CANCER COMMUNICATION, UNCERTAINTY, AND PATIENT SATISFACTION:
INVESTIGATING THE EFFECT OF PATIENT NAVIGATORS ON THE BREAST
CANCER TREATMENT DECISION-MAKING PROCESS

A Dissertation in
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ABSTRACT

A breast cancer diagnosis coupled with the necessity that treatment decisions be made soon after diagnosis often results in a great deal of stress and fear for patients. A key element of effectively engaging cancer patients in their diagnosis, treatment, and survivorship is appropriate and effective communication. The role of the patient navigator has emerged in breast cancer care over the last decade to help integrate information and care processes. A patient navigator is a cancer-care provider who offers support and guidance to breast cancer patients. Having a patient navigator on a cancer-care team may enhance the patient-centered care and significantly improve the effectiveness of communication during cancer treatment. Breast cancer treatment is a preference-sensitive decision because in most cases of breast cancer treatment, there is no clear best clinical choice. Instead, patients apply their personal values and beliefs to select the option they feel is best. Throughout the process of cancer screening, diagnosis, treatment and survivorship, there are many points of uncertainty. The purpose of the research reported herein was to assess the communicative influence of patient navigators on breast cancer patients’ decision-making process. Specifically, I sought to determine if women who have access to a patient navigator during breast cancer treatment decision-making better manage uncertainty and experience greater patient satisfaction with the overall care experience than women who do not have access to a patient navigator.

Participants in an online survey included 124 female breast cancer survivors who had finished active breast cancer treatment within three years of participating. The survey was distributed via convenience snowball sampling. Measures of interest were patient-centered communication, decisional conflict, and patient satisfaction. Qualitative interviews were conducted with 11 women who were selected via a purposeful random sampling procedure from
the sample of online survey participants in the interests of better understanding the nuanced experience of breast cancer patients’ treatment decision-making experience. Factor analysis revealed clusters appropriate to the dimensions of patient-centered communication, decisional conflict, and patient satisfaction.

Independent samples t-tests and multiple regression analyses were used to test hypotheses. Several significant results surfaced in comparisons of participants who had a patient navigator on their cancer-care teams and others who did not. Participants who had a patient navigator as part of their cancer-care teams scored significantly higher on patient engagement, individual confirmation, decisional support, and patient satisfaction with the care experience than ones who did not. Patient-centered communication was a predictor of both decisional conflict and patient satisfaction, but only interpersonal sincerity and patient engagement revealed significant relationships when controlling for the other predictor variables.

For the qualitative analysis, 19 categories emerged from semi-structured interviews with breast cancer survivors who had finished active treatment during the last three years. Categories included: (a) communication of the diagnosis, (b) uncertainty following diagnosis, (c) communication about treatment options, (d) information-processing of treatment options, (e) treatment decision-making process, (f) decision time pressure, (g) uncertainty during decision-making, (h) information-seeking, (i) decision-makers, (j) decisional support, (k) satisfaction with treatment decisions, (l) emotional support during decision-making, (m) cancer-care team composition and roles, (n) communication with patient navigators, (o) advanced provision of information/avoiding surprises, (p) communication between cancer-care team members, (q) fertility decisions, (r) survivor support, and (s) uncertainty of finishing treatment. Categories were further
sub-divided for easier interpretation of quantitative data using qualitative feedback, which is described in detail.

The results of this quasi-experimental examination of communication during cancer care and the influence on decisional conflict and patient satisfaction offer insights related to theoretical significance, the importance and the impact of patient navigators as members of a cancer-care team, and the practical implications for breast cancer-related communication. There appears to be a critical influence of nonverbal aspects of communication, namely proxemics, in the structural layout of cancer centers relating to a patient’s ability to manage uncertainty. Implications for breast cancer communication involve a need to create consistency in patient navigation research and practice, improve communication about the timeframe necessary for breast cancer decision-making, and ensure patients receive sufficient social support throughout treatment decision-making.
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Chapter 1: GUIDING LITERATURE AND THEORY

Introduction

“She called me at home at 9:00 P.M. the night before Thanksgiving and said, ‘I’m so sorry, you have breast cancer’” (P10). This phrase, or something similar, shares the news of a breast cancer diagnosis and is uttered to one out of every eight American women (American Cancer Society, 2014). The way in which women learn about their cancer diagnosis is just the beginning of the communication they will experience throughout treatment and it can have devastating physical and emotional effects on patients (Boehmke & Dickerson, 2006; Brown, Stewart, & McWilliam, 1999; Nussbaum, Baringer, & Kundrat, 2003).

Each year millions of Americans receive a cancer diagnosis. Treatments continue to improve, and more patients are experiencing a 5-year survival rate than ever before (American Cancer Society, 2012). Breast cancer is the most common type of cancer among women, and although it can affect both genders, women are nearly 100 times more likely to develop the disease (Centers for Disease Control and Prevention, 2014). Although treatment and survival rates are improving, the rate at which new cases are diagnosed has remained constant over the last 10 years (Howlander et al., 2014). Additionally, receiving a breast cancer diagnosis is often one of the most traumatic and stressful events in a woman’s life (Brown, Stewart, & McWilliam, 1999). With such a high incidence rate and serious physical and emotional consequences of the disease, the patient experience during diagnosis and treatment of breast cancer continues to be an important research area.

The initial emotional trauma of being diagnosed can be compounded by the fact that patients are also expected to listen to and comprehend large amounts of information about

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1 Interview excerpts are indicated by a code that indicates “P” for participant and a numerical identifier.
treatment options (Diefenbach et al., 2009). Even though this can be a highly distressing period, research consistently suggests that breast cancer patients want as much information as possible about all aspects of the disease (Vogel, Bengel, & Helmes, 2008). The desire for information initially begins with the pathology report and clinical description of the disease, but quickly moves to questions about which treatment options are available and which could possibly be utilized for treatment. The initial anguish of being diagnosed is compounded by the many healthcare decisions that one must make (O’Hair et al., 2003). With breast cancer, there are decisions about surgery, pharmaceutical treatments, and reconstruction, which are influenced not only by clinical recommendations, but also by the preferences of the patient (Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007; Wennberg, Fisher, & Skinner, 2002). When patients are faced with preference-sensitive conditions, the decisions they must make include several options with equally viable clinical outcomes (Elwyn et al., 2001; Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007). With similar clinical outcomes presented for various choices, the “next level” of distinction among choices involves personal values and beliefs of patients.

Women who face treatment decisions for breast cancer have several options to consider. Randomized clinical trials relating to early-stage breast cancer treatment show similarities in outcomes from women who undergo lumpectomy compared to those who have mastectomy (Fisher et al., 2002). Essentially, when a woman is diagnosed with breast cancer, there may not be a single treatment plan that is most effective, which opens the decision-making considerations to values, beliefs, and preferences. When making decisions about breast cancer treatment, there are few “right” or “wrong” answers. In turn, formal healthcare providers must communicate options and information to patients immediately after diagnosis, when the cancer patient is apt to be at a point of extreme stress and anxiety (Brown, Stewart, & McWilliam, 1999). The often
emotional reaction of patients following diagnosis also makes it difficult for patients to comprehend information completely (Lerman, et al., 1995; Sepucha, Belkora, Tripathy, & Esserman, 2000). When breast cancer patients received information about risks related to treatment choices, comprehension decreased because of the high level of stress they felt during diagnosis and treatment (Lerman et al., 1993). Additionally, Sepucha, Belkora, Tripathy, and Esserman (2000), reported that even when a personalized consultation about treatment options and expected clinical outcomes was available, many participants remained overwhelmed by the process of making a decision for breast-cancer treatment. Therefore, it seems to follow that the communication offered by members of a cancer-care team must not only effectively include messages about options and clinical treatments, but also address the seriousness of the disease and account for patient distress during decision-making.

Selecting the treatment plan that best addresses the available clinical information and aligns with a patient’s values, beliefs and long-term goals can be an incredibly challenging task. This act of making decisions about treatment increases feelings of stress, anxiety, fear, and anger (Dean & Street, 2014), for which and competent communication can help patients better cope (Beaver, Luker, Owens, Leinster, Degner, & Sloan, 1996; Kreps, 2003; Northouse, 1989). In fact, patients who are able to communicate their preferences about treatment and ask appropriate questions during decision-making ostensibly have better health outcomes than those who are unable or avoid these communicative behaviors (Benbassat, Pilpel, & Tidhar, 1998). Of particular interest for the present study was determining whether or not women having access to a patient navigator during decision-making experience less decisional conflict and greater patient satisfaction with the overall care experience.
Since a breast cancer diagnosis and the subsequent decision-making required of patients results in a great deal of uncertainty (Babrow, Kasch, & Ford, 1998; O’Connor, 1995), the extent to which the communication offered by patient navigators helps patients manage uncertainty was of primary interest in this study. Patient navigators provide communicative support that is representative of patient-centered communication in breast cancer treatment decision-making influences patient satisfaction with the care experience overall (Aharony & Strasser, 1993; Lochman, 1983). Additionally, as uncertainty management is often considered one of six fundamental functions of effective communication between patients and providers (Epstein & Street, 2007), I used principles of Uncertainty Management Theory (UMT) not only to ground my rationale for the associations between variables, but also to explain and interpret the results.

The subsequent sections of Chapter 1 provide a review of pertinent literature and an explanation of the theoretical foundation for this study. This chapter is organized in line with the concepts of UMT, beginning with the premise that communication is a means by which uncertainty is managed in health contexts (Brashers, 2001). First, I review the literature on communication in cancer treatment and introduce the patient navigator as unique source of patient-centered communication for breast cancer patients. I then focus on the theoretical foundations of UMT by showing that uncertainty is inherent in the breast cancer decision-making process, as well as explain that uncertainty can be conceptualized as decisional conflict in this context. Finally, I use the fundamental arguments of UMT to explain how a breast cancer patient’s management of decisional conflict is related to patient navigator communication. Finally, I build on research from the Patient Navigation Research Group in exploring the connection between the presence of patient navigators and patient satisfaction with the care experience.
Role of Communication in Cancer Treatment

Cancer is a complex disease, and each patient has unique experiences stemming from the type of cancer, the stage at which it is diagnosed, the availability of treatment options, and one’s physical responses to treatment. A key element of effectively engaging cancer patients in their diagnosis, treatment, and survivorship is appropriate and effective communication, which requires that providers understand and practice strategies that address the “psychological and socioemotional issues surrounding different individual’s experiences with cancer” (Kreps, 2003, p. 163). Communication is ubiquitous during every step of the cancer patient’s disease progression, including screening, diagnosis and treatment, and survivorship. An important role of medical providers is to ensure that messages align with the needs and preferences of the patient (Politi & Street, 2011). It is much more likely that patients and providers will agree to a treatment plan when patients actively participate in decision-making by asking questions, sharing goals, and exhibiting understanding of the information by saying it back to the provider (Politi & Street, 2011).

Communication during cancer diagnosis and treatment is important and affects many physical and psychological patient outcomes. Research suggests a connection between aspects of communication and long-term patient health outcomes (Kerr, Engel, Schlesinger-Raab, Sauer, & Holzel, 2003; Lerman et al., 1993; Roberts, Cox, Reintgen, Baile, & Gibertini, 1994; Vogel, Leonhart, & Helmes, 2009). For instance, when patients perceived that information was shared openly and thoroughly during treatment, they reported a higher quality of life six months after treatment (Vogel, Leonhart, & Helmes, 2009). Additionally, Kerr, Engel, Schlesinger-Raab, Sauer, and Holzel (2003) noted that quality of life was significantly higher four years later for patients who reported having clear communication with providers. Emotional well-being is also
affected by improved communication between providers and patients. Roberts, Cox, Reintgen, Baile, and Gibertini (1994) discovered that when providers showed empathy and provided sufficient information about treatment, patients had improved psychological outcomes.

Kreps and Chapelsky Massimilla (2002) undertook an extensive review of the literature that revealed connections between cancer-related communication and health outcomes. In the review, they noted that interpersonal communication experienced by cancer patients from providers can result in reduced anxiety and depression (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Larsson, Widmark Peterson, Lampic, von Essen, & Sjoden, 1998; Pollak et al., 2007), improved satisfaction with care (Gamble 1998; Parker, Aaron, & Baile, 2008), and improved quality of life (Kreps, 2003). Additionally, Levinson, Roter, Mullooly, Dull, and Frankel (1997) reported that providers who provide poor communication, such as failing to tell patients what to expect from treatment, not encouraging them to ask questions, and avoiding opportunities to check for patient understanding, are much more likely to incur malpractice lawsuits. Effective communication with breast cancer patients, specifically, can help the patients better adjust to acute treatment and feel less distress (Lerman et al., 1993), while also having more optimism about the disease overall and an improved quality of life following treatment (Vogel, Leonhart, & Helmes, 2009). It is reasonable to conclude from the data that the interpersonal communication strategies used by medical providers to share information and discuss treatment options can have significant long-term effects on cancer patients.

Specific communication practices can directly affect a patient’s ability to manage the emotional effects of cancer, which include, disease information provision, use of effective interpersonal skills, and offering messages that instill hope (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994). One of the most important ways in which providers effectively deal with cancer
patients throughout diagnosis and treatment is by employing effective communication strategies, such as encouraging them to ask questions, showing empathy, and verifying that the patients understand information accurately. Although communication can improve the treatment process and the survivorship experience, not all patients are realizing such benefits (Diefenbach et al., 2009; Eggly, Albrecht, Kelly, Prigerson, Sheldon, & Studts, 2009; Lerman et al., 1993). Lerman et al. (1993) recommended that the quality of communication during breast cancer decision-making would be improved if providers communicated information more clearly. They also suggested that creating a setting in which patients feel more comfortable asking questions and expressing their feelings improves their ability to understand information communicated to them by providers (Lerman et al., 1993). Nearly 15 years later, Eggly et al. (2009) summarized the current communicative role of physicians and contended that information from providers about treatment decision-making can lead to “confusion, frustration, and medical mistrust” (p. 70). The recommendation to improve the quality of communication received by patients also touched on the need for increased quantity of communication. Communication could be improved by having several different formats from which it is shared and by having nurses and other members of healthcare teams share information at more frequent intervals during the decision-making process (Eggly et al., 2009). Research that investigates the clinical care experience and the communication experienced by breast cancer patients during diagnosis and treatment may further improve long-term patient outcomes.

The Cancer-Care Team

Communication with providers is important, but it does not always entail simple dyadic interaction with one individual. Instead, patients may see five or more specialists at various stages in the treatment process. The clinical advances in cancer treatment have resulted in
complex plans requiring patients and families to spend a great deal of time navigating the healthcare system (Campbell, Craig, Eggert, & Bailey-Dorton, 2010). This includes locating providers, submitting insurance claims, managing emotional challenges and side effects, and working with employers when patients must be absent from work. Some of the providers patients may see include general practitioners and gynecologists for screenings, radiologists to report results of biopsies, oncologists for diagnosis and treatment recommendations, general surgeons if mastectomy or lumpectomy is required, plastic surgeons for breast reconstruction, and a great many complementary providers, such as physical therapists, psychologists, nurse practitioners, and case managers. This intricate network of providers comprises the “cancer-care team.” Street, Makoul, Arora, and Epstein (2009) suggested that considering the communication between the patient and all members of the health care team was a more accurate depiction of the patient experience than considering only one patient-provider dyad. Each patient will have a cancer-care team, whose job of helping one through the cancer diagnosis and treatment process is demanding on both an emotional and physical level (Thorne, Bultz, Baile, & SCRN Communication Team, 2005).

The cancer-care team includes specialized healthcare providers, including physicians, nurses, advanced practice providers (e.g., nurse practitioners, physician assistants, etc.), psychological support providers (e.g., psychiatrists, psychologists, etc.), pharmacists, dietitians, social workers, patient navigators, and hospice providers (Levit, Balogh, Nass, Ganz, & the Committee on Improving the Quality of Cancer Care, 2013). There are several types of physicians who specialize in cancer care and treatment (American Society of Clinical Oncology, 2012). The surgical oncologist performs surgical removal of cancer cells, whereas radiation oncologists develop and carry out radiation treatment plans and medical oncologists focus on
treated cancer with medication like chemotherapy (American Society of Clinical Oncology, 2012). Depending on the anatomical system that is affected by cancer, other specialists may be involved, such as plastic surgeons for breast reconstruction following mastectomy, gastroenterologists for colon cancer, or dermatologists for early-stage melanoma. Regardless of the location of the cancer cells within the body, the medical oncologist is typically the primary physician involved in a patient’s cancer care and treatment (Levit et al., 2013).

Another important source of specialized care is nurses, who can include licensed practical nurses (LPN), registered nurses (RN), or advanced practice registered nurses (APRN). The different types of nurses are distinguishable on the basis of the amount of training and education they receive; LPNs have the least training, whereas APRNs typically have a bachelor’s degree with a registered nurse training (American Nurses Association, 2012; Levit et al., 2013). The role of nurses in the cancer diagnosis and treatment process can range from such simple support procedures as taking blood pressure to ordering tests and referring patients to specialists (Levit et al., 2013). Often, nurses who work with cancer patients receive specialized training in oncology and are accordingly called oncology nurses. These nurses have extended roles that can include giving chemotherapy and assisting patients with care coordination throughout cancer treatment (American Society of Clinical Oncology, 2012).

Advanced practice providers, which include nurse practitioners and physician assistants, are able to collaborate with physicians to counsel patients and discuss treatment approaches with the physicians (American Society of Clinical Oncology, 2012). These providers can perform health assessments, order and interpret diagnostic and laboratory results, and help patients manage side effects (Levit et al., 2013). Many patients who visit the medical oncologist also
regularly consult with the advanced practice provider who collaborates with that provider (American Society of Clinical Oncology, 2012).

Psychological support providers, such as psychiatrists and psychologists, provide emotional support using behavior modification and psychotherapy (Levit et al., 2012). Stress, fear, and depression are common outcomes of a cancer diagnosis (Brown, Stewart, & McWilliam, 1999), and the support offered by these specialized providers can help patients better manage emotional concerns. Additional cancer-care team members who provide emotional support include social workers and patient navigators.

Social workers typically have a graduate degree in social work and are specialized in helping patients by suggesting community resources that can help reduce the burden of cancer treatment schedule and suggesting ways to manage financial strain throughout treatment (American Society of Clinical Oncology, 2012). Patient navigators may be lay community members or specially trained nurses who help patients navigate the health system throughout cancer treatment (Freeman, 2006). They offer many services to patients, such as providing emotional support, explaining treatment information, arranging transportation or other tangible support services, and coordinating care between several doctors (American Society of Clinical Oncology, 2012).

The actions of each cancer-care team member have the potential to influence patients positively and negatively. Nonverbal aspects of communication, such as limited time for appointments stemming from to high patient volume can negatively impact perceptions of patients regarding the provider’s openness and willingness to answer questions (Liang et al., 2002). Alternately, when providers communicate information about treatment options, emotional challenges that patients may face, and available support resources to help with logistical burdens,
breast cancer patients are better able to manage stress during treatment (Kerr, Engel, Schlesinger-Raab, Sauer, & Holzel, 2003). Kerr, Engel, Schlesinger-Raab, Sauer, and Holzel (2003) further note that simple communication skills, including asking if the patient has additional questions, checking for understanding of important information, and listening attentively, conjure feelings of social support in patients. The patient navigator is one member of the cancer-care team who addresses barriers to care and provides patient-centered communication (Freeman, 2006).

**Patient Navigator: A Communication-focused Provider**

Patient navigators (PN) were established to improve patient-centered care and to help decrease health disparities through improved access to care (Freeman, 2006; Hook, Ware, Siler, & Packard, 2012). The first patient navigation program was established in 1990 at Harlem Hospital in New York City (Freeman, 2006). These first navigators had an understanding and appreciation of the culture and needs in the Harlem community and helped patients by providing recommendations to community support services (Curran, 2003). These navigators were lay members of the community who sought to improve patient care in the neighborhood. Since this first navigation program, hospitals across the United States are adopting support personnel to help patients understand treatment processes and find the resources they need to manage their health and daily needs effectively. However, even before Dr. Freeman’s implementation of patient navigators, desire for nurse specialists on the cancer team as a means of educating patients was growing (Wilkinson, Maguire, & Tait, 1988).

Establishing a single point person who consistently meets with a patient helps to decrease confusion about the system and treatment process, while also serving as a liaison between providers to ensure consistency and continuity of care (Swanson & Koch, 2010). Support of
patient navigation programs extends into the United States legislature, with Congress having passed several bills that support patient navigators as “part of model programs to provide . . . prevention, early detection, treatment, and appropriate follow-up care services” (Dohan & Schrag, 2005, p. 849). The Patient Navigator Outreach and Chronic Disease Prevention Act (2005) was signed into law as a means of allowing the Department of Health and Human Services to authorize grants for projects involving the implementation of patient navigator programs. This law aimed at funding projects that demonstrate the role of patient navigators for improving patient health outcomes. Subsequently, two bills were introduced to the House of Representatives that built on the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005.

The first bill was submitted to the House Subcommittee on Military Personnel in 2007 as the Wounded Warriors Joint Health Care Patient Navigators Act (S. 1577, 2007). This bill would require the Department of Defense to establish a patient navigator program where wounded veterans would be assigned a patient navigator to improve healthcare outcomes (S. 1577, 2007). The second bill was introduced in 2012 to require a state’s Medicaid plan to provide reimbursement of patient navigator services for people with cancer or other chronic diseases (S. 6521, 2012). This bill was later submitted as the Patient Navigation Assistance Act of 2014 to the House Subcommittee on Health (S. 4168, 2014). Although neither of the two subsequent bills had been signed into law as of May 2015, the implication of these legislative actions is that the U.S. government views patient navigators as an important part of health care and health outcome improvement. This suggests that patient navigators will likely continue to increase in number and have a long-standing role within the cancer-care team.
As patients move through the breast cancer diagnosis, treatment, and survivorship process, they interact with many medical providers and the role of the PN has emerged in breast cancer care over the last decade to help integrate information and care processes (Yosha et al., 2011). Fischer, Sauaia, and Kutner (2007) described the role as one that includes “case management, patient education, social work, and advocacy” (p. 1023). Meanwhile, the National Cancer Institute’s Patient Navigation Research Program (PNRP) describes a patient navigator as someone who provides, “support and guidance . . . to persons with a new cancer diagnosis in accessing the cancer care system . . . overcoming barriers . . . and facilitating timely, quality care in a culturally sensitive manner” (Freund et al., 2008, p. 3392). In short, the person in this role helps patients understand the process of diagnosis and treatment, find resources that can help them manage daily activities, and communicate in a personal and individual manner so that patients can fully engage in the cancer-treatment process.

The background and specialty of patient navigators varies a great deal. In the study by Fiscella et al. (2012), navigators were laypersons from the community who were specifically trained to complete the tasks necessary for this role. Further, Curran (2003) described them as paid employees (nurses, social workers, etc.) or, alternately, volunteers. Freeman (2006) also revealed a variable background of navigators by adding that PNs are “most often lay people selected form the community and assure that any barrier a patient encounters in seeking screening, diagnosis and treatment is eliminated” (p. 140). There are arguments for why various backgrounds would be helpful in patient navigation. Koh, Nelson, and Cook (2011) suggest that navigators who serve specific ethical or cultural communities would do better with a lay person as the navigator as a result of a greater likelihood of comfort between patient and navigator, whereas other roles in the cancer-care process may require more specialized training, like
registered nurses, social workers, case managers, patient advocates, community health workers, or other health coordinators (Freund et al., 2008; Koh, Nelson, & Cook, 2011).

Similar inconsistency appears in the titles used to represent navigators at U.S. health systems. Although this may not seem to be important, the lack of standardization creates challenges for researchers building the literature on the influence of patient navigation as a member of a cancer-care team. Typically, the title of patient navigator is used interchangeably with other titles such as nurse navigator or care coordinator (Campbell, Craig, Eggert, & Bailey-Dorton, 2010), oncology nurse navigator or oncology social worker (Swanson & Koch, 2010), nurse case manager (Goodwin, Satish, Anderson, Nattinger, & Freeman, 2003), and patient advocate (Dohan & Schrag, 2005). Likely, a good deal of the confusion in both titles and specialization also stems from a long-standing limitation in identifying a standard definition of patient navigation (Dohan & Schrag, 2005, p. 850; Fischer, Sauaia, & Kutner, 2007). However, Fiscella et al. (2012) attempted to close this gap by suggesting the definition used by the PNRP, which states that patient navigation is “instrumental and emotional support for patients during diagnosis and treatment for cancer” (p. 1673). This definition served as the conceptualization of patient navigation this study.

The variation in patient navigator conceptualization, background, and job title is a concern for nursing scholars who suggest that navigation programs “vary on multiple levels, including the qualification of the navigator, scope of practice, [and] healthcare setting . . .” (Hook, Ware, Siler, & Packard, 2012, p. 380). Some organizations now offer nurse-navigator certification programs in which nurses participate in a one or two day workshop and then complete an examination to establish competency in the navigator role (National Consortium of Breast Centers, 2013). However, these certifications are not required for hospitals to assign staff
or volunteers to the PN role. Even research by scholars who contribute to the PNRP is inconsistent in the description of navigator training and background. Freund et al. (2008) stated that “prior training, skill sets, and educational background of navigators include lay community peers, health educators and advocates, medical assistants, social workers and nurses” (p. 3393).

Establishing consistency in credentials and titles could be difficult in light of the range of activities that navigators perform. Some of the most common include, suggesting sources of financial support (Campbell, Craig, Eggert, & Bailey-Dorton, 2010; Fiscella et al., 2013; Fischer, Sauaia, & Kutner, 2007), arranging transportation to and childcare during appointments (Curran, 2003; Fischer, Sauaia, & Kutner, 2007; Freund et al., 2008), coordinating care between many providers (Campbell, Craig, Eggert, & Bailey-Dorton, 2010; Dohan & Schrag, 2005; Freund et al., 2008), educating patients about treatment and health information (Campbell, Craig, Eggert, & Bailey-Dorton, 2010; Chen et al., 2010; Dohan & Schrag, 2005; Fischer, Sauaia, & Kutner, 2007; Korber, Padula, Gray, & Powell, 2011), suggesting applicable community resources (Freund et al., 2008; Fiscella et al., 2013), helping with paperwork and employment concerns (Dohan & Schrag, 2005; Fiscella et al., 2013), scheduling appointments with multiple providers (Curran, 2003; Freund et al., 2008; Fiscella et al., 2013), following up on test results (Fiscella et al., 2013), providing translation services (Curran, 2003), going to appointments (Fiscella et al., 2013), providing emotional support (Campbell, Craig, Eggert, & Bailey-Dorton, 2010; Chen et al., 2010; Curran, 2003; Fischer, Sauaia, & Kutner, 2007; Freund et al., 2008; Korber, Padula, Gray, & Powell, 2011; Yosha et al., 2011), and generally assisting patients throughout the course of treatment (Dohan & Schrag, 2005). When considering this wide range, the fact that a standard definition of patient navigation is not adopted universally could mean that patients are having very different experiences with navigators, even when the same job title is used.
Efforts to establish functions and titles of the PN are still evolving and projects such as the PNRP are serving to create a more specific description of the role, mandated credentialing of specialists, and validated measures to test effectiveness (Fischer, Sauaia, & Kutner, 2007; Freund et al., 2008). As such, this lack of consistency suggests challenges in evaluating patient navigator programs. However, the presence of a patient navigator can influence communication within a healthcare setting and in the way the entire team delivers care (Dohan & Schrag, 2005).

Additionally, Freund et al. (2008) conceded that the title for this role varies greatly, but suggested that the general understanding of a patient navigator was someone who provided support and guidance to people with new cancer diagnoses. For this reason, the operationalization of patient navigator in this study is the self-reported presence of one of the following providers on the patient’s cancer-care team: (a) patient navigator, (b) nurse navigator, (c) nurse case manager, and (d) oncology social worker. Although the point at which this person begins helping a patient has previously been the time of a new cancer diagnosis (Freund et al., 2008), this restriction did not apply in the present inquiry.

Research that reviews the effectiveness of patient navigators shows improved patient satisfaction with the treatment process (Hook, Ware, Siler, & Packard, 2012), lowered distress during in-patient cancer care (Swanson & Koch, 2010), and reduced barriers to receiving treatment for breast cancer patients (Pieters, Heilemann, Grant, & Maly, 2011). In a nonexperimental retrospective review involving 103 breast cancer patients who had regular access to patient navigators throughout treatment, the clear majority felt overall satisfaction with the care experience (Hook, Ware, Siler, & Packard, 2012). In the same study, 84 percent of patients felt that patient navigation services were necessary for the effective care of patients, 80 percent of patients felt that patient navigators improved their overall cancer experience, and 93
percent would recommend that all breast cancer patients receive patient navigation services (Hook, Ware, Siler, & Packard, 2012). The nonexperimental design, however, suggests a need to continue assessing satisfaction when a patient navigator is available to patients. A comparative study of patients seen by an oncology nurse navigator during in-patient care for a cancer diagnosis and patients not seen revealed that those with access to navigation services reported less distress during the in-patient experience (Swanson & Koch, 2010). This suggests that when patient navigators are available to “answer questions and provide . . . education about the disease” (p. 69), patients feel less overall stress than ones who do not receive navigation support.

The process of treatment and receiving care was also improved with the help of a patient navigator. In a qualitative study that reviewed the experience of older breast cancer survivors, participants who had access to patient navigation services reported that they received a great deal of information and emotional support (Pieters, Heilemann, Grant, & Maly, 2011). Additional responses further suggested that the availability of patient navigation services improved accessibility to care (Pieters, Heilemann, Grant, & Maly, 2011). Care coordination also improved with access to a patient navigator because individual challenges with transportation to the treatment center or limited family social support resulted in a more personalized treatment plan that addressed these needs (Pieters, Heilemann, Grant, & Maly, 2011). The implication suggested in the work of Pieters, Heilemann, Grant, and Maly (2011) is that when patients have access to a patient navigator, the care process can be carried out more effectively and individual patient’s barriers to receiving care are better addressed.

Continued work that assesses the presence of patient navigators as members of a cancer-care team should help show whether needs are being met to improve treatment and patient outcomes. The trust between patients and the patient navigator is built on the presumption of
individualized communication and recommendations based on each patient’s perspective are the focus of interactions (Fischer, Sauaia, & Kutner, 2007; Vourlekis, Ell, & Padgett, 2005). This level of personalized communication suggests that patient-centered communication can be improved when a cancer-care team member offers support and help, which is exemplified by patient navigators (Korber, Padula, Gray, & Powell, 2011).

**Patient-Centered Communication**

Patient navigators afford the opportunity to provide individualized support and communication to patients. This addition to a cancer-care team can help to make the experience more efficient for health systems and less complex and overwhelming for patients. The concept that is often used to describe the service offered by patient navigators is patient-centered care (Chen et al. 2010; Koh, Nelson, & Cook, 2011). Patient-centered care is an idea that has been discussed for nearly half a century, with scholars describing the idea as a method of patient care where the acknowledgement and understanding of patient needs are placed at the forefront (Balint, 1969; Bardes, 2012; Levenstein, McCracken, McWhinney, Stewart, & Brown, 1986). In cancer care, the patient-centered variety focuses on the informational, emotional, and tangible needs of the patient; along with the clinical efforts needed to address the disease (Diefenbach et al., 2009). Generally speaking, patient-centered care has become an indicator of effective dialogue between providers and patients (Mead, Bower, & Hann, 2002).

