breast cancer survivors was important to some of the participants as well.

You know, I have a niece by marriage that lives in Baltimore. When she first got the news that I was going to have surgery for this, she had a girlfriend, someone that she worked with has been through the same thing but she ended up having reconstruction. She had her to call me and tell me some things that I could expect.... she stayed on the phone with me probably 3 or 4 times a week, you know just talking to me” (Lynn. 05,161-172).

“Well, two cousins. One had breast cancer. And my other cousin, she goes with me to all my chemo and all my radiation.... It made it easier, cause I could bounce my ideas.” (Maria, 07,187-190).

“Yea, it made it easier cause she was telling me what she had went through and how it affected her and I would see things and think oh she did tell me that, and it happened and stuff like that” (Maya, 06,49-51).

One participants’ knowledge came from personal experience. She took care of her mother who died of breast cancer.

“.. well she had...My mother, they got rid of it, and then hers came back. They said that she was supposed to only live for like five years but she lived longer than that. My mother passed away at the age of 77. Hers came back in another place though because when they diagnosed her with the breast cancer for the first time, she just went ahead and had both of hers removed even though the other one didn’t have it” (Kara, 11,183-187).

Spirituality. The expression of *Spirituality* as evident in how the participants made their decisions and garnered divine strength. When asked how did you make the decision about what you were going to do?

One participant said:

“Talked to the man up there....“So, you just prayed about it? Yes.” (Maria, 07, 179-181).

Being unable to participate in church was hard for one participant.

“It seemed like on Sunday when I could not go to church, I would sit here and that’s when the hard times would come. I would get so depressed.” (Anna 03,107-709).

Having a strong spiritual foundation was paramount to one woman.

“That’s why I have to read the word and all the scriptures on Him. Doctors give facts but the truth is, by His stripes I’m healed. That’s what I’ve got to lean on. I use the position for the youth. It still takes God, even with medication.” (Joy,09,143-147).

Women's Treatment Decisions

Women's treatment decisions were based on all of the aforementioned components. This grounded theory highlighted that this treatment decision making process is reciprocal. After the treatment plans are laid out any additional decisions would start the process all over again. Sometimes the women had to make decisions based on whatever information was available at that particular time. However, if any new diagnostic information became available, this would then drive communication with their physician and the need to choose a decisional pathway again (see Figure 1). One woman describes paternalistic decision making with her initial diagnosis....

"They basically made them. I didn't make any. I assumed I was going to go right into chemo or radiation after my surgery but when they said I didn't need any I said oh, okay. I left it mainly up to them" (Diana, 01,96-98).

...and described shared decision making after additional diagnostic information revealed that she was at a higher stage than originally thought.

"Then I met with an oncologist, and the oncologist gave me choices. Then he told me what was going to happen and the choices that I had." (Diana, 01,16--22).

Research Questions

This section will address the research questions initially proposed for this study to describe the treatment decision making process. In

grounded theory the initial research questions provided a basis for analysis. As the study evolved some of the research questions were more pertinent than others. Several of the interview questions were changed or removed to highlight the emergence of the grounded theory (see Appendixes A-B for interview guides).

Research question 1: How do African American women describe the process of making decisions about breast cancer treatment?

Participants described their treatment decision making in a myriad of ways. It was imperative to understand their processes in a coherent way to capture the phenomenon. The components of the treatment process the women describe were discussed in the section *Explication of the Grounded Theory*. In order to understand the phenomenon thoroughly five additional questions were asked and will be answered below.

1a. How do women participate in treatment decisions? Participants described various levels of participation in their treatment decisions. Half of the participants described autonomous decision making. They explained reading and looking up material prior to making their decisions. Other participants described paternalistic decision making where they voluntarily give the physician permission to make the decision(s) regarding their treatment. Other participants described paternalistic decision making where they felt powerless and did not feel they had the autonomy to make their own decisions. Finally, there were

several participants who vacillated between autonomous and shared and described a combination of both types of decision making (see Table 4).

Table 4

Types of Participant Decision Making Styles

Decision Making Style	Number (% of sample)
Autonomous Decision Making	5 (42%)
Paternalistic Decision Making	6 (50%)
Shared Decision Making	1 (8%)
Autonomous and Shared Decision Making	2 (16%)
Paternalistic and Shared Decision making	1 (8%)

1b. How is a woman's participation in their treatment decisions facilitated? Facilitation with treatment decisions for these participants came from more than one source. Participants described being assisted with their decisions by family, friends, communication with their physicians, independent research (see Table 5), trust in their physician or several combinations of these factors. The facilitation was tied to the decisional pathway described participants. For the participants who described autonomous decision making, they described being assisted by family and independent research. For the participants who described paternalistic decision making, they described being assisted first by communication with the physician, trust in their physician, and lastly by family and friends. Finally, the participants who described shared

decision making described being assisted by communication with their physician, family, and independent research.

Amy (08) praised her doctors, really cared for her doctors, continues to take the time to call her doctors, even her oncologist and the radiologist to talk about her progress and to talk about what is going on with her(184-187).

Table 5

Types of Additional Informational Resources

Types of additional informational resources
Internet: And then I looked online and did a lot of research. (Diana)
Books: The books they gave me one of them I call it my chemo bible. (Anna) the books they gave you were pretty thorough (Crystal) I read books. (Lynn) I read a lot of books (Celine). Books (Elise)
Pamphlets: I read the pamphlets they gave me (Teresa) Pamphlets (Elise)
Movies: I came home with movies (Lynn)

1c. How is a woman's participation in their treatment decision

hindered? To gain insight into this question the participants were asked to describe, "Who made their decision harder or worse"? None of the participants were able to give an answer to this question. Because of the nature of breast cancer, some decisions were made quickly after diagnosis. In these instances, participants did not feel that anything

hindered a decision. Therefore, to capture a problem with decision making, the question was re-framed to “How comfortable were you with the treatment decisions that were made?” to which several participants spoke about not being satisfied with their decisions (i.e., having decisional regret). There were several factors that were germane to dissatisfaction with their decisions including being given false or incorrect information at the time of diagnosis,

“That’s what I wondered. You know, was the machine just misdiagnosing me and saying that I was clean when I wasn’t? Because I have had it done every year for over 20 years. In fact, I am wondering were they growing in my lymph nodes the whole time.., you know, because there’s no way they could... When they were doing the mammograms they could see in there.”(Maria, 07, 270-273).

making hasty decisions, losing trust in their physician, losing confidence with their initial decision, and not having enough knowledge to make an informed decision.

“My stepdaughter asked me that, because she thought the mastectomy, everything happened so fast. Within 2 weeks I had had a mastectomy. I was diagnosed on like the 19th of December last year and before Christmas I had had my breast removed....It was extremely fast and she thought maybe I should have waited, but I don’t know and I’m not quite sure.” (Diana. 01,79-82).

1d. How do women describe their patient-physician communication and interaction in relation to treatment decision making? The participants were thorough in their descriptions regarding communication with their physicians. They remembered in vivid detail how they were diagnosed and what their interactions were with their various physicians. The communication was described as being either positive or negative. The participants who described positive communication with their physician

described being comfortable speaking to and asking questions of the physician(s). They also described getting positive feedback from their physician.

“He will tell me stuff, you doing good, better than the rest of them, you know stuff like that.” (Maya, 06,126-127).

Others described negative communication with their physician such as breakdown in communication, lack of communication, feeling disrespected, language barriers,

“And I think it would be helpful if, when there’s a language difference between the patient and the staff person –if there was an English person there to help facilitate that.” (Elise, 12. 108-110).

and being unable to discuss their cancer progress. One woman reported:

“My surgeon didn’t talk to me about nothing” (Lynn,05,91).

1e. What additional resources do they utilize in making their treatment decision? Participants identified survivor support as being a key factor in helping with their treatment decisions. In addition, the participants used their interactions with past survivors as a way to gauge their treatment plans. They were able to ask questions of their physicians based on information gleaned from past survivors. Some of the participants valued and followed what the past survivors told them over what their physician instructed.

“Sometimes the medication, pain pill, make me constipated so I told him don’t give me that no more, give me something else, and he asked me why. I say cause I be constipated. He say, oh yea I forgot to tell you that. I say

yea I know my niece told me. I said I don't want that no more so he gave me another prescription for something else.” (Maya, 06,144-149).