Patient-centered communication is a concept that has been subject to debate, with variations in operationalization and measurement (McCormack et al., 2011). Although the differences exist, the general understanding of the concept is consistent with the focus remaining on the skills necessary for providers to communicate with patients using a patient-centered approach. Levenstein, McCracken, McWhinney, Stewart, and Brown (1986) were among the
first scholars to suggest a skills-based approach to the concept, in stating that the “crucial skill is to be receptive to cues offered by the patient” (p. 27). These cues give information about a “patient’s expectations, feelings, and fears” and providers should adjust the patient interaction accordingly to address them (Levenstein, McCracken, McWhinney, Stewart, & Brown, 1986, p. 26). Generally speaking, patient-centered communication is about creating interpersonal relationships between patients and providers, such that the interaction between them is the primary method for exchanging information about the treatment experience (Mallinger, Griggs, & Shields, 2005; Ong, de Haes, Hoos, & Lammes, 1995). An interpersonal relationship is one in which providers understand the values, beliefs, and background of patients (Arora, 2003). Mallinger, Griggs, and Shields (2005) suggest that the ability of providers to “elicit patients’ concerns, to consider the patients’ psychosocial needs, and to involve the patient in treatment decision-making” (p. 342) are means by which this interpersonal relationship can be established in the cancer setting.

The conceptualization of patient-centered communication is still being considered and refined, which makes measurement of the concept more complicated and requires of critical analysis of the situation and of the desired research outcome (McCormack et al., 2011). Epstein and Street (2007) published a monograph concerning patient-centered communication in cancer care for the National Institutes for Health in which they suggested that the concept is described best as six core functions of communication. In this description of communication functions, each equally influences all others and all functions ultimately influence health outcomes. The six functions include managing uncertainty, responding to emotions, exchanging information, making decisions, fostering healing relationships, and enabling patient self-management (Epstein & Street, 2007). Managing uncertainty was described as an important means of helping patients
deal with the many treatment options and emotions that arise during cancer care (Epstein & Street, 2007). Enabling patients to communicate with providers in such a way that their uncertainty is both acknowledged and addressed leads to a better experience overall. Cancer is an emotional experience even before patients have received notice of a diagnosis and the function of emotional response allows for providers to explore patient emotions and respond in an appropriate way (Epstein & Street, 2007). Exchanging information is the way in which all of the other factors are influenced (Epstein & Street, 2007). Patient-centered communication is most effective when a dialogue between patients and providers allows for the interaction to take shape naturally based on comments and responses from both sides. Making decisions was listed as a function of patient-centered communication because a patient’s values and beliefs must be incorporated into treatment decision-making and the means by which this information is acquired is through effective communication (Epstein & Street, 2007). The fifth function encourages patients to participate in self-management by enabling coping, information seeking, and other proactive steps to staying involved in one’s care (Epstein & Street, 2007). Finally, the function of fostering healing relationships helps to set up the roles and responsibilities of the provider-patient relationship, such that expectations are known and understood at the beginning of the treatment process. Subsequently, McCormack et al. (2011) contributed to this work by suggesting that several domains of each function cut across functions and would include, (a) communication about the time and setting for patient-provider interactions, (b) the composition and structure of the cancer-care team such that patients know who to contact in different situations, and (c) partnership-building behaviors, which expands on the function of fostering healing relationships to add interpersonal skills like listening and eye contact.
For this study, the conceptual definition of patient-centered communication was interaction that “involves the patient in the consultation, explores the patient’s ideas and concerns, and assesses and responds to the patient’s understanding . . . as a means of focusing on the patient as ‘whole person’ in the context of his or her psychological and social circumstances” (Mallinger, Griggs, & Shields, 2005, p. 343). Operational definitions derived from Takayama, Yamazaki, and Katsumata’s (2001) view of the behavior of providers as a combination of “task-oriented, affective, and partnership building” (p. 1336). The idea of partnership building in the medical interaction includes the long-standing idea that mutual trust is established when the patient and provider are able to communicate effectively (Irwin, McClelland, & Love, 1989). In considering these ideas, the functions of a patient navigator clearly emerge, including the provision of information, management of emotional needs, and recommendations for tangible support during cancer treatment (Fiscella et al., 2012).

Emotional support is one of the essential elements of provider communication during cancer treatment, as some of the most salient responses to a cancer diagnoses are fear, sadness, anger, anxiety, and worry (Dean & Street, 2014). However, clinicians continue to struggle in executing the communication they intend for helping cancer patients cope with their distress effectively (Arora, 2003). Arora (2003), in a review of scholarly literature concerning physician communicative behavior with cancer patients, noted that observations of physician behavior were often unrelated to the patient’s perception of the provider interaction. This suggests that although providers may be attempting to provide effective and appropriate communication through information exchange, messages conveying empathy, and exhibiting warmth and friendliness, patients are not interpreting the messages in the same way (Arora, 2003). If the
transmission of messages from providers to patients is improved, patients may be able to better cope with the stress of a cancer diagnosis.

Recently, research in cancer care revealed that oncologists have challenges relating to patients in an empathetic way, especially when patients presented emotion-laden comments or complaints about their condition (Pollak et al., 2007). One of the reasons for such a lack of empathy in responses to patients was the limited time that providers can spend with patients due to demanding schedules (Pollak et al., 2007). There are likely other explanations for limited provision of empathy by providers, including systematic influences of the individual cancer center, such as a drive to increase profits through heavier patient loads. The amount of time a patient spends with a provider is just one of the factors in limited emotional support being available to patients, but it stands to reason that the integration of specialized patient navigators could provide additional patient-centered communication to address these gaps.

Managing emotions is a prominent need throughout the cancer process. Prades, Ferro, Gil, and Borras (2014) determined that when patients were provided with information that anticipated illness-related outcomes, such as hair loss with chemotherapy, they were able to better cope with the emotional effects of experiencing those issues. As related to patient-centered communication, providing this caution of emotional response to patients creates a stronger partnership with added trust between the patient and the cancer-care team. Patient navigators could provide more enhanced partnership building between patients and the cancer-care team by sharing additional information and spending time with patients. There were no examples in extant scholarly literature suggesting that offering patient navigators was in any way detrimental or negative to the patient experience. As Vogel, Bengel, and Helmes (2008) have pointed out,
cancer patients typically want all of the information about their disease. Thus, the provision of a patient navigator would be one additional source of information and support for the patient.

Patient-centered care and communication during cancer treatment are enhanced when patient navigators are on the cancer-care team because patient navigators have specific job functions like, helping to coordinate care (Freund et al., 2008), providing information about treatment and health (Campbell, Craig, Eggert, & Bailey-Dorton, 2010), and acting as a source of emotional support (Yosha et al., 2011). In fact, the description of patient-centered communication Politi and Street (2011) offer mirrors the job functions of the patient navigator, including the identification of individual barriers for and concerns about treatment, development of personal care plans that take individual factors into account, and management of each patient case from diagnosis through treatment. Considering the team of cancer-care professionals that help patients, we can assume that the cancer-care teams having patient navigators also provide improved support and guidance to patients through improved patient-centered communication aimed at overcoming tangible barriers to care, ensuring timely, quality care that improves the patient experience and communicating in a personal, engaging, and relevant manner (Freund et al., 2008). This suggests the following hypothesis connecting patient-centered care and the presence of a patient navigator as a member of the cancer-care team:

**H1:** Participants who had a PN, as a member of their cancer-care teams, will report experiencing more patient-centered communication than participants who did not have a PN as a member of their cancer-care teams.

**Decision-Making in Cancer Care**

Beyond having a connection to cancer communication, patient-centered communication appears to improve patient health outcomes (Benbassat, Pilpel, & Tidhar, 1998). Improved
outcomes are also evident in psychosocial indicators, such as satisfaction with care (Makoul & Curry, 2007), compliance with treatment regimens, better decision-making (Ong, de Haes, Hoos, & Lammes, 1995), and recall of relevant health information (Stewart, 1995). Researching and confirming some of these connections were at the base of the study described herein. Although improved decision-making and decision quality have received some attention, it is not necessarily applicable in breast cancer treatment—when a preference-sensitive decision is being considered (Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007). Instead, each choice offers outcomes that could be viewed as the best option for some patients, but a worse choice for others. Rather than measuring decision quality, the uncertainty experienced by breast cancer patients in making decisions about care could be better assessed by considered the decisional conflict experienced by patients.

A breast cancer diagnosis often arouses a great deal of stress and fear for patients. The fact that patients must also make treatment decisions at the same time can be highly distressing (Parker, Aaron, & Baile, 2008). Decisions about breast cancer require that patients, doctors, and sometimes, family members or friends contribute to the decision-making process. An additional challenge to decision-making following a breast cancer diagnosis is the timeframe between when a woman is diagnosed and when treatment begins, which is usually just 10-14 days (Caplan, May, & Richardson, 2000; Harcourt et al., 2003). It is during this brief period that a woman learns she has been diagnosed, emotionally responds to the diagnosis, considers treatment options, and moves forward with a treatment plan (Brown, Carroll, Boon, & Marmoreo, 2002; Jim, Richardson, Golden-Kreutz, & Andersen, 2006). It is during this short and emotionally charged time when patients frequently receive large amounts of information about treatment
options, disease state, outcome expectations, likelihood of side effects, and systematic issues like payment and insurance.

Breast cancer treatment decisions vary widely and require different considerations for each patient. Factors that influence the options available for treatment include the stage at which the cancer is detected, genetic background, family history of the patient, personal preferences, and many others (O’Hair et al., 2003). Most such decisions have no clear best clinical choice, because they are preference-sensitive decisions (Elwyn et al., 2001; Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007). Preference-sensitive decisions can activate an uncertain decision-making process for which patients must consider the information available to them and apply their personal values and beliefs to select the option they feel is best.

A cancer diagnosis triggers a series of difficult and uncertain decisions. Communication with patients after diagnosis and during treatment is critical for improving the decision-making process and ensuring that patients are making the best choice they can for their personal beliefs and situation (O’Hair et al., 2003). The process of making any medical decision is complex and stressful. Consequently, patients often look to others to help manage this stress and make decisions. Benbassat, Pilpel, and Tidhar (1998) assert that patients use the support of healthcare providers, family, friends, and others to consider options and make final decisions about the course of treatment. The actual decisions that women make for breast cancer treatment are influenced by the options presented and the communication they experience following diagnosis. Communication about medical decisions is often discussed under the umbrella of shared decision-making, which can be complicated by the emotional response following diagnosis and the fact that patients need to understand and process information about treatment options (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994).
The role of patient participation in decision-making has been evolving over the last few decades, with several concepts at the forefront of the discussion (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Edwards & Elwyn, 2006; Gattellari, Butow, & Tattersall, 2001). Decision-making requires that patients can understand information about their condition, trust the expertise and opinion of the provider, and ask for support from family and others to make the decision that is best for the patient (Elwyn et al., 2001). Requiring patients to make a choice or even participate in decision-making could result in negative outcomes, such as distress (Butow, Dunn, Tattersall, & Jones, 1994) or anxiety (Pierce & Hicks, 2001), but also help patients feel empowered and in control during a time of uncertainty (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994). Encouraging active participation and individual decision-making by the patient is the major tenant in the argument for informed-decision making. The initial suggestion of informed decision-making was made by Braddock, Edwards, Hasenberg, Laidley, and Levinson (1999) and called for greater participation by patients in clinical decision-making. Some criticism of informed decision-making draw on the idea that patients have limited cognitive resources when they have just been diagnosed and the burden of responsibility may be too great (Pierce & Hicks, 2001).

Instead of placing the burden of decision-making process primarily on patients, providers should instead encourage patients to provide feedback about their desire to participate. This suggestion is a foundation of the idea of shared decision-making. Shared decision-making encompasses the idea of a equal participation approach, but in which patients recognize that providers contribute clinical knowledge of the disease and providers acknowledge that patients bring an intimate understanding of their own values, believes, and preferences for their health (Edwards & Elwyn, 2006; Gattellari, Butow, & Tattersall, 2001). Some scholars suggest that
shared decision-making is a dyadic relationship between a patient and one provider (LeBlanc, Kenny, O’Connor, & Legare, 2009). A similar conception, which also encourages equal participation of the provider and patient, is collaborative decision-making (O’Grady & Jadad, 2010). However, the use of the term “collaborative decision-making” in health care has been used in other contexts and suggests the idea of group decision-making rather a one-on-one encounter between a patient and a provider (Laxmisan, Hakimzada, Sayan, Green, Zhang, & Patel, 2007; Trede & Higgs, 2008).

Scholars tend to debate the aspects of decision-making in which patients feel comfortable participating (Arora & McHorney, 2000; Benbassat, Pilpel, & Tidhar, 1998; Singh et al., 2010). A continuum of participation is suggested in the decision-making literature between patient preferences for paternalistic relationships to patient preferences full involvement in all aspects of the decision-making process (Arora & McHorney; 2000; Politi & Street, 2011; Singh et al., 2010). An explanation for this suggested continuum is the distinction between the actual decision-making moment (e.g., when a care plan is implemented) and the decision-making process (e.g., the description of treatment options, communication with providers and members of the patient’s support circle). Edwards and Elwyn (2006) conceptualize the “decision-making process” (p. 315) as the time when patients learn of their treatment options, seek independent information from their own sources, and decide who will have responsibility for making the actual decision. The “decision-making moment” is conceptualized as the specific act of choosing the treatment, or having “decisional responsibility” (Edwards & Elwyn, 2006, p. 315). Patient decision-making, considered as a process, is an opportunity for information sharing, deliberating, and stating preferences about care and expected outcomes (Politi & Street, 2011).
The process of making a medical decision is different for each patient, but some research suggests that breast cancer patients have similar patterns and preferences for participation in the decision-making process (Brown, Carroll, Boon, & Marmoreo, 2002). These patterns include seeking information about the condition, potential treatment options, and risks related to each treatment option. When breast cancer patients are involved in the decision-making process, main outcomes include greater satisfaction with decision-making and reduced depression in the three months following the decision (Vogel, Leonhart, & Helmes, 2009). Also, the active participation of patients in decision-making leads to increased feelings of responsibility by patients (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994). With this added responsibility, feelings of conflict in making the decision can arise. This can add to already high levels of stress and make decisions even more difficult (Pierce & Hicks, 2001).

Regardless of the specific method for eliciting the thoughts and participation of patients, simply providing patients with information about choices is better than not doing that at all. In a study by Morris and Royle (1987), depression and anxiety were higher in women who were not given choices about their breast cancer treatment plan compared to women who were given information about options. However, even when patients are provided the opportunity to participate in decision-making, a great deal of uncertainty remains and affects how patients view available choices (O’Hair et al., 2003). In the next sections, I describe the decision-making process that occurs during breast cancer diagnosis and treatment and how UMT can help to explain the influence of patient navigators in managing a patient’s decisional conflict. Then, I review the research involving patient satisfaction with care and show how Discrepancy Theory serves to establish a connection between the presence of a patient navigator and patient satisfaction with the care experience.
Theoretical Foundation: Uncertainty Management in Decision-Making

The communication provided by a cancer-care team has the opportunity to influence a patient’s feelings of uncertainty during decision-making. Uncertainty arises during every step of the decision-making process about breast cancer care and treatment plans. Uncertainty in health decision-making results from many factors (Babrow, Kasch, & Ford, 1998; Mishel, 1988), and breast cancer diagnosis and treatment is no different. When a woman seeks preventive screening for breast cancer, uncertainty arises by considering the chance that a tumor may be found. During diagnosis, there is uncertainty concerning whether or not the tumor is cancerous, and, if it is, of what stage the cancer is (Nelson, 1996). The prospect of treatment decisions lead to uncertainty regarding the best option for avoiding recurrence (Nelson, 1996). Following treatment, uncertainty arises about the potential for cancer recurrence and emotional challenges persist (van den Bueken-van Everdingen, Peters, de Rijke, Schouten, van Kleef, & Patijn, 2008). Decisions about breast reconstruction following mastectomy can cause patients to feel uncertain because women have mixed perceptions of body image following surgery (Begum, Grunfeld, Ho-Asjoe, & Farhadi, 2011) and emotional outcomes from the breast reconstruction surgery vary from patient to patient (O’Shaughnessy & Fine, 2006). The uncertainty faced by patients during decision-making is due to many factors including, the complexity of a cancer diagnosis, information overload, and managing patient preferences (Babrow, Kasch, & Ford, 1998; Mishel, 1988).

Throughout the process of cancer screening, diagnosis, treatment, and survivorship, there are many points of uncertainty (Babrow, Kasch, & Ford, 1998). The management of uncertainty for breast cancer patients is unique because of the preference-sensitive nature of many decisions (O’Connor, 1995). Appropriate and effective communication can help one manage uncertainty
during decision-making because it allows providers to better understand the perspective of patients, which makes it easier to know when patients feel concerned and addressing those feelings through information, empathy, and possible revisions to the treatment plan (Pierce & Hicks, 2001). This study drew on concepts used in UMT as the foundational element and rationale for arguments that suggest the presence of patient navigators on the cancer-care team would influence uncertainty management in breast cancer patients.

A primary theoretical goal of the research reported herein was to apply the principles suggested in UMT to the context of communication when patient navigators are available to patients during breast cancer decision-making. UMT holds that people use communication as a way of managing uncertainty in health-related decisions (Brashers, 2001; Ford, Babrow, & Stohl, 1996). Conceptualizations of uncertainty in health have evolved over the last 30 years. Initial theoretical arguments suggested that by communicating with others, the individual could better cope with the stressors that cause uncertainty and, thereby reduce it. This idea of uncertainty reduction is a main premise of Uncertainty Reduction Theory (URT; Albrecht & Adelman, 1987; Berger & Calabrese, 1975). URT suggests that uncertainty needs to be ultimately reduced, such that the primary goal of someone facing an uncertain situation is to use communication (i.e., information-seeking, asking questions) as a means of reducing uncertainty. Managing uncertainty is different from reducing uncertainty in that there may be times when people feel uncertain, but do not wish to reduce it, such as when patients are trying to cope with the possibility of a negative health outcome. Maintaining a level of uncertainty allows patients to sustain a sense of hope that the negative outcome will not happen (Brashers, 2001; Ford, Babrow, & Stohl, 1996). Therefore, Ford, Babrow, and Stohl (1996) observed that communication does not always reduce uncertainty, but still can be used to manage it. In the case
of breast cancer diagnosis and treatment, UMT would seem to imply that the uncertainty felt by
patients during the decision-making process could be managed through communication with
members of the cancer-care team. The theoretical framework for this research is to use the
concepts of UMT for hypothesizing and explaining relationships between communication and
uncertainty in the breast cancer decision-making process.

Previous research involving UMT has identified many conceptualizations for
communication including social support communication (Goldsmith & Albrecht, 2011), patient-
centered communication (Politi & Street, 2011), and intergroup communication (Gundykunst,
1993). The concept of patient-centered communication was specifically investigated in this
study. Politi and Street (2011) described patient-centered communication as a medical provider’s
“effort to elicit, understand and validate a patient’s perspective, to [involve] the patient in care
and decision making to the extent he or she needs or wants to be, to [provide] clear
understandable explanations, and to [foster] a relationship characterized by trust and
commitment” (p. 580). When patients receive quality patient-centered communication, they can
better manage uncertainty while making choices concerning treatment and care (Mishel et al.,
2005; Politi & Street, 2011). Understanding the individual patient’s perspective and needs is a
more patient-centered approach, and effective communicative behavior that encourages patient
participation in decision-making and elicits questions and feedback during treatment is the means
by which providers can better understand each patient (Politi & Street, 2011). This suggests that
offering an additional opportunity and venue for patients to communicate with members of the
cancer-care team should lead to improved management of uncertainty during the decision-
making process. A patient navigator acts as a supporting member of the cancer-care team, in
providing individualized information and support for patients, both of which are foundational
elements in a patient-centered approach. If patient navigators provide such communication, then one could surmise that the presence of a patient navigator on the cancer-care team would lead to improved abilities of patients to manage uncertainty effectively.

In the context of health decision-making, decisional conflict is a construct that can be used to operationalize uncertainty. Decisional conflict, according to O’Connor (1995), is “uncertainty about the course of action [one should] take” (p. 25) when faced with competing options. The series of decisions faced by breast cancer patients suggests that uncertainty arises because patients must choose between several options throughout the diagnosis and treatment process. By applying the concept of decisional conflict to the experience of breast cancer patients within the context of UMT principles, it can be argued that the communication with a patient navigator would help patients better manage decisional conflict.

The PNRP has an aim to better understanding the relationship between the presence of a patient navigator on a cancer-care team and improved patient clinical and psychological outcomes (Freund et al., 2008). Decisional conflict is one outcome that they have not identified, but a better understanding of the connection between patient navigators and decisional conflict would provide a new context in which to consider the premise that communication leads to improved uncertainty management. Pierce (1993) suggested several ways in which breast cancer patients experience decisional conflict when many treatment choices were presented and (a) the patient had a preference for treatment, but it was discouraged or not offered; (b) it was difficult to discriminate among several choices, but one still had to reach a conclusion in the end; and (c) an option was presented as the best choice, but it was not preferred by the patient. Each of these situations leads to uncertainty about decisions and requires additional information and communication with the cancer-care team. O’Connor (1995) asserted that decisions during
cancer treatment often carry substantial risks because patients must anticipate the outcome of a choice and manage possible feelings of regret.

Patient navigators have the opportunity to help patients through cancer diagnosis, treatment, and survivorship by providing communication that addresses emotional, informational, and tangible needs (Koh, Nelson, & Cook, 2011). By providing an improved sense of support through communication, the patient navigator may help patients more effectively manage uncertainty. A patient navigator interacts with patients on a personal level so that they can better understand the patient’s values and beliefs (Dohan & Schrage, 2005). By having a more in-depth understanding of these important patient factors, the patient navigator can provide pertinent and necessary information for helping patients make a decision with the least amount of conflict. As Pierce and Hicks (2001) point out, “[D]ecisional conflict ensues when there is a disjunction between the presented alternatives and the individuals’ values” (p. 269). Thus, by providing the services of a patient navigator, patients should feel less decisional conflict. More specifically:

**H2:** Participants who had a PN as a member of their cancer-care teams will score significantly lower on measures of decisional conflict than participants who did not have a PN as a member of their cancer-care teams.

Describing communication provided by a patient navigator as patient-centered communication, suggests the means by which the presence of a patient navigator can influence responses to decisional conflict. Patient-centered communication is the process by which patients can engage openly with providers to participate equally in care and gain information to make the decision that is best for the patient (Politi & Street, 2011). However, some research suggests that the way in which a provider communicates options could influence the confidence of patients for
making the best decision for them (Benbassat, Pilpel, & Tidhar, 1998). From the perspective of patient-centered communication, one can assume that the provider is actively engaging with the patient to gain her feedback and to confirm that she understands the information being presented. Mallinger, Griggs, and Shield (2005) view this technique of responding to and assessing a patient’s understanding as a cornerstone in the operationalization of patient-centered communication. Thus, one can expect a relationship between patient-centered communication and decisional conflict, such that when more patient-centered communication is being employed, patients feel less decisional conflict. That is:

**H3:** Patient-centered communication will have a negative relationship to the reported amount of decisional conflict of female breast cancer patients.

**Patient Satisfaction**

Patient satisfaction is a concept that some believe is derived from a model of healthcare delivery where “the patient [is] the consumer” (Bardes, 2012, p. 782). This view is apparent in policies required by the Centers for Medicare and Medicaid Services (CMS; 2014). Recently, CMS has implemented policies that make a hospital’s annual reimbursement payments for patient care determinant on patient-reported satisfaction with the care experience. The policy requirements of health systems to ensure patients are satisfied with the care experience suggests a need to better understand the mechanisms responsible for patients’ satisfaction with the overall care experience. Some scholarly literature exists that bolsters the importance of addressing and improving patient satisfaction with care in an applied setting.

Patient satisfaction commonly serves as a predictor of compliance with medical regimes (Ware & Hays, 1988; Williams, 1994), where patients who report more satisfaction being more likely to comply with complicated at-home care and self-management. Additionally, there exists
a positive relationship between patient satisfaction with the care experience and quality of
service (Pascoe, 1983), which was exemplified in an experimental study by Mowen, Licata, and
McPhail (1993). In their study, Mowen, Licata, and McPhail (1993) reported that patient
satisfaction with the care experience was higher in emergency room patients who received
advance information about the expected waiting time before being seen by a doctor. Patients who
received information about what to expect also responded more favorably to patient satisfaction
measures asking about perceived trust and responsiveness from providers, (Mowen, Licata, &
McPhail, 1993). More recently, a negative relationship was established between patient
satisfaction with experienced provider communication and filed malpractice suits (Stelfox,
Gandhi, Orav, & Gustafson, 2005), such that providers who had higher patient satisfaction
ratings of the care experience were significantly less likely to receive malpractice claims even for
serious medical care mistakes. Health outcomes are also influenced by patient satisfaction with
the care experience and with outcomes from treatment; one example is reported by Gupta,
Rodeghier, and Lis (2014) in a study that suggested a patient’s likelihood of survival following
diagnosis of non-small cell lung cancer was greater in patients who answered more favorably to
measures of patient satisfaction for the care experience. Additionally, when providers asked
open-ended questions during the medical consultation, patients reported improved satisfaction
with the health care experience and with their treatment results (Lis, Rodeghier, & Gupta, 2009).

The curious thing about patient satisfaction research that looks at the communicative
behaviors of healthcare providers is that some studies reveal no influence–or inverse influence of
communication on satisfaction with the care experience (Butow, Dunn, Tattersall, & Jones,
1995; Lis, Rodeghier, & Gupta, 2009). In the same study by Lis, Rodeghier, and Gupta (2009),
patients who asked more questions were actually less satisfied with the consultation, presumably
because they felt the provider was not engaging completely with them. Butow, Dunn, Tattersall, and Jones (1995) also detected no relationship between patient satisfaction with the care experience and a program that encouraged breast cancer patients to talk more openly about their fears and concerns with the disease progression. The collection of these data about the reported influence of patient satisfaction with the care experience suggests a need to continue building the literature and establishing mechanisms that help explain the influence of patient-reported satisfaction with care.

Patient satisfaction with the care experience is an important outcome variable to consider when assessing how patient navigators may influence a breast cancer patient’s care experience, primarily because the Patient Navigation Research Group (PNRP) identified patient satisfaction as one of their primary outcomes of patient navigator success and effectiveness (Freund et al., 2008). Although there exist several conceptualizations of patient satisfaction in pertinent research, that which is defined by the PNRP is used for this research. The conceptual definition provided by the PNRP is “the extent to which patients’ healthcare experiences match their expectations” (Jean-Pierre et al., 2011, p. 854).

This definition states that patient satisfaction with the care experience is a comparison of a patient’s healthcare experiences with his or her expectations for what the experience should be like. This suggests alignment the perspective of the Expectancy-Disconfirmation Theory, which posits that patients form expectations about their healthcare outcomes in advance of treatment (Oliver & DeSarbo, 1988). However, patient satisfaction, as described and operationalized by the PNRP, is measured without asking about expectations or making comparisons at all. Moreover, a focus on expectations can limit the applicability of measure because assessing expectations for the cancer care experience would be highly challenging. The challenge arises primarily because
an assessment of expectations before diagnosis would be necessary for empirical investigation of causation. One would have to assess expectations for a large number of healthy women and then follow those who are later diagnosed to have breast cancer to gain an assessment after treatment. Although the PNRP conceptualization of patient satisfaction with the care experience addresses expectations, the operationalization focuses more on what Pascoe (1983) described as “reactions of the patient to their immediate experience” (p. 186).

An alternate theoretical approach to patient satisfaction can be explained in Discrepancy Theory, which holds that patients consider their expected psychological response from a healthcare experience and compare it to the actual outcome, such that any discrepancy from what is expected results in dissatisfaction (Pascoe, 1983). Since the patient satisfaction items from the PNRP’s measure do not ask about expectations for the treatment and care experience, Discrepancy Theory is seemingly the theoretical approach taken by the PNRP. A primary goal of the PNRP is to establish and encourage inclusion of patient navigators in cancer-care teams, which is suggested to improve a patient’s reported satisfaction with the care experience. This study aims to contribute to the scholarly literature that explains conceptual connections between patient navigators and patient satisfaction with the care experience. By building on the primary outcome of patient satisfaction with the care experience that were described by the PNRP, the entire of field of navigation could benefit by having additional literature available to show the impact of patient navigators on the patient experience.

Research that specifically connects patient satisfaction with the care experience to the presence of a patient navigator is limited; nevertheless, Goodwin, Satish, Anderson, Nattinger, and Freeman (2003) did suggest that nurse case managers appeared to improve patient satisfaction with the care experience in a population of older breast cancer survivors.
Additionally, Koh, Nelson, and Cook (2011) contend that patients were satisfied with patient navigators overall. Recent research using the PNRP’s measure of patient satisfaction with the care experience revealed a positive relationship between reported quality of navigation and patient satisfaction with the overall experience with cancer-care teams (Jean-Pierre et al., 2013).

Not in evidence was the difference in scores on measures of patient satisfaction with the care experience between patients who reported they did have patient navigator on their cancer-care teams and those who reported they did not. Patient navigators came into being to improve patient-centered communication and decrease barriers to care; an expected outcome was improved patient satisfaction with the overall care experience (Hook, Ware, Siler, & Packard, 2012). This suggests that the addition of the patient navigator on the cancer-care team could contribute to improved overall patient satisfaction with the care experience. In particular:

H4: Participants who had a patient navigator as part of their cancer-care teams will report experiencing more patient satisfaction with the cancer care experience than participants who did not have a patient navigator as part of their cancer-care teams.

The connection between patient-centered communication and patient satisfaction with care in general is clear in some work (Aharony & Strasser, 1993; Lochman, 1983). There appears to be a positive relationship of patient satisfaction with the care experience to: information-sharing (Mallinger, Griggs, & Shields, 2005), opportunities for patients to ask questions (Davidson & Mills, 2005), understandable explanations of diagnosis and treatment by providers (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994), friendliness and general interpersonal skills (Aharony & Strasser, 1993), time spent with the provider (Arraras et al., 2013), and patient understanding of the illness and treatment process (Davidson & Mills, 2005). Additionally, we know that the provision of emotional support during decisions leads to greater satisfaction.
Each of these functions is commonly associated with the definition of patient-centered communication (Epstein & Street, 2007). Consequently:

**H5:** Patient-centered communication will have a positive relationship to patient satisfaction with the cancer care experience.
Chapter 2: PRE-STUDY INVESTIGATION

This chapter explains the process by which the study was assessed for viability in capturing the necessary sample and achieving the goals set forth in the initial research proposal. First, I provide an overview of the pre-study investigation, then I describe the methods that were taken, and finally, I summarize outcomes and suggest modifications for the final study methodology.

Overview

The initial proposal for this study focused on the specific decisions faced by breast cancer patients relating to breast reconstruction and how communication with their social support networks influences the decision-making process. Decisions concerning breast reconstruction are considered preference-sensitive because there is no best practice from a clinical perspective (Wennberg, Fisher, & Skinner, 2002). Instead, the preferences, beliefs, and values of individual patients are the most important factors for determining the preferred treatment protocol for each patient, as choosing to have reconstruction and not choosing to have reconstruction are both “correct” choices. Although this may appear to be a simple process, inasmuch as women make decisions about breast reconstruction based on their own preferences and values, prior work suggested that there might be other factors influencing this type of preference-sensitive decision (Kruper, Xu, Henderson, & Bernstein, 2011).

Factors that increase the likelihood of immediate reconstruction include age (younger), race (Caucasian), insurance status (private), socioeconomic status (high), and education (higher levels; Kruper, Xu, Henderson, & Bernstein, 2011). One possible explanation for these disparities in breast reconstruction rates could be that patients are receiving communication and information that may influence the decision-making process. The precise communication women
receive from their cancer-care teams may vary based on age, ethnic background, race, and socioeconomic status. However, reports describing this communicative experience and the influence of communication on the process of decision-making experienced by patients are not available in scholarly literature.

As mentioned, decision-making about breast reconstruction is complicated, and a great deal of uncertainty is involved in the process. Uncertainty arises during the breast reconstruction decision-making process because of unclear information relating to options (Begum, Grunfeld, Ho-Asjoe, & Farhadi, 2011), complexity of information concerning surgical procedures (Pomahac, Recht, May, Hergrueter, & Slavin, 2006), and unpredictable outcomes in respect to aesthetic appearance of the reconstructed breast (Rowland, Desmond, Meyerowitz, Berlin, Wyatt, & Ganz, 2000; Reaby, 1998). Even if patients feel certain that they want to pursue breast reconstruction, there is no assurance that they will be pleased with the appearance of the reconstructed breast (Hu et al., 2009). This remaining uncertainty may only be resolved after the surgery has occurred, which further extends anxiety-producing concerns of patients through the decision-making and surgical processes. Theoretical explanations for why communication may influence the uncertainty felt by patients who are making breast reconstruction decisions derive from Uncertainty Management Theory (UMT; Ford, Babrow, & Stohl, 1996). In the context of breast-reconstruction decisions, UMT could provide theoretical guidance about concerning communication can help patients manage uncertainty, and the assessment of the communication involved could explain differences in the process and outcome of decision-making for women of varying demographic profiles.

The methodology envisioned to study the communication received by women about breast reconstruction and better understand how it influenced their decision-making process
represented a mixed methods approach that included a quantitative survey and semi-structured informational interviews. The participants were to be women who had made a decision of immediate reconstruction following mastectomy and would be subdivided by education status to reveal how decisions differed across various levels of education. Parsing out the specific decision-making process that the patient went through for the specific decision breast reconstruction would be difficult. The timeframe within which patients must make decision is very short—typically only 10-14 days (Harcourt et al., 2003)—and the patient is making other decisions concerning treatment at the same time. Gathering data while women were in the process of making decisions about breast reconstruction would ensure that all the communication they experienced could be gathered without suffering from recall loss often characteristic of retrospective studies.

**Methodology**

With proposed methodology centered on talking with women about the specific decision of breast reconstruction—an option selected by roughly 20 percent of patients (Hershman et al., 2012), finding a cancer center where I could access a large volume of patients was imperative. Although selection of a snowball sample incorporating fliers or messages on social media may have resulted in some participants’ volunteering, it would have nevertheless been a lengthy process to gather sufficient data for analysis. A partnership with cancer centers where new patients would receive information about the study appeared to be the best way to recruit newly diagnosed patients. To set this process into motion, I determined that cancer centers would be the best location for patients to receive information about the study. However, this plan would require that cancer centers approve the research and also encourage staff to share information with new patients. Although the Penn State University Hershey Medical Center could have
provided an opportunity to recruit participants from its cancer facility, I acquired information from previous students in the Communication Arts and Sciences Department at Penn State University about the research approvals process before pursing that possibility. One student mentioned that in her work involving breast cancer patients and communication, the yield of participants compared to the effort required to gain approval was limited (C. Fisher, personal communication, January 31, 2014). One reason was that it was challenging to encourage and incentivize staff to remember to share information with patients about the study. Thus, I did not pursue a partnership with Penn State University Hershey Medical Center, even though there was a natural connection of my research as being a Penn State University project. Instead, I reached out to three cancer centers—two in the San Diego, CA area and one in central Illinois—to gauge their interest in helping with recruitment. These cancer centers were selected because I live in San Diego, as well as had local connections that helped me reach appropriate decision-makers in those facilities, and personal contacts who work closely with the cancer center in central Illinois.

The three cancer centers that I reached out to included the Blessing Hospital Breast Center in Quincy, Illinois, the University of California San Diego (UCSD) Moore’s Cancer Center, and the Sharp Health System in San Diego. In the next few paragraphs, I explain the process and outcomes of my interactions with each cancer center beginning with Blessing Breast Center.

**Blessing Breast Center.** My personal family connections provided an email introduction to the Director of the Blessing Breast Center. Our email communication resulted in an in-person meeting in which the Director stated that she would “pull the patient navigator in for the meeting because [the patient navigator] communicates with patients on a day-to-day basis” (L. Wilkey, personal communication, January 11, 2013). The meeting took place at the Blessing Breast
Center in Quincy, Illinois and lasted 1 hour. Attendees included the Director of the Breast Center, the patient navigator for the Breast Center, and me. During this meeting, I explained my research and described how the Breast Center might be able to help me with the recruitment of participants. The response from the Director and patient navigator about the purpose the study was positive, and both felt that approvals could be granted. However, they commented that the average number of patients at the Breast center who were choosing breast reconstruction was only 20 per year, which would mean a particularly long recruitment period to have a sufficient sample. The small number of patients treated annually at the Blessing Breast Center led to concern about the proposed methodology of gathering longitudinal data from patients as they move through the decision-making process. Likely, only a small percentage would be interested in participating, and of those, an even smaller number might meet eligibility requirements.

During the conversation with the Director and patient navigator, I described the disparities that currently existed in the rates of breast reconstruction among patients. After explaining that younger women are having reconstruction more than older women, the patient navigator quickly responded that the statistics made sense because “older women don’t really need to have reconstruction” (S. Hermsmeier, personal communication, January 23, 2013). Upon hearing this, I was struck by the framing of her message. It led me to believe that she likely had communicated this underlying belief to patients—whether by not sharing the necessary options about breast reconstruction or sharing the information, but implying that it is something that an older woman would want. Prior scholarly literature supports the fact that communication during cancer care influences patient’s feelings of uncertainty during decision-making (Brashers, 2001), but what I felt might also be a specific factor is the communication provided by patient navigators. The Blessing Breast Center patient navigator provided examples of interactions with
patients in which she was the sole emotional support for some women. One example involved an older patient whose husband was uncomfortable discussing her breast-cancer diagnosis, and she had few other people with whom she could talk about her breast cancer diagnosis. The patient navigator “talked to [the patient] all the time—even just to say hello and hear what [the patient] was giving her grandkids for Christmas” (S. Hermsmeier, personal communication, January 23, 2013). It seemed that the sheer volume of communication in which patients at the Blessing Breast Center appeared to engage with the patient navigator indicated that it was important to the patients during treatment.

A woman with over 20 years of experience as a registered nurse in oncology treatment was the patient navigator at the Blessing Breast Center, but she had only just started acting in that capacity. Patient navigator was a role that the Blessing Breast Center implemented in January 2012 to help patients move through the breast cancer treatment process. What struck me when I heard that the role had been in place only a year was that perhaps this was a source of communication for some breast cancer patients, but not all patients in the U.S.; the availability of a patient navigator could then result in differences between patients who communicated with a navigator and those who did not.

The meeting with the Director and patient navigator of the Blessing Breast Center ended with the Director’s offer to connect me to the Research Ethics and Approvals Committee of the hospital and to support recruitment of new patients to the center. The Research Ethics and Approvals Committee required that I submit my approved IRB application from Penn State, along with any recruitment materials I planned to use at the Blessing Breast Center. These materials were submitted in February 2014, and approval was granted in March 2014 to
distribute them to new breast cancer patients through the Blessing Breast Center patient navigator.

**UCSD Moore’s Cancer Center.** A Communication faculty member from San Diego State University who conducts research concerning communication about cancer among families provided an email introduction to an oncologist at the UCSD Moore’s Cancer Center. The oncologist and I exchanged email about my research and methodological goals. She felt that the best person for me to talk with was the center’s patient navigator. The oncologist’s rationale was that the patient navigator was a provider on the cancer-care team who meets with all patients after diagnosis and had a great deal of interpersonal interaction with them. The patient navigator reportedly was someone who “could easily provide information about the study to patients after diagnosis” (W. Stanton, personal communication, February 27, 2013).

An in-person meeting with the patient navigator at UCSD Moore’s Cancer Center resulted in my learning more about the role that patient navigators in general play in the breast cancer experience of patients. The patient navigator first explained that her philosophy was “to provide as much information as possible to patients—no matter who they are, you never know what their goals are” (B. Mangerich, personal communication, March 14, 2013). The navigator walked me through the typical explanation she provided to patients about breast reconstruction. The interaction involved: (a) sharing pamphlets of information that listed the various surgical options for breast reconstruction; (b) reviewing before and after pictures comparing types of reconstruction; (c) walking through the process and timeline that is typical for breast reconstruction; (d) talking about the option of not having breast reconstruction and looking at images of women who chose no reconstruction following mastectomy; (e) looking at and physically touching breast prostheses, which are an option for women who choose against breast
reconstruction; (f) and sharing stories of women with whom she has worked and their experiences with breast reconstruction. On the whole, it was a comprehensive and unbiased representation of how breast reconstruction options could be communicated to patients.

During my discussion with the patient navigator at UCSD Moore’s Cancer Center, I described the disparities in breast reconstruction choices. The patient navigator then commented that the UCSD Moore’s Cancer Center tends to have very little diversity in socioeconomic status among patients. The facility is located in an affluent area of San Diego. Often, the logistics of traveling to the center is challenging for individuals who do not have a reliable form of transportation (B. Mangerich, personal communication, March 14, 2013). The navigator suggested that if I were interested in finding a more diverse sample, it would be worthwhile for me to reach out to the patient navigator at Sharp Health System (B. Mangerich, personal communication, March 14, 2013). We finished our meeting with the patient navigator (a) agreeing to connect me with the research oversight department at UCSD Moore’s Cancer Center to determine whether or not my study could be approved to recruit participants at the cancer center and (b) providing the contact information for the patient navigator connection she had at Sharp Health System.

**Sharp Health System.** The patient navigator from UCSD Moore’s Cancer Center provided an email introduction to a patient navigator at Sharp Health System. We emailed back and forth several times and settled on having a telephone meeting because of scheduling conflicts. This conversation with the patient navigator at Sharp Health System confirmed that the breast cancer population was more diverse than that of UCSD Moore’s Cancer Center. She added that a main function she serves for breast cancer patients is help in accessing resources that can help with financial concerns, transportation, and other logistical concerns (K.
Brandstein, personal communication, March 29, 2013). The tangible support in addition to emotional support suggested by the patient navigator at Blessing Breast Center and the informational support offered by the patient navigator at the UCSD Moore’s Cancer Center. These responses suggested that patient navigators play an important, multifaceted role in their interactions with breast cancer patients.

The patient navigator at Sharp Health System indicated that there was a slim chance that a researcher from outside the Sharp Health System would be granted access to patients for recruitment because “there are so many projects going on at Sharp and there aren’t enough patients to go around for participant pools” (K. Brandstein, personal communication, March 29, 2013). Despite that, she provided an introduction to the Research Approval Advisor so that I could apply to conduct research at Sharp Health System. I communicated with the Research Approval Advisor about forms that I should complete in seeking approval, but the bureaucratic nature of the system resulted in weeks’ going by during which my questions to the Advisor went unanswered. Throughout that time I emailed the patient navigator to keep her updated on my progress and ask her help in navigating the research approvals process. Eventually, after many weeks of back and forth the patient navigator suggested that I pursue other cancer centers for participant recruitment.

Outcomes and Implications

The purpose of the pre-investigation study was to determine whether or not the methodology and focus of the study proposal might require alteration. My investigation with three cancer centers revealed three main outcomes: (a) the recruitment process to achieve a sample with ample power would take a great deal of time and require agreement from many cancer centers to participate and encourage recruitment; (b) patient navigators offer specific and
personal communication to patients; and (c) the implementation of patient navigators is limited across the U.S., which suggests that we can compare the influence of cancer-care teams that have patient navigators with cancer-care teams that do not have patient navigators. The common theme in all of my discussions was the patient navigator. Each time I contacted a cancer center and described my research, the contact would suggest that the patient navigator was the best person to speak with about recruiting individual patients.

Initially I set out to better understand the specific decision-making process women go through when considering breast reconstruction. I suggested that a longitudinal study that assessed the individual communication experiences of patients using surveys, diary entries, and interviews. The most effective means of reaching newly diagnosed patients was through cancer centers because the time period between diagnosis and treatment is short and recruitment in any other venue would be nearly impossible. The logistics of recruiting patients during that short time period following diagnosis, but before decisions have been made seemed monumental. Additionally, this time period is extremely stressful and upsetting for patients who are now facing a life-threatening diagnosis (Harcourt et al., 2003). Thus, I revised my research plans to look at the influence of patient navigators on the decision-making process of breast cancer patients. Specifically, I was interested in assessing how the availability of patient navigators in cancer-care teams affected the uncertainty patients felt during decision-making and their ability to manage it effectively.
Chapter 3: QUANTITATIVE METHODOLOGY

This chapter explains the quantitative methodology employed in this research, which primarily focused on assessing the process that breast cancer patients undergo when making decisions about breast cancer. Organization for the remaining sections is as follows: (a) research design, (b) recruitment, (c) data collection, (d) participants, (e) measures, and (f) analysis strategy.

Research Design

This study was conducted as a quasi-experiment where participants were assigned to groups based on the retrospective recollection of their cancer-care team. Thus, a causal link between the cancer-care teams where a patient navigator is present and when they are not cannot be established. Instead, the data serve to consider resulting associations that are discovered between variables. Mixed-methods include combined “elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding” in a single study (Johnson, Onwuegbuzie, & Turner, 2007, p. 123). Research in which quantitative methods are dominant, but with the “concurrent addition of qualitative data and approaches” will benefit the study and assessment of concepts is known as quantitative-dominant (Johnson, Onwuegbuzie, & Turner, 2007, p. 124). This research project took a quantitative dominant mixed methods approach, with the results being informed by further qualitative data. This strategy complemented previous research, which investigated the breast cancer treatment and decision-making process (Howell et al., 2008; Vilhauer, 2009). Additionally, the details of a decision-making process were expanded upon via qualitative interviews, with the generalizable theoretical relationships being more appropriately assessed via the quantitative data. The preference-
sensitive nature of breast cancer decisions suggested that there are individual factors that can perhaps be best illuminated using qualitative methods.

The purpose of the quantitative element of the mixed-methods approach adopted was to consider concepts from Uncertainty Management Theory in the context of the cancer-related communication provided by cancer-care teams with patient navigators and to replicate the use of the Patient Navigation Research Group’s assessment of patient satisfaction with the cancer care experience. Use of an online survey allowed for validated scales to assess the experience of breast cancer patients to further these goals.

**Recruitment**

Participants for this study were recruited via a convenience snowball sampling procedure. This methodology was used primarily because it was most likely the best manner in which to reach women who met the eligibility criteria. A snowball sampling process is one in which a researcher asks any recruited participants to subsequently invite any other eligible people to also participate (Browne, 2005; Goodman, 1961). Breast cancer is a disease for which survivors often come together to support one another both during and following active treatment (Bender, Jimenez-Marroquin, Ferris, Katz, & Jadad, 2013; Sharf, 1997). This made it a good participant population for which to employ snowball sampling procedures because once I found one woman who was interested in participating, she would likely be connected to other women who were also eligible. The opening message of the survey asked participants to share information about the study with other potentially eligible breast cancer survivors.

A web address was purchased for the online survey, www.BreastCancerSurvey.com, to allow easy access by participants and provide for quick modification of survey questions, if necessary, without changing the website access link. The first communication shared was an
email to 80 of my personal and professional contacts asking them to share information about the study with anyone who may be a breast cancer survivor or have access to survivors that may be interested in participating. To maintain confidentiality of the people receiving the message, all emails were hidden using the blind carbon copy function of the email program. A direct link to the survey was included in the message and recipients were asked to forward the email to others or post information on social media. Three times throughout the recruitment process, I posted information about the study to my personal Facebook page asking my network of Facebook friends to share the information on their personal pages. The posts were each shared more than 5 times, liked by more than 30 people, and commented on more than 15 times total.

Following the initial communication from my personal email and Facebook account, recruitment efforts ranged from communicating with hospitals and patient navigators to contacting community organizations and establishing connections with national and international breast cancer survivor support communities. The help and support of hospitals and medical institutions was limited as a result of required internal approvals, inadequate staffing support to share information about the study, and limitations on external research projects. Hospitals that were contacted included Blessing Hospital in Quincy, IL, and Sharp HealthCare, Scripps Health, and Moores University of California San Diego (UCSD) Cancer Center, all in San Diego, CA. Additionally, an oncologist at Columbia Presbyterian and a personal connection in the marketing department at New York University Langone Medical Center, both in New York, NY were contacted. Support from these institutions was limited to Blessing Hospital, Scripps Health, and Moores UCSD Cancer Center. Blessing Hospital required review of all materials and then allowed distribution of information through fliers to patients and survivors through their Breast Center and a Breast Cancer Awareness meeting with survivors and local advocates. Scripps
Health provided support through one of their patient navigators who distributed information about the study to a network of 250 survivors and over 50 patient navigators and medical team members. The message encouraged those who received it to share the information with their contacts as a means of reaching more people. Moores UCSD Cancer Center provided recruitment support through one of the genetic counselors on staff. This team member shared information about the study with patients and survivors with whom she had worked in the past and displayed my fliers in the cancer resource center, which was available to patients, families, and community members.

Several local San Diego organizations and businesses further assisted with the recruitment of participants for the study. The Jewish Family Service of San Diego provided information about the study to the women who access their services and they invited me to attend a community event where I made an announcement about the research. The Women’s Health Boutique (WHB) in Escondido, CA is a specialty store that sells breast prostheses, bras, and other garments designed specifically for breast cancer survivors. WHB distributed fliers to women who use their services and invited me to attend one monthly support group meeting to talk with the women and share information about the study. The Loft Hair Design Studio in Escondido, CA provides free beauty services to breast cancer patients who are currently undergoing treatment and to those who have recently completed treatment. This business shared fliers with their clients and encouraged the staff to share information with family and friends. Hera Hub is a women’s coworking space in the San Diego area that provides physical space and networking opportunities to female entrepreneurs, consultants, and freelancers. They shared information about the study in their private Facebook group and through their e-newsletter. Circle of Faith is a San Diego faith-based support group for women of color who are also breast
cancer survivors. This organization shared information about the study with its members and made paper surveys available to anyone interested.

Several National organizations provided access to their members and gave support for recruitment by sharing information about the study. Team Survivor is a national organization that provides support and activities to female cancer survivors. The San Diego chapter shared information about the study to their local members and also provided information about the study to other Team Survivor chapters across the country. After Breast Cancer Diagnosis (ABCD) is a national organization that provides peer mentoring for current breast cancer patients and resources through online and local affiliates. The ABCD Wisconsin-based chapter posted information about the study to their Facebook page and also sent a private email message to mentors, who have all finished active treatment. Women’s Survivor Alliance is an international organization that puts on an annual convention for female cancer survivors. Information about the study was shared through email to their network of survivors and through a post on their private Facebook page. Susan G. Komen is a national organization that helps to support breast cancer patients and survivors across the country. The Southeast Wisconsin Affiliate posted information about the study to their private Facebook group, they tweeted about the study, and they included information about the study in their monthly e-newsletter.

In addition to having local affiliates that provide services to survivors, the Susan G. Komen organization holds walk/run events across the country. I was invited to attend two local events in the San Diego area by the organization, Breast Cancer Solutions, who was a vendor and partner for both walks. During the walks, I went around to women who were wearing shirts indicating that they were survivors and asked them if they would be interested in receiving an email with details about the survey. More than 70 women provided their email, and a message
was sent to them the following day with information about the study and a direct link to the survey.

Several Facebook-based communities helped to recruit participants, including “Flat and Fabulous,” “Breast Friends,” “Amidex: Friend or Foe,” and “Beyond the Pink Moon.” All of the posts to these groups were written by members of the group or by the group organizer. Since responses were collected online via an anonymous link, it is impossible to know the source of recruitment for participants. However, the largest increase in response came from the initial distribution of information to my personal network, the Facebook posts to the Beyond the Pink Moon group, and the email communication with eligible women from the Komen Breast Cancer walks.

**Procedure**

Although a paper-based format was available for completing the survey, all participants used the online survey collection method. Informed consent was presented as the first page of the survey when participants visited the website. If they agreed to participate given the explanation of the study, they were asked to simply click forward as implied consent for participation. Eligibility questions followed the implied consent and included the following criteria: a) female gender; b) diagnosed with breast cancer; c) over 18 years of age; d) finished active breast cancer treatment in the last 36 months; and d) fluent in written and spoken English. Initial recruitment for this study (May 2014-August 2014) included the eligibility requirement that active breast cancer treatment was received at a U.S. treatment center. Following discussions with cancer activists and support organizations regarding the similarity of treatment process and availability of patient navigators in other countries, a revision was submitted to the Penn State Institutional Review Board to remove this requirement. Data collection from September 2014-November
2014 did not include this question in the survey screener, which led to three participants’ reporting that they received treatment outside the U.S.

Items in the survey had participants provide information about their personal breast cancer experience, including the treatments they received, and other demographic data. Self-report measures were then presented, which were used to assess the variables of interest for this study. At the end of the survey, interested participants were able to enter a drawing for $50.00 as incentive for participating in the research. Those participants provided their names and contact information. Twenty addresses were randomly selected for the incentive using Randomizer.org and contacted at the email or phone number they had provided. Additionally, as previously mentioned, participants were to indicate whether or not they would be willing to be considered for a follow-up one-on-one interview about their experience. This item and any affirmative responses were used as the sample for semi-structured interviews that were conducted to supplement survey responses as a mixed method approach.

Participants

Sufficient power in statistical analysis is an important factor in limiting error and providing valid suggestions of theoretical data. To determine sample size necessary for achieving acceptable power, an analysis was conducted using G*Power (Erdfelder, Faul, & Buchner, 1996). Each statistical test that I conducted was at the 0.05 level of confidence with the probability of rejecting a false null hypothesis 0.80, as suggested by Rubin (2013). First, I determined the necessary sample size for conducting independent samples t-tests using an effect size of 0.4, which is the “recommended minimum effect size for social science data” (Ferguson, 2009, p. 533). The a priori assessment indicated that 156 participants (n=78 in each group) would yield an effect size of 0.4 and power of 0.8 at the $p < .05$ level. Next, I conducted an
analysis for linear multiple regression with three predictors (i.e., decisional conflict, patient-centered communication, and patient satisfaction), a power of .8 and effect size of .2, which is the recommended minimum according to Ferguson (2009). This a priori analysis suggested a sample size of 59 ($p < .05$). In considering the highest suggested sample size, a minimum of 160 participants was needed for adequate power.

The participants included 130 female breast cancer survivors who had finished active breast-cancer treatment within three years of taking the survey. Sixteen quit the survey before reaching the demographic items. Therefore, numerical values were calculated based on fewer than the total number of participants. The average age of participants was 35 years old ($SD = 8.10$, Range 18-55, n=102). Curiously, nine participants indicated nonsensical ages; one participant indicated she was seven years-old, one participant listed her age as 10, one indicated she was 13 years-old, five participants listed their age as 14 years-old, and one who indicated her age was 15 years-old. The participant IDs and responses that aligned with these age responses were dropped from the calculation of average participant age, but were not dropped from the study overall. The rationale for inclusion was that responses to the conceptual questions of the survey did not indicate suspicious responses or outliers, suggesting that the age responses may have been typographical errors. Most participants reported their race as Caucasian (73.8%), with the remaining ones selecting a combination of Caucasian, Hispanic, and Native American (4.5%), Asian only (3.1%), Hispanic only (3.1%), Black or African American (0.8%), and other (0.8%). Most had private health insurance while going through treatment (81.3%), with a few having Medicare (2.7%), Medicaid (2.7%), other government insurance (3.6%), MediCal BCCTP (2.7%), or other (7.1%). Educational status varied, but the majority had completed some college work (29.7%), followed by graduate or professional degree completion (25.2%),
Bachelor’s degree (22.5%), Associate’s degree (9.0%), High School Graduate (8.1%), some graduate work (3.6%), and a trade certificate or degree (1.8%). The majority of participants were current residents of California (40.4%), followed by Pennsylvania (9.6%), Wisconsin (6.1%), New Jersey (4.4%), Texas (3.5%), and Florida (3.5%). There were three participants from outside the U.S. (2.6%), and all other states accounted for 2.6 percent or less of participant responses.

Breast cancer treatment procedures experienced by participants varied widely. Frequencies for each treatment were as follows (n=130) radiation (57.7%), chemotherapy (66.2%), immunotherapy (3.8%), tamoxifen (46.9%), other pharmaceutical treatment (29.2%), lumpectomy (43.1%), unilateral mastectomy (15.4%), bilateral mastectomy (53.1%), other surgical breast or tumor removal (24.6%), and breast reconstruction (48.5%). Most participants had chemotherapy following surgical breast or tumor removal (65.5%), and the majority was told the stage of their cancer (81.4%). Most participants were classified as either Stage 1 (30.5%) or Stage 2 (37.1%), with a few having Stage 0 (carcinoma in situ; 10.5%), Stage 3A (8.6%), Stage 3B (8.6%), and Stage 4 (2.9%). One participant indicated being between stages 0 and 1. Of the women who had breast reconstruction, seventy-eight percent had a choice concerning what type of reconstruction they wanted.

Measures

Cognitive interviewing is a method whereby participants who match the description of the proposed sample pre-test a questionnaire (Drennan, 2003). The purpose of cognitive interviewing is to understand how study participants will likely interpret questions while taking the survey of interest (Drennan, 2003). This helps one to identify potential problems before a survey is distributed for data collection. Cognitive interviewing is a process by which researchers
conduct semi-structured interviews with participants to review a questionnaire and ask questions about comprehensibility, ability to recall feelings and perspectives about the matters being addressed in the survey, and the participant’s general feelings about answering the questions (Collins, 2003). I conducted cognitive interviews with two breast cancer survivors to ensure appropriate sensitivity and to gain information about framing questions based on the actual breast cancer treatment experience. Questions for each measure were modified or deleted based on feedback from survivors. Further description about these changes for each scale is provided in detail under each measure heading.

**Presence of a patient navigator (PN).** The presence of a PN was a dichotomous dummy-coded measure that represents whether a participant had a PN on her cancer-care team or did not. Participants were asked, “Which of the following medical team members made up your cancer care team?” The response options included: patient navigator, nurse navigator, nurse case manager, oncology social worker, medical oncologist, surgical oncologist, plastic surgeon, radiologist, nurse practitioner/physician assistant, rehabilitation/occupational/physical therapies, psychologist/psychiatrist/therapist, genetic counselor, nursing staff, or other team members. Participants who selected other team members were to provide qualitative explanations of who these members were, which included radiation oncologist, nurses, surgeon, breast surgeon, and general surgeon. Responses to this question were dichotomized so that participants who selected any of the following, (a) patient navigator, (b) nurse navigator, (c) oncology social worker, and (d) nurse case manager, were placed in the “PN present” group (=1), and participants who selected none of those four members were placed in the “PN not present” group (=0). The four titles were included in the “PN present” group because formative research suggested that all four titles serve to identify cancer-care team members who act according to the conceptualization of
PN that was used for this study. The assignment of participants to either the “PN present” or “PN not present” groups was based on the location at which the participant received treatment. Patient navigators are health care providers offered as a service to patients at some hospitals, health systems, and cancer care centers, but not all (B. Mangerich, personal communication, March 14, 2013). Since patients cannot select whether or not a patient navigator is available to them during treatment, it suggests that the variable is not related to individual participant factors.

**Patient-centered communication (PCC).** Patient-centered communication was indicated via seven dimensions of two different scales, the Perceived Physician’s Communication Style scale and the Primary Care Assessment Survey. Some measures were removed from and added to each dimension as a result of cognitive interviews. The process is described in the following sections.

**Perceived Physician’s Communication Style Scale (PPCS).** The PPCS is a 27-item measure that taps a patient’s perception of the physician’s behavior and communication style during the medical encounter (Takayama, Yamazaki, & Katsumata, 2001). This tool uses a five-point response continuum ranging from *strongly disagree* to *strongly agree* for each item, where high values indicate better patient-centered communication by the physician. Four dimensions are represented in the scale, acceptive (10 measures), patient-centered (11 measures), attentive (3 measures), and facilitative (3 measures). Estimated reliability of $\alpha = .90$ surfaced for the composite, and for individual dimensions $\alpha$ ranged from 0.73-0.90. The PPCS was initially developed for Japanese cancer patients in a visit-specific encounter with a physician, which suggests differences in the cultural context and nature of the health care experience being evaluated (Takayama, Yamazaki, & Katsumata, 2001). The present study was designed to improve understanding of perceptions of patient-centered communication with cancer-care teams.
over the diagnosis to treatment period, which resulted in questions’ being revised to being the
respondents’ experience with their “cancer-care teams” rather than the “physician.” Additionally,
measures were revised to ask about the diagnosis through treatment experience rather than a
single visit. All 27 items were included in cognitive interviews with breast cancer survivors and
suggested revisions resulted in 11 measures covering the four dimensions: affective (3
measures), patient-centered (3 measures), attentive (3 measures), and facilitative (2 measures).
The reliability estimates for all of the measures in this abbreviated scale was high (α = .90), but
some individual dimensions had lower coefficients (affective: α = .60; patient-centered: α = .58;
attentive: α = .87; facilitative: α = .75). Participants recorded responses on 5-point scales, from
\textit{strongly disagree} to \textit{strongly agree}, where higher values indicated more patient-centered
communication.

\textit{Primary Care Assessment Survey (PCAS).} The PCAS scale was initially developed by
Safran et al. (1998) to capture patient perceptions of communication with primary care
physicians. The measure has patients rate their experience on a scale ranging from zero to 100
where higher values indicate more of the attribute in question. Mallinger, Griggs, and Shields
(2005) used one dimension of the PCAS in the assessment of patient-centered care with breast
cancer survivors. The participants responded on a six-point scale, with higher scores indicating
greater feelings of patient-centeredness from their oncologist. The use of this scale in the
research by Mallinger, Griggs, and Shields (2005) suggested a similar format, but with only five
intervals ranging from \textit{strongly disagree} to \textit{strongly agree} to assess feelings of patient-centered
communication, such that higher values indicated more patient-centeredness.

Safran et al. (1998) reported that fifty-one items reflected 11 dimensions of the PCAS
scale: organizational, financial, longitudinal, visit-based, contextual knowledge of the patient,
preventive counseling, clinician-patient communication, thoroughness of physical exams, interpersonal treatment, and trust. All of the dimensions had high reliability coefficients (α = .70-.95). Three dimensions of the original scale were assessed in cognitive interviews, clinician-patient communication (6 items), trust (8 items), and contextual knowledge of the patient (5 items), as survivors indicated that many items were redundant and resulted in survey fatigue. To address these concerns each dimension was reduced to a total of nine items, three for each scale. The three-dimension scale reliability for this study was high (α = .91). For each dimension, reliability coefficients were also high: clinician-patient communication (α = .83), trust (α = .81), and contextual knowledge of the patient (α = .89).

Measuring patient-centered communication is a challenging task for scholars because many conceptual definitions exist, and situational factors in the health experience determine the necessity and relevance of measures (McCormack et al., 2011). For the present study, patient-centered communication was indexed via two scales: 11 items from the PPCS (Takayama, Yamazaki, & Katsumata, 2001) and nine items from the PCAS (Safran et al., 1998). The combination of these measures was based on initial face validity of questions when assessing which were relevant for the unique experience of breast cancer treatment. Additionally, the research entailed a retrospective approach and asked about the entire cancer experience. Since the PPCS was initially developed for episodic care, rather than longitudinal care, some dimensions of the PCAS scale were removed when the focus was on episodic patient care. The decision regarding use of only seven dimensions (i.e., PPCS = 4 dimensions; PCAS = 3 dimensions) was further supported by the cognitive interviews with survivors by showing them both complete scales and asking if any other original dimensions from either the PPCS or the PCAS should be included in the study. Survivors agreed that the established scale of four PPCS
dimensions (11 items) and three PCAS dimensions (9 items) was appropriate. A 5-point scale ranging from *strongly disagree* (=1) to *strongly agree* (=5), such that higher values indicated more patient-centered communication was used for recording responses to each item. The combined 20-item scale had a very high reliability coefficient (α = .95; see Appendix A).