Research Question 2: What factors of cultural capital do women utilize when making treatment decisions?

A detailed explanation for cultural capital can be found in the section title “*Conceptual Framework*”. In review, the definition of cultural capital is people’s symbolic and informational resources for action (Bourdieu, 1986). It is further explained as ‘resources’ in the forms of: knowledge, operational skills, linguistic styles, values, norms, education, and advantages that a person has acquired through life long socialization (Abel, 2008). It was imperative to assess what forms of cultural capital these participants utilized in their decision making. In the current study, the main cultural capital that all of the participants accessed was in the form of fortitude. This theme was evident in their decision making process and explained earlier in the section “*Fortitude in Treatment Decision Making*.” There were other types of cultural capital accessed to assist the women in their decision making. The following questions were developed to specifically outline how this was accomplished.

2a. What social supports do women utilize when making treatment decisions? One important type of culture capital for these participants was in the form of family support. In addition, the added capital of being connected with past breast cancer survivors was an unexpected finding. The participants oftentimes depended completely on the advice of the past survivors and held on to their words, which

increased their fortitude. Finally, the additional capital of spiritual support was essential to many of the women as a foundation that was used to increase their fortitude as well (see Table 6).

Table 6

The Descriptions of Social Capital-Spiritual Support

Participants Descriptions of Social Capital-Spiritual Support
Attends church:
I got spiritual support from my pastor and my church family (Anna)
I've been active in my church all my life (Elise)
I go to church and they pray for me and stuff, and I had good support (Maya)
I am a pastor of a church with three locations (Joy)
I go to church. I am Baptist (Kara)
Reading the bible:
I read the bible a lot (Teresa)
I have a prayer bible that you pray with the word (Joy)
What I do some days I read a chapter, some days two, depends on what I'm reading (Lynn)
Prayer:
My mother is a Jehovah's Witness. I did talk to Jehovah's Witnesses at one time (Teresa)
My aunts that would come and pray for me (Amy)
TV ministries. I call on the hotline and get support. (Celine)
One of my friends, she's an Evangelist and she comes to visit me (Celine)
I have 5 am prayer that I listen to. We had prayer today at 3 pm and I go to my girlfriends' church and they have prayer at 7 pm. (Joy)
Spiritual beliefs:
"That the Lord don't make no mistakes, and I'm still here, so I got a purpose" (Maria)
"My inspiration comes from Him getting me up out of bed every day." (Lynn)
"That's why I say you must have God in your life." (Anna)

2b. How do economic circumstances affect treatment decision

making? Seven of the participants did not feel money was an important factor in the treatment decisions. However, five of the participants that expressed concerns, the concerns came from not having insurance or the money for copays required for visits and or medication. When asked “What money concerns do you have?”

“...at the time I did it could have been the fact that I was unemployed and didn’t have insurance at that time” (Maria, 07, 154, 155).

and, “What concerns do you have about paying for care and/or medicine?” one participant explained:

“There is always concern with your co-pay. Because when you have bills and your credit goes down the tube because of sickness. And when they give you 30 days and turn things over to collection, and you have insurance, it don’t mean nothing until you give them money and you can expect it. But I do have a problem when the collector calls and there is no compassion or empathy” (Joy, 09, 168-171).

“The only drug I worry about is medication that I take to help me walk which is \$1300 a month for 30-day supply. I am going to call the drug company that makes it and they will be able to help me” (Anna, 03, 188-191).

2c. How do important cultural values or beliefs influence women when

making treatment decisions? Many of the participants in this study were not able to answer this question in a meaningful way. When asked “Tell me about any specific beliefs or personal values that were important to your treatment decisions?” most of the participants spoke about their spiritual beliefs. A few women gave information on their personal beliefs but they did not specifically feel it was a belief held by their cultural

society. One participant explains about her belief in the changes she's made in her life.

"The things I used to do, I don't do them no more. I tell you, if I met the person that I was 40 years ago, I wouldn't like her. I love me! I can live with me now. You know what I'm saying? I have did a transformation baby. It's a shame to say, but I think my health is what made me transform to who I am today. And too bad I couldn't have did this when I was healthy and moving around" (Lynn, 05, 270-275).

Another participant believes we get cancer from food:

"Myself, I think it's a lot of this food you be eating. I really believe that. They put all this stuff in the food and I would not a ate a lot of stuff. Cause you can get a chicken born one month, and the next month you eating it. When we was coming up you didn't eat no chicken that fast. They putting all this stuff in them to make them grow fast and that stuff get in your body so it change your body and stuff. I always believe that (Maya, 06, 225-230).

2d. How do cultural concerns influence their treatment decisions?

This question was asked to highlight any connections between perceived racism and its effect on their decision making. During the interviews I would have to restate this question and explain what I meant each time. Therefore, when the participants were asked "Do you feel like the treatments that you have received are any different because of your race?" The majority of the participants were emphatic that this was not the case. They felt comfortable with how they were cared for during their treatment visits. They would comment on how grateful they were for the professionalism of the staff. However when one participant was asked specifically about racism she explained how she was treated based on her treatment status and looks:

“I think if I wouldn’t have been a test bunny, I would have got treated worse. I’m sure I would have. But I was a test bunny because I was in a case study. That’s what I call them. That’s what we call them in the hospital too. So I think –

Q: - So you think because you were in a clinical trial, you got treated better, but you felt like because you were black you probably would have been treated worse?

A: Bingo! And there’s a lot of nurses that are not like that but there were so many of them that you could just feel it. They acted like they were scared to touch me. Oh boy, and then when I tell them that I’m an ICU technician but that I just don’t work at the hospital anymore, then everything is, ‘Wow. Ohhhhh!’ Yea. See, but they were looking at me with my nose being pierced and my eyebrow being pierced and the earrings in my ears and my hair color, because I’ll go from purple to pink to green to blue to orange....that’s just me” (Celine,10, 340-350).

Another participant felt there was inherent racism in a particular institution and that racism played a part in how she was informed of her diagnosis and then subsequently misguided through this particular institutions’ healthcare system. So during her story when asked “o you feel like your race had anything to do with it?” She explained:

“To me, it was. Now everybody know R...Memorial is a killing hospital. Everybody know that. But, I was with Dr. S... and she was with R.....Memorial for so long til when I was getting my mammogram it was just easier to just keep going to the place that I was going to. Stupid me! And by me being a layman and new to that part of the game, I didn’t know that I should have consulted an oncologist before the surgery. So in my layman’s terms I’m thinking well, since they referred me to Dr. M... (surgeon), then he already know the deal and he go’n tell me, but no. I went from surgeon to oncologist. So the damage was pretty much already done when I got to Dr. S... (oncologist). So that’s probably why we went at an accelerated rate..... This doctor was recommended because they said I needed surgery. No mention ever came up from the radiologist or anyone in that room to contact or to get an oncologist until I went to Dr. M... (after my surgery) and he asked me did I have anybody in mind, or he could recommend somebody” (Maria, 07, 131-147).

Additional Findings

An additional finding of risk assessment was noted after four of the participants were interviewed about genetic testing. Genetic tests can check for BRCA1 and BRCA2 mutations in people with a family history of cancer that suggests the possible presence of a harmful mutation in one of these genes (NIH, 2014). Three participants reported being tested. Two participants did not have the gene. When asked about genetic testing one participant reported she had been tested. When asked about “knowing if she had a family history?” she stated:

“Not of breast cancer. I have a family history of emphysema. My grandmother died of lung cancer. But like nobody had breast cancer. Mammograms are not recommended until age 40, so the doctor said it was rare for a female my age” (Amy, 08, 60-62).

The other participant responded:

“No. I don’t have the genes, family history. I don’t know where. It’s such a shock” (Crystal, 04, 190-191).

The third participant was positive for the BRCA gene and therefore had a double mastectomy along with a hysterectomy to manage her cancer risk. When asked about “whether or not her mother had breast cancer?” she responded:

“No, she had ovarian cancer..... So, because she had that and breast cancer ran in my dad’s family, I got the double whammy. So I have an overactive cancer gene. So that’s what took everything from me” (Celine, 10, 207-210).