**Decisional Conflict Scale (DCS).** The decisional conflict scale developed by O’Connor (1995) provides a way of determining self-reported uncertainty about health care choices. This 16-item scale contains measures that assess three dimensions: decision uncertainty (3 items), factors contributing to uncertainty (9 items), and perceived effectiveness of decision-making (4 items). One item in the perceived effectiveness of decision-making dimension is framed for surveys that are completed prospectively and was dropped from this study due to differences in methodology. Previous research indicated estimated reliabilities for the total scale range ranging from 0.78 to 0.92 (Koedoot et al., 2001; O’Connor, 1995).

During cognitive interviews, four items were contested by participants and dropped from this research entirely. Participants commented that the question derived from the original scale, “My decision shows what is important to me,” should be removed because breast cancer is something that transcends feelings of personal importance, in that every decision is based on the importance of survival and moving toward remission. They also suggested that this question downplayed the sensitivity necessary for communicating with breast cancer survivors. For the questions referencing the risks and benefits of the decisions, both participants agreed that the number of questions about those issues was redundant and that the two items concerning whether or not the participant knew the risks and benefits were best for assessing decisions in breast cancer survivors. Modifications of some words were suggested to reflect the actual breast cancer treatment decision-making process rather than the decisional moment. Feedback from survivors
resulted in more appropriate wording without losing the meaning of the question (e.g., I wanted more advice versus I needed more advice).

Because the clinical treatment of breast cancer requires that each patient receive an individual treatment plan, new measures were added to address the multiple decisions faced by patients. Separate items were added for each measure to address decisions concerning, “treatment,” “surgery,” “breast reconstruction,” and the “type of breast reconstruction.” Patients who indicated that they received radiation, immunotherapy, chemotherapy, tamoxifen, or other pharmaceutical therapy answered questions about their “treatment” experience. Patients who selected lumpectomy, mastectomy, or another type of surgery as parts of their breast cancer treatment completed measures that focused on “surgery” experiences. Since a mastectomy and other types of surgery can indicate that breast reconstruction is a surgical option, participants who indicated that they had a mastectomy or “other type of surgery” responded to the decisional conflict questions about “breast reconstruction.” If the participant indicated that she had breast reconstruction as part of their breast cancer treatment, she also responded to items about decisional conflict in respect to the “type of breast reconstruction” she had. Participants responded to between one and four sets of the treatment-specific items (e.g., treatment; surgery; breast reconstruction; type of breast reconstruction).

The resulting inventory had 44 possible items. Due to a small sample size of participants who indicated that they had choice in their reconstruction (n = 42) compared to the total responses to the other three decisions, these items were dropped from the analysis. The removal of these items resulted in 33 possible items. All three dimensions were captured on five-point scales from strongly disagree to strongly agree and relating to each constituent item. During analysis, some items were recoded to create consistency among all variables and interpretation of
the scale, such that lower values meant more decisional conflict. Additional items were removed from each dimension and that process is described in the following sections.

Two items from the “Decision Uncertainty” dimension were dropped following cognitive interviews. Breast cancer survivors commented that decisions about breast cancer treatment and surgery were necessary for survival, which meant that considering the difficulty of the decision would be complicated given that the choices resulted in survival. This led to two items being dropped. Six items remained for the “decision uncertainty” dimension (see Appendix B). The reliability coefficient for this 6-item scale was high (α = .83).

Three measures from “Factors Contributing to Uncertainty” were dropped following cognitive interviews. Survivors commented that there was little pressure from others about treatment or surgery decisions because the focus was on helping the patient rid herself of the cancer. One final item was eliminated for participants who answered decisional conflict questions regarding breast reconstruction. The item was eliminated because survivors viewed it as redundant to another item. This resulted in 15 items for the “factors contributing to uncertainty” dimension. The reliability coefficient for this dimension was high (α = .85).

All six items representing “Perceived Effectiveness of Decision-Making” were retained, and two were added based on feedback from cognitive interviews: “I would make the same treatment choices if I had to do it all over again” and “I would make the same surgery choices if I had to do it all over again.” These items were suggested during interview as a means of assessing whether or not a patient was still satisfied with her choices regarding cancer treatment and surgery, respectively. One survivor commented during the cognitive interviews that she had two breast cancer diagnoses over a span of 10 years. In her first, she opted to have a lumpectomy, and the cancer returned. Looking back, she wished that she had selected a mastectomy to avoid
future positive diagnoses or complications with treatment. The resulting 8-item measure had a high reliability coefficient (\(\alpha = .93\)).

**Patient Satisfaction with Cancer Care (PSCC).** The concept of patient satisfaction with the cancer care experience was primarily measured via the PSCC, which was developed as one of the primary outcome variables in the NCI-sponsored Patient Navigation Research Program (PNRP; Jean-Pierre et al., 2011). This 18-item measure expanded the measure of patient satisfaction in cancer care, in that it “spanned the spectrum of cancer-related care from screening to treatment of diagnosed cancer” (Jean-Pierre et al., 2011, p. 855). The scale is one-dimensional, uses 5-point scales ranging from *strongly agree* to *strongly disagree* to record responses to items, and showed high reliability when tested with breast, cervical, colorectal, and prostate cancer patients (\(\alpha = .95-.96\)).

Several items were dropped as a result of feedback from survivors and conceptual consideration of hypotheses. Additionally, three items were added to the patient satisfaction measure. One item was removed because it was more visit-specific than applicable to the full breadth of decision-making process being considered (“I felt I had enough time with my doctor.”). Additionally, this question would be difficult for survivors to answer when considering the entire cancer-care team. Another item was removed because survivors responded in cognitive interviews that it was an obvious question and did not completely address the experience of breast cancer treatment and decision-making (“I received all the services I needed from the cancer care team.”). Four items were dropped because survivors felt they were redundant with other questions in the survey (“I felt that my breast cancer concerns were understood by my cancer care team,” “I felt encouraged by the cancer care team to talk about my breast cancer concerns,” “The cancer care team communicated well about my cancer treatment,” and “I knew
who to contact when I had a question outside of my regular appointments.”). Two items in the original measure addressed whether or not the patients felt they received high-quality care from their regular primary-care physicians and whether or not they received high-quality care from their specialists. Because the present study was concerned with the collective of the cancer-care team, the two items were consolidated (“I received high-quality care from my cancer-care team.”). Two more items were removed in response to the observation that neither was representative of the breast cancer treatment and decision-making process (“My cancer care team told me how to take care of myself during treatment,” and “My cancer care team kept my regular doctor informed about the results of the test I go.”). Participants suggested that the first question was too paternalistic, in that cancer-care teams do not tell you what to do, but instead provide education and guidance. For the other item, respondents both agreed that the cancer care treatment experience was separate from their regular doctor and that any updates would be included in their charts that would be shared at future routine care visits. One question was removed following feedback indicating that it seemed unrelated to the other measures (“I felt confident in how I dealt with the health care system.”) A second item was retained that helped to assess satisfaction with systematic issues in cancer treatment. Finally, survivors felt that the question, “I was totally satisfied with my cancer care team,” was redundant to all of the other measures included in the scale and was removed. Following these modifications, seven measures were retained from the original scale. One item from the original PSCC scale was expanded into three items to address the various decisions faced by breast cancer patients. The question, “I felt included in decisions about my health,” was expanded to encompass treatment, surgery, and breast reconstruction decisions respectively. Finally, one additional measure was drawn from the Decisional Conflict Scale as a means of assessing feelings of support from the cancer-care team.
I received the right amount of support from my cancer care team.”). Following these modifications, the result was a 12-item scale with high estimated reliability ($\alpha = .87$; see Appendix C). For this study, the 5-point scale was reversed (1=strongly disagree; 5=strongly agree) for consistency with other variables, such that higher values indicated more satisfaction.

**Data Preparation**

The following section describes the methods and outcomes of data preparation and the procedures used for analyzing hypotheses. The first section provides an overview of the methods and outcomes of data preparation, including: (a) data screening, (b) measurement analysis, (c) variable labels, and (d) normality assessments. The second section describes the methods by which hypotheses were assessed, with results from the analyses presented in Chapter 5.

The process of preparing data for analysis requires several steps, including: screening for outliers, measurement analysis to ensure appropriate factor structure, and assessments of data normality to ensure that parametric methods are appropriately applied in hypothesis testing. This section provides an overview of the methods and the resulting outcomes of these methods in preparing data for hypothesis testing.

**Data screening.** Responses were screened for missing data and outliers. Six participants did not complete the survey (i.e., closed the survey browser window before finishing) before responding to items relating to two of the criterion variables. Thus, they were eliminated from the analysis entirely. This resulted in 124 participants. Sixty-nine participants had missing data for at least one measure. Reasons for missing data included: (a) a valid skip within the survey design, (b) refusal to answer a question/left blank, (c) selected “not sure,” or (d) selected “prefer not to answer.” The majority of missing data was attributable to valid skip patterns. Valid skips applied to items for which some responses resulted in participants’ skipping other portions of the
questionnaire. For instance, if a participant indicated that she did not have lumpectomy, mastectomy, or any other type of surgery, she skipped items in the survey relating to her experience with surgery. Twenty-seven participants had missing data only because of valid skips.

The three remaining reasons (e.g., blank responses, “not sure,” or “prefer not to answer”) for missing data accounted for only 1.3% of cases (100 missing cases). Of these 100 cases, 69 were blank responses, 28 “not sure” as the selected response, and 3 “prefer not to answer.” The 100 missing cases occurred for 47 measures and no measure had more than five missing cases.

Missing data are common in social scientific research, and there are many accepted strategies for dealing with them (Acock, 2005; Graham, 2012). The reasons typically fall into three categories: missing completely at random (MCAR), missing at random (MAR), and not missing at random (NMAR). The missing data in this study qualified as MAR and NMAR. MAR means that missingness may depend on another variable, but not on the specific one that is missing (Allison, 2001). NMAR means that the missingness depends on both other variables and the variable where missingness occurs (Allison, 2001).

The missing data attributable to valid skips could be considered MAR because they were dependent on responses to previous items in the survey, but not on the item because participants did not review it (Allison, 2001). For the responses “not sure” and “prefer not to answer,” the missingness was likely due to NMAR. This seems reasonable because the participants read the question and had responded to it in a way that lay outside the Likert format. For missingness involving leaving the question blank, the reason and category for the missing data are difficult to determine. Participants could have left an item blank due to NMAR; reading the question and deciding they did not want to or know how to respond to it. Alternately, it could qualify as MAR if the participant accidentally left it blank or moved forward in the online survey and failed to
return to it. The specific reason for missingness when there is not a valid skip is hard to judge precisely unless one asks participants for a reason or the format of the scale lack an appropriate category.

It was difficult to determine which process to use for addressing missing data. There are many powerful statistical methods for estimating missing data so as to provide a complete dataset for all participants (Graham, 2012). However, I never felt it was completely appropriate simply to impute a response for a participant who failed to respond to an item and did so. An alternate approach that is one of the most common methods for dealing with missing data is casewise deletion. This method simply drops cases with missing data from the analysis and is often the process built into statistics programs (Howell, 2007). The benefit of casewise deletion for MAR missingness is that the resulting estimates are unbiased representations of the sample. However, because some of the missing data may have been attributable to NMAR, there could be some bias (Howell, 2007). As previously described, the missing data that may have been NMAR included items that were simply left blank, as well as those where either “not sure” or “prefer not to answer” was selected. Only 97 cases (1.3%) were missing due to the three possible types of NMAR missingness, which suggested that very little bias would be introduced by using casewise deletion as the missing data strategy. Another approach is mean substitution, but this reduces variance and limits estimations of standard errors (Graham, 2012).

Data were then screened for univariate outliers using z-scores, such that any items with a score greater than |3.29| were analyzed further (Tabachnick & Fidell, 2007). Seventeen of the 62 criterion variable measures had outliers. Thirty-six total cases were considered outliers. No single measure had more than five such cases. Consequently, casewise deletion of outliers was implemented to meet statistical assumptions necessary for analyzing the data further. The
removal of outliers can be problematic if the outlier is actually a legitimate response from the correct sample population because it can remove variability that may be a better representation of the population-level construct (Burke, 2001). However, even after conducting casewise deletion of the 36 outliers, the majority of items revealed maximum and minimum scores representative of the full, 5-point scale. Twenty-three items were reduced to 4-point range (i.e., 2 to 5), and six items were reduced to 3-point ranges (i.e., 3 to 5). A minimum 3-point scale in the Likert format is reportedly suitable (Matell & Jacoby, 1972). Multivariate outliers were assessed using the Mahalanobis’ $d^2$ to assess any values below .001, which is considered a statistically significant possible outlier (Tabachnick & Fidell, 2007). No outliers were identified, as all values were above the recommended level.

**Measurement Analysis.** Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA), when appropriate, serve to reveal and confirm the dimensionality of constructs. Pertinent scholarly literature suggested dimensional structures for decisional conflict, patient satisfaction, and patient-centered communication, respectively. This meant that an initial CFA to assess the model fit of the theorized factor structures was necessary.

Structural equation modeling for CFA is often used because it combines methods for CFA with multiple regression analysis, which accounts for measurement error and provides model fit statistics to assess the dimensionality from factor structures supported by literature or resulting dimensions from EFA procedures (Kline, 2011). The AMOS (version 22.0) software (Arbuckle, 2006) was used in performing a confirmatory factor analysis (CFA) on data for 124 participants. One challenge faced in this study was the presence of missing data. When using SEM to conduct CFA, it is desirable conduct analyses with no missing data present because one can review modification indices for covariances between variables (i.e., latent variables,
observed variables, and error). Having these indices allow the researcher review localized areas of strain in the model to add connections of covariance between variables to help improve model fit (Brown, 2006). However, as previously described a substantial number of participants were missing data due to valid skips in the questionnaire. If the participants with missing data had been eliminated for CFA, then the model fit would be representative of only patients who had treatment, surgery, and breast reconstruction; as any other participant, such as one who had only surgery, would have received a valid skip pattern in the questionnaire and not answered questions about treatment or breast reconstruction. Thus, all participants were retained for the analysis and modification indices were not assessed.

Although all 124 participants are being used for the CFA, Kline (2011) suggests that a minimum of 200 participants be used with SEM. However, maximum likelihood (ML) methodology, which is the most common procedure for SEM and was used in this study, requires that researchers consider the ratio of cases (n) to model parameters (q; Jackson, 2003). Model parameters can be calculated by totaling: (a) the number of proposed factors, (b) the number of items, and (c) the variances of each item (Schreiber, Nora, Stage, Barlow, & King, 2006). An ideal sample size to parameter ratio (N:q) would be 20:1 (Jackson, 2003), but 5:1 is considered acceptable (Bentler & Chou, 1987). The analysis was conducted despite the small number of participants because it could provide a sense of the model structure for available sample.

In addition to considering the sample size, multicollinearity should be assessed. Multicollinearity occurs when latent variables are highly correlated, which Brown (2006) identifies as |.85| or more. High correlations suggest a lack of discriminate validity (Brown, 2006) and can lead to inaccurate coefficient estimation (Grewal, Cote, & Baumgartner, 2004). Some methods for addressing multicollinearity are to drop variables or gather more data.
(Grewal, Cote, & Baumgartner, 2004); other more robust ones include partial-least-squares-based ridge estimation (see Jagpal, 1982). However, even after reviewing several methods, Grewal, Cote, and Baumgartner (2004) suggested, “none of the approaches for managing multicollinearity seems entirely satisfactory” (p. 521).

Next, the fit indexes of the measurement model should be reviewed to determine whether or not the proposed factor structure accurately represents the constructs. There are several acceptable fit indices when using ML estimation, all of which have ranges of recommended acceptability, rather than hard and fast rules for determining model fit (Schreiber, Nora, Stage, Barlow, & King, 2006). For the present study, model chi-square, relative model chi-square, comparative fit index (CFI), and root mean square error of approximation (RMSEA) were used. The model chi-square ($\chi^2$) is the first fit index that should be considered. It is actually referred to as a “badness-of-fit” assessment because the interpretation of the value is such that smaller chi-square values, which are accompanied by higher $p$-values, indicate a better model fit (Kline, 2011). An important limitation to this index is that sample size and the number of parameters in a model can affect the score, such that larger samples and fewer parameters may result in a lower chi-square when the difference between observed and predicted covariances is small (Kline, 2011). With smaller sample sizes or models having more parameters, chi-square may be rather large, which corresponds with a small $p$-value and indication of a bad model fit (Kenny & McCoach, 2003). An index that helps account for this limitation is the relative chi-square, or the ratio of the chi-square value divided by the degrees of freedom ($\chi^2/df$; Kenny & McCoach, 2003). There is some disagreement about the interpretation of this index, but the values between 2.0 and 3.0 are typically considered acceptable (Baker, Denniston, Zabora, Polland, & Dudley, 2002); whereas values less than 2.0 indicate a good fit (Tabachnick & Fidell, 2007). The
comparative fit index (CFI) is one that reveals the improvement in fit of a model from a statistical baseline (Kline, 2011). Although there is some controversy in the use of this fit statistic, Schreiber, Nora, Stage, Barlow, and King (2006) suggest that it is a preferable index for one-time CFA analyses using SEM. A CFI value greater than .90 is considered an appropriate model fit (Schreiber, Nora, Stage, Barlow, & King, 2006).

Finally, the root mean square error of approximation (RMSEA) is considered based on the recommended procedures from Kline (2011). Similar to the model chi-square fit index, the RMSEA is a “badness-of-fit” index where a value of zero indicates the best model fit and larger values suggest a bad model fit (Kline, 2011). Values that are less than or equal to .10 are considered a bad fit, while values between .05 - .08 are a reasonable fit and those less than .05 are a good fit (MacCallum, Browne, & Sugawara, 1996). Interpretation of the index also utilizes confidence intervals for which lower bounds less than .05 constitute evidence of a close fit and upper bounds greater than .10 are considered a bad fit (Kline, 2011).

The model that I tested first was that which was representative of the pertinent literature for two measures of patient-centered communication, one with three factors (Safran et al., 1998) and one with four factors (Takayama, Yamazaki, & Katsumata, 2001), decisional conflict with three factors (O’Connor, 1995), and patient satisfaction with one factor (Jean-Pierre et al., 2011). Fit indices indicated an average fit ($\chi^2 = 173.99$, $df = 52$, $p = .000$; $\chi^2/df = 3.35$; RMSEA = .138 [90% CI: .116 to .161]; CFI = .91; see Figure 1). Although this model fit could be considered reasonable based on the previously described indices, the Akaike Information Criterion (AIC) should also be considered. Kline (2011) describes this index as assessing model complexity and means by which competing models that consider the same data can be compared. Models with a smaller AIC are more likely to be replicated in the population (Kline, 2011).
In considering these results, an EFA was thus conducted because, (a) several scales were used to assess patient-centered communication and a factor structure could reveal a hybrid measure; (b) correlations between dimensions of the two measures of patient-centered communication were strong (see Table 1), which suggests they could be measuring the same construct, (c) the decisional conflict scale having not been assessed with the additional items included for each breast cancer treatment choice (i.e., treatment choices, surgery choices, reconstruction choices), and (c) research employing the Patient Satisfaction with Cancer Care scale had not yet established a clear factor structure with the added items due to multiple decisions required of patients. The following sections describe the results of an exploratory factor analysis (EFA) for each of the three outcome variables (i.e., patient-centered communication, decisional conflict, and patient satisfaction). If resulting factor structures were too different from those in prior published research, CFA was necessary.
Figure 1:

Table 1

*Measurement model from pertinent literature: covariances and correlations*

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<th>PTCN</th>
<th>KNO</th>
<th>TU</th>
<th>COM</th>
<th>DU</th>
<th>FAC</th>
<th>EFDM</th>
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<td>.41*(.13)</td>
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</table>

**Exploratory factor analysis (EFA) method.** Exploratory factor analysis (EFA) was conducted first because this methodology does not, “require a priori hypotheses about factor-indicator correspondence or even the number of factors” (Kline, 2011, p. 116). By completing an EFA, I was able to see if the previous dimensionality described in the literature was maintained with this sample. The first step in exploratory factor analysis is to assess the factorability for each of the criterion variable scales. For this study, several analyses were made, including (1) Pearson correlations among items, (2) the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy, and (3) Bartlett’s test of sphericity. First, the inter-item Pearson correlations were assessed, which considers inter-item correlations above .3 as acceptable (Tabachnick & Fidell, 2007). If there are no correlations above .3, then factor analysis may not be useful because the items are not homogeneous (Tabachnick & Fidell, 2007). The KMO measure of sampling adequacy has been used for decades as a means of assessing whether a set of data are factorable. Kaiser (see Dziuban & Shirkey, 1974a) suggested that a KMO result of .5 is the bare minimum required, scores in the .6 - .7 range are mediocre, values between .7 - .8 are middling, and those above .8 were meritorious. In this study, KMO values above .6 were considered acceptable. The KMO is also calculated for individual variables, which are found in the diagonal of the anti-image correlation matrix (Dziuban & Shirkey, 1974a. The same index of acceptability was used to assess the KMO values for individual variables and any that fell below the established .6 value should be removed. The next method was Bartlett’s test of sphericity, which is a way of analyzing the inter-item correlation matrix, such that a significant chi-square value indicates that the data are appropriate for factor analysis (Dziuban & Shirkey, 1974b). Therefore, to determine factorability, I looked for inter-item Pearson correlations revealing a homogeneous set of measures, KMO values greater than .6 for the entire scale and for individual items, and a
significant result for Bartlett’s test of sphericity. Once factorability was established using these
criteria, the communalities of all measures were assessed. Communality is the shared variance of
one factor compared to all of the other factors combined, where values range from 0, no common
variance, to 1, all variance is explained by the other items (Hogarty, Hines, Kromrey, Ferron, &
Mumford, 2005). Extracted communalities reveal the shared variance between individual items
and the factors; these values should be greater than .2 (Tabachnick & Fidell, 2007). Extracted
communalities that are less than .2 indicate the item may need to be removed.

The EFA utilized principal axis factoring (PAF), which assumes that each variable
provides information about another variable and that there is shared variance (Warner, 2008). In
social science research, PAF is often the approach suggested because we are trying to understand
the shared variance of several factors, which suggests a larger construct (Warner, 2008). As a
means of allowing for items to load on the most appropriate factor – a true exploratory approach,
I began the analysis by looking for factors with eigenvalues greater than 1.0 (DeVellis, 2012).
Assessing eigenvalues is a common practice first described by Kaiser (see DeVellis, 2012) as a
way of showing how much variance each factor explains. Higher eigenvalues indicate more
explained variance. The goal of factor analysis is to determine the most efficient model—one that
has the fewest possible factors with the most explained variance (DeVellis, 2012). In SPSS,
unless the analyst specifies the number of factors that should be extracted, any eigenvalue greater
than 1.0 will create a factor in the output, but the analyst must also consider factor loadings and
determine when the benefit of parsimony outweighs additional variance explained (Ford,
MacCallum, & Tait, 1986). After reviewing the eigenvalues, the factor loadings for each item
should be reviewed to ensure that each item has a primary loading of .4 or more on at least one
factor (Ford, MacCallum, & Tait, 1986). Once the factor structure is sufficient, Cronbach’s alpha
can be used as a means of assessing the reliability and internal consistency of each dimension. This test was developed by Lee Cronbach in the 1950s and reveals the extent to which a group of items is capturing the same concept (Tavakol & Dennick, 2011). Values of Cronbach’s alpha range from 0 to 1, with scores greater than 0.7 considered acceptable.

**Exploratory factor analysis (EFA) outcome.** The factor analysis function in SPSS (version 22.0) was used to conduct the EFA with following parameters: (1) no pre-determined factor structure, instead eigenvalues greater than 1.0 were used as the initial method of determining factorability and (2) principal axis factoring with Promax rotation (IBM Corp., 2013). The sample size for exploratory factor analysis was not ideal, as Tabachnick and Fidell (2007) suggest that any sample less than 200 is considered poor. However, additional assessments were previously described as being effective for determining the factorability of a measure (i.e., KMO measure of sampling adequacy, Bartlett’s test of sphericity). In the remainder of this section, I present results for the EFA of the three outcome variables, patient-centered communication, decisional conflict, and patient satisfaction, respectively.

Patient-centered communication was assessed for factorability using the KMO measure of sampling adequacy (.88) and Bartlett’s test of sphericity ($\chi^2 (190) = 1755.01, p < .01$). Both of these analyses suggested that the data were appropriate for factor analysis. The correlation table for all variables revealed that each item was significantly correlated with at least one other item at .3 or greater, which suggests homogeneous items (See Appendix E).

Next, the exploratory factor analysis was conducted using principal axis factoring with Promax rotation. The anti-image correlation table was examined, and none of the variables had values less than .6, which indicated the KMO measure of sampling adequacy was met for the scale and for all individual items. Communalities were then reviewed and one item was below
the recommended minimum of .3 (Item 8 = .27). Although the anti-image correlation was acceptable for this item, it was dropped from the analysis due to low variance in common with other items. The analysis was conducted again after dropping item 8 and all anti-image correlations and communalities proved to exceed recommended values.

Review of the initial eigenvalues revealed three factors with eigenvalues greater than one and collectively accounted for 70.5% of variance. The first factor explained 57.5%, the second factor 6.6%, and the third 6.3%. The three-factor model was deemed appropriate given the theoretical underpinnings of the patient-centered communication concept and the statistical data in the pattern structure. All items except two had primary loadings greater than .4. Item 17 had a primary loading of .48, and Item 4 had a primary loading of .49, both on factor 2. Even though these factor loadings were relatively low, the reliability coefficients increased only slightly if the two items were eliminated (Δα = .91 to .93). An alpha coefficient greater than .90, suggested that it would be appropriate to retain the items on the scale, even with the low primary factor loadings. Several items cross-loaded on two factors, but the primary loadings were all above .5, which indicates sufficient stability. Additionally, correlations between factors revealed strong associations (see Table 2). The factor loading matrix and reliability coefficients for the final solution appear in Table 3. This resulting three-factor model was not the same as that in the prior literature from which the scales derived (Mallinger, Griggs, & Shields, 2005; Safran et al., 1998; Takayama, Yamazaki, & Katsumata, 2001). Later in the chapter, I present a confirmatory factor analysis (CFA), for which review the results, share final factor structure, and new variable labels.
Table 2

*Factor correlation matrix for patient-centered communication*

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<th>Factor 2</th>
<th>Factor 3</th>
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</thead>
<tbody>
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<tr>
<td>Factor 2</td>
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<td>Factor 3</td>
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<td>.68</td>
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Table 3

*Factor loadings and reliability coefficients for patient-centered communication items*

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<td>Item 11</td>
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<td>Item 20</td>
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<td>Item 6</td>
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<td>Item 7</td>
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<td>Item 14</td>
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<td>Item 12</td>
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<td>Item 16</td>
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</table>

Note. Factor loadings less than |.30| not reported. Item text displayed in Appendix A.
Next, the decisional conflict scale was assessed using EFA methods. There was not a large sample size for some decisional conflict items because the casewise deletion of missing data due to valid skips resulted in the elimination of many cases. However, the KMO measure of sampling adequacy and Bartlett’s test of sphericity assessments determined whether factor analysis was appropriate. Both revealed that data were sufficient for conducting factor analysis (KMO = .77; \( \chi^2 \) (406) = 1332.82, \( p < .01 \)). Items were determined to be homogeneous, as each had a significant correlation greater than .3 with at least one other item (see Appendix F).

Diagonals of the anti-image correlation matrix all exceeded .6, except for items 14 and 15 (.47 and .38, respectively). Item 15 was the only measure with a communality less than .3, which suggests that it did not share much variance with other items on the scale. Given these indicators, item 15 was dropped, and the analysis was repeated. After reassessment, the KMO measure of sampling adequacy remained high (.78) and the Bartlett’s test of sphericity was significant (\( \chi^2 \) (378) = 1310.66, \( p < .01 \)). Anti-image correlations revealed that Item 20 was under .6 ( = .51), but communalities were all well above .3. Therefore, Item 20 was retained in reviewing the factor structure.

Initial eigenvalues exceeding 1.00 revealed seven factors accounting for 78.0% of the total variance. The first explained 41.4%, with second, third, fourth, and fifth explaining 10.4%, 7.3%, 5.8%, and 5.1%, respectively. The remaining two factors had eigenvalues just over one, and each accounted for around 4% of the variance. The analysis was then conducted using Principal Axis Factoring and Promax rotation to assess the data as a one, two, three, four, and five factor model, respectively. A five-factor model explaining 70% of the variance was selected because, (a) the eigenvalues leveled off after the fifth factor and accounted for very little
additional variance, and (b) the more parsimonious structure allowed for stronger factor loadings and more interpretable theoretical connections between dimensions.

Item 22 was eliminated because it had a low primary factor loading, .34, and it cross-loaded on two factors (Factor 1 and Factor 3), with low factor loadings on both. Item 4 was also eliminated because of low factor loadings (.47). Additionally, Item 2 was eliminated because it did not load on any factors. Once these items were removed, all items had primary loadings greater than .4. Several items cross-loaded on other factors, but none greater than |.33|. All five factors had high reliability coefficients ($\alpha$ range = .80-.92). Due to the clear loading structure and high reliability coefficients, the five-factor structure was used. Item 5 had a high negative loading on Factor 2, so it was reverse coded to align with the other items. Table 4 shows the factor loading matrix and reliability coefficients for the final solution. Correlations between factors varied from .17 to .59 and appear in Table 5. As with the patient-centered communication variable, the factor structure identified in the exploratory factor analysis was different from the three-factor structure suggested by O’Connor (1995). The next section provides the results of a confirmatory factor analysis for the proposed five-factor structure of decisional conflict.

Table 4

*Factor loadings and reliability coefficients for decisional conflict items*

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<td></td>
<td></td>
<td></td>
<td>.89</td>
<td></td>
</tr>
<tr>
<td>Item 16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.73</td>
</tr>
</tbody>
</table>

Cronbach’s α | .92 | .81 | .86 | .82 | .80 |

Note. Factor loadings less than |.30| not reported. Item text displayed in Appendix B.