The forth participant did not remember being tested even though her mother had been diagnosed with breast cancer twice. When asked “Did her mother or sister have breast cancer?” She stated

“My mother..... She had both of hers removed... they got rid of it, and then hers came back. They said that she was supposed to only live for like five years but she lived longer than that” (Kara,11, 39,42,183).

When asked “Did you look up more information because your mother had breast cancer?” She responded:

“No, because I knew a lot of it from my mother” (Kara, 11,179).

This participant did not seem to relate her risk for breast cancer to her family history.

Chapter Summary

This chapter describes the grounded theory “The Treatment Decision Making Process of African American Women Diagnosed with Advanced breast Cancer.” Each major concept and its related subcategories were presented. Characteristics of the sample and a synopsis of each the participants were provided. Finally, an in-depth discussion of how the data addressed each research question was provided.

Chapter Five

Discussion and Recommendations

The grounded theory study of *Treatment Decision Making in African American Women with Advanced Breast Cancer* (see Chapter Four) yielded three major findings about the Treatment Decision Making process including: 1) Emergence of the basic social process of *Fortitude*, 2) How integral communication was with the physicians and/or healthcare teams, and 3) The dichotomy of physician trust and mistrust from this communication. In addition, integration of the findings with the framework cultural capital yielded several important subcategories including: connections with past breast cancer survivors, family support, spirituality, and information regarding risk assessment. This chapter will first discuss the findings in relation to the literature and the study's conceptual framework. Then, the study's limitations will be outlined. Third, implications for nursing practice will be provided. Lastly, recommendations for future research will be presented.

Integration with the Literature

An appraisal of the findings of this study will be provided based on related literature. The concepts of patient-physician communication and physician trust and mistrust will be compared with the existing decision making literature. Next, the grounded theory of *Fortitude* will be discussed. Finally, a discussion on the additional findings of this study will be addressed.

Patient-Physician Communication

This study found that the communication interaction between the participants and physician or health provider team was complex in that it could be both positive and negative in a single encounter. In addition, this communication process was vital because it provided a range of information yet it could be difficult because the informational messages were overwhelming. This was comparable to research by Sheppard, Adams, Lamdan, and Taylor (2010) that found patient-provider relationship was the most notable factor that influenced treatment decision making. Specifically, the women's relationships with their providers influenced their knowledge about their diagnosis, perceived efficacy about treatment, understanding of their treatment options, and their acceptance of and subsequent adherence to recommended treatment. The current study was divergent from research by Williams et al. (2008) which found that in order for communication to be effective the physicians had to first establish a relationship with patients and families facing cancer. The participants in this current study did not describe having time to establish a relationship with their new referred oncologist and surgeons.

Physician Trust/Mistrust

This study showed a dichotomy between physician trust and mistrust. Where trust was described by participants who preferred a

passive role in decision making and mistrust was described by participants who preferred a more active role in decision making. This was similar to research by Kraetschmer, Sharpe, Urowitz and Deber (2004) which found that respondents who wished for an autonomous role in decision making tended to have lower trust in their providers. And those participants who desired a more passive role in decision making had higher levels of trust. Similarly research by Kaiser et al. (2010) found that participants reported high levels of trust in their regular physicians and an even greater trust in their cancer diagnosing and treating physicians.

This was in contrast to research by Arora and Gustafson (2008) who found that patient trust changed over time. In the time period closer to diagnosis, informational, emotional and decision making support from physicians were all significantly associated with patient trust. However, at the two and five month's assessments decision making support was not associated with trust. The current grounded theory study did not assess time in relation to trust, since data were collected primarily from a single interview.

Fortitude

The basic social process of *Fortitude* underlies the decision making process for African American women facing an advanced breast cancer diagnosis and treatment. The discussion on *Fortitude* and its embeddedness is found in Chapter Four.

Additional Findings

Decisional Pathways

Variations in the patterns of decisional involvement and decisional preferences, were present in the tenants in the seminal research by Denger et al. (1997) where women describe a substantial discrepancy between their preferred and attained levels of involvement with breast cancer treatment decision making. Half of the participants in this study describe *Autonomous and Shared Decision Making*, while the other half described *Paternalistic Decision Making*. Even with these robust descriptions there were still other participants who described a combination of the decision making pathways outlined above. This is consistent with the research by Hawley et al. (2007) where women report variations in their actual decisional involvement in breast cancer treatment decision making, which resulted in a discrepancy between patients' actual and preferred levels of involvement. This current study was also congruent with research by Vogel, Helmes, et al. (2008) which found that newly diagnosed breast cancer patients preferred the physician to make the treatment decision. This study differs from research by O'Brien et al. (2008) which found complex treatment decision making processes with most of the women having viewed the physician treatment recommendations as giving them confidence in their own treatment decisions, resulting in the women having sought their physician opinion.

Information needs. Informational needs were an important factor for participants who described *Autonomous and Shared Decision Making* as was found in the seminal research by Bilodeau and Denger (1996). Specifically, participants in this current study describe performing additional research before making Autonomous or Shared treatment decisions, was consistent with research done by Spittler, Pallikathayil, and Bott (2012) which found that women viewed information needs as very important and often chose treatments that most likely would enhance their life expectancy after being diagnosed with breast cancer. This differs with research by Lally (2009) which found women described gathering information to become knowledgeable about breast cancer and treatment options even before hearing the surgeon's initial explanation of the new diagnosis and treatment options. Furthermore, in research by Vogel, Bengel, et al. (2008) the informational needs of the patients changed over time. Where there was a decrease in the importance of specific informational needs over a six month timeframe.

Integration of the cultural capital finding with the literature.

Understanding the relationship between cultural associations and decision making was relevant to this study population as with the research done by Fowler (2006b). The literature describes social capital as one of the forms of the cultural capital framework. This is where group membership, relationship, networks of influences and support are garnered (Bourdieu, 1986). The participants in this study describe social

capital in the form spirituality where going to church, prayer and belief in God (see Table 6) were germane to their treatment decision making. This was congruent with research by Lynn, Yoo, and Levine (2013) that found women who belonged and did not belong to a religious institution talked about how spirituality and prayer helped them cope with their illness. This was also similar to research by Roff, Simon, Nelson-Gardell, and Pleasants (2009) which found that the women received religious/spiritual support from a variety of sources. Specifically, they reported support from God, congregational members and their clergy. However the current study differs from research by Simon, Crowther, and Higginson (2007) which examined stage specific spirituality and found that spirituality was a key component in women's coping process from diagnosis through recovery and on to survivorship. This current study did not assess spirituality apriori to their breast cancer diagnosis.

Family support. The participants in this study were very clear in describing how supportive their families were with their decision making and throughout their treatment regimens. This was supported by research from Maley et al. (2006) and Hawley (2009) that evaluated the role of the patient's family and friends in decision making and receipt of surgery for breast cancer. Their research found that women of different racial and ethnic backgrounds indicated that the opinions of their spouse, family, and/or friends were important in their decision making. This is further supported by research from Lillie et al. (2014) which

found that most partners positively appraised their experiences across the elements of the treatment decision making process, as the majority reported receiving sufficient information, having a high amount of actual involvement in the decision process, and feeling that this amount of involvement was sufficient. It is important to note that there is limited literature on the concept of family support in the context of treatment decision making in breast cancer for African American women.

Connections with past breast cancer survivors. This study found that for most of the participant's their connection with past breast cancer survivors was an important factor. Participants reported how this connection reduced anxiety, increased participants' sense of control, and provided a valuable source of knowledge about the treatment process. As stated by one participant who connected with a breast cancer survivor:

"...this was somebody that didn't know me, never met me, but she stayed on the phone with me probably 3 or 4 times a week, you know just talking to me. That long distance, not knowing a person, that was some valued friendship and information." (Lynn).

Participants reported several reasons why they trusted the survivors.

The most common reason was that the survivors could relate to having breast cancer. Alternatively, participants who did not report connection with past breast cancer survivors either had no one they knew with breast cancer or did not speak to this in their interview. Therefore, it is unknown why these participants did not utilize past survivor support as an option in their treatment decision making. Interestingly, there is no

published literature that examines African American breast cancer survivors that serve in a role of assisting other women diagnosed with advanced breast cancer with treatment decision making. This finding suggests several future avenues of inquiry including: why newly diagnosed women place such implicit trust in survivor's advice, how important this role of support is for newly diagnosed women, how this relationship potentially affects treatment decisions and what other consequences (positive or negative) can result from these relationships. Being it is not common for nurse navigators to help facilitate newly diagnosed women to make connections with survivors, it will also be important to explore what training the survivors should receive in order to maximize interacting with newly diagnosed women in supportive ways. Conversely, it will be important to explore the degree to which the trust between a newly diagnosed woman and a survivor resonates when survivors are family members versus non-family members.

Risk Assessment

The findings regarding risk assessment were evident with only four of the participants however, these findings were analogous to the study by Spector et al. (2009) which compared breast cancer risk perception between Caucasian and African American women with a family history of the disease. Specifically, the study examined how perceived risk relates to risk reduction behaviors. Spector et al. found that most women perceived themselves to be at increased risk for breast cancer and more

African American women (66%) than Caucasian women (30%) perceived their risk as moderate to high. In comparing Caucasian women and African American women the investigators noted that according to the Gail Model 5 year risk estimates, 90% of Caucasian women and 33% of African American women were clinically at increased risk for breast cancer.

Risk perception for the participants in this study was not measured, however healthcare providers view family history of breast cancer as an important risk factor. This was a disadvantage for the women in this study perhaps because if they were aware of the risk factors they might have made the decision to seek breast healthcare sooner. As in the Spector et al. (2009) study women who perceived their risk were more vigilant in seeking care. This current study demonstrates that awareness of breast cancer risk factors should be a foremost initiative of healthcare providers and advocates for breast cancer.

Other Findings

There were several other findings in this study that warrant further exploration in future research. First there were several participants who were diagnosed and then were later told that they needed additional treatment. There were three participants who were given a diagnosis and then found out that the initial information was either incorrect or not communicated by the physician. Diana felt she was misdiagnosed. She was given an initial diagnosis and 7 months later told that she had a

more severe diagnosis and now needed chemotherapy and radiation.

Maria was first told she had breast cancer over the phone. Next, she was never referred to an oncologist. Lastly, her surgeon never disclosed her breast cancer stage, instead, she learned this information by reading her medical record. Another participant, Joy, was told to have a breast conserving surgery lumpectomy by one physician. She was then told to have a mastectomy by another physician. She decided to go with the physician who recommended the lumpectomy but was later told she was not responding to treatment and should have had a mastectomy. She then had the mastectomy, chemotherapy, and radiation. These participants' disparities in diagnosis is congruent with research by Fedewa et al. (2011) which found that African American and Hispanic women had higher 30 to 90 day diagnostic delays than Caucasian women for stages I to III breast cancer. These investigators found these delays were due to access to care, specifically patients that were referred to the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), geographical distances to the treatment facility, and cost barriers.

Another finding included several participants who did not seek out family support for their decision making. Those participants who choose paternalistic decision making did not describe family as being germane to their decision making. However, these participants reported family support for treatment. When making decisions, this group of participants

all reported physician trust as being the most important factor. It is not clear from the data who had family present during the physician consultations, at the point of diagnosis. Inquiring into this area in greater depth is recommended in future studies.

Limitations

While the results of this study provide insights into the decision making process for African American women with advanced breast cancer, there were several study limitations. The first limitation was the small convenience sample. This small sample limits generalizability to other populations, although being a qualitative study, transferability was prioritized over generalizability. Secondly, this study focused on African American women who received treatment in an urban area with relatively easy access to care. This sample may not be representative of African American breast cancer patients in rural areas or women with barriers to care. Third, inclusion criteria for the study included women who were already in treatment or had previous treatment in the past four years who reported treatment compliance. Study findings could potentially differ among women who decline treatment or have withdrawn treatment.

The forth limitation involved variations in elapsed time between diagnosis and participation in this study. Participant's interviews were retrospective reflections of their decision making process, and views were likely informed by the many experiences of diagnosis and treatment since the initial diagnosis. The decision making process may have been

different if all the participants were discussing their experiences current with actually making those decisions instead of reflecting back on those decisions. The participants in this study were unable to articulate their cultural views. This might be because of the embeddedness of racism in their interactions with their physicians and engagement within the healthcare industry on a consistent basis that they were unable to recognize this as problematic or felt uncomfortable stating this as a reality.

A final limitation was the absence of the role of the nurse in the participants' descriptions of their decision making process. It is known that the participants came in contact with nurses at several points in their decision making process. However, their descriptions did not reveal these relationships. All of the participants were highly articulate about the relationship with their physicians. Yet, the support participants received from nurses mainly centered on their treatment experiences. Nursing needs to seek new and more meaningful ways of engaging with patients to change patients' perceptions and experiences with breast cancer treatment decision making.

Study Strengths

A strength of this study was the breadth of characteristics of the sample. The participants that were interviewed had diverse experiences with the decision making process. Beyond diverse experiences, there were wide variances marital status, age range, income level, and

education among participants (see Table 1). The richness of these data was illustrated in the theoretical model (see Figure 1).

Implications for Nursing Practice

Findings from this study provide nurses with a more thorough understanding of the decision making process in African American women facing advanced stage breast cancer. The need for more positive communication in the initial interactions with patients at the point of diagnosis by nurse navigators and all members of the healthcare team cannot be overstated. The model for treatment decision making shows a need for understanding the cultural supports that aid in decision making and helping to facilitate these connections so that patients optimize the cultural capital those supports can provide to the patient during this challenging time. Findings also suggest that nurses consider linking newly diagnosed patients with past breast cancer survivors as early in the decision making process as possible. Also, providing more guidance with written and oral communication and explicit directions about the selected treatment options is a key facilitator that would benefit patients. Nurses are in a position to offer their breast cancer patients direct and thorough answers to patient's questions. Follow-up telephone calls to reinforce teaching and availability and openness to answering additional questions have proven successful. Furthermore, there is a need for breast cancer patients to have anticipatory post-treatment information, guidance and support on multiple levels.

This study was conducted in a cancer center. Another implication this study findings offer involves setting protocols for how to communicate with patients within diagnostic and treatment centers. The lack of consistency in communication to patients suggests the need to increase continuity within communication to patients from the point of receiving diagnostic results through the treatment process. Such continuity would involve coordinated efforts from nurses in the diagnostic center, including nurses in the roles of, navigator, treatment, and radiology. Patients require multiple steps in their progression through the different levels of care. For example, those patients who enter into clinical trials should have research nurses included in communication protocols. Communication protocols need to address many issues including, who is present when the patient is given their breast cancer diagnosis, and perhaps a team approach would be beneficial.

Another implication from this study is that the nurse's role in the diagnosis process should involve providing more information to the patients as they come in for diagnostic mammograms and/or subsequent breast cancer diagnosis. Examples of information that could be gleaned from patients in this setting include: a) Assessing the timing and flow of information; specifically, how much information they want and when they want it; and b) Assessing what other support patients need such as information about the process and what other steps might be involved.

Implications for Policy

This study was conducted at a time when new federal laws in the Affordable Care Act (ACA) were being implemented. There are policies surrounding breast cancer treatment that are in flux, given there are several potential unknown implications of the ACA. The first implication is the NBCCEDP that provides funding and services for women who meet income guidelines (usually women with no or low- income). Whether this program will continue or be changed is unknown. Research by Levy, Bruen, and Leighton (2012) found that even with the increased number of women transitioning from being uninsured to insured, the NBCCEDP programs in Massachusetts, for example, would still only be able to serve one-third of the remaining uninsured women eligible for services. The NBCCEDP is a grant program and its funding is limited to federal and state appropriations; the program has never had sufficient funds to serve all eligible women. Instituting the ACA is projected to only marginally affect these eligibility numbers. This program is important for treatment because once a woman is diagnosed there are problems with referrals to specialist and payment for treatment.

Second, the ACA mandates that insurance companies pay for an annual mammogram and cervical papanicolaou exam for women who are insured and underinsured. However, there are no mandates for treatment. It will be vital to have systems in place for the women who will be diagnosed and require treatment. Third, findings from this study

combined with health care system changes created by the ACA, suggest that more physicians and nurse practitioners are needed to provide treatment and follow up services for the increased demand of millions of uninsured women now becoming enrolled. This increased demand for services has the potential to reduce the time available for communication between patient and providers, which has the potential to cause further treatment delays. Finally, there are potential problems with timely access to care to treatment facilities. Some women who are eligible for the NBCCEDP program already have to wait for treatment services, because some sites, especially in rural areas, are already overwhelmed with patients due to provider shortages.