Table 5

*Factor correlation matrix for decisional conflict*

<table>
<thead>
<tr>
<th></th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
<th>Factor 4</th>
<th>Factor 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 2</td>
<td>.44</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 3</td>
<td>.59</td>
<td>.46</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor 4</td>
<td>.24</td>
<td>.37</td>
<td>.38</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Factor 5</td>
<td>.45</td>
<td>.26</td>
<td>.37</td>
<td>.17</td>
<td>1.0</td>
</tr>
</tbody>
</table>
Finally, an EFA was conducted for the items used to measure patient satisfaction. Several assessments were used to determine whether factor analysis was appropriate for the items measuring patient satisfaction including the KMO measure of sampling adequacy (.85) and Bartlett’s test of sphericity ($\chi^2 (66) = 446.73, p < .01$), which suggested that data were sufficient. All items had at least one statistically significant correlation of .3 or greater with at least one other item, suggesting items were homogeneous (See Appendix G). Values on the diagonal of the anti-image correlation matrix were all over .6, and all communalities exceeded .3. Item 7 had a communality that was relatively low (.31), but it was nevertheless retained to assess factor loadings. Principal axis factoring with Promax rotation was used for the analysis and eigenvalues suggested a two-factor model, which explained 54.2% of variance. No eigenvalues beyond a two-factor model were greater than 1. This indicated an appropriate interpretation of the factor structure. Although the correlation between the two factors was relatively low (.32), the reliability coefficients were acceptable (.90 and .68, respectively). The two-factor model was used and the factor loadings and reliability coefficients are shown in Table 6. The exploratory factor analysis revealed a two-factor structure, which was different from the single-factor structure suggested by Jean-Pierre et al., (2011). The next section provides the results of confirmatory factor analyses (CFA) for the three outcome variables (i.e., patient-centered communication, decisional conflict, and patient satisfaction). In that section, I provide the CFA for patient satisfaction and a proposed revision to the factor structure.
Table 6

Factor loadings and reliability coefficients for patient satisfaction items

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 8</td>
<td>.86</td>
<td></td>
</tr>
<tr>
<td>Item 1</td>
<td>.83</td>
<td></td>
</tr>
<tr>
<td>Item 2</td>
<td>.78</td>
<td></td>
</tr>
<tr>
<td>Item 9</td>
<td>.75</td>
<td></td>
</tr>
<tr>
<td>Item 6</td>
<td>.75</td>
<td></td>
</tr>
<tr>
<td>Item 4</td>
<td>.70</td>
<td></td>
</tr>
<tr>
<td>Item 3</td>
<td>.70</td>
<td></td>
</tr>
<tr>
<td>Item 5</td>
<td>.68</td>
<td></td>
</tr>
<tr>
<td>Item 7</td>
<td>.50</td>
<td>.88</td>
</tr>
<tr>
<td>Item 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 12</td>
<td>.63</td>
<td></td>
</tr>
<tr>
<td>Item 11</td>
<td>.57</td>
<td></td>
</tr>
</tbody>
</table>

Cronbach’s α | .90 | .68 |

Note. Factor loadings less than |.30| not reported. Item text displayed in Appendix C.

Confirmatory factor analysis (CFA) method. Since the factor structures that were suggested in exploratory factor analysis were different those presented in the literature, a confirmatory factor analysis was necessary to determine if the structures appropriately fit the data. A limitation that should be mentioned was the use of the same sample for both EFA and CFA. Best practice suggests the use of two samples from the same population, one for EFA and then one to confirm the model in another sample of the population (Kline, 2011). However, that was not possible given the constraints of recruitment time and funding. Thus, the CFA was conducted on the same sample as the EFA to gain a sense of model fit, but future assessments of the revised structure should be conducted using different samples from the same population.

With a proposed modification to the factor structure in the literature, a CFA was conducted to assess model fit. The model being tested is that which was established in the exploratory factor analysis (EFA), where decisional conflict was characterized by five factors,
patient-centered communication three factors, and patient satisfaction two factors. The model fit indicated an average fit ($\chi^2 = 94.56, df = 32, p = .000; \chi^2/df = 2.96; \text{RMSEA} = .147 [90\% \text{ CI}: .114 \text{ to } .182]; \text{CFI} = .897; \text{AIC} = 177.34$). These fit statistics represented an acceptable fit of the data. Standardized parameter estimates are provided in Figure 2. Although the model fit is similar to the theoretical model, it does suggest some improvement. The new model revealed a big improvement in AIC, which means that the newly identified model has “better fit and fewer free parameters compared with competing models” (Kline, 2011, p. 220). Other factors to consider include the high reliability of the revised factors and the fact that patient-centered communication is now collapsed to three factors with at least five items for each factor, which makes the mean scores more stable when extreme values are present. Thus, the revised factor structure was used for the remainder of this study.

Upon review of the correlation and covariance matrices, several interesting issues were present (see Table 7). All of the correlations between the identified factors of each variable were significant, which suggested that the relationships support the combination of factors as representing a higher order construct. However, some of the correlations were rather weak ($r$ range = .30-.39; Marque de Sa, 2007). One of these weak correlations was between the two factors of patient satisfaction (i.e., satisfaction with the care experience and perceived inclusion in treatment decision-making; $r = .35$). What was surprising was that satisfaction with the care experience was actually very highly correlated with all three dimensions of patient-centered communication ($r$ range = .81 to .91). This suggests that satisfaction with the care experience is more related to the dimensions of patient-centered communication than to perceived inclusion in treatment decision-making. The strength of those correlations pose challenges related to multicollinearity, which Brown (2006) suggests is defined by inter-item correlations over .85.
Problems with multicollinearity mean that discriminate validity between those factors is limited; that is, they may simply be measuring the same thing. Although some of the correlations were high, multicollinearity remains a problem that has few widely accepted processes for managing it (Brown, 2006).
Figure 2:

The measurement model based on EFA outcome with standardized beta coefficient. Note Curved lines indicate covariances, thus unstandardized coefficients provided for those associations. ITC = informed treatment choice; CBR = clarity of breast reconstruction choice; STC = satisfaction with treatment choice; IU = informational uncertainty; DS = decisional support; SCE = satisfaction with care experience; PI = perceived inclusion in treatment decision-making; IS = interpersonal sincerity; PE = patient engagement; IC = individual confirmation.
Table 7

*Measurement model for identified factors from EFA: covariances and correlations*

<table>
<thead>
<tr>
<th></th>
<th>ITC</th>
<th>CBR</th>
<th>STC</th>
<th>IU</th>
<th>DS</th>
<th>SCE</th>
<th>PI</th>
<th>IS</th>
<th>PE</th>
<th>IC</th>
</tr>
</thead>
<tbody>
<tr>
<td>ITC</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBR</td>
<td>.58* (.02)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STC</td>
<td>.60* (.02)</td>
<td>.55* (.03)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IU</td>
<td>.30* (.04)</td>
<td>.37* (.09)</td>
<td>.47* (.08)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DS</td>
<td>.52* (.02)</td>
<td>.30* (.02)</td>
<td>.38* (.01)</td>
<td>.31* (.06)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCE</td>
<td>.36* (.01)</td>
<td>.20* (.01)</td>
<td>.49* (.02)</td>
<td>.32* (.07)</td>
<td>.40* (.02)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PI</td>
<td>.59* (.01)</td>
<td>.49* (.02)</td>
<td>.46* (.01)</td>
<td>.25* (.03)</td>
<td>.39* (.01)</td>
<td>.35* (.01)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IS</td>
<td>.46* (.02)</td>
<td>.29* (.02)</td>
<td>.53* (.02)</td>
<td>.26* (.06)</td>
<td>.39* (.02)</td>
<td>.90* (.05)</td>
<td>.42* (.01)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PE</td>
<td>.23* (.01)</td>
<td>.12* (.01)</td>
<td>.39* (.01)</td>
<td>.27* (.05)</td>
<td>.42* (.02)</td>
<td>.87* (.04)</td>
<td>.29* (.01)</td>
<td>.81* (.03)</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>IC</td>
<td>.31* (.01)</td>
<td>.15* (.01)</td>
<td>.36* (.02)</td>
<td>.30* (.08)</td>
<td>.43* (.02)</td>
<td>.82* (.06)</td>
<td>.30* (.01)</td>
<td>.78* (.05)</td>
<td>.80* (.04)</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. Covariances in parentheses. ITC = Informed treatment choice; CBR = clarity of breast reconstruction choice; STC = satisfaction with treatment choice; IU = informational uncertainty; DS = decisional support; SCE = satisfaction with care experience; PI = perceived inclusion in treatment decision-making; IS = interpersonal sincerity; PE = patient engagement; IC = individual confirmation; *p < .01
Summary of measurement analysis. An initial CFA was conducted to assess the model fit for the factor structures presented in the literature (Jean-Pierre et al., 2011; O’Connor, 1995; Safran et al., 1998; Takayama, Yamazaki, & Katsumata, 2001). This analysis revealed an average fit of the data with a high AIC value. Due to model fit statistics and the way in which variables were measured, an EFA was conducted. EFA outcomes and CFA confirmation resulted in modification from previous literature for the dimensional structure of all three variables.

The patient-centered communication variable was assessed via two scales: the Perceived Physician’s Communication Style Scale (PPCS; Takayama, Yamazaki, & Katsumata, 2001) and the Primary Care Assessment Survey (PCAS; Safran et al., 1998). The Takayama, Yamazaki, and Katsumata (2001) scale originally included 27 items, but was reduced to 11 in this study following cognitive interviews with survivors. Additionally, Safran et al. (1998) suggested that the patient-centered communication construct be measured using the 51-item PCAS scale. In this study, items from the PCAS scale were reduced to nine. The previously reported factor analysis revealed a total of three dimensions, which was a hybrid of the initial dimensions presented in the work of Takayama, Yamazaki, and Katsumata (2001) and Safran et al. (1998; see Table 3).

The decisional conflict variable was measured using O’Connor’s (1995) scale, which originally included 16 items dispersed on three dimensions. In an effort to account for decisional conflict for each decision point during breast cancer treatment decision-making, a total of 33 items were used to measure decisional conflict in this study (see Appendix B). Confirmatory factor analysis suggested a modified factor structure with five dimensions (see Table 4). The first emergent dimension included only items from what O’Connor (1995) labeled as “factors contributing to uncertainty.” A new variable label was warranted because there were some items from O’Connor’s (1995) scale that loaded on other dimensions. A discussion of variable labels is
provided in the next section. The second dimension was comprised of 6 items, two items from each of the three original dimensions described by O’Connor (1995; i.e., decision uncertainty = 2 items; factors contributing to uncertainty = 2 items; perceived effectiveness of decision-making = 2 items). One reason for this difference could have been that O’Connor’s (1995) scale failed to address specific decisions that breast cancer patients must make. I included items about decisional conflict for each type of decision that breast cancer patients had to make (i.e., about surgery choices, about pharmaceutical treatments, and about breast reconstruction). The third dimension included four items, all from the original dimension labeled “perceived effectiveness of decision-making” (O’Connor, 1995). The fourth dimension included five items from the “decision uncertainty” and “factors contributing to uncertainty” dimensions of O’Connor’s (1995) scale. Finally, the fifth factor was comprised of two items from the “factors contributing to uncertainty” dimension a la O’Connor’s scale (1995). As previously described, a new variable label was assigned because item loadings varied from the original scales described by O’Connor (1995).

The patient satisfaction measure used for this study was the PSCC (Jean-Pierre et al., 2011) and initially was conceived as an 18-item single factor scale. Of the 18 items in the original scale, 11 were used in this study based on cognitive interviews with survivors. One additional item from the Decisional Conflict Scale (O’Connor, 1995) was added to the measure and loaded strongly with the single-factor PSCC measure (combined $a = .83$), which resulted in 12 total items being used in this study to measure patient satisfaction with cancer care. Exploratory and confirmatory factor analysis, however, revealed that the items comprised two factors (see Table 6). The factors were labeled “satisfaction with the cancer care experience” and “perceived inclusion in treatment decision-making.”
In view of the revised factor structure suggested by the exploratory and confirmatory factor analyses, tests of the research hypotheses were modified to suggest specific associations based on dimensions of the criterion variables. Due to the lengthy list of revisions, the revised hypotheses appear in Appendix H.

**Variable labels.** This section addresses variable labels that appear to best reflect patient-centered communication, decisional conflict, and patient satisfaction. As previously described, none of the factor structures was the same as those in prior scholarly literature (Jean-Pierre et al., 2011; Mallinger, Griggs, & Shields, 2005; O'Connor, 1995; Safran et al., 1998; Takayama, Yamazaki, & Katsumata, 2001). Since differences were evident and the CFA suggested reasonable model fit for the new dimensions, the labels below were assigned as an aid to interpret the data.

Labeling variables is an important component of interpreting the connections among items following factor analysis (DeVellis, 2012). In determining variable labels, DeVellis (2012) suggests “examining the items that most strongly exemplify each factor (i.e., that have the largest loadings on a particular factor)” (p. 147). Labeling factors is easiest when several items have factor loadings greater than .65, as they suggest a common issue or concept (DeVellis, 2012). The process for this study was first to consider factors that loaded at .65 or higher, then those with lower factor loadings to ensure commonality in the themes. As DeVellis (2012) pointed out, “If the analysis yielded one factor with items that seem dissimilar, it probably is best not to take the factor too seriously as an indicator of a latent variable” (p. 147). Further explanation concerning variable labels is provided in each of the following subsections: patient-centered communication, followed by decisional conflict, and then patient satisfaction.
**Patient-centered communication.** The three hybrid dimensions used to assess patient-centered communication in this study; they were labeled, “interpersonal sincerity,” “patient engagement,” and “individual confirmation.” Items comprising the first factor in the patient-centered communication construct focused on issues of trust experienced by the patient toward the cancer-care team, along with interpersonal attentiveness and effectiveness that was communicated by the cancer-care team. The final three items had factor loadings less than .65, the value recommended by DeVellis (2012) as the threshold for considering factors that played a greater role in the variable meaning. These lower-loading items focused more the information shared by the cancer-care team during interpersonal exchanges with the cancer-care team (items 14 and 12) and nonverbal behavior that suggest openness and effective interpersonal communication (item 3). With most of the factors centering on interpersonal communication and trust, the factor was labeled “interpersonal sincerity.”

The second factor had four items with high factor loadings and two with much lower loadings (item 17 = .48; item 4 = .49). In alignment with recommendations by DeVellis (2012), the first four items were most important for interpreting meaning. These items focused on the interaction between the patient and cancer-care team with most items centering on the idea of the cancer-care team engaging patients in the treatment process. The open dialogue between patients and the cancer-care team and encouragement of patient communication suggested the label name “patient engagement.”

Finally, the third factor was assigned the label “individual confirmation” because items focused on issues related to how well the cancer-care team knew the patient as an individual, the patient’s beliefs and values. The fourth item had a factor loading of .63; since that is close to the .65 loading suggested by DeVellis (2012) was considered in the interpretation. This item, as well
as the final item (with a low factor loading = .55), both focused on the idea of the cancer-care team encouraging the patient to share information and providing confirmation of the patient’s opinions and understanding. Thus, the variable label of “individual confirmation” addresses the understanding of the cancer-care team about the individual patient and the confirmation of their opinions and beliefs about treatment plans. Table 8 provides the item text and corresponding factor loadings for all dimensions of patient-centered communication.

Table 8

*Patient-centered communication items with corresponding factor loadings*

<table>
<thead>
<tr>
<th>Item Text</th>
<th>Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 1: “Interpersonal sincerity”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 18: All things considered, I trusted my cancer care team.</td>
<td>.88</td>
</tr>
<tr>
<td>Item 11: My cancer care team listened to my questions attentively.</td>
<td>.81</td>
</tr>
<tr>
<td>Item 20: My cancer care team always told me the truth about my health, even if it was bad news.</td>
<td>.80</td>
</tr>
<tr>
<td>Item 6: My cancer care team gave me a chance to ask questions.</td>
<td>.71</td>
</tr>
<tr>
<td>Item 7: My cancer care team looked me in the eye when speaking to me.</td>
<td>.65</td>
</tr>
<tr>
<td>Item 14: My cancer care team offered helpful advice about making decisions for my cancer treatment.</td>
<td>.58</td>
</tr>
<tr>
<td>Item 12: My cancer care team provided clear explanations about my breast cancer treatment options.</td>
<td>.57</td>
</tr>
<tr>
<td>Item 3: My cancer care team was friendly and warm.</td>
<td>.52</td>
</tr>
<tr>
<td><strong>Factor 2: “Patient engagement”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 19: I felt like I could tell my cancer care team anything.</td>
<td>.81</td>
</tr>
<tr>
<td>Item 9: During my appointments, my cancer care team waited to hear about all my problems and concerns.</td>
<td>.80</td>
</tr>
<tr>
<td>Item 13: My cancer care team asked thorough questions about how I was feeling during my breast cancer treatment.</td>
<td>.77</td>
</tr>
<tr>
<td>Item 10: My cancer care team encouraged me to tell them everything I thought was important about my cancer treatment.</td>
<td>.61</td>
</tr>
<tr>
<td>Item 4: My cancer care team was my main source of information about my breast cancer treatment options.</td>
<td>.49</td>
</tr>
<tr>
<td>Item 17: My cancer care team showed a good understanding about my concerns.</td>
<td>.48</td>
</tr>
</tbody>
</table>
Table 8 (cont.)

<table>
<thead>
<tr>
<th>Item Text</th>
<th>Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 3: “Individual confirmation”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 15: My cancer care team showed a good understanding about me as a</td>
<td>.89</td>
</tr>
<tr>
<td>person, my values, and beliefs.</td>
<td></td>
</tr>
<tr>
<td>Item 16: My cancer care team showed a good understanding of my responsibilities at home, work, or school.</td>
<td>.68</td>
</tr>
<tr>
<td>Item 5: My cancer care team showed a good understanding of my past health history.</td>
<td>.66</td>
</tr>
<tr>
<td>Item 1: My cancer care team regularly asked whether I had any opinions about my cancer treatment.</td>
<td>.63</td>
</tr>
<tr>
<td>Item 2: My cancer care team regularly confirmed that I understood the explanations they provided about my breast cancer treatment.</td>
<td>.55</td>
</tr>
</tbody>
</table>

*a Indicates item was reverse-coded*

**Decisional conflict.** The first decisional conflict factor had six items with factor loadings exceeding .65, which meant that those items should be considered heavily in interpreting the variable label (DeVellis, 2012). The first six items related to feeling aware of possible choices for treatment and surgery and knowing the risks and benefits of treatment choices. These elements provided an overall sense of whether or not the patient felt informed about the choices available to them; this suggested that “informed treatment choice” was an appropriate label.

The second factor was labeled “clarity of breast reconstruction choices.” All items focused on breast reconstruction, the clarity of available information, and the general satisfaction patients felt about their breast reconstruction choice.

The third factor included four items having the same two root questions, but different endings concerning treatment choices and surgery choices, respectively (see Table 9). These four questions focused on the satisfaction patients felt with their choices and whether or not they would make those choices again. This suggested “satisfaction with treatment choices” as an appropriate label.
The fourth factor focused on items addressing how patients felt about treatment information and whether or not they desired more advice and information to make decisions. Thus, the label was identified as “informational uncertainty.” The items defining this factor were not reverse-coded, since they were all negatively worded and directionally consistent. If they had been recoded, the label would be more appropriate as informational *certainty* since more of the attribute would suggest the patient did not need more advice and was sure of what to do in decision-making.

Finally, the fifth factor included only two items having high factor loadings, both of which were considered heavily in labeling. The item text focused on perceptions of support during decision-making, which led to the factor label of “decisional support.” The item text with corresponding factor loadings for all decisional conflict dimensions appears in Table 9.

Table 9

*Decisional conflict items with corresponding factor loadings*

<table>
<thead>
<tr>
<th>Item Text</th>
<th>Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 1: “Informed treatment choice”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 7: I was aware of the choices available to me for my breast cancer treatment.</td>
<td>.89</td>
</tr>
<tr>
<td>Item 13: I feel that I knew the benefits for each of the breast cancer surgery options.</td>
<td>.85</td>
</tr>
<tr>
<td>Item 14: I feel that I knew the risks for each of the breast cancer surgery options.</td>
<td>.83</td>
</tr>
<tr>
<td>Item 8: I feel that I knew the benefits for each of the breast cancer treatment options.</td>
<td>.75</td>
</tr>
<tr>
<td>Item 12: I was aware of the choices available to me for my breast cancer surgery.</td>
<td>.70</td>
</tr>
<tr>
<td>Item 17: I was aware of the choices available to me for breast reconstruction.</td>
<td>.67</td>
</tr>
<tr>
<td>Item 9: I feel that I knew the risks for each of the breast cancer treatment options.</td>
<td>.54</td>
</tr>
<tr>
<td>Item 25: I felt that I made an informed choice about my breast cancer surgery.</td>
<td>.51</td>
</tr>
</tbody>
</table>
Table 9 (cont.)

<table>
<thead>
<tr>
<th>Item Text</th>
<th>Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 2: “Clarity of breast reconstruction choices”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 6: There was a clear choice that was best for me when deciding whether or not I should have reconstruction.</td>
<td>.76</td>
</tr>
<tr>
<td>Item 5: The decision about whether or not to have breast reconstruction was difficult for me to make. (^a)</td>
<td>-.72</td>
</tr>
<tr>
<td>Item 29: I am satisfied with the choices that were made about whether or not to have breast reconstruction.</td>
<td>.71</td>
</tr>
<tr>
<td>Item 28: I felt that I made an informed choice about whether or not to have breast reconstruction.</td>
<td>.67</td>
</tr>
<tr>
<td>Item 18: I feel I knew the emotional benefits of breast reconstruction.</td>
<td>.54</td>
</tr>
<tr>
<td>Item 19: I feel that I knew the emotional risks of breast reconstruction.</td>
<td>.53</td>
</tr>
<tr>
<td><strong>Factor 3: “Satisfaction with treatment choices”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 27: I would make the same surgery choices if I had to do it all over again.</td>
<td>.89</td>
</tr>
<tr>
<td>Item 24: I would make the same treatment choices if I had to do it all over again.</td>
<td>.82</td>
</tr>
<tr>
<td>Item 26: I am satisfied with the choices that were made about the type of breast cancer surgery I had.</td>
<td>.80</td>
</tr>
<tr>
<td>Item 23: I am satisfied with the choices that were made for my breast cancer treatment.</td>
<td>.56</td>
</tr>
<tr>
<td><strong>Factor 4: “Informational uncertainty”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 15: I needed more advice and information about breast cancer surgery choices.</td>
<td>.78</td>
</tr>
<tr>
<td>Item 10: I wanted more advice and information about breast cancer treatment choices.</td>
<td>.71</td>
</tr>
<tr>
<td>Item 1: I was unsure what to do in the decision about my breast cancer treatment.</td>
<td>.65</td>
</tr>
<tr>
<td>Item 3: I was unsure what to do in the decision about my breast cancer surgery.</td>
<td>.64</td>
</tr>
<tr>
<td>Item 20: I wanted more advice and information about breast reconstruction options.</td>
<td>.59</td>
</tr>
<tr>
<td><strong>Factor 5: Decisional Support”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 11: I had the right amount of support from others when making decisions about my breast cancer treatment.</td>
<td>.89</td>
</tr>
<tr>
<td>Item 16: I had the right amount of support from others when making decisions about my breast cancer surgery.</td>
<td>.73</td>
</tr>
</tbody>
</table>

\(^a\) Indicates item was reverse-coded

Patient satisfaction. For Factor 1, the label “patient satisfaction with care experience” was assigned because the items concerned the scope of the patients’ experience and their
perceptions of how it compared with positive expectations. The last item had a factor loading below the recommended .65 level (see DeVellis, 2012), which meant that it played a lesser role in interpreting the factor. The second factor was labeled “perceived inclusion in treatment decision-making” as all three items focused on whether or not the patient felt included in the decision-making at each point in treatment. Table 10 contains item text and factor loadings for both dimensions.

Table 10

*Patient satisfaction items with corresponding factor loadings*

<table>
<thead>
<tr>
<th>Item Text</th>
<th>Factor Loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 1: “Patient satisfaction with care experience”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 8: I received high-quality care from my cancer care team.</td>
<td>.87</td>
</tr>
<tr>
<td>Item 1: I received the right amount of support from my cancer care team.</td>
<td>.84</td>
</tr>
<tr>
<td>Item 2: My questions were answered to my satisfaction.</td>
<td>.79</td>
</tr>
<tr>
<td>Item 6: My cancer care team kept me updated about what the next step in my treatment process would be.</td>
<td>.77</td>
</tr>
<tr>
<td>Item 9: I understood my illness better because of my cancer care team.</td>
<td>.75</td>
</tr>
<tr>
<td>Item 4: My cancer care team gave me the advice that I needed to better manage my physical health during cancer treatment.</td>
<td>.71</td>
</tr>
<tr>
<td>Item 3: My cancer care team treated me with courtesy and respect.</td>
<td>.70</td>
</tr>
<tr>
<td>Item 5: My cancer care team gave me the advice that I needed to better manage my emotional health during cancer treatment.</td>
<td>.67</td>
</tr>
<tr>
<td>Item 7: Making an appointment to see the members of my cancer care team was easy.</td>
<td>.50</td>
</tr>
<tr>
<td><strong>Factor 2: “Perceived inclusion in treatment decision-making”</strong></td>
<td></td>
</tr>
<tr>
<td>Item 10: I felt that I was included in decisions about my breast cancer treatment.</td>
<td>.87</td>
</tr>
<tr>
<td>Item 12: I felt that I was included in decisions about my breast cancer surgery.</td>
<td>.64</td>
</tr>
<tr>
<td>Item 11: I was included in decisions about breast reconstruction</td>
<td>.56</td>
</tr>
</tbody>
</table>

**Normality assessments.** With the dimensionality of all three variables confirmed through CFA, normality assessments and transformations were considered. This section provides an assessment of normality for the defined factors of each variable by considering skewness and
kurtosis. When data do not appear to exhibit a normal distribution, certain analyses are precluded. Hence, tests for skewness and kurtosis are important. First, to prepare the variables, the item scores are averaged to create a composite variable for each dimension. These mean scores for each variable’s dimension are then examined for skewness and kurtosis. Skewness approximates data symmetry (Bulmer, 1979), and kurtosis refers to the normality of data distribution (Kline, 2011). For the research reported here, skew was corrected at the population level.

Bulmer (1979) suggested that distributions are approximately symmetrical when skew is between -0.5 and 0.5. When data are moderately skewed (moderate negative skew: -1.0 to -0.5; moderate positive skew: 0.5 to 1.0) or substantially skewed (substantial negative skew: less than -1.0; substantial positive skew: greater than 1.0). Tabachnick and Fidell (2001) identify transformation equations that can correct for skewed data; moderate skew can be addressed using the equation: SQRT(x), where SQRT is the notation for taking the square root of a value, and x is the composite variable value. Substantial skew is addressed with the following equation: Lg10(x), where Lg10 is the notation for taking the logarithm transformation of the variable value (Tabachnick & Fidell, 2001). For negative skew, a constant (K) is subtracted from the variable value so that the smallest score is greater than zero (Tabachnick & Fidell, 2001). The constant (K) is equal to the largest score in the scale plus 1.0, which in the present study was 6.0.

In respect to kurtosis, values greater than |10| should be considered problematic (Kline, 2011). In the following three paragraphs, I assess the normality of each variable dimension and provide descriptive statistics, beginning first with patient-centered communication, then decisional conflict is described, and, finally, patient satisfaction.
**Patient-Centered Communication.** A three-factor model was confirmed via CFA, and the dimensions were assessed for normality. The first factor was affected by negative skew, but had an acceptable level of kurtosis (skewness = -.74, SE = .22). The skewness was more pronounced for the second factor, but kurtosis was still not a problem (skewness = -.87, SE = .22). Finally, the third factor was assessed for skewness and kurtosis, which revealed moderate negative skew, but no kurtosis problems (skewness = -.55, SE = .22). All three items were transformed to address skew in accord with methods suggested by Tabachnick and Fidell (2001) for instances of moderate and substantial negative skew. The first and third factors were addressed for moderate negative skew using the \( \sqrt{K + x} \) equation. Resulting values were in line with recommended acceptable skew values (Factor 1, transformed skewness = .48; Factor 3, transformed skewness = .15). The second factor fell within the guidelines for moderate negative skew, but the transformation recommended for that level was not sufficient to bring the skew into acceptable range. Therefore, a more substantial log transformation was conducted to address the value \( \log_{10}(K - x) \), and an acceptable skew was established (Factor 2, transformed skewness = .06). Table 11 displays the descriptive statistics for the dimensions of patient-centered communication including kurtosis values.

Table 11

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>SD</th>
<th>Skew</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interpersonal Sincerity</strong></td>
<td>124</td>
<td>2.6</td>
<td>5.0</td>
<td>4.34</td>
<td>.64</td>
<td>.48</td>
<td>-1.11</td>
</tr>
<tr>
<td><strong>Patient Engagement</strong></td>
<td>124</td>
<td>1.0</td>
<td>5.0</td>
<td>3.86</td>
<td>.95</td>
<td>.06</td>
<td>-.74</td>
</tr>
<tr>
<td><strong>Individual Confirmation</strong></td>
<td>124</td>
<td>1.0</td>
<td>5.0</td>
<td>3.85</td>
<td>.85</td>
<td>.15</td>
<td>-.46</td>
</tr>
</tbody>
</table>

Note. Recorded mean values are those before skewness transformation. Skew represents post-transformation values.
**Decisional Conflict.** The five-factor decisional conflict variable was first analyzed for skewness and kurtosis prior to assigning variable labels. None of the factors showed problems in respect to kurtosis (range = -.42 – 1.07, SE range = .43–.50), but skewness was problematic for all but one factor. The first factor had moderate negative skew (skewness = -.98, SE = .22), and even though the skewness was within the moderate skew designation (|-.5|–|1.0|), the variable was transformed using the log transformation procedures suggested by Tabachnick and Fidell (2001). This was necessary because the weaker square root transformation resulted in maintaining moderate skew. Resulting skew from the \textit{Lg10} transformation fell within the recommended acceptable limits (log transformed skewness = .23). Skewness for the second factor was technically within acceptable range for negative skew, but it was at the low end of the spectrum (skewness = -.48, SE = .25). When the two groups (i.e., PN present vs. PN not present) were compared, transformation was necessary to address skew. A square root transformation was conducted. The resulting evidence of skewness was within acceptable range (transformed skewness = .14). Skewness was both negative and substantial for the third factor (skewness = -1.08, SE = .22). The \textit{log10} \((K – X)\) equation was used for transformation, which resulted in acceptable skew (skewness = .32). The fourth factor showed no problems in respect to skewness ( = .19, SE = .22) and, hence, did not undergo transformation. Finally, the fifth factor exhibited substantial negative skew (skewness = -1.22, SE = .22) and was corrected using the log10 procedure. The resulting skew fell within acceptable limits for factor 5 (skewness = .39). Descriptive statistics for all the factors appear in Table 12.
Table 12

Descriptive statistics for five-factor model of decisional conflict

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>SD</th>
<th>Skew</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed treatment choice</td>
<td>124</td>
<td>1.9</td>
<td>5.0</td>
<td>4.21</td>
<td>.70</td>
<td>.23</td>
<td>-.77</td>
</tr>
<tr>
<td>Clarity of breast reconstruction choices</td>
<td>91</td>
<td>2.0</td>
<td>5.0</td>
<td>3.96</td>
<td>.73</td>
<td>.14</td>
<td>-.76</td>
</tr>
<tr>
<td>Satisfaction with treatment choices</td>
<td>124</td>
<td>1.7</td>
<td>5.0</td>
<td>4.23</td>
<td>.79</td>
<td>.32</td>
<td>-.98</td>
</tr>
<tr>
<td>Informational uncertainty</td>
<td>124</td>
<td>1.0</td>
<td>4.8</td>
<td>2.76</td>
<td>.92</td>
<td>-.19</td>
<td>-.63</td>
</tr>
<tr>
<td>Decisional support</td>
<td>124</td>
<td>1.0</td>
<td>5.0</td>
<td>4.14</td>
<td>.92</td>
<td>.39</td>
<td>-1.02</td>
</tr>
</tbody>
</table>

Note. Recorded mean values are those before skewness transformation. Skew represents post-transformation values.

Patient Satisfaction. The two-factor structure related to this criterion variable was assessed for skewness and kurtosis. Factor 1 showed moderate negative skew (skewness = -.58, SE = .22) and Factor 2 substantial negative skew (skewness = -1.11, SE = .22). Neither showed kurtosis greater than |10|. Both factors were transformed to address issues with skewness in line with Kline’s (2011) recommendations. That is, $\sqrt{K - X}$ was performed for Factor 1, and the $\log_{10}(K - X)$ equation was applied to Factor 2, where $K$ was 6.0. Following transformation, both factors exhibited acceptable skewness values (Factor 1 = .27; Factor 2 = .43). Descriptive statistics for both factors are in Table 13.
Table 13

Descriptive statistics for two-factor model of patient satisfaction

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>M</th>
<th>SD</th>
<th>Skew</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient satisfaction with care experience</td>
<td>124</td>
<td>2.3</td>
<td>5.0</td>
<td>4.08</td>
<td>.70</td>
<td>.27</td>
<td>-.86</td>
</tr>
<tr>
<td>Perceived inclusion in treatment decision-making</td>
<td>124</td>
<td>2.0</td>
<td>5.0</td>
<td>4.47</td>
<td>.59</td>
<td>.43a</td>
<td>-1.24</td>
</tr>
</tbody>
</table>

Note. Recorded mean values are those before skewness transformation. Skew represents post-transformation values.