In spite of the expected increased access to care as a result of the ACA, there are women who will likely continue to face barriers with affordability, because their premium payments will exceed eight percent of their annual income (Rosenbaum, 2012). Furthermore, there may be breaks in enrollment coverage due to families experiencing fluctuations in their income for various reasons (Rosenbaum, 2012). These gaps in coverage during periods when a woman is actively undergoing diagnosis and treatment could potentially create challenges to achieving optimal outcomes. There is still the potential for African American women to continue experiencing delays in screening, diagnosis, and treatment as explained by Levy et al. (2012) because while the ACA eliminates cost sharing (co-pays) for cancer screening, low- income and moderate-

income women may still be unable to afford cost-sharing that remains in effect for diagnostic services after receiving an abnormal screening result.

Patient centered healthcare is another approach from the ACA (Rosenbaum, 2012). This study has raised the need for a more patient-centered approach in decision making in breast cancer centers. The current medical model is physician-centric and therefore care driven by the medical model. This is most evident in the current study (see Physician Communication). However, this study demonstrates the need to ensure that all women have the necessary tools to make informed decisions regarding their health care (Charles, 2004). A paradigm shift is need to ensure that physicians and other healthcare providers move toward a more collaborative approach to patient care, that is, to fully and meaningfully include patients in the plan of care, thus facilitating their decision making processes.

Implications and Recommendations for Research

There are several recommendations for future research that arose from this study. Many of these proposed studies cover various aspects of the decision making process. It is imperative to add to the body of knowledge for African American women diagnosed with advanced breast cancer. The list below only covers a small sample of proposed studies.

1. Communication interactions at various stages of treatment over time with healthcare providers.

2. The effects of time between diagnosis and actual treatment on decision making.
3. The effects of family support on the decision making process.
4. The effects of perceived body image on treatment decision making
5. The effects of racism on physician trust and treatment decision making in African American women.
6. Intimacy after having a mastectomy.
7. An assessment of the different forms of cultural capital on treatment decision making.
8. Interventional study on breast cancer survivor support on decision making and the level of involvement over time.
9. Healthcare system and institutional barriers on the obtainment of timely diagnosis and treatment for African American women diagnosed with advanced stage breast cancer.

Chapter Summary

This chapter provided an appraisal of the literature as it related to existing literature. Next, the results were discussed in relation to the conceptual framework. Then, the limitations of this study were discussed followed by implications for nursing practice. Finally, recommendations for future research were provided.

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Appendix A

Protection of Human Subjects



Department of University Safety & Assurances

Jessica Rice
 IRB Administrator
 Institutional Review Board
 Engelmann 270
 P. O. Box 413
 Milwaukee, WI 53201-0413
 (414) 229-3182 phone
 (414) 229-6729 fax

<http://www.irb.uwm.edu>
ricej@uwm.edu

New Study - Notice of IRB Expedited Approval

Date: October 22, 2012

To: Jennifer Doering, PhD
Dept: College of Nursing

Cc: Dauphne Sims

IRB#: 13.112

Title: Treatment Decision Making in African American Women Diagnosed with Advanced Breast Cancer

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Categories 6 & 7 as governed by 45 CFR 46.110.

This protocol has been approved on **October 22, 2012** for one year. IRB approval will expire on **October 21, 2013**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found on the IRB website.

Unless specifically where the change is necessary to eliminate apparent immediate hazards to the subjects, any proposed changes to the protocol must be reviewed by the IRB before implementation. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB and maintain proper documentation of its records and promptly report to the IRB any adverse events which require reporting.

It is the principal investigator's responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities the principal investigator may seek to employ (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.) which are independent of IRB review/approval.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,

Jessica P. Rice
 IRB Manager



Winner Of The Lincoln Award For Excellence

March 29, 2012

Dauphne Sims, MSN, RN, APN, CNS
University of Wisconsin at Milwaukee, College of Nursing
6352 Valhalla Drive
Loves Park, IL 61111

RE: IRB APPROVAL OF PROPOSED STUDY

Dear Ms. Sims:

Please be advised that the SwedishAmerican Hospital Institutional Review Board approved your request for research at its meeting on this date. A one year approval has been granted to your protocol, "Decision Making in African American Women Diagnosed with Advanced Breast Cancer."

In this interim time period of approval, you are reminded that any changes in research activity or changes in approved research may not be initiated without IRB approval. Any adverse reactions encountered in this study are to be reported immediately to the IRB.

This study will be reviewed in March of 2013. A progress report, or final report must be provided to the IRB via Anna Frank in the Office of Clinical Research no later than the first week of March, 2013 *or at the end of the study if it precedes that date*. Failure to provide this update will result in termination of study approval.

This signature certifies that the information contained in this IRB notice is true and correct as verified by the minutes and records of the SAH IRB. It also certifies that the SAH IRB is in full compliance with the FDA Code of Federal Regulations, GCP Guidelines and ICH Guidelines. Thank you for presenting this interesting protocol.

If you have any questions, please feel free to contact me.

Sincerely,

Anna Frank, Research Coordinator
SwedishAmerican Hospital

1401 East State Street, Rockford, Illinois 61104-2315 Phone (815) 968-4400 www.swedishamerican.org
A Teaching Hospital Affiliated With The University Of Illinois College Of Medicine At Rockford

"Through excellence in healthcare and compassionate service, we care for our community."



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Modification/Amendment - IRB Expedited Approval

Date: June 14th, 2013

To: Jennifer Doering, PhD
 Dept: College of Nursing

Cc: Dauphne Sims

IRB#: 13.112

Title: Treatment Decision Making in African American Women Diagnosed with Advanced Breast Cancer

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has received modification/amendment approval for:

- Minor changes to questions in the interview guide

IRB approval will expire on October 21, 2013. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a Continuation for IRB Approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found on the IRB website.

Unless specifically where the change is necessary to eliminate apparent immediate hazards to the subjects, any proposed changes to the protocol must be reviewed by the Institutional Review Board before implementation.

Please note that it is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the University of Wisconsin – Milwaukee and its Institutional Review Board. It is the principal investigator's responsibility to maintain proper documentation of its records and promptly report to the Institutional Review Board any adverse events which require reporting.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,

Jessica Rice
 IRB Administrator



Melissa Spadanuda
 IRB Manager
 Institutional Review Board
 Engelmann 270
 P. O. Box 413
 Milwaukee, WI 53201-0413
 (414) 229-3173 phone
 (414) 229-6729 fax

Continuing Review - Notice of IRB Expedited Approval

<http://www.irb.uwm.edu>
spadanud@uwm.edu

Date: October 21, 2013

To: Jennifer Doering, PhD
Dept: College of Nursing

Cc: Dauphne Sims

IRB#: 13.112

Title: Treatment Decision Making in African American Women Diagnosed with Advanced Breast Cancer

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has received continuing approval as minimal risk Expedited under category 6 and 7 as governed by 45 CFR 46.110.

This protocol has been approved on **October 21, 2013** for one year. IRB approval will expire on **October 20, 2014**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a Continuation for IRB Approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found in IRBManager.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. The principal investigator is responsible for adhering to the policies and guidelines set forth by the UWM IRB, maintaining proper documentation of study records, and promptly reporting to the IRB any adverse events which require reporting. The Principal Investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,

Melissa C. Spadanuda
 IRB Manager

Appendix B
Consent Form

Informed Consent

IRB Protocol Number:

Version:

IRB Approval Date:

UNIVERSITY OF WISCONSIN – MILWAUKEE CONSENT TO PARTICIPATE IN RESEARCH

1. General Information

Study title:

Decision making in African American women diagnosed with advanced breast cancer.

Person in Charge of Study (Principal Investigator):

Dauphne Sims, MSN, RN, APN, CNS-Student Investigator and Doctoral Candidate

Jennifer Doering, PhD, RN, Associate Professor and Ms. Sims' (Advisor)

2. Study Description

You are being asked to participate in a research study. Your participation is completely voluntary. You do not have to participate if you do not want to.