Hypothesis Testing Strategy

Three analytic procedures were used to test the hypotheses via IBM SPSS 22.0 statistics software: independent samples *t*-tests and multiple regression analysis (IBM Corp., 2013). The level of confidence was set at *p* ≤ .05 for all analyses, which is a standard and accepted value (Marque de Sa, 2007).

Hypothesis testing was conducted starting with independent samples *t*-test for hypotheses 1, 2, and 4. This method of analysis is used when the means of two independent groups are tested (Marque de Sa, 2007). In the project at hand, the two groups included Participants who had a PN on the cancer-care team and those who did not. These groups were independent because the patients, in thinking about the entirety of their cancer-care teams, noted the presence or absence of a patient navigator. Since the three hypotheses were directional, the test was one-tailed (Marque de Sa, 2007). The first consideration regarding independent samples is homogeneity of variance (Levene, 1960). It was important to determine whether or not the variability of the two groups was equivalent, as this is an assumption underlying the independent sample *t*-test. The null assumption of Levene’s test is that variance between the two groups is equal. Rejecting the null means that the variance is not equal and the non-parametric output of test statistics should be reported.
Multiple regression analysis was used in testing Hypotheses 3 and 5. Hypotheses will be analyzed such that the three dimensions of patient-centered communication are predictor variables and each dimension of both decisional conflict (i.e., informed treatment choice, clarity of breast reconstruction choices, satisfaction with treatment choices, informational uncertainty, and decisional support) and patient satisfaction (i.e., patient satisfaction with the care experience and perceived inclusion in treatment decision-making) are criterion variables. With multiple factors identified for the predictor variable, the two other dimensions may affect the relationship between one dimension of patient-centered communication and the criterion variable. Thus, multiple regression analysis was used because it is a means by which relationships between variables can be assessed while controlling for the variance accounted for by other predictors in the study (Keith, 2006). Multiple regression analysis is similar to bivariate correlation, which assesses the magnitude of interdependence between two variables (Chen & Popovich, 2002), and it is related to partial correlation, which assesses the relationship of the predictor with a criterion while controlling for the other predictors in the model (Marque de Sa, 2007). This methodology was selected to assess Hypotheses 3 and 5 because experienced patient-centered communication is comprised of three factors and these factors likely influence any relationships that exist between each predictor dimension and the criterion variables (Green & Salkind, 2011).

Establishing a linear relationship between variables is the first step in ensuring that linear multiple regression analysis is appropriate for assessing the relationship (Green & Salkind, 2011). A significant F statistic in the analysis of variance assessment of the regression analysis indicates that the predictors appear to have a linear relationship (IBM Corp., 2013). In SPSS, two values, β and $r^2$, should be considered when assessing how strongly the regression analysis predicts the criterion variable (Green & Salkind, 2011). The β value indicates the strength of the
relationship between predictor and criterion in the overall regression equation and provides the relative change in standard deviation of the criterion variable, per standard deviation change in the predictor variable (Green & Salkind, 2011). Thus, a positive $\beta$ indicates a positive relationship between variables and a negative $\beta$ is the opposite. Meanwhile, $r^2$ is the squared value of $r$, which is the correlation between variables, and it indicates the percent variance accounted for by variables. There is an $r^2$ for the full model with all predictors included and the individual partial correlation ($r_{p}^{2}$) for each relationship controlling for the others can also be assessed. Because an a priori order of importance for predictor variables was not established, the predictors were entered into the model at the same time and in no specific order. The nature of multiple regression analysis as an assessment of correlations between variables means that the magnitude difference between predictor variables cannot be assessed, but we can determine if one predictor variable seems to account for more or less variance when controlling for the other predictors (Green & Salkind, 2011). For the present study, the level of confidence was .05.
Chapter 4: QUALITATIVE METHODS

The mixed-methods approach taken in this research reflected the fact that previous studies of breast cancer treatment and decision-making have been of this sort (Howell et al., 2008; Vilhauer, 2009). An additional rationale was that including a qualitative component could help to identify mechanisms that influence the decision-making process not currently in evidence. Hence, there appeared to be a potential heuristic value in the approach. Ashling-Giwa et al. (2004), in conducting qualitative research to understand the breast cancer experience of women, described the importance of ethnic background on breast cancer survivors’ health-related quality of life. Without the qualitative data, mechanisms by which we understand the survivor experience may not have expanded to consider specific ethnic differences. The use of qualitative research was further important because of the potential implications of individual experiences for improving the clinical experience (Al-Busaidi, 2008; Berkwits & Inui, 1998). Theoretical explanations are important for changes in practice to improve communication and care overall, but the more nuanced one often deriving from qualitative research can be equally important in ensuring that the treatment decision-making process for breast cancer patients is effective, efficient, and aligned with the actual patient experiences. This chapter serves to explain the procedures of the qualitative portion of this study and is organized in following manner: (a) recruitment, (b) procedure, (c) participants, and (d) qualitative analysis strategy.

Recruitment

Semi-structured qualitative interviews were conducted two months after survey data collection was finished. The final items in the survey had participants indicate willingness to receive information about a follow-up interview. Those who indicated they would participate constituted the recruitment population. Participants were selected via purposeful random
sampling based on the members who they reported on their cancer-care teams. This method of selection has support in the qualitative methods literature, which emphasizes that although samples need not be large, they nevertheless should be representative of the population under consideration, as well as appropriate for answering the questions (Kuzel, 1999).

Prospects were first divided on the basis of whether or not they had a patient navigator on their cancer-care team. Then, I broke out the titles of the members that each participant reported having on her cancer-care team, which included the four job titles indicative of having a patient navigator: (a) patient navigator, (b) nurse navigator, (c) oncology social worker, and (d) nurse case manager. The combinations of conceptualized patient navigator roles were then recorded, and participants were sorted on the basis of the combination they reported (e.g., patient navigator only, patient navigator + nurse navigator, nurse navigator + nurse case manager + oncology social worker, etc.). There were 12 combinations of patient navigator roles. Once the participants were sorted by the combinations of patient navigator roles, they were numbered, with the first participant of the combination receiving a “1,” the second a “2,” and so on until all participants were numbered. Then, all participants who received a “1” were contacted about participating in a one-hour interview.

After the first interview, it became clear that participants who did not report having a patient navigator on their cancer-care teams should also be interviewed so that differences could be assessed. Thus, all participants who indicated they would be interested in being contacted for an interview, but also reported that they did not have a patient navigator on their cancer-care teams, were assessed for the total number of people they reported on their cancer-care team. I noted a 1 by each reported member of the cancer-care team aside from the patient navigator roles (e.g., radiologist, medical oncologist, etc.) and then summed the values. The minimum number
of reported cancer-care team members was two, and the most was eight. Then, I randomly selected two participants with the highest number of cancer-care team members and two participants with the lowest number of cancer-care team members. These four potential participants received an email asking them to participate in a one-hour interview.

**Procedure**

Interviews were conducted in-person, over the telephone, and via videoconference (i.e., Skype). Each participant had the option of using her preferred method, but only those who were located in San Diego, CA could have in-person interviews because of a limited research budget. In-person interviews were conducted in a location of the participant’s choosing and were all held at various coffee shops and cafes. Four in-person interviews were held in the San Diego area. Participants were asked to suggest a location where they felt most comfortable. I met them at the location and asked the participant to select the table or area they preferred. All of these efforts were designed to ensure that participants felt comfortable while being interviewed and that they felt they had their preferred level of privacy.

I dressed casually to match what I anticipated the interviewee would be wearing as a way of helping them to feel comfortable sharing their experience with me. I brought my smartphone to use as the recording device and used the Voice Memo mobile application, which is a standard program on all Apple iPhones. To avoid distractions from my smartphone if a phone call or text message occurred during the interview, I turned the phone to “airplane mode,” which allows the use of all programs, but disables the cellular and Internet connections of the phone.

The remaining seven interviews occurred virtually—five via telephone and two videoconference using Skype. During the virtual interviews, I sat in a quiet place with few outside activities so as to avoid occurrences that could affect the interview. For telephone and
videoconference interviews, I used the Garageband program, which is standard a standard audio and video recording program on all Apple MacBook laptops. Although a video recording option is available, only audio recordings were made during interviews. During the in-person and videoconference interviews, I took limited notes, as I wanted to focus my eye contact and attention on the participants as a means of showing my interest and engaging them in conversation. I took a few notes concerning topics or issues that the participant mentioned but failed to elaborate on; these were ones that I revisited with follow-up questions later in the interview. During the telephone interviews, I was able to take much more detailed notes, but the content still focused on issues to raise at a later point in the interview. Transcription of the audio recordings for all interview venues served as the primary data source for analysis. The analysis is the subject of the next section.

I conducted all interviews via a semi-structured process, in which probing and follow-up questions varied on the basis of the flow of the interview and details raised by each participant (see Appendix D). Scholarly discussions of qualitative research methods support the fact that interviews have variation and modifications stemming from the individual participant and the flow of the conversation. As Miller and Crabtree (1999) suggested, “[N]o two interviews are the same” only the main goal of the interview is “standard,” but even that “may change from interview to interview” (p. 100). The interviews lasted between 35 and 180 minutes and were audio recorded. I transcribed all interviews and reviewed transcripts for themes and key messages. In reviewing key messages and themes, I removed irrelevant utterances and asides so that the key message was pronounced and clear. Additionally, when necessary descriptive information was included in brackets, I replaced pronouns with context from the overarching
message. Both procedures are appropriate in reporting qualitative responses (Rubin & Rubin, 2005).

**Participants**

Eleven participants, out of 16 people contacted, took part in a one-on-one semi-structured interview. Three never responded to messages inviting them to participate, and two women declined as a result of scheduling conflicts. Since all interview participants had also participated in the survey portion of the study, demographic information was pulled from their responses to those questions on the survey. The participants ranged in age from 18 to 44 (M = 35.5, SD = 7.3). None reported being 18 at the time of this interview, and it is likely that this age was a typographical error in the original survey. Nine participants identified themselves as Caucasian, one woman selected Hispanic, and one did not answer questions about race. There was a range of educational attainment, with one participant listing “high school graduate,” three indicating “some college,” four reporting having a “bachelor’s degree,” and three stating that they held a “graduate or professional degree.” Five participants currently resided in California, two in Wisconsin, and one each in Louisiana, Nevada, New Jersey, and Washington. Eight women were married during treatment, one was in a long-term relationship, one indicated that she was single, and one did not respond to questions about relationship status. Seven women indicated that they had private health insurance, one listed “other government insurance,” two selected “other,” and one indicated that she was uninsured. Eight participants had a patient navigator on their cancer-care teams; three did not. Four women indicated that they were diagnosed as Stage 1, four were diagnosed as Stage 2, two were diagnosed as Stage 3, and one was not told the stage of her cancer.
Analysis Strategy

Semi-structured interviews were conducted, and the audio recordings were transcribed. The interviews took place over a two-week period, during which I reviewed transcripts. Rubin and Rubin (2005) suggest this as a way of ensuring that information is being captured as intended and that new information that is learned can be incorporated in future interviews. In addition to completing transcripts after each interview, I wrote a general summary of the conversation—a process recommended by scholars to allow for easier and more effective analysis later in the process (Burnard, 1991).

I did all of the transcription myself and used the Garageband program to play the recordings as I transcribed them. This is an audio and video-editing program, which is a standard program on all Apple MacBook laptops. This program allows the user to slow the tempo of a recording, which made it much easier to type the interview content along with the recording. After the recording was transcribed using the slower tempo, I increased the tempo to the normal rate and listened again while reading through the text and making any corrections or inclusions. The style of the transcription was based on the recommendation that the transcript be a verbatim account of the text, which included “uhmms,” “ahhs,” and pauses with the notation, “...” (Mergenthaler & Stinson, 1992).

In the reporting of the interview responses, though some of these vocalized pauses were removed when the context was an environmental distraction resulted in pauses (e.g., a café employee came to clear glasses during the interview, and there was a knock on the door at the home of a woman participating in a phone interview). The removal of some of these pauses provided a clearer sense of the message being shared by the participant. However, in instances in which the participant struggled to find a word or seemed bothered by the response and paused
mid-statement, vocalized pauses were included. Rubin and Rubin (2005) recommended this process as a way of using the “level of detail we are likely to analyze” (p. 205).

All identifying information was removed from the transcript (e.g., names of family members or friends, names of physicians or cancer-care team members, and specific locations. This was done to maintain the confidentiality and all identifying information was limited to the recording only. Revealing details were replaced with pronouns or substitutions that maintained the sentiment of the statement, but kept the source anonymous.

Each interview was transcribed as a separate Microsoft Word document and saved as a password protected file. I then printed all documents and read each interview twice to develop a better sense of the data and remain aligned with the processes of analysis described by Rubin and Rubin (2005). During the first perusal, I read the text completely beginning to end. When I read the text the second time, I made notes in the margins of the page and highlighted comments and excerpts that aligned with the key issues being addressed in the research and ideas that seemed important from a communicative perspective of breast cancer treatment decision-making. This process is called as “open coding” because ideas freely emerge and categories become apparent. After I read all transcripts twice and reviewed them using open-coding procedures, I noted in writing all of the data categories that emerged. I began with one transcript, and listed all of the categories that emerged, and then moved on to the next transcript. If the same category appeared again, I kept a tally of the number of times the ideas surfaced throughout the interviews. The resulting categories were represented in at least four participants’ accounts of their breast cancer treatment and decision-making process. Across the 19 categories there was a range in the amount of times each category was addressed by participants (range of participants who described categories: n = 4-11). The one exception was the category of fertility, which was only discussed
by two participants. This topic was still identified as a category because only interviewees were
of childbearing age during treatment and both brought up this issue in the interview. General
categories that emerged revealed that many aligned with the hypotheses addressed in this
research, but other ideas emerged. The categories included (n = participants who addressed this
issue in their interview): (a) communication of the diagnosis (n = 4), (b) uncertainty following
diagnosis (n = 6), (c) communication about treatment options (n = 6), (d) information-processing
of treatment options (n = 5), (e) treatment decision-making process (n = 10), (f) decision time
pressure (n = 4), (g) uncertainty during decision-making (n = 8), (h) information-seeking (n = 8),
(i) decision-makers (n= 5), (j) decisional support (n= 6), (k) satisfaction with treatment decisions
(n= 4), (l) emotional support during decision-making (n = 10 ), (m) cancer-care team composition
and roles (n= 6), (n) communication with patient navigators (n= 11), (o) advanced provision of
information/avoiding surprises (n= 8), (p) communication between cancer-care team members
(n= 7), (q) fertility decisions (n= 2), (r) survivor support (n= 8), and (s) uncertainty of finishing
treatment (n= 6).

I next reviewed the categories to determine which were concepts and which were themes,
as well as whether some could be combined. Rubin and Rubin (2005) define a concept as “a
word or term that represents an idea important to your research problem” (p. 207). A theme is “a
statement or explanation of what is going on (Rubin & Rubin, 2005, p. 207). The primary reason
for making this distinction has to do with the nature of this study, that is, a mixed-methods
approach. As I previously described, a mixed-methods approach has both qualitative and
quantitative elements (Johnson, Onwuegbuzie, & Turner, 2007). However, because in the present
study, quantitative data were dominant, conceptual relationships were first identified by
quantitative methods and then examined in terms of the qualitative results (Johnson,
Onwuegbuzie, & Turner, 2007). The categories that were subsequently identified as concepts were used to illuminate the quantitative data, whereas those that were identified as themes served in contributing additional results beyond the planned analyses.

To determine which categories were concepts and which were themes, I first created a separate Microsoft Word document for each category and went through all of the transcripts and copied excerpts from the text that aligned with each of the categories. Rubin and Rubin (2005), describe these individual excerpts as data units, or “blocks of information that are examined together” (p. 202). The important component of their philosophy on data units is that the same excerpt of text can be assigned to several data units (Rubin & Rubin, 2005). This is critical because qualitative research results often reflect numerous concepts and themes. Therefore, I reviewed each data unit to determine if it fit only a single category or more. After review of the transcripts and previously identified hypotheses, I classified the following categories as concepts, (a) communication about treatment options, (b) information-processing of treatment options, (c) treatment decision-making process, (d) uncertainty during decision-making, (e) information-seeking during decision-making, (f) decision-makers, (g) decisional support, (h) satisfaction with treatment decisions, (i) emotional support during decision-making, (j) cancer-care team composition and roles, and (k) patient navigator communication. The categories identified as themes were: (a) decision time pressure, (b) advanced provision of information/avoiding surprises, (c) communication among cancer-care team members, (d) structural influences on uncertainty, (e) fertility decisions, (f) survivor support, and (g) uncertainty of finishing treatment. Once the concepts and themes were established, the individual data units were assigned to illuminate each one. In the qualitative results (Chapter 6), each concept and theme is described and exemplified using a sampling of key data units.
Chapter 5: QUANTITATIVE RESULTS

This chapter covers the results from the quantitative survey, including (a) descriptive statistics, (b) group dichotomization, (c) hypothesis testing, and (d) summary of significant results.

Descriptive Statistics

For the most part, participants reportedly experienced patient-centered communication during breast cancer treatment decision-making. Their responses suggested, on average, that they developed a trusting and personal relationship with members of their cancer-care teams ($M = 4.34$, $SD = .64$). Patients felt, on average, engaged in the treatment decision-making process as a result of communicative behavior exhibited by their cancer-care teams ($M = 3.92$, $SD = 1.01$). Additionally, patients reported that, on average, members of their cancer-care teams regularly confirmed that their individual needs and questions were being addressed ($M = 3.85$, $SD = .85$). On average, participants felt that they had made an informed treatment choice ($M = 4.21$, $SD = .70$), were clear in their choice about whether or not to have breast reconstruction ($M = 3.96$, $SD = .73$), felt satisfied with their treatment choices overall ($M = 4.23$, $SD = .79$), and reportedly received the right amount of support for their breast cancer treatment options ($M = 4.14$, $SD = .92$). Furthermore, on average, participants did not feel uncertainty about whether or not they needed more information to make treatment decisions ($M = 2.76$, $SD = .92$). Patients also, on average, were satisfied with their cancer care experience over all ($M = 4.08$, $SD = .70$) and included in the treatment decision-making process ($M = 4.47$, $SD = .59$).

One-way ANOVAs served to reveal mean differences, if any, for the dimensions of the three constructs of interest (e.g., patient-centered communication, decisional conflict, and patient satisfaction) on the basis of age, racial background, educational attainment, marital status during
treatment, the type of health insurance held during treatment, and the stage at which the cancer was diagnosed. Mean comparisons involving age, racial background, educational attainment, health insurance status, and reported cancer stage primary interest revealed no significant differences \((p < .05)\). All analyses were conducted individually, with the demographic category as the predictor variable and each construct dimension as the criterion variable. For the comparison relating to age, the variable was treated as a categorical variable where each discrete age value was a single point of consideration (range: 18-55 years old; mode: 33 years old).

A mean difference was detected for one dimension of decisional conflict when comparing across the eight marital status groups (e.g. single, long-term relationship, engaged, married, separated, divorced, divorced and remarried, and widowed). When marital status was assessed via one-way ANOVA for mean differences in participants’ uncertainty about whether or not they needed more information to make treatment decisions, data indicated that there was a difference across groups, \(F (7, 105) = 2.88, p < .05\), partial \(\eta^2 = .16\). A post hoc Tukey analysis was conducted, which resulted in an error message because one group, participants who were engaged during treatment, had an \(n\) of 1. To enable the program to run post hoc tests, this participant was removed from the analysis to determine the statistically significant differences among the other seven marital status groups. The resulting one-way ANOVA for mean differences of the remaining seven marital status groups considering participants’ uncertainty about whether or not they needed more information to make treatment decisions suggested that there remained a difference across groups, \(F (6, 105) = 2.90, p < .05\), partial \(\eta^2 = .14\). Tukey post hoc comparisons of the seven groups indicated that women who were married during treatment reported significantly more uncertainty about whether or not they needed more information to make treatment decisions \((M = 2.91, SE = .10)\) than women who reported being separated during
treatment ($M = 1.27, SE = .50$). All other comparisons between marital status groups were not statistically significant at $p < .05$.

**Group Dichotomization**

For this study, the experience of two groups as compared, that of participants who had a PN on their cancer-care teams and that of participants who did not have a PN on their cancer-care teams. Groups were dummy-coded on the basis of responses to an item concerning the composition of the participant’s cancer-care team. Responses to this question were dichotomized so that participants who selected any of the following, (a) patient navigator ($n = 29$), (b) nurse navigator ($n = 48$), (c) oncology social worker ($n = 12$), and (d) nurse case manager ($n = 30$), were placed in the “PN present” group ($= 1$) and participants who selected none of those four members were placed in the “PN not present” group ($= 0$). Several participants indicated that more than one of the four titles was represented in their cancer-care teams. After accounting for duplicate selections, a total of 78 participants were dichotomized to the “PN present” group and 46 participants were assigned to the “PN not present” group.

Overall, there were no mean differences between participants who had a PN on their cancer-care teams and participants who did not have a PN on their cancer-care teams. Reported demographic information for the two groups revealed no significant differences for age, racial background, educational attainment, marital status during treatment, the type of health insurance held during treatment, and the stage at which the cancer was diagnosed.

The average age of participants in the “PN present” group was 35.3 years ($SD = 8.04$, Range 18-55, $n = 66$) and for the “PN not present” group was 34.7 years ($SD = 8.31$, Range 18-48, $n = 36$); an independent samples $t$-tests revealed that the groups were not statistically different in age ($t(100) = -.34, p = .73$).
Racial status for both groups was predominantly Caucasian (PN present = 75.6%; PN not present = 80.4%), and both groups had two participants each who identified as “Asian.” Differences in racial breakdown included no Black/African American participants in the “PN present” group and one Black/African American participant in the “PN not present” group. Additionally, there were six participants in the “PN present” group who selected “Hispanic,” while no participants in the “PN not present” group selected this racial status. In both groups, at least one participant selected “Native American” as a portion of their racial background (PN present, n=3; PN not present, n=1). A chi-square test comparing groups based on participants’ reported racial status revealed no significant differences between groups ($\chi^2 (7, N = 112) = 7.55, p = .37$).

In regard to educational status, both groups reported having high levels of educational attainment. For the “PN present” group, 34.6 percent of participants reported having a baccalaureate (n = 12) or graduate degree (n = 15). Another large percentage reported having finished at least some college (n = 24) or some graduate school (n = 4). Meanwhile, nearly 57 percent of participants in the “PN not present” group reported having a baccalaureate (n = 13) or graduate degree (n = 13). None of the participants in the “PN present” (HS graduate, n = 8; trade/technical school, n = 1; associates degree, n = 8) or “PN not present” group reported having below a high school diploma (HS graduate, n = 1; trade/technical school, n = 1; associates degree, n = 2; some college, n = 9). There were six participants in the “PN present” group and seven participants in the “PN not present” group who failed to provide information concerning educational attainment. Although there were some differences in educational attainment between groups, they were not statistically different ($\chi^2 (6, N = 111) = 11.22, p = .08$).
Marital status was also similar for the two groups, with most women reporting that they were married during treatment (PN present = 65.4%; PN not present = 63.1%). Other reported marital statuses (i.e., single, long-term relationship, separated, divorced, and widowed) were comparable, except for the status of “engaged.” No participants in the “PN present” group reported being “engaged,” but one participant in the “PN not present” group was engaged during breast cancer treatment. Overall, the groups did not differ statistically as a function of marital status during treatment, \( \chi^2 (7, N = 113) = 2.92, p = .89 \).

Insurance status was not significantly different between groups (\( \chi^2 (5, N = 112) = 2.55, p = .77 \)), with 73.1 percent of participants in the “PN present” group and 73.9 percent of participants in the “PN not present” group stating that they had private insurance during breast cancer treatment. The only difference in reported health insurance status between groups was that three participants in the “PN present” group reported having Medicare during breast cancer treatment, while zero in the “PN not present” group reported having Medicare during breast cancer treatment.

Participants were to report the stage at which their cancer was diagnosed. The majority in both groups selected either Stage 1 (PN present, n = 18; PN not present, n = 14) or Stage 2 (PN present, n = 23; PN not present, n = 14). Additionally, the groups were relatively similar in all stages of disease progression except Stage 4, where four participants in the “PN present” group selected Stage 4 disease, but no participants in the “PN not present” group selected Stage 4 disease. Although some frequency differences existed, when the stages were given a numerical value where each advancing stage was one more than the next (e.g., Stage 0 carcinoma in situ = 1, Stage 1 = 2, Stage 2 = 3, Stage 3A = 4; Stage 3B = 5; Stage 4 = 6), the average reported age was relatively equal for both groups (PN present = 2.92, \( SD = 1.34 \); PN not present = 2.85, \( SD = \)
1.31). A chi-square test indicated that groups were not significantly different in respect to the stage at which their cancer was diagnosed, \( \chi^2 (6, N = 100) = 3.85, p = .70 \).

**Hypothesis Testing**

As just described, the dimensions identified in the factor analyses led to alterations in what data applied to the overarching (main) hypotheses, but with no change in the tests that were previously described. However, doing this would create multiplicity in the analyses, which is what occurs when one conducts the same statistical test many times on the same data (McDonald, 2014). Multiplicity in analysis can lead to a Type I Error, which suggests that a more conservative significance level should be used. One method for addressing multiplicity is to use Bonferroni corrections, which takes initial significance level (identified as \( p < .05 \) in Chapter 3) and divide it by the number of hypotheses that use the same statistical test (Schafer, 2004). For example, tests of Hypotheses 1, 2 and 4 all involved independent \( t \)-tests, with the presence of a patient navigator on a cancer-care team as the predictor variable. The Bonferroni correction for these 10 tests would be \( p < .005 \). With a significance level this conservative, one runs the risk of increasing the probability of a Type II Error and could retain the null hypothesis in situations in which it is not an accurate representation of the data.

However, it should be recognized that effect sizes are an important consideration of practical significance and interpretation of results when conducting social science research (Cohen, 1992; Ferguson, 2009; Rosnow & Rosenthal, 1989). As described by Ferguson (2009), effect sizes offer the opportunity to assess the magnitude of the association between variables. An important benefit of effect size evaluation is that the test is resistant to sample size variations, which suggests a more accurate assessment of the association (Ferguson, 2009). For instance, in significance testing, a very large sample size will typically result in significant findings, even if
the difference in the association is actually very small. Whereas with effect size measures, the association is considered based on the outcome scores and standard deviations. A commonly used metric for comparing the associations between groups is Cohen’s $d$ (Cohen, 1992). The index for considering this metric suggests that effect sizes where $d < .2$ are considered small, those where $d = .5$ are moderate, and a large effect is seen when $d > .8$ (Ferguson, 2009). When assessing correlational relationships, effect sizes are reported as $r^2$ (Ferguson, 2009). When evaluating effect size with $r^2$, the index for assessing strength of the effect is slightly different than when using $d$. The index is as followings: small effect is $r^2 \leq .10$, medium effect is $r^2 = .243$, and large effect is considered $r^2 \geq .371$ (Grissom & Kim, 2012).

Therefore, the significance level for this study was revised from $p < .05$ to $p < .01$ as a means of addressing multiplicity and Type I Error. However, consideration of effect sizes will help limit the possibility of completely dismissing a relationship that may have important practical significance. Hypotheses were tested with the aid of SPSS 22.0 (IBM Corp., 2013), $p$-values were set at $p < .01$, and effect sizes were calculated using a specialized online calculator for Cohen’s $d$ and in SPSS output for $r^2$ (Becker, 2000). To test Hypotheses 1, 2 and 4, independent samples $t$-tests were used. Hypotheses 3 and 5 were tested via use of multiple regression analysis. Of concern for these two hypotheses were relationships between dimensions of patient-centered communication and the two criterion variables (decisional conflict and patient satisfaction), respectively.

**Hypothesis 1.** This group of hypotheses considered mean differences of experienced patient-centered communication (PCC) by participants who had a PN on their cancer-care teams and those who did not have a PN on their cancer-care teams. Independent samples $t$-tests were used to assess the relationships raised by this hypothesis, where the participants were grouped by
the “presence of a PN on their cancer care team” (1 = yes; 0 = no), and the criterion variables were interpersonal sincerity, patient engagement, and individual confirmation – the dimensions of patient-centered communication.

Hypothesis H1a suggested that participants who had a PN on their cancer-care teams would experience more interpersonal sincerity than in participants who did not have a PN on their cancer-care teams. The results indicated that participants who had a PN on their cancer-care teams reported experiencing more ($M = 4.44, SD = .60$) interpersonal sincerity than participants who did not have a PN on their cancer-care teams ($M = 4.17, SD = .60$), but it was not a significant difference, $t(122) = 2.32, p = .011, d = .42$. Thus, H1a was not supported by significance testing, but effect size indicated a moderate practical significance.

Next, H1b, which suggested that participants who had a PN on their cancer-care teams would experience more patient engagement than those who did not have a PN on their cancer-care teams, was assessed. This hypothesis was supported because participants who had a PN as part of the cancer-care team reported that they experienced significantly more patient engagement ($M = 4.06, SD = .84$) than participants who did not have a PN as part of their cancer-care teams ($M = 3.53, SD = 1.04$), $t(122) = 3.12, p < .01, d = .56$.

Finally, hypothesis H1c was assessed to determine if participants who had a PN on their cancer-care teams experienced more individual confirmation than participants who did not have a PN on their cancer-care teams. There was a significant mean difference between groups ($t(122) = 3.12, p < .01, d = .56$), with participants who had a PN on their cancer-care teams reporting that they experienced more individual confirmation ($M = 4.02, SD = .81$) than participants without a PN on their cancer-care teams ($M = 3.56, SD = .84$). This indicated that H1c was supported.
**Hypothesis 2.** Independent samples $t$-tests were used to test Hypothesis 2; of interest were mean differences between groups of participants who did have a PN on their cancer-care teams ($= 1$) and participants who did not have a PN on their cancer-care teams ($= 0$). The outcome variables included the five dimensions of decisional conflict (i.e., informed treatment choice, clarity of breast reconstruction choices, satisfaction with treatment choices, informational uncertainty, and decisional support).

Hypothesis H2a predicted that participants who had a PN on their cancer-care teams would score significantly higher on measures representing informed treatment choice than patients who did not have a PN on their cancer-care teams. Those who had a PN on their cancer-care teams ($M = 4.31$, $SD = .62$) did score higher on informed treatment choice than those who did not have a PN on their cancer-care teams ($M = 4.03$, $SD = .80$), but the difference was not significant ($t(122) = 1.93$, $p = .03$, $d = .35$). This meant that the null hypothesis for H2a was retained using significance testing, but the effect size indicated a moderate practical significance.

For Hypothesis H2b, the two groups—participants who had a PN on their cancer-care teams and participants who did not have a PN on their cancer-care teams—were compared to determine if those with a PN would score significantly higher on clarity of breast reconstruction choices than those without a PN. An independent samples $t$-test indicated that patients with PN on their cancer-care teams scored higher on clarity of breast reconstruction choices ($M = 4.00$, $SD = .67$) than participants who did not have a PN on their cancer-care teams ($M = 3.90$, $SD = .81$), but the difference was not significant ($t(89) = .55$, $p = .29$, $d = .12$), and H2b was not supported.