Study description:

The purpose of this study is to describe the decision making of African American women who have been diagnosed with advance stage breast cancer. If you join this study you will be interviewed and asked to share your experience making decisions about breast cancer treatment.

The goal of the study is to learn about the decision making processes that African American women use on their journey with breast cancer.

The study will take place in your home or other comfortable meeting place. About 20 women will be in the study.

To be in this study you will need to be:

- African American
- You have been diagnosed with stage II to IV breast cancer in the past 4 years.
- Able to understand and speak English
- Over the age of 30
- Have been in treatment, about to start treatment or actually receiving treatment

You cannot be in this study if you have Dementia, Alzheimer's, Traumatic Brain Injury, or Mental Retardation.

If you qualify for this study you will be asked to do an interview with Ms. Sims the interview will take 1-2 hours and Ms. Sims may ask you to do a second shorter interview. Each interview will be recorded with a digital tape recorder so that we can make sure we hear what you say correctly.

Informed Consent
Version:

IRB Protocol Number:
IRB Approval Date:

3. Study Procedures

What will I be asked to do if I participate in the study?

If you join this study you will be asked to share your experiences with being diagnosed and treated for breast cancer. The interview will take place in your home or in a place that is comfortable for you. This interview will be audio taped to ensure that your story is accurately recorded. This interview should take approximately 1-2 hours. If you choose not to be audio taped, you may still participate in the study. Ms. Sims will take notes during the interview. You may be asked to do a second interview to check that we are telling your story correctly.

If you agree to enroll in this study, you will do the following:

- a. describe treatment decisions
- b. recall things that happened in treatment
- c. speak about your cultural values
- d. speak about the support you get from family and friends
- e. speak about your breast cancer treatment finances

4. Risks and Minimizing Risks

What risks will I face by participating in this study?

The potential risk for being in this study is minimal.

Psychological:

There is a potential for you to become uncomfortable or sad talking about your past experiences with breast cancer. You may choose to stop at anytime during the interview. You do not have to answer any questions that make you uncomfortable. You can also choose not to do a second interview if asked.

5. Benefits

Will I receive any benefit from my participation in this study?

There are no direct benefits to you other than to further research.

6. Study Costs and Compensation

Will I be charged anything for participating in this study?

There is no cost to you to be in this research study

Are subjects paid or given anything for being in the study?

Informed Consent

IRB Protocol Number:

Version:

IRB Approval Date:

To thank you for your time, you will be given a \$20.00 cash gift card at the end of the first interview. You will not be paid if asked to give a second interview.

7. Confidentiality

What happens to the information collected?

All information collected about you during the study will be kept confidential to the extent permitted by law. We may decide to present what we find to others, or publish our results in scientific journals or at scientific conferences. Only the Principal Investigator (Dr. Doering) and Student Doctoral Candidate (Ms. Sims) will have access to the information. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

You will be identified on tape and on paper with a made up name (pseudonym), your interviews will also have a coded number. After your audio tape is recorded into a computer file your information will be stored on a password protected computer. Any written notes will be put into a word document, organized and stored on the same computer. The audio recording will be erased after the study is completed and published. Once the study is complete the de-identified study information will be kept in a password protected computer by the Student Investigator indefinitely for teaching purposes.

8. Alternatives

Are there alternatives to participating in the study?

There are no known alternatives available to you other than not taking part in this study.

9. Voluntary Participation and Withdrawal

What happens if I decide not to be in this study?

Your participation in this study is entirely voluntary. You may choose not to take part in this study. If you decide to take part, you can change your mind later and withdraw from the study. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with the University of Wisconsin Milwaukee.

10. Questions

Who do I contact for questions about this study?

For more information about the study or the study procedures or treatments, or to withdraw from the study, contact:

Dauphne Sims, MSN, RN, APN, CNS
 Doctoral Candidate
 University of Wisconsin at Milwaukee- College of Nursing.

Informed Consent
Version:

IRB Protocol Number:
IRB Approval Date:

6352 Valhalla Drive
Loves Park, IL 61111
(815) 885-3070 home phone
(815) 543-7550 cell phone

Who do I contact for questions about my rights or complaints towards my treatment as a research subject?

The Institutional Review Board may ask your name, but all complaints are kept in confidence.

Institutional Review Board
Human Research Protection Program
Department of University Safety and Assurances
University of Wisconsin – Milwaukee
P.O. Box 413
Milwaukee, WI 53201
(414) 229-3173

11. Signatures

Research Subject's Consent to Participate in Research:

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study, you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read or had read to you this entire consent form, including the risks and benefits, and have had all of your questions answered, and that you are 18 years of age or older.

Printed Name of Subject/ Legally Authorized Representative

Signature of Subject/Legally Authorized Representative

Date

Research Subject's Consent to Audio/Video/Photo Recording:

It is okay to audiotape me while I am in this study and use my audiotaped data in the research.

Please initial: ____Yes ____No

Principal Investigator (or Designee)

I have given this research subject information on the study that is accurate and sufficient for the subject to fully understand the nature, risks and benefits of the study.

Printed Name of Person Obtaining Consent

Study Role

Signature of Person Obtaining Consent

Date

Appendix C
Recruitment Flyer



A Research Study on Treatment Decision Making with Breast Cancer

**Dauphne Sims, MS, RN, APN, CNS
University of Wisconsin-Milwaukee
Doctoral Student**

#9-815-543-7550

Study approved by UWM IRB Protocol #

1. I am a nurse doing research on decision making in African American women diagnosed with breast cancer.

2. The goal of this study is to learn how African American women make decisions about treatment.

3. I would like to hear your story about how you made treatment decisions. This study will take about 1-2 hours of your time.

4. If you would like to learn more about this study, please tell your nurse and I will call you.

Thank You



College of Nursing

Appendix D
Interview Guide

Script:

Hello my name is Dauphne Sims, I am a doctoral student in Nursing finishing my degree at the University of Wisconsin. Thanking you for taking the time to meet with me today. I have some questions I would like to ask you about your breast cancer diagnosis.

Before we start I want to remind you that if you get tired, we can take as many breaks as you need during this interview. Also, if there are any questions you are not comfortable answering, just tell me you want to skip that question. Do you have any questions?

Interview Guide

1. What were you told about which type of breast cancer you have?
2. Were you told which stage of breast cancer you have?
3. What was it liked between you and your health care provider when you were told you had breast cancer?
 - a. Describe your feelings about your communication with your health care provider?
4. Tell me about a time when you were not treated with respect by your doctors, nurses, or anyone else where you get treatment.
5. How do you feel about talking to your health care providers about your breast cancer?
 - a. How much do you feel like you can really share your concerns with your health care provider?
6. Do you feel you are treated different than other people where you get treatment?
 - a. If yes, how are you treated differently? If not, do you see others being treated differently?

7. A lot of women say that trust between them and their health care providers is important. Tell me about how much you trust your healthcare providers?

8. Who made the decision about whether or not you would have treatment?

a. How comfortable were you with the treatment decisions that were made?

9. Tell me about how you made decisions about which treatment methods to use?

10. Tell me about the people who helped you with your treatment decisions.

a. How did they make your decision better or easier?

b. How did they make your decision worse or harder?

11. What has your treatment been like?

12. Please tell me about any side effects you have had with your treatment.

a. Were you told you could get these side effects prior to treatment?

b. Tell me how being in treatment has affected your life.

13. Do you feel like the treatments that you have received are any different because of your race? If yes, how does this make you feel?

a. What have you tried to get around your being treated differently?

14. How long did your healthcare provider tell you that you may live with/without treatment?

a. How often you discuss your cancer progress with your health care providers?

b*What was the length of time between when you were told you have breast cancer to the time you had surgery?

15. What money concerns do you have about treatment?

16. What concerns do you have about paying for care and/or medicine?

17. Who has supported you with money since your diagnosis?
 - a. What other types of support do you get and who gives you that support?
 - b. Tell me about any spiritual support you get.
18. Since you were diagnosed, what kind of talks do you have with your family or friends about your cancer?
19. Other women tell me they do not feel like they know everything about their breast cancer is this true for you too? If yes, how?
 - a. If not, did you search for any additional information about your breast cancer? From where?
 - b. Please tell me about, any other technology or library resources you have used.
20. If you could go back in time and change what you experienced, what would you change?
 - a. What do you know now that you wish you had known back when you were diagnosed or deciding on treatment?
21. Tell me about any specific beliefs or personal values that were important to your treatment decisions.
22. What treatment advice would you give to African American women who have just been diagnosed with breast cancer?
23. What else do you want to share with me?
24. What questions can I answer for you?