Hypothesis H2c questioned whether participants who had a PN on their cancer-care teams would score significantly higher on satisfaction with treatment choices than participants
who did not have a PN on their cancer-care teams. Although participants who had a PN on their cancer-care teams \((M = 4.20, SD = .82)\) did score higher on satisfaction with treatment choices than participants who did not have a PN on their cancer-care teams \((M = 4.30, SD = .74)\), the difference was not significant \((t(122) = .04, p = .48, d = .007)\). This suggested that the null hypothesis should be retained for H2c.

For Hypothesis H2d, it was predicted that participants who had a PN on their cancer-care teams would score significantly lower on informational uncertainty than those who did not. The data indicated directional differences consistent with expectations, but was not statistically significant \((t(122) = 1.15, p = .13, d = .21)\). Although it was not a statistically significant difference, those who had a PN on their cancer-care teams did score lower on informational uncertainty \((M = 2.69, SD = .89)\) than the participants who did not have a PN on their cancer-care teams \((M = 2.88, SD = .96)\). The results, therefore, required retention of the null hypothesis for H2d, but the effect size suggests a small practical significance between variables.

Finally, in the case of H2e, participants who had a PN on their cancer-care teams scored significantly higher on decisional support \((M = 4.33, SD = .79)\) than participants who did not have a PN on their cancer-care teams \((M = 3.80, SD = 1.04)\), \(t(122) = 3.18, p < .01, d = .58\). Thus, H2e was supported.

**Hypothesis 3.** Hypothesis 3 posited a relationship between patient-centered communication and decisional conflict. To address the modified dimension structure found for both patient-centered communication and decisional conflict in the factor analysis, Hypothesis 3 was assessed using multiple regression analysis by regressing the dimensions of patient-centered communication (i.e., interpersonal sincerity, patient engagement, and individual confirmation) on the each dimension of decisional conflict—informed treatment choice, clarity of breast
reconstruction choices, satisfaction with treatment choices, informational uncertainty, and decisional support. In total, five multiple regressions were conducted to assess the relationships.

H3a assessed the regression of interpersonal sincerity, patient engagement, and individual confirmation on informed treatment choice, which revealed an overall significant result, $F (3, 120) = 17.52, p < .01, r^2 = .30$. All three bivariate correlations were positive and significant, as predicted, but when controlling for the other two predictors, only two of the predictors—interpersonal sincerity ($\beta = .73, t = 5.07$) and patient engagement ($\beta = -.40, t = -2.64$) —were significantly ($p < .01$) associated with the informed treatment choice (see Table 14). The percent of variance explained by interpersonal sincerity was 18%; over half of the total variance explained by the predictor variables combined, which supported H3a1. Although patient engagement was a significant predictor when controlling for interpersonal sincerity and individual confirmation, the directionality of the relationship between patient engagement and informed treatment choice was not predicted ($r_p = .24, r_p^2 = .06$). Thus, H3a2 was not supported due to the direction of the relationship when controlling for the other predictors. H3a3 was not significant when controlling for the other predictor variables and the relationship had a small effect size, suggesting that the null should be retained.
Table 14

*Multiple regression of patient-centered communication on informed treatment decision, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$r$</th>
<th>$r_p$</th>
<th>$r_p^2$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Sincerity</td>
<td>.51*</td>
<td>.42*</td>
<td>.18</td>
<td>.73</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.32*</td>
<td>-.24*</td>
<td>.06</td>
<td>-.40</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.39*</td>
<td>.10</td>
<td>.01</td>
<td>.14</td>
</tr>
</tbody>
</table>

*p < .01

$r_p$: Indicates partial correlation

H3b considered the regression of patient-centered communication on clarity of available breast reconstruction choices. There was a significant linear relationship between predictor variables and the criterion variable, $F(3, 87) = 4.10, p < .01, r^2 = .12$. Only one variable, interpersonal sincerity ($\beta = .58, t = 3.17$) was a significant ($p < .01$) predictor of the clarity of available breast reconstruction choices when controlling for the other predictor variables. Thus, H3b1 was supported, but neither H3b2 nor H3b3 received sufficient support (see Table 15).

Table 15

*Multiple regression of patient-centered communication on clarity of breast reconstruction choices, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$r$</th>
<th>$r_p$</th>
<th>$r_p^2$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Sincerity</td>
<td>.29*</td>
<td>.32*</td>
<td>.10</td>
<td>.58*</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.12</td>
<td>-.16</td>
<td>.02</td>
<td>-.29</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.15</td>
<td>-.04</td>
<td>.002</td>
<td>-.08</td>
</tr>
</tbody>
</table>

*p < .01

$r_p$: Indicates partial correlation
Hypothesis H3c was assessed using multiple regression analysis by regressing interpersonal sincerity, patient engagement, and individual confirmation on satisfaction with treatment choices. The regression equation was significant, \( F (3, 120) = 13.76, p < .01, r^2 = .26 \), but only one predictor variable – interpersonal sincerity (\( \beta = .53, t = 3.55 \)) was significantly (\( p < .01 \)) associated with the satisfaction with treatment choices (see Table 16). These results suggested that H3c1 was supported, but neither H3c2 nor H3c3.

Table 16

*Multiple regression of patient-centered communication on satisfaction with treatment choices, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>( r )</th>
<th>( r_p )</th>
<th>( r_p^2 )</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Sincerity</td>
<td>.50*</td>
<td>.31*</td>
<td>.10</td>
<td>.53*</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.42*</td>
<td>.06</td>
<td>.003</td>
<td>.10</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.35*</td>
<td>-.09</td>
<td>.01</td>
<td>-.14</td>
</tr>
</tbody>
</table>

\( *p < .01 \)

\( r_p \): Indicates partial correlation

Multiple regression analysis was used to assess Hypothesis H3d, which regressed interpersonal sincerity, patient engagement, and individual conformation on informational uncertainty. The equation was a significant predictor of informational uncertainty (\( F (3, 120) = 4.77, p < .01, r^2 = .11 \)). However, the positive relationship was not expected (\( r = .33 \)). None of the predictor variables were significantly (\( p < .01 \)) associated with informational uncertainty. Thus, H3d1, H3d2, and H3d3 were not supported. Table 17 exhibits correlation and partial correlation of the model.
Table 17

*Multiple regression of patient-centered communication on informational uncertainty, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$r$</td>
<td>$r_p$</td>
<td>$r_p^2$</td>
<td>$\beta$</td>
</tr>
<tr>
<td>Interpersonal Sincerity</td>
<td>.28*</td>
<td>.05</td>
<td>.002</td>
<td>.09</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.28*</td>
<td>.01</td>
<td>.000</td>
<td>.02</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.32*</td>
<td>.14</td>
<td>.02</td>
<td>.24</td>
</tr>
</tbody>
</table>

*p < .01

$r_p$: Indicates partial correlation

Hypothesis H3e considered the multiple regression analysis where interpersonal sincerity, patient engagement, and individual conformation were regressed on decisional support. The resulting overall regression was significant, $F(3, 120) = 10.75, p < .01, r^2 = .21$, but none of the predictor variables were significantly ($p < .01$) related to decisional support when controlling for the other variables in the equation (see Table 18). This resulted in retaining the null for H3e1, H3e2, and H3e3.

Table 18

*Multiple regression of patient-centered communication on decisional support, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$r$</td>
<td>$r_p$</td>
<td>$r_p^2$</td>
<td>$\beta$</td>
</tr>
<tr>
<td>Interpersonal Sincerity</td>
<td>.42*</td>
<td>.07</td>
<td>.004</td>
<td>.11</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.44*</td>
<td>.12</td>
<td>.014</td>
<td>.22</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.42*</td>
<td>.10</td>
<td>.01</td>
<td>.16</td>
</tr>
</tbody>
</table>

*p < .01

$r_p$: Indicates partial correlation
**Hypothesis 4.** To test Hypothesis 4, independent samples *t*-tests were conducted to assess mean differences between groups of participants who did have a PN on their cancer-care teams (=1) and participants who did not have a PN on their cancer-care teams (=0). The outcome variables included the two dimensions of patient satisfaction (i.e., satisfaction with the care experience and perceived inclusion in treatment decision-making).

Hypothesis H4a was that participants who have a PN on their cancer-care teams would score significantly higher on satisfaction with the care experience than patients who did not have PN on their cancer-care teams. Results from the independent samples *t*-test indicated that participants who had a PN on their cancer-care teams (*M* = 4.23, *SD* = .64) did score significantly higher on patient satisfaction with the care experience than participants who did not have a PN on their cancer-care teams (*M* = 3.84, *SD* = .74; *t*(122) = 3.03, *p* < .01, *d* = .55) and H4a was supported.

Data used to assess Hypothesis H4b revealed higher scores for perceived inclusion in treatment decision-making among participants who had a PN on their cancer-care teams (*M* = 4.50, *SD* = .57) compared to participants who did not have PN on their cancer-care teams (*M* = 4.41, *SD* = .61), but the difference was not significant (*t*(122) = .82, *p* = .21, *d* = .15). Hence, the null hypothesis for H4b was retained.

**Hypothesis 5.** Hypothesis 5 predicted relationships between patient-centered communication and patient satisfaction. To address the modified dimension structure suggested for both patient-centered communication and patient satisfaction in the factor analysis, Hypothesis 5 concerns the relationship between each dimension of patient-centered communication (i.e., interpersonal sincerity, patient engagement, and individual confirmation) and each dimension of patient satisfaction (i.e., satisfaction with care experience and perceived
inclusion in treatment decision-making). To address possible influence that each dimension of patient-centered communication may have on each relationship, the relationships were assessed while controlling the other two dimensions. Thus, multiple regression analysis was used such that interpersonal sincerity, patient engagement, and individual confirmation were regressed on each dimension patient satisfaction. In total, two multiple regressions were conducted and results are provided in the following section.

Multiple regression analysis was used to assess H5a, which regressed interpersonal sincerity, patient engagement, and individual confirmation on satisfaction with the care experience. The overall regression was significant \((F(3, 120) = 321.94, p < .01, r^2 = .89)\) and explained 89% of the variance of satisfaction with the care experience in the sample. Only two of the predictor variables—interpersonal sincerity \((\beta = .53, t = 9.30)\) and patient engagement \((\beta = .35, t = 5.84)\)—were significant predictors of satisfaction with the care experience (see Table 19).

These results suggested that H5a1 and H5a2 were supported, but H5a3 was not.

Table 19

*Multiple regression of patient-centered communication on satisfaction with the care experience, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>(r)</th>
<th>(r_p)</th>
<th>(r_p^2)</th>
<th>(\beta)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Sincerity</td>
<td>.91*</td>
<td>.65*</td>
<td>.42</td>
<td>.53*</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.88*</td>
<td>.47*</td>
<td>.22</td>
<td>.35*</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.81*</td>
<td>.19</td>
<td>.04</td>
<td>.12</td>
</tr>
</tbody>
</table>

\(*p < .01\)

\(r_p\): Indicates partial correlation

H5b examined the regression of interpersonal sincerity, patient engagement, and individual confirmation on perceived inclusion in treatment decision-making. Using multiple
regression with all three predictors entered in one step, a significant overall equation resulted \((F(3, 120) = 10.99, p < .01, r^2 = .22)\). In evaluating the predictors, only interpersonal sincerity was a significant \((p < .01)\) predictor of perceived inclusion in treatment decision-making \((\beta = .54, t = 3.54)\). Table 20 exhibits the correlations and partial correlations for the model. Thus, H5b1 was supported, but H5b2 and H5b3 were not.

Table 20

*Multiple regression of patient-centered communication on perceived inclusion in treatment decision-making, reported by each patient-centered communication predictor variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>(r)</th>
<th>(r_p)</th>
<th>(r_p^2)</th>
<th>(\beta)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Sincerity</td>
<td>.46*</td>
<td>.31*</td>
<td>.10</td>
<td>.54*</td>
</tr>
<tr>
<td>Patient Engagement</td>
<td>.35*</td>
<td>-.06</td>
<td>.003</td>
<td>-.10</td>
</tr>
<tr>
<td>Individual Confirmation</td>
<td>.34*</td>
<td>.00</td>
<td>.00</td>
<td>.00</td>
</tr>
</tbody>
</table>

*\(p < .01\)

\(r_p\): Indicates partial correlation

**Summary of Significant Results**

This section provides a brief summary of aforementioned analyses that revealed significant results, which is organized based on the type of test used to assess the hypotheses (e.g., \(t\)-test and regression analysis).

Independent samples \(t\)-tests revealed significant results between participants who had a PN on their cancer-care teams and participants who did not have a PN on their cancer-care teams. The data for Hypotheses H1b and H1c revealed that that Participants who had a PN as part of their cancer-care teams experienced significantly more patient engagement and individual confirmation, respectively, than participants who did not have a PN as part of their cancer-care teams. Additionally, participants who had a PN on their cancer-care teams reported significantly
more decisional support (H2e) and greater patient satisfaction with the care experience (H4a) than those without a PN on their cancer-care teams.

Multiple regression analyses revealed some significant relationships when regressing interpersonal sincerity, patient engagement, and individual confirmation on each of the dimensions of decisional conflict (i.e., informed treatment choice, clarity of breast reconstruction choices, satisfaction with treatment choices, informational uncertainty, and decisional support). All of the linear multiple regression equations were significant, suggesting that informed treatment choice, clarity of breast reconstruction decisions, satisfaction with treatment choices, informational uncertainty, and decisional support are predicted by the amount of patient-centered communication experienced by participants. A surprising finding was that the relationship between patient-centered communication and informational uncertainty was positive ($r = .33$), suggesting an opposite interaction that was expected. Only one dimension–informed treatment choice–revealed a large effect size ($r^2 = .31$) when all three predictors were in the model. This suggests that 31% of the variance observed for informed treatment choice could be explained by the amount of patient-centered communication participants reported experiencing. Two other criterion variables revealed medium-sized effect sizes–satisfaction with treatment choices ($r^2 = .26$) and decisional support ($r^2 = .21$)–when all three predictors were included in the equation. Bivariate, zero-order correlations were nearly all significant, but partial correlations resulted in fewer significant relationships. When controlling for patient engagement and individual confirmation, interpersonal sincerity maintained significant relationships with informed treatment choice, clarity of breast reconstruction choices, and satisfaction with treatment choices. All effect sizes would be considered medium to small for these relationships. This supported H3a1, H3b1, and H3c1, respectively. Additionally, when controlling for interpersonal sincerity
and individual confirmation, patient engagement maintained a significant relationship with informed treatment choice, but it changed direction (e.g., positive zero-order correlation, but negative partial correlation). Thus, H3a2 was not supported due to directionality and the effect size was small.

In assessing the relationship between patient-centered communication and patient satisfaction, multiple regression analysis was employed. Whereby interpersonal sincerity, patient engagement, and individual confirmation, were significant predictors of satisfaction with the care experience and perceived inclusion in treatment decision-making, respectively, when included in a single model. Resulting effect size for the model with satisfaction with the care experience as the criterion revealed a large effect size ($r^2 = .89$) and the model with perceived inclusion in cancer care had a medium to small effect size ($r^2 = .22$). These results suggest that construct of patient-centered communication as it is measured in this study is a significant predictor of both dimensions of patient satisfaction. Bivariate correlations were all significant between predictor and criterion variables were all significant, but partial correlations revealed some differences. When controlling for patient engagement and individual confirmation, interpersonal sincerity maintained a significant positive relationship with both satisfaction with cancer care and perceived inclusion in treatment decision-making. The effect sizes were large and medium to small, respectively, which suggests that H5a1 and H5b1 were supported. Meanwhile, when controlling for interpersonal sincerity and individual confirmation, patient engagement maintained a significant positive relationship with satisfaction with the care experience. Thus H5a2 was supported using significance testing and there was a medium to small effect size.
Chapter 6: QUALITATIVE RESULTS

This chapter presents the results from the semi-structured qualitative interviews conducted as part of the research project reported herein. As previously described, semi-structured interviews were conducted and audio recordings of them transcribed for subsequent analysis. In the reporting of the interview responses, some vocalized pauses (e.g., “umm,” “uhhh,” etc.) were removed when the context was an environmental distraction that resulted in the pauses (e.g., a café employee came to clearing glasses during the interview, there was a knock on the door at the home of a woman participating in a phone interview, etc.). Also, the removal of some such pauses provided a clearer sense of the message being shared by the participant. Any identifying details were replaced with pronouns or substitutions that maintained the sentiment of the statement, but was anonymous.

This chapter is organized by first reviewing the employed qualitative methodology, then presenting concepts and data units that exemplify those concepts, and finally introducing themes and providing corresponding data units. The order in which concepts are explained is: (a) communication about treatment options, (b) information-processing of treatment options, (c) treatment decision-making process, (d) uncertainty during decision-making, (e) information-seeking during decision-making, (f) decision-maker, (g) decisional support, (h) satisfaction with treatment decisions, (i) emotional support during decision-making, (j) cancer-care team composition and roles, and (k) patient navigator communication.

Following that, I provide an explanation of the themes and give examples of data units that are representative of each. There were many ideas shared during qualitative interviews, but several participants organically suggested seven themes beyond the concepts that were previously discussed. The order in which themes are addressed is as follows: (a) decision time
pressure, (b) advanced provision of information/avoiding surprises, (c) communication among
cancer-care team members, (d) structural influences on uncertainty, (e) fertility decisions, (f)
survivor support, and (g) uncertainty concerning finishing treatment.

**Review of Qualitative Methodology**

Semi-structured qualitative interviews were conducted two months after the survey data
collection was finished. Participants were selected using purposeful random sampling based on
the members they reported were on the cancer-care team. A total of 11 women agreed to
participate in a semi-structured interview. All interviews were conducted using a semi-structured
interview process, which means that probing and follow-up questions vary based on the flow of
the interview and details raised by each participant (see Appendix D). Interviews lasted between
35 and 180 minutes, were audio recorded, and transcribed. Additional information about
qualitative methodology is presented in Chapter 4.

**Concepts**

The defined concepts referred to “words or terms that [represent] an idea important to
your research problem” (Rubin & Rubin, 2005, p. 207). For this research, there were 11 concepts
identified following a review of the transcript data. The following sections provide a brief
description of the concept and an example of data units that are representative of the concept.

**Communication about treatment options.** This concept encompassed ideas regarding
how treatment options were shared with participants. In total seven of the 11 participants
described their communication about treatment options. Comments from participants suggested
that, following diagnosis, one or more members of the cancer-care team shared information with
patients about the treatment options that were available to the patient. This concept supports data
about patient-centered communication experienced by participants. There were discrepancies
participants shared, with some describing experiences for which the cancer-care team provided clear and thorough explanations about treatment options given that woman’s personal needs and experience, and others feeling that more information could have been communicated about treatment options from the cancer-care team. The following excerpts revealed of experiences reveals that a wide range of experiences existed for women when breast cancer treatment options were communicated to them.

My oncologist was always very clear about my treatment options. [S]he’s like, “Ok, if we keep the pregnancy, then we’ll do surgery in the first trimester, then there’s chemo that’s safe to start in the second trimester and like this is the series of events.” When I lost the pregnancy I had two different options. I could do chemo first and then surgery or surgery first and then chemo and she was really good about laying out the pros and cons and what she recommended. (P8)

[A]t my very first meeting with the surgeon, I would have liked her to have present other options—other than lumpectomy, chemo, radiation. And at least we should have talked about what could happen, but I never felt like I got that information. I sort of felt like I was being smacked with what was happening as it was happening, but no body ever said this could happen in advance. So I think that that was a problem. [F]rankly, going through what I went through, if I had to do it all again, I would have a bilateral mastectomy from the beginning and never have gone through radiation and chemo[therapy]. But, [it wasn’t] an option that was presented to me. I mean . . . could I have chosen that? I guess, but nobody ever said that you could do this. (P9)

**Information-processing of treatment options.** The identified concept of “information processing of treatment options” was focused on ideas and words that described how participants
processed the information and communication that was provided to them after diagnosis. This concept supports the results about decisional conflict and helps to support how communication may influence a patient’s feelings of uncertainty during decision-making.

[T]he first [meeting] with the breast surgeon was very broad, I guess, which was probably better at the time because we were so overwhelmed with emotion that it’s probably better that he gave us a broad overview and kind of let it sink in. Two days later we saw the oncologist we had had more time to process it all and we were able to sit down with the oncologist and he was able to give us a more detailed overview of everything. I think we were more ready at that point to process more information, so it was actually kind of a good segue. (P10)

**Treatment decision-making process.** The “treatment decision-making process” concept aimed at explaining how patients made decisions about breast reconstruction. Knowing the process of how patients made decisions and what factors influenced them has the opportunity to reveal where patient-centered communication from the cancer-care team could improve the decision-making process for patients. Some women commented that they made the treatment decision entirely on their own; whereas some women felt that their cancer-care team played a more influential role in her breast cancer treatment decision-making process.

So as far as my cancer team, they really didn’t have any input. When I went to see my breast surgeon, my husband and I walked in and she comes in, introduces herself, and she goes, “We’ll talk a little bit about breast cancer, we’ll discuss your pathology report, and then we’ll talk about options.” And I said, “That’s great, I don’t know that much about breast cancer. I said, as far as options, there are no options. I’m having a bilateral mastectomy, no reconstruction. Preferably, no chemo, preferably, no radiation, but that is
going to depend on obviously what you find when the breasts are removed.” She didn’t try to pressure me at all to have reconstruction or anything. She said, “I do have to go over reconstruction with you.” I said, “I know, informed consent, but make it quick because it’s just not an option.” (P6)

I wanted to make sure that [the cancer] was gone and actually I requested that they take both and that way I would never have to worry about it. You know, I figured at 55, you know my husband and I . . . it’s not a big deal for us. I still wish they would have taken both because it’s exceptionally difficult to match—so I can’t wear sweaters or anything like that because one is way up by my chin and one is way down by my belly, so it’s very hard. They refused to do both because they said it was so small. They didn’t even want to do the mastectomy. And then afterwards, they said they were really glad because they would have had to do that anyway because it had spread. So I think we know as people, men and women, we know our bodies better than anyone else. I don’t think [I could have gotten the double mastectomy], I tried and tried. I had documentation on why [a double mastectomy] would be better and no. They said no. (P4)

**Uncertainty during decision-making.** This concept supports previous literature about the uncertainty faced by women during breast cancer decision-making (Nelson, 1996). Women in this study supported the previously published literature where situations were described that posed a significant sense of uncertainty while making breast cancer treatment decisions. Some participants felt more uncertainty following communication with providers, while other reported that the communication helped to reduce stress and manage uncertainty.

[A]t my very first meeting with the surgeon, I would have liked her to have present other options . . . other than lumpectomy, chemo[therapy], radiation. And at least we should
have talked about what could happen, but I never felt like I got that information. I sort of felt like I was being smacked with what was happening as it was happening, but no body ever said this could happen in advance. So I think that that was a problem. (P9)

I had several options and my oncologists, who were wonderful. I love my oncologist, she really laid out my options for treatment really very well in ways that made a lot of sense. (P8)

**Information-seeking during decision-making.** One of the means by which patients manage uncertainty is through seeking information during treatment decision-making (Vogel, Bengel, & Helmes, 2008). This idea was represented in this research through participants’ comments regarding their desire to gain information as a means of making a decision that manages uncertainty and best aligned with their preferences, values, and goals.

She has a tendency to order a bunch of lab work without telling me what it is she’s looking at. Whether it’s because they don’t want to worry me or I don’t know . . . I just don’t know why they don’t do that. Especially, I try to tell them, I’m a nurse, I’m interested in these kinds of things, I want to know. I get that some people would have more anxiety if they were told–oh, I’m looking for multi-myeloma, I’m looking for copper deficiency, but I try to tell them, I’m someone who wants to know. I’m into numbers, I’m into the science, I’m into the curiosity of it. I just get really turned off when I don’t get told. (P11)

In addition to gaining information from the cancer-care team, many participants commented that an important source of information included online resources.
I Googled breast MRI and YouTube has some great videos. Some nice videos like this is what’s going to happen and then that’s exactly what happened so I wasn’t afraid when I got there, but it was still uncomfortable and weird. (P3)

I just did a lot of research on the Internet. I looked at John Hopkins, there’s a cancer treatment center in [Los Angeles], a couple in Seattle. I went to different blogs to read what people were saying about different places. [B]ecause I knew this was a life-changing thing, I wanted to make sure I made the right decisions for me. (P4)

**Decision-maker.** The process of decision-making also includes a moment when the actual decision is made (Edwards & Elwyn, 2006). Literature suggests that some women want to make the final decision about care, while others want providers, family members, or others to make the final decision about care (Benbassat, Pilpel, & Tidhar, 1998). The preferences of the participants in this study varied from some participants insisting that their preference be the final say in the matter of treatment decision-making, some participants sharing their preferences strongly, but ultimately leaving it up to the providers, and some participants looking to their providers to provide advice and make the final decision.

I did feel a lot of trust in [my cancer team]. Absolutely. The oncologist had us come into his office and he brought up his computer and showed us all of the [options] that I could have—what were the benefits and the negatives. And he explained them all to me and I felt really good with that. Because it gave me the choice instead of the doctor saying, this is the one you’re going to do. (P4)

I felt like I was in control the whole time, but for some reason I just really trust their choices, so . . . I kind of went exactly with what they had planned out . . . mapped out for me. (P1)
I feel as though the oncologist had the final decision . . . because he was the one that was driving my treatment and so since we felt like we didn’t know as much as he did. Obviously we had only just gone through a crash course in breast cancer. (P10)

**Decisional support.** This concept focused on the idea of whether or not the participant received support from others about her decision and during the decision-making process. Support could have come from family members or members of the cancer-care team, but it was the general sense that other people supported the decision and the decision-making process. Some participants commented that it was a particularly supportive environment from others while going through treatment; while other participants did not receive the support she needed from others.

When they finished chemo[therapy] and I explained to my oncologist that we still desired to have another baby. He felt more comfortable with the option of letting me take tamoxifen for 2-3 years and taking a break from it and trying to get pregnant and then revisiting it for a few years after that. So, that’s kind of the road that we decided to take. We ended up doing that and took a break from the tamoxifen to try to get pregnant and I’m actually pregnant right now, I’m due in 4 weeks with our 2nd baby. So, everything’s going really well. And then after I have the baby, I’ll get back on tamoxifen and finish out those couple of years. (P10)

I talked to my husband [about my decision]. I talked to some family members and they were very opposed. Most people can’t understand why you would choose to [have a mastectomy]. My sister, she said, “You don’t want to do that. You’re going to be a freak. Your husband won’t want to be with you anymore.” I said, you know, “We’ve already
decided and he said it was ok.” I had people say it would make me less than a female. I would never be able to wear a V-neck or any kind of low-cut. (P4)

**Satisfaction with treatment decisions.** The concept of “satisfaction with treatment decisions” represents an established idea that is supported by the Patient Navigation Research Program, which uses patient satisfaction as a primary outcome variable for determining the success of patient navigator programs (Jean-Pierre et al., 2011). Interviewees revealed that the satisfaction patients felt about their treatment decisions varied from some feeling completely satisfied that their decision aligned with their values, beliefs, and preferences, whereas other participants commented that if they had a chance to go back and make treatment choices again, they would have selected different options.

I felt very confident with the decision at the time. And I still feel like I’ve made the right decision. (P11)

Looking back, even though some of the decisions were really hard to make and they definitely had short-term consequences, I feel like the long-term benefitted of extending my life and preventing a reoccurrence definitely outweigh the very short-term side effects that I experienced. I’m glad that I did it now, but in that moment of three years ago and having those tough choices and tough decisions, I wasn’t sure that I was going to feel that way at the end of this, but I’m now glad that I did all of those [treatments] and I don’t regret any of the decisions that I made and I’m glad that I did all that I did to get me to where I am today. (P10)

It was a nightmare. I would never do [chemotherapy] again. I don’t care if the cancer comes back, I don’t care where I get it. Never again, but, as I said before, no one ever warned me of the possibility of this happening. (P9)
**Emotional support during decision-making.** Emotional support is an important component in treatment decision-making. Fiscella et al. (2012) describes emotional support as a means of showing support for the treatment decisions of a patient and also helping to reduce uncertainty during decision-making. Participants described emotional support as occurring during treatment decision-making both through face-to-face communication and computer-mediated communication.

I saw a psychology oncology nurse. I was referred to her; she was like a counselor but a nurse. And I saw her like once a month, I’d say. And talking to her, that was more like counseling–talking about my feelings about things and how things were going with my family and with support and things like that. And that was really helpful–to have somebody like that to talk to. It’s not that I couldn’t have gotten it from the nurses, but I would sit with her for 45 minutes and a nurse couldn’t sit with me for 45 minutes during my treatment because they are treating other people too. So that was helpful too. (P5)

One of the things I wish I had had during the time of treatment that I had after treatment was an online support group called “Our Circle.” It consisted of two facilitators and people writing in and asking questions and saying, “Did you experience this? How did you handle it?” Actually, that was very helpful, it would have been nice to have it during the chemo[therapy] and radiation. (P9)

**Cancer-care team composition and roles.** The structure and integration of the cancer-care team was different for each interview participant. Some women commented that the team worked well together, while others suggested that improvements could be made. Additionally, the roles that cancer-care team members played in helping women through treatment decision-making varied greatly.
I can’t really say enough about how great all of the people were at the cancer center. It just seemed that the most compassionate people go into cancer care. There was never anybody who was impatient or crabby or rude. (P5)

[My oncologist] was probably the most helpful. I mean he is still managing this whole process, even now. A friend of mine said, “You’ve got a think of this as a project. so there’s a beginning; a middle; and an end.” I said [to my oncologist], “This like a project and you are the project manager.” My oncologist was just like, “Okay.” So he really coordinates every single step of this entire process. Even after he had to hand off the radiation portion of the program to the radiation oncologist, he stayed in the loop. (P3)

When I think back on [my oncologist], sometimes I get really angry and I think, I really didn’t have–this is going to sound really weird–I didn’t have the kind of cancer experience that I should have. I talked to other women and they all would say, oh, I love my oncologist. And I would think–who loves their oncologist? Now I get it. (P11)

Patient navigator communication. The roles and functions of patient navigators varied among participants, but three main categories emerged. Based on accounts by the participants, patient navigators provided (a) informational support about the disease and treatment options, (b) emotional support, and (c) instrumental support with resources available to patients.

I looked up each individual thing on the report. At the time I remember feeling a little confused about the word, in situ. I think the nurse [navigator] helped me understand a little bit more. And I remember that she also gave me a very detailed pamphlet. (P2)

The navigator had a lot of compassion. She just seemed to know right away–like, she seemed genuine that she wanted to help me in any way that she could. The best help
that I got from her was her encouraging me to come to the support group that she runs. (P11)

[The oncology social worker] was really good in helping me find resources. We lived 100 miles from [the cancer center] and it includes a ferry ride, which is $30 each trip. And my chemo[therapy] treatment consisted of once per week for six months, so it was quite a bit. My PN found a foundation that pay for all of my travel expenses. All my ferry tickets, all my parking tickets, and gave us gas money. It was a huge help. It’s been 4.5 years later and we’re still friends [the social worker and I], we still communicate. (P4)

Themes

Rubin and Rubin (2005) described themes as “statements or explanations of what is going on” (p. 207). The purpose of identifying themes was to expand upon the conceptual and theoretical parameters outlined in the hypotheses. The themes that emerged from qualitative interviews revealed several ideas that were not initially hypothesized, but were described by at least two participants as being important parts of the breast cancer decision-making process. Identifying and interpreting the themes can extend theory and influence practical recommendations for patient care. This section is organized in such a way that themes are first explained and then data units that exemplify the theme are provided. Themes are presented in the following order: (a) decision time pressure, (b) advanced provision of information/avoiding surprises, (c) communication among cancer-care team members, (d) structural influences on uncertainty, (e) fertility decisions, (f) survivor support, and (g) uncertainty of finishing treatment.