Appendix E

Interview Guide/Research Question Matrix

<p>Decision Making in African American women Research Question Matrix</p>	
<p>Script:</p> <p>Hello my name is Dauphne Sims, I am a doctoral student in Nursing finishing my degree at the University of Wisconsin. Thanking you for taking the time to meet with me today. I have some questions I would like to ask you about your breast cancer diagnosis. Before we start I want to remind you that if you get tired, we can take as many breaks as you need during this interview. Also, if there are any questions you are not comfortable answering, just tell me you want to skip that question. Do you have any questions?</p>	

Research Questions	Interview Guide Questions
<p>1. How do African American women describe the process of making decisions about breast cancer treatment?</p> <p>a. how do women participate in treatment decisions?</p> <p>b. how is women's participation in their treatment decisions facilitated?</p> <p>c. how is women's participation in their treatment decision hindered?</p> <p>d. how do women describe their patient-health care provider communication and interaction in relation to treatment decision making?</p> <p>e. what additional resources do they utilize in making their treatment decision?</p>	<p>1. How were you told about which type of breast cancer you have?</p> <p>2. Were you told which stage of breast cancer you have?</p> <p>3. What was it liked between you and your health care provider when you were told you had breast cancer?</p> <p>a. Describe your feelings about your communication with your health care provider?</p> <p>4. Tell me about a time when you were not treated with respect by your doctors, nurses, or anyone else where you get treatment.</p> <p>5. How do you feel about talking to your health care providers about your breast cancer?</p> <p>a. How much do you feel like you can really share your concerns with your health care provider?</p> <p>7. A lot of women say that trust between them and their health care providers is important. Tell me about how much you trust your healthcare providers?</p> <p>8. Who made the decision about whether or not you would have treatment?</p> <p>a. How comfortable were you with the treatment decisions that were made?</p> <p>9. Tell me about how you made decisions about which treatment methods to use?</p> <p>11. What has your treatment been like?</p> <p>12. Please tell me about any side effects you have had with your treatment.</p> <p>a. Were you told you could get these side effects prior to treatment?</p> <p>b. Tell me how being in treatment has affected your life.</p> <p>14. How long did your healthcare provider tell you that you may live with/without treatment?</p>

	<p>a. How often do you discuss your cancer progress with your health care providers?</p> <p>19. Other women tell me they do not feel like they know everything about their breast cancer is this true for you too? If yes, how?</p> <p>a. If not, did you search for any additional information about your breast cancer? From where?</p> <p>b. Please tell me about, any other technology or library resources you have used.</p> <p>20. If you could go back in time and change what you experienced, what would you change?</p> <p>a. What do you know now that you wish you had known back when you were diagnosed or deciding on treatment?</p>
<p>2. What cultural capital do women utilize when making treatment decisions?</p> <p>a. what social supports do women utilize when making treatment decisions?</p> <p>b. how do economic circumstances affect treatment decision making?</p> <p>c. how do important cultural values or beliefs influence women when making treatment decisions?</p> <p>d. how do cultural concerns influence their treatment decisions?</p>	<p>6. Do you feel you are treated different than other people where you get treatment? If yes, how are you treated differently? If not, do you see others being treated differently?</p> <p>10. Tell me about the people who helped you with your treatment decisions.</p> <p>a. How did they make your decision better or easier?</p> <p>b. How did they make your decision worse or harder?</p> <p>13. Do you feel like the treatments that you have received are any different because of your race? If yes, how does this make you feel?</p> <p>a. What have you tried to get around your being treated differently?</p> <p>15. What money concerns do you have?</p> <p>16. What concerns do you have about paying for care and/or medicine?</p> <p>17. Who has supported you with money since your diagnosis?</p> <p>a. What other types of support do you get and who gives you that support?</p> <p>b. Tell me about any spiritual support you get.</p>

	<p>21. Tell me about any specific beliefs or personal values that were important to your treatment decisions.</p> <p>18. Since you were diagnosed, what kind of talks do you have with your family or friends about your cancer?</p>
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Appendix F
Demographic Form

Demographic Form

Please check the boxes that best apply:

How long ago were you diagnosed?

- | | |
|--|---|
| <input type="checkbox"/> Less than 1 month ago | <input type="checkbox"/> 6 months ago |
| <input type="checkbox"/> 2 months ago | <input type="checkbox"/> 7 months ago |
| <input type="checkbox"/> 3 months ago | <input type="checkbox"/> 8 months ago |
| <input type="checkbox"/> 4 months ago | <input type="checkbox"/> 9 months ago |
| <input type="checkbox"/> 5 months ago | <input type="checkbox"/> more than 1 year ago |

What type of treatments do you get?

- ☐ I will start treatment soon
- ☐ Chemotherapy
- ☐ Radiation
- ☐ Chemotherapy and Radiation
- ☐ Other _____

How often do/did you get treatments? _____

What is your age? _____ years

Are you:

- ☐ Single
- ☐ Married
- ☐ Widowed
- ☐ Divorce
- ☐ Other _____

What type of medical coverage do you have?

- ☐ Medicare
- ☐ Medicaid
- ☐ Commercial (through employer)
- ☐ None (self-pay)
- ☐ Other _____

What is your annual household income before taxes? What is your Zip code? _____

- ☐ \$0 - 20,000
- ☐ \$21,000 - 40,000
- ☐ \$41,000- 60,000
- ☐ \$61,000-80,000
- ☐ \$81,000-100,000
- ☐ over \$100,000

Appendix G
Revised Interview Guide

Revised Interview Guide

1. Tell me how you were you told about your breast cancer?
2. Were you told which stage of breast cancer you have?
 - a. What type of breast cancer do you have?
3. Describe your feelings about your communication with your health care provider?
4. How much do you feel like you can really share your concerns with your health care provider?
5. A lot of women say that trust between them and their health care providers is important. Tell me about how much you trust your healthcare providers?
6. Who made the decision about whether or not you would have treatment?
 - a. How comfortable were you with the treatment decisions that were made?
7. Tell me about how you made decisions about which treatment methods to use?
 - a. What was the order of your treatment plan?
 - b. Tell me about the first step of your treatment plan.
 - c. What was next step? Etc.
8. Before you let your physician know of your choices to whom did you speak with about your treatment decision(s)?
 - a. Women say that they thought it was important in their treatment decision to consider the way their body would look with or out their breast. Is this true for you? If so, tell me about it?

9. Tell me about the people who helped you with your treatment decisions.

- a. How did they make your decision better or easier?
- b. How did they make your decision worse or harder?

10 What has your treatment been like?

11. Please tell me about any side effects you have had with your treatment.

- a. Were you told you could get these side effects prior to treatment?
- b. Tell me how being in treatment has affected your life.

12. Do you feel like the treatments that you have received are any different because of your race? If yes, how does this make you feel?

- a. What have you tried to get around your being treated differently?

13. How long did your healthcare provider tell you that you may live with/without treatment?

- a. How often you discuss your cancer progress with your health care providers?

14. What was the length of time between when you were told you have breast cancer to the time you had surgery?

15. What money concerns do you have about treatment?

16. What concerns do you have about paying for care and/or medicine?

17. Who has supported you with money since your diagnosis?

a. What other types of support do you get and who gives you that support?

b. Tell me about any spiritual support you get.

18. Since you were diagnosed, what kind of talks do you have with your family or friends about your cancer?

19. Other women tell me they do not feel like they know everything about their breast cancer is this true for you too? If yes, how?

a. prior to making your treatment decisions, did you search for any additional information about your breast cancer? From where?

b. Please tell me about, any other technology or library resources you have used.

20. If you could go back in time and change what you experienced, what would you change?

a. What do you know now that you wish you had known back when you were diagnosed or deciding on treatment?

21. When you think about your treatment what word(s) comes to mind that describe your experiences.

a. one the words I have heard is fortitude, does this word describe any of your experiences? If so, tell me how?

22. Tell me about any specific beliefs or personal values that were important to your treatment decisions.

23. What treatment advice would you give to African American women who have just been diagnosed with breast cancer?

24. What else do you want to share with me?

25. What questions can I answer for you?

Appendix H
Confirmability Study

CONFIRMABILITY STUDY

TREATMENT DECISION MAKING IN AFRICAN AMERICAN WOMEN DIAGNOSED WITH ADVANCED BREAST CANCER

I agree with the emerging concepts and theories that this grounded theory process uncovered. The researcher has moved from substantive codes generated from the participants own words through more abstract leveled categories, ultimately resulting in the building blocks of theory. Purposive and theoretical sampling along with simultaneous data collection and analysis yielded theories relevant to the data. I do not believe any muddling of methods or compromise to grounded theory occurred. Beginning with open and selective coding, at each level, the theory became more refined yielding, what I believe was a parsimonious integration of abstract concepts that explained and covered the decision making process. I recalled nothing to suggest premature closure or the inability to transcend the initial in vivo level of analysis; thus, the theories generated appear original. A deeper understanding of concepts grew from the participants descriptive phrases.

I believe combining interpersonal perceptiveness with conceptual thinking resulted in theoretical sensitivity. Through the coding process, along with ongoing and constant revisions to the field notes and the mainstay of reflective journaling grounded the dependability of the data. The discovery of “fortitude” as a major construct necessary to manage the myriad of challenges within the decision making process for women diagnosed with breast cancer, appears to played out at many interactional levels of experience for the women. This study was credible in that it captured the essence of the treatment decision-making process of African American women diagnosed with advanced breast cancer.

Thank you for the opportunity to offer this opinion.

Sincerely,

Dr. Thomas James Loveless, MSN, CRNP, PhD

Curriculum Vitae

Dauphne Annette Sims, PhD, RN, APN, CNS

Academic Degrees:

University of Wisconsin at Milwaukee

Doctoral Degree in Nursing May 2014

University of Illinois at Chicago Rockford, IL

MS in Nursing, 2003

Northern Illinois University, Dekalb, IL

BS in Nursing, 1998

Rock Valley College, Rockford, IL

Associates Degree, 1996

Rock Valley College, Rockford, IL

Associates of Applied Science in Nursing (ADN), 1985

Dissertation Title: Treatment Decision Making in African American Women Diagnosed with Advanced Breast Cancer

Credentials

Registered professional nurse licensure 041-230775

Advanced practice nurse licensure 209-006065

Certifications: Community Nurse Specialist ANCC, 2004

Professional Organization Membership

Public Health Nurses association

National Coalition of Ethnic Minority Nurses Association (NCEMNA)

Midwest Nursing Research Society (MNRS)

Sigma Theta Tau-Phi Omicron Chapter

Professional Experience

August 2008: Promoted to Assistant Professor.

August 2004 to Present: St. Anthony's College of Nursing; Instructor.

September 2003 to August 2004: St. Anthony Medical Center; Case management.

January 2003 to September 2003: Alma Nelson Manor; Nursing Supervisor.

February 2001 to May 2002: Park Ridge Terrace, Ltd; Director of Nursing.

Professional Development

Nursing Expo 2006

10/06-11/06 Health Disparities Workshop

Nursing Expo 2007-presentation of speaker

Nursing Expo 2008-presentation of speaker

MNRS research conference, Indianapolis, IN 2008

MNRS research conference, Minneapolis, MN 2009-Oral presentation on Grounded Theory; a study on Post-partum Fatigue.

MNRS research conference, Kansas City MI 2010-Oral presentation on Decision making in African American women diagnosed with breast cancer

Nursing Expo 2011 Introduction of speaker/Poster Presentation on Post-partum Fatigue in low income urban women.

Nursing Expo 2012 Introduction of speaker/Poster Presentation on Decision Making in African American women diagnosed with breast cancer-Pilot Study

July 2012 Church women fellowship; Presentation on Breast cancer awareness in collaboration with the American Cancer society.

Nursing Expo 2014 Program committee and Introduction of speaker The have and have nots of a colonoscopy

Teaching Experience

St. Anthony College of Nursing, Fall 2004 to Spring 05 Undergraduate Program

- Co-taught in senior level Nursing Leadership and Management course
- Co-taught in senior clinical course; lecture areas: chronic cardiac, chronic neurological, acute neurological, integument and renal systems.

Fall 2005 to Spring 2006 Undergraduate Program

- Course coordinator for Nursing leadership and management course; developed online format for this course; developed syllabus and administered grades. Exam construction and administration.
- Co-taught in senior clinical course; lecture areas: chronic cardiac, chronic neurological, acute neurological, integument and renal systems. Responsible for completing student clinical schedule.

Fall 2006-2008 Undergraduate Program

- Course coordinator for Nursing leadership and management course; mentoring and co-teaching course with new faculty online. Developed syllabus, course schedule and grades.
- Co-teaching with a four member nursing faculty; content areas renal and chronic neurological systems. Responsible for student and faculty clinical schedules. Exam construction and administration.

Fall 2008 thru Fall 2011-Undergraduate Program

- Course coordinator for Nursing leadership and management course, online.

- Co-teaching in clinical course 401.

Spring 2012-reduced workload for dissertation

- Course coordinator for nursing leadership and management course.

Fall 2012

- Course coordinator for Nursing leadership and management course; online.
- Co-taught in senior clinical course; lecture areas: chronic neurological, renal systems. Responsible for completing student clinical schedule.

Fall 2013

- Course coordinator for Nursing leadership and management course; online
- Co-taught in senior clinical course; lecture areas;

Committee Work

Sigma Theta Tau Counselor 2012-present

Chair Undergraduate admission and progression committee 2013-

Undergraduate admission and progression committee 2012-2013

CCNE Subgroup B 2011-2013

Academic Standards Committee 2004-2011

Curriculum committee 2004-06

Academic standards committee-Faculty Secretary 2006-2007

Faculty Affairs-Chairperson 2006-2010

Long Range Planning Committee 2006-2007

Higher Learning Commission Subgroup A 2006-2007

Sigma Theta Tau task force 2007-2008

Scholarly Activities/Poster Presentations

Presented at health care symposium; African American Women and Breast Cancer

Poster Presentation on Health Disparities

Abstract accepted for MNRS on post-partum fatigue in low income women.

Presentation MNRS decision making in African American women diagnosed with breast cancer.

Breast cancer presentations-Church group July 2012

Doering, J. J. & Sims, D. A. (2010, June). Postpartum Fatigue in Lower-Income Urban Women with Depression Symptoms. SLEEP 2010 Annual Conference, San Antonio, TX. (peer reviewed). (poster). (national).

Sims April, 2010, Abstract for MNRS Pilot study of decision making in breast cancer of African American women.

Mentoring:

- Nursing Expo Spring 2014 Speaker Sheila Stanfield presentation titled "The have and have not's of a colonoscopy"
- Spring 2013: Graduate Student Melissa Fischer –Teaching Practicum; Saint Anthony College of Nursing

Committee member with Char Sanford for Melissa Fischer: Integrative literature review title: *Effects of High-Fidelity Human Patient Simulation on Baccalaureate Nursing Student's Confidence Levels and Critical Thinking Skills: An Integrated Literature Review*

- Fall 2013: Graduate Student for Deleon Addison- Teaching Practicum; Gonzaga University, Spokane, WA.
- **Hagenbruch, L. & Sims, D.** (2014, March). *Methods for improving patient trust in vaccinations*. Poster presented at Nurses EXPO 2014, Rockford, IL. Winner of Best Student Poster Award.
-

Publications

Book Review

Sims, D. (2002). HIV a journey to the source of HIV and AIDS. *Leadership in Public Health*, 5(3).

Sims, D. (2007). The special world of teaching. *Perspective UIC College of Nursing*, 11(2).

Unpublished Documents

Masters Thesis: African American women and cervical and breast cancer Research: African American Women and Mammography: Who's Being Screened?

HLC Accreditation self study 2007

CCNE Accreditation self study 2012

Community Service

Nursing Expo Program Committee

Camp Nursing

Parish Nursing

American Cancer Society-making strides

Scholarship

UWM Chancellor Award Scholarship 2007-2009
Nursing Expo: Received a Doctoral Scholarship March 2012