Decision time pressure. Several participants commented that they made decisions quickly after diagnosis because they wanted to address the disease immediately. Two reasons
emerged for why patients felt that the decision must be made immediately after diagnosis: fear and pressure from the cancer-care team.

I think at that point it was driven more by fear and kind of like a fight or flight in my head of wanting to kind of just remove everything. So, I didn’t have to worry about anything later on in life. At that point, my adrenaline rush was pretty high and I just knew I wanted to do everything I possibly could to treat this immediately. (P10)

I felt very rushed in the process, but I felt like we had to move along and make decisions and do it because I was terrified of having this thing in my body. (P9)

**Advanced provision of information/avoiding surprises.** Many participants commented that there were times when things happened during treatment—whether it was an added treatment protocol or a side effect—which participants did not expect. Participants agreed that unexpected issues can arise, but the overarching theme was that additional information about the gamut of possible side effects should be shared.

My oncologists I feel like kind of gave me the bare bones minimum of what to expect. He sat down and told me about the two chemo[therapy] drugs that I was going to get and the expected side effects and the most common, like, so you know hair loss, things like that. So we kind of knew the broad things to expect, but stuff like weight gain, I wasn’t told to expect that. Especially as a young women, that’s something that I was pretty self-conscious about and I would have liked to have known up front. And when I brought it up to him, he kind of just brushed it off and I think that maybe they don’t’ see that as a big deal to us because you know, you’re surviving, you’re tolerating the chemo[therapy] well, we’re not really worried that you’re gaining weight. But that’s something that . . . especially to a young women . . . I had acne breakouts because of the steroids that they
prescribed. I would kind of liked [sic] to known what was normal and that that was going to happen. You know, it’s a hard thing to be a young women and go through a double mastectomy and then be bald because of chemo[therapy] and you have all of these other side effects on top of that. [I]t’s kind of a lot to your self-esteem all at once. I think that, maybe knowing more of what to expect from chemo[therapy] or from the entire treatment process would have helped me a little bit better. (P10)

Additionally, participants seemed to agree that the treatment plan was understandably fluid based on test results. However, treatments that had been ruled out or not introduced from the beginning, but were later suggested as necessary came as a shock and caused upset.

So, all along, I’d been told 17, 17, 17 [chemotherapy sessions]. Then, the representative of [the drug maker] came to [my oncologist’s] office and explained, no it’s not 17, it’s 18 doses that you’re supposed to have to be effective. So, I get how that mistake was made, but they completely forgot to tell me about it. [B]etween all of the different phone calls that I made back and forth and going to Dr. Google and calling [the drug maker] myself and all of this, finding out that it was 18 [doses] was what I was supposed to have. And what bothered me was that they knew this for 4 months before they thought to tell me about it and they acted like it was no big deal and they didn’t understand that I had taken work off to celebrate my last day– I had vacation time planned around there, I had a huge party to celebrate around there. I made signs for my front yard saying, “honk! Because I’m done with chemo[therapy]!” you know, I just had a lot of plans. [I] felt like I was running a marathon and I’m almost to the end and then they go, oh no! The officials just decided to make it 3 miles longer– so you have 3 miles to go, it’s no big deal. (P11)
I wish they would have told me reconstruction takes a long time. I wanted implants. [S]o it’s like you’re kind of stuck in a way because I have to go through it. I thought about it the other day, maybe I should have done this – just let it be the way it is. I’m just dreading going in [for surgery] again. (P7)

Communication among cancer-care team members. Participants described the communication among cancer-care team members in the context of tumor boards and general discussion among providers regarding the process of a patient’s care. Some participants commented that the communication among cancer-care team members was effective and contributed to trust in the providers; while others felt providers had limited communication.

[J]ust learning that there was a tumor board of more than one physician giving input on patients and thinking oh, they’re talking about me and the doctors are coming up with a plan collectively, kind of. It’s kind of nice now too, even though I trust my onco[logist] completely, it’s nice to know that other people are giving their input–that’s the way it should be. (P5)

I don’t know what happened behind the scenes. I don’t even know if the oncologist and the surgeon talked. [Y]ou would think they have to or they would just go by my record. Now that I think about it, maybe they were just going by my record. (P2)

Structural influences on uncertainty. Several participants commented on the structural layout of the cancer center where they received treatment and met with providers. Feedback about the layout seemed to arise when participants had a particularly good experience while going through treatment and some of this was due to the proximity and ease of maneuvering through a cancer center’s system.
I think maybe because [the cancer center] is a relatively new center—maybe 8 years old—they probably planned it that way to offer it to the patients. I think it really did make a difference of being helpful. Like I said, one less thing to worry about. To go to different places and have to learn where different places were—just knowing that I was going to see the onco[logist] after the surgeon; I could just stay in one place. The nurses would literally lead me from one place to the other—because the surgeons had their little side of the complex and the onco[logist]s had another side. Because there was a little maze of hallways in the back—like the public side of the building is all around the perimeter and the interior is where all the offices and patient rooms and labs are. So, my oncologist was on the same center as the breast care center and that was on the same floor as the day hospital, they can just walk through the middle and the little maze of hallways and they don’t even go out to the main walkways. It was really clear and nice to not worry about logistics. (P5)

**Fertility decisions.** Two of the women interviewed were younger than 35 years when they were diagnosed. Both of them commented that fertility was an important issue to their diagnosis and treatment plans. One of them women was pregnant before being diagnosed and suffered a miscarriage about two weeks before pregnancy. While the other woman was pregnant at the time of diagnosis and found out she miscarried after beginning treatment decision-making. Both participants had young children at diagnosis, but the women wanted more children in the future. Participants commented that the treatment decision-making process was made more difficult because of the their concerns about how breast cancer treatment may influence their fertility in the future.
We went back and forth for awhile-[our fertility plan] was a debate. [The oncologist] ultimately didn’t know enough at the time and we were still in that kind of scared and overwhelmed phase and we talked with our doctor and stuff, but he said we should do the treatment. [W]e were going to listen to him because we felt that he knew a lot more than we did. But looking back now and all the research that I’ve done I feel like he may have just been also just scared as we were and he didn’t have enough information at the time to make an informed decision either way. (P10)

So then, when I met with my radiation oncologist, he was like, “Is there any chance you could be pregnant?” and I was like, “I guess so.” And they did a pregnancy test and 1 week later I found out I was pregnant, which was awesome. But this delayed a lot of treatment—I couldn’t do a lot of the diagnostic tests while they were trying to figure out what was going on, while I tried to figure out what I wanted to do and. (P8)

**Survivor support.** From the moment of diagnosis, women receive a influx of attention—from the medical team, from family members and friends, and many others—when treatment is finished survivors often feel as though the abrupt ending does not recognize the serious and life-threatening experience they have just gone through.

Not one doctor told me I may have depression *after* my treatment was over. I was truly surprised at how depressed I was after the fact and it took me, personally almost a year to feel better from it. I often wonder if it would have been mitigated had I been told to expect it. I truly feel that survivorship, what to do and expect, is overlooked. Once you're done with the acute treatment, it's like turning 18 and your parents hand you a key to the U-haul parked out front and says, "Good luck." (P11)
I know for me everyone was having their second and third babies and doing things like a new playgroup and things like that. And I was just worried about growing my hair back. So it was definitely hard. Everyone just thinks you’re just done—like, yeah, you’re done with treatment, you finished, you’re alive, everything’s normal again, right? But it’s not and it takes awhile to realize you’ve just been through something really traumatic . . . like, “How am I going to get back on my feet?” I think following up with [patients] or continuing to follow [patients] a short time after treatment would be really beneficial. (P10)

**Uncertainty of finishing treatment.** Participants reiterated the trauma that research has suggested takes place during diagnosis, but they also suggested that finishing treatment was equally as traumatic. The uncertainty faced by participants seemed to center on the fact that they were no longer being monitored as closely and women felt that the disease had a greater chance of reoccurring more quickly with less oversight.

I actually looked at my oncologist half kidding and half not kidding, can’t we do just one more round. It’s a safety net. It really is. In other words, when you’re going through you’re seeing your breast surgeon, you’re seeing your oncologist. So, there was always that safety net. Then, you’re done with chemo and you go back in a week and you get your blood work and if your blood work is good—in other words, it seems like it would be fine because your blood work keeps going good, but they’re going, “Ok, we’ll see you in a month.” And you’re going, “One month!? What if . . . how will I know if the cancer came back? What would happen?” (P6)

Seeing other survivors I know that it’s a common theme that we all experienced. It’s like PTSD—you know, basically you finish treatment and realize . . . what just
happened to me and how do I put my life back together? And especially as a young woman and a young mother or a young wife. [B]eing sick with cancer and treatment and all of that in your life it’s hard to move forward. How do you find your new normal and how do you put your life back together? (P10)

**Summary of Qualitative Data**

In sum, there were 11 concepts and seven themes that emerged following semi-structured interviews with breast cancer survivors who had finished active treatment in the last three years. Concepts included, (a) communication about treatment options, (b) information-processing of treatment options, (c) treatment decision-making process, (d) uncertainty during decision-making, (e) information-seeking during decision-making, (f) decision-maker, (g) decisional support, (h) satisfaction with treatment decisions, (i) emotional support during decision-making, (j) cancer-care team composition and roles, and (k) patient navigator communication. While identified themes included, (a) decision time pressure, (b) advanced provision of information/avoiding surprises, (c) communication among cancer-care team members, (d) structural influences on uncertainty, (e) fertility decisions, (f) survivor support, and (g) uncertainty of finishing treatment. In the next chapter I provide a discussion of the results where data units that align with concepts were used to help interpret the quantitative results and the data units identified for themes were addressed and interpreted for how they may be able to explain additional experiences in the breast cancer treatment process.
Chapter 7: DISCUSSION

Communication that occurs during breast cancer diagnosis and treatment is a critical component in creating an optimal patient experience that aligns with the patient’s beliefs and values for breast cancer care (Edwards & Elwyn, 2006; Gattellari, Butow, & Tattersall, 2001; O’Hair et al., 2003). The composition of the cancer-care team influences how information is shared and treatment options are discussed. This patient-provider communication can affect the treatment choices patients make, which has long-term effects on overall quality of life (Kerr, Engel, Schlesinger-Raab, Sauer, & Helmes, 2009).

Such a complex disease requires treatment and management from many specialists, nurses, and support staff. This research project considered how the presence of a patient navigator on a cancer-care team contributes to a positive and effective communicative experience for female breast cancer patients. Patient navigators offer the opportunity for patients to have a single point person where they can review information about the disease and treatment options (Freeman, 2006; Yosha et al., 2011), gain emotional support to help them manage distress and worry (Fiscella et al., 2012), receive support to navigate the health system (Swanson & Koch, 2010), and hear recommendations for local resources (Curran, 2003).

An aim of the present study was to expand the communication literature by first showing a connection between the presence of a patient navigator and the experienced patient-centered communication of patients, which is a concept that is theoretically manifested by the role and functions of patient navigators (Fiscella et al., 2012; Mallinger, Griggs, & Shields, 2005). Uncertainty Management Theory was explored in this study by conceptualizing uncertainty as decisional conflict (O’Connor, 1995) and assessing relationships in an applied setting. The following sections provide a discussion of the results from the study and is organized as follows:
(a) review of the results, (b) theoretical significance, (c) explanation and interpretation of results, (d) implications for breast cancer communication, (e) limitations, and (f) recommendations for future study.

**Review of Results**

This section provides a review of quantitative results and information concerning whether or not the research hypotheses were supported. Hypotheses 1, 2, and 4 were tested using independent samples *t*-tests comparing groups of participants who had a PN on their cancer-care teams and those who did not. Hypotheses 3 and 5 involved suspected relationships of decisional conflict and patient satisfaction, respectively, to patient-centered communication and drew on correlation data for testing them.

Data for Hypothesis 1 revealed that participants who had a PN on their cancer-care teams experienced more patient-centered communication (i.e., interpersonal sincerity, patient engagement, and individual confirmation) than participants who did not. However, only patient engagement and individual confirmation revealed statistically significant differences in experienced patient-centered communication.

Hypothesis 2 posited mean differences between groups (PN present vs. PN not present) on the dimensions of decisional conflict (i.e., informed treatment choice, clarity of breast reconstruction choices, satisfaction with treatment choices, informational uncertainty, and decisional support). The data revealed that participants who had a PN on their cancer-care teams had higher scores on measures of informed treatment choice, clarity of breast reconstruction choices, satisfaction with treatment choices, and decisional support than participants who did not have a PN on their cancer-care teams. However, the only significant difference was for decisional support. Informational uncertainty was expected to show an opposite mean difference;
that, participants with a PN on their cancer-care teams would have lower scores on informational uncertainty that participants without a PN on their cancer-care teams. As predicted, participants who had a PN on their cancer-care teams scored lower on informational uncertainty than participants who did not have a PN on their cancer-care teams, but the difference was not significant.

Hypothesis 3 revealed that patient-centered communication was a significant predictor of how well-informed participants felt about their treatment choices, the reported clarity of available breast reconstruction options, the satisfaction participants felt about the decisions they made for treatment, and the amount of decisional support participants felt. Although patient-centered communication was a significant predictor of the uncertainty participants felt about the amount of information they received, it was not in the predicted direction (r = .33). As such, prior work suggested that informational uncertainty would have a negative relationship to patient-centered communication dimensions, such that less informational uncertainty would mean more patient-centered communication (Diefenbach et al., 2009).

Multiple regression analysis was conducted such that predictor variables included the three dimensions of patient-centered communication—interpersonal sincerity, patient engagement, and individual confirmation—entered together and regressed on dimensions of decisional conflict (i.e., informed treatment choice, clarity of breast reconstruction choices, satisfaction with treatment choices, informational uncertainty, and decisional support). These analyses revealed that when controlling for patient engagement and individual confirmation, interpersonal sincerity continued to have a significant relationship with informed treatment choice, clarity of breast reconstruction choices, and satisfaction with treatment choices. Additionally, when controlling for interpersonal sincerity and individual confirmation, patient
engagement maintained a significant relationship with informed treatment choice, but it was in
the opposite direction than was predicted. This suggests that the portion of patient engagement
that is independent of interpersonal sincerity and individual confirmation is negatively correlated
with informed treatment choice.

Hypothesis 4 related to between group differences (PN present vs. PN not present) in
satisfaction with the care experience and perceived inclusion in treatment decision-making,
respectively. Participants who had a PN on their cancer-care teams had higher scores for both
satisfaction with the care experience and perceived inclusion in treatment decision-making than
participants who do not have a PN on a cancer-care team. However, only the difference for
satisfaction with the care experience was statistically significant.

Hypothesis 5 focused on multiple regression equations with interpersonal sincerity,
patient engagement, and individual confirmation being regressed on satisfaction with the care
experience and perceived inclusion in treatment decision-making, respectively. These results
indicated that patient-centered communication was a significant predictor of both patient
satisfaction dimensions. Patient-centered communication explained 89% of the variance in
satisfaction with the cancer experience and 22% of the variance in perceived inclusion in
treatment decision-making. The multiple regression analysis also revealed that when controlling
for patient engagement and individual confirmation, a positive significant relationship remained
between interpersonal sincerity and both satisfaction with the care experience and perceived
inclusion in treatment decision-making. Additionally, when controlling for interpersonal
sincerity and individual confirmation, patient engagement maintained a significant positive
correlation with satisfaction with the care experience.
Theoretical Significance

A primary purpose of this research was to determine whether or not the communication provided by cancer-care teams that included patient navigators influenced the uncertainty patients felt during the breast cancer treatment decision-making process. The results offer potentially significant advances in Uncertainty Management Theory (UMT). They support the premise that improved patient-centered communicative behavior, which includes eye contact and expressing warmth through vocal tone (Politi & Street, 2011; Epstein & Street, 2007), are means of helping patients better manage uncertainty during treatment decision-making. The importance of this outcome is bolstered by the fact that the study considered the concepts of UMT in the context of actual breast cancer patient experiences. Broadening the context in which theory is applied is a critical contribution of scholarship, as it is important to examine how theoretical relationships manifest themselves in different settings. As described by Craig (1999), communication theory requires that theoretical discourse and practical discourse come together to assess how theory applies to real communication problems. In this study, concepts of UMT were applied in the context of decision-making related to breast cancer treatment. The methodology used reflected the theoretical notion that communication can help people manage uncertainty (Brashers, 2001; Ford, Babrow, & Stohl, 1996) as tied to the actual experience of uncertainty felt by breast cancer patients while going through treatment-related decision making. By considering the influence of communication with patient navigators on such decision-making, the applicable context of our theoretical understanding of UMT principles is expanded. Communication science should continue the application theory in everyday settings as a means of adding context to theoretical explanations.
In addition to further establishing the applicability of UMT in a practical setting, there were two aspects of communication uncovered that appear to influence feelings of uncertainty among breast cancer patients. The first was the composition of the cancer-care team and sense that people were always available to talk with the participant, provide information, or help with any questions. The second aspect of communication that influences uncertainty was the physical structure of the cancer-care facility and proxemic aspects of treatment spaces.

**Composition of the cancer-care team.** Previous research suggested that patient navigators hold promise to help patients by simply “being there” and offering support while women make decisions concerning treatment (Korber, Padula, Gray, & Powell, 2011, p. 47). Results from this study suggest that this presence also carries over into more effective uncertainty management while making such decisions. The way in which survey items were structured in the questionnaire had participants consider the entirety of their cancer-care teams when responding to matters relating to patient-centered communication. In addition, the associations between variables, such as uncertainty via decisional conflict, were made according to whether or not a patient navigator was a member of the cancer-care team. These two methodological decisions allowed the assessment of the composition of cancer-care teams and its influence on the breast cancer experience, rather than direct patient navigator-patient interaction.

The significant theoretical discovery concerning the composition of a cancer-care team and uncertainty management was solidified by qualitative interviews where women reported having access to a patient navigator, but not necessarily interacting with them. This further supported the view that it was not the direct influence of or communication from patient navigators, but the entire composition of the team that provided for more effective uncertainty
management. What came across in the data was the idea that the treatment and decision-making process could have been improved simply by the availability of a patient navigator.

Things would have gone much smoother if I had had the navigator from the beginning. If I had recognized all they could have done for me—I think it could have been easier. (P11)

Even when patient navigators were available, but the services were not regularly used, participants commented that it was nice to know that someone was available if they ever needed help or information.

We did have [a patient navigator], but I only had contact with her after my diagnosis and I started to plan what we are going to do . . . I mean . . . she was certainly available the whole time, but I felt I had enough support at home and I did not contact her. [S]he was wonderful, there was nothing wrong with her—she was there and she wanted to help and she said call me if you have any questions, if you don’t understand your diagnosis (P2)

The data from the quantitative survey, which revealed that the presence of a patient navigator on the cancer-care team seems to have an association with helping patients more effectively manage uncertainty, and the comments of participants in the interviews suggest that the nonverbal aspect of simply offering patient navigators as an option to patients can positively affect a patient’s ability to manage uncertainty. This represents an extension from what we already know about UMT because it moves beyond the direct communication offered by cancer-care team members and considers how the composition of the team—even from the perspective of patients just knowing that providers are available—can affect feelings of uncertainty and how patients manage it. Further experimental research that assesses how various team structures and variations patient navigator communication competency influence uncertainty could help to
show that there is a direct effect between the type and quality of cancer-care team members who are available to patients and effective management of uncertainty.

**Influence of proxemics on uncertainty management.** The second significant theoretical implication has to do with influence of proxemics—through the structural space of the cancer center—on uncertainty management of breast cancer patients. Proxemics have to do with the “perception, use, and structuring of space as communication” (Burgoon, Buller, & Woodall, 1996, p. 70). In the context of breast cancer diagnosis and treatment, proxemics can refer to many things, such as the location in which providers and patients situate themselves when communicating (e.g., is the provider sitting behind a desk, next to the patient on a bench, or standing next to the patient while the patient sits on an exam table, etc.; see Parrott, 2004). In a study of the influence of electronic medical records on the medical interview, the location of the medical record was an element of proxemics that influenced how the exam room was set up (McGrath, Arar, & Pugh, 2007). The spatial arrangement of the room reportedly influenced the amount of effective communication a provider could have with a patient while also using electronic medical records.

In this study, proxemics refers to where the various provider offices were located, as well as the treatment areas (i.e., infusion center and surgical suite) that patients had to access. These proxemic factors influenced the patient experience and ability to manage uncertainty. The structural set-up of the cancer center had a big impact on the experience of four interview participants, two of which are represented here.

[Y]ou know, once I could think about it I thought, well this is really nice to have this all right here. And actually my friend is at a different hospital and it’s a little less connected. Like her onco[logist] is in one building and she has to leave the building and across the
street to get the chemo. Which just wouldn’t be as nice as having it all in one place. [S]o it took away some of the stress to have everything right there and not have to figure out a new place to go or where anything is. (P5)

So, I don’t know I mean obviously, [the local branch I went to and the main hospital] are connected, they are both really close to each other—they are like 5 minutes a part, but I felt like there was a big pool of resources that I wasn’t aware of. In the long run, I loved being at [the local branch], it was a really small hospital. Like when I was admitted to the hospital for days, it’s tiny and it feels much more . . . much less overwhelming than a big huge high rise hospital, but it was like [the branch] oncology unit is kind of operating independently than all of this other stuff that is happening [at the main hospital], so I don’t know how they are connected, but it didn’t seem like they were connected very much. (P8)

The role of the patient navigator was initially added to cancer-care teams as a means of helping patients more easily access services within the healthcare system (Freeman, 2006). However, another element of helping patients to navigate the system more effectively and manage the uncertainty of now knowing where appointments are being held and treatments being administered comes through improved structural planning of cancer centers. Future research involving this theoretical phenomenon could improve our understanding of how uncertainty differs between patients who complete treatment at structurally disjointed facilities and patients who complete treatment at facilities where proxemic variables relating to structural elements of treatment have been carefully planned.

Applying theory was one of the primary purposes of this research project. Outcomes revealed important contextual support for the application of UMT during breast cancer treatment
decision-making and the extension of communicative influences on the management of uncertainty. Further research to address communicative means by which uncertainty can be managed in applied health settings will continue to expand our theoretical and practical understanding of UMT.

**Interpretation of Results**

Breast cancer patients who had finished active treatment within three years were recruited for this study and completed an online survey to understand the composition of their cancer-care teams, assess their perceptions of patient-centered communication and decisional conflict during treatment, and gauge participants’ feelings of satisfaction about the cancer care experience (n = 124). Subsequently, eleven women were recruited to participate in semi-structured interviews about their breast cancer experience. The following section first reviews the results that characterize the role that a patient navigator played on a participant’s cancer-care team. Then, an interpretation of quantitative hypotheses with supplemental data from qualitative responses are presented in the latter part of the section, which is organized in terms of the three concepts considered in this research, (a) patient centered communication, (b) decisional conflict, and (c) patient satisfaction.

**Patient navigator role.** The job titles for a PN described in prior scholarly literature and those surfacing in the pre-study investigation were consistent with the titles that participants suggested during interviews. Examples of what participants reported included, patient navigators, nurse navigators, social workers, oncology social workers, and nurse case specialists. Previously, I described how the titles used for cancer-care team members performing functions of patient navigators are not consistent (Hook, Ware, Siler, & Packard, 2012), which was supported by interview transcripts. However, the responses were consistent with previous
research about the functions of patient navigators. Functions described in previous literature included, emotional support (Yosha et al., 2011), information about the disease and treatments (Campbell, Craig, Eggert, & Bailey-Dorton, 2010), navigating the health system (Dohan & Schrag, 2005), and recommendations about resources that could help patients during treatment (Fiscella et al., 2013). These functions were echoed in the comments of seven participants.

Representative statements included:

[The nurse navigator] was just right there to help me with getting back on my feet. Would I be ok once I was sent home? Did I have someone to help me out? She gave me information on care providers [and] home health care providers, if I needed it. I mean, just knowing that I was never going to be able to go back to work again. She helped me go through the whole process to apply for social security. The nurse navigators, they were just amazing too. Even though they hadn’t experienced what I was going through, they had talked to so many other women that they could relate to my worries and concerns. (P1)

The social worker would help me understand why people say things that they say. Why maybe certain family members that I thought would be there—weren’t necessarily there and others came from out of the woodwork and always wanted to be there. (P4)

At the beginning of this whole diagnosis, you’re just so frazzled and upset at everything. I think it was helpful that I didn’t have to do any [appointment scheduling]. It was nice to have [the patient navigator] set up all of the people I needed to see before I even saw the oncologist. (P5)

Meanwhile, other patients could describe the role that a patient navigator should play, but they did not receive this type of support from the navigator. Suggesting that even when a
navigator is not meeting the needs of the patients, the patient recognizes the communication need. The patient navigator is uniquely positioned to provide communication and services that can help improve the patient experience.

I know that there’s always a sense of trying to empower the patients and have the patients do as much as they can for themselves, but sometimes when I was going through the cancer treatment and my emotional roller coaster was all over the map, it would have been helpful to have somebody who would have taken the load of finding out some information for me. (P11)

I went to a cancer support group that was only breast and gynecological cancer and it wasn’t very supportive. It was run by a social worker and the nurse navigator and I guess I was extremely disappointed in that I was having all these cardiac issues, not one person was supportive enough to even do anything or help. (P9)

I do remember one time me calling and saying, you know, this is the part of treatment that’s making it really difficult is that [none of the navigators] are getting back to me. At the time, I didn’t know if I wanted to wear a wig or not. I didn’t know if wanted to get into naturopathic stuff and [whom] do I contact? But, there’s the other stuff, like you’re trying to navigate–do I want a wig? Don’t I want to wear a wig? How do I do this? How do I find this out? Is there anything I should be doing? I mean, that was the difficult part. I still don’t have the answers. (P6)

I didn’t even know there were navigators. I hadn’t been informed, there’s all these resources over at [the main hospital location], but I feel like I was at [the branch location], I kind of didn’t get a lot of that information. (P8)
With reliable functional results of the patient navigator role and similarly consistent data in the lack of consistency with the titles used in practice, I will continue to use “patient navigator” when referring to these cancer-care team members who were members of the participants’ cancer-care teams. I am doing this primarily for ease of understanding by the reader, but in a future section, I provide arguments for why a common title should be adopted in healthcare systems.

It is clear that the role of a patient navigator is important for providing a single point person for addressing patient needs and decreasing stress related to navigating the health system (Swanson & Koch, 2010). Patients had varying experiences concerning how the patient navigator actually contributed to the experience. One patient had a positive interpersonal experience with the patient navigator:

The navigator had a lot of compassion. She just seemed to know right away; she seemed genuinely that she wanted to help me in anyway that she could. (P11)

On the other hand, some participants reported an opposite experience with a patient navigator. One woman shared her thoughts about the support she needed, which the navigator did not supply.

I did have a [patient] navigator who was not terribly helpful. You know, my sense of what the nurse navigator would do would be to run interference for example when I was having all these issues, I would think that they would call the doctor, investigate other medications, investigate . . . something! Be supportive at least, but that didn’t happen. (P9)

Since patient care is an interpersonal relationship, differences will exist between each patient’s experiences. This consideration could explain some of the variation that was seen
between participants who had a patient navigator on their cancer-care teams and those who did not. The training and credentials of providers working in the patient navigator role is not regulated (Academy of Oncology Nurse and Patient Navigators, 2015), thus the communication competencies of patient navigators likely have variability. This would suggest that the variation in communication competency of patient navigators could be responsible for the differences that are seen in this study.

Another possible alternate explanation could be patient engagement in the care experience. For this research, patients are asked to recollect their cancer decision-making experience and report the members of their cancer-care team. This retrospective response was the way in which participants were divided into groups to consider differences in experiences between those who had a patient navigator and those who did not. Thus, it could be that the participants who remembered having a patient navigator were simply more engaged in their care and experience such that they were better able to remember the patient navigator now after time has passed. An increase in general engagement in this group of participants could be a confounding explanation for the variation between participants who had a patient navigator on their cancer-care teams and those who did not.

However, the general valence of the experience should be similar if patient navigators are providing patient-centered communication. In this study, some participants who were included in the “patient navigator present” group provided feedback during qualitative interviews, which suggested that patient navigators were not a prominent influence on their experience. Thus, patient-navigation may have been more about the collective of cancer providers rather than patient navigators specifically. This speaks to assertions by Dohan and Schrag (2005), suggesting that the patient navigator may be most influential on the dynamic of the entire cancer-care team.
They stated that the mere availability of a patient navigator could influence the “culture of the health care setting itself and influence the way the health care team as a whole delivers care” (Dohan & Schrag, 2005, p. 854). Thus, when the cancer-care team includes a patient navigator, hospital systems and clinics may be better able to provide patient-centered communication. These qualitative data suggest that interpretation of the results in this study should focus on not the specific provisions of care by the patient navigator, but on the collection of support that women receive when they do and do not have a member on the team who is providing the services of a patient navigator.

The role of the cancer-care team in supporting patients’ decisions is an important element of emotional and informational support. Korber, Padula, Gray, and Powell (2011) suggested that patient navigators could help patients by “just being there” (p. 47) and offering intentional presence for the patient who is making a decision. Subsequent research that considered the variation in support felt by patients when making treatment decisions could provide helpful practical implications about expanding the cancer-care team to include patient navigators.

Implications of hypotheses. With the role and functions of a patient navigator established from the combination of existing literature and data from qualitative interviews, the context by which we can interpret the remaining data resulting from this study is established. The following section provides interpretation of the hypotheses presented in Chapter 3 and is organized according to the three concepts of primary interest: (a) patient-centered communication, (b) decisional conflict, and (c) patient satisfaction.

Patient-centered communication. The concept of patient-centered communication (PCC) refers to communication that “involves the patient in the consultation, explores the patient’s ideas and concerns, and assesses and responds to the patient’s understanding . . . as a means of
focusing on the patient as ‘whole person’ in the context of his or her psychological and social circumstances” (Mallinger, Griggs, & Shields, 2005, p. 343). Data from this study revealed that three dimensions emerged from two measures of patient-centered communication (Mallinger, Griggs, & Shields, 2005; Safran et al., 1998; Takayama, Yamazaki, & Katsumata, 2001): (a) interpersonal sincerity, (b) patient engagement, and (c) individual confirmation.

We know that when patients have more support during treatment, they report a better overall care experience (Jean-Pierre et al., 2011) and also experience improved health outcomes (Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Larsson, Widmark Peterson, Lampic, von Essen, & Sjoden, 1998; Pollak et al., 2007). When a patient navigator was included on the cancer-care team, patients reported higher scores on all dimension so patient-centered communication. Although these results are exciting, they are not necessarily surprising. The presence of a patient navigator revealed that patients reported experiencing significantly more engagement in the treatment experience and confirmation that their individual needs were being addressed. This suggests that there is a connection between the communicative practices of cancer-care team members and the reported experience of patients.

In this study, the inclusion of a patient navigator as part of a patient’s care experience implies an underlying appreciation from the team to better understand patient needs and make communication accommodations accordingly. If a health system is willing to hire patient navigators and offer them to patients during care, then they likely place importance on communication and patient-centered care, which helps one to understand the significant differences between patients with a patient navigator on the team versus those who did have a patient navigator on the team. The associations with and influence of patient-centered
communication on decisional conflict and patient satisfaction are discussed in subsequent subsections.

**Decisional conflict.** Decisional conflict is an important concept when it comes to improving the experience of breast cancer patients because the disease requires patients to make many decisions about treatment (O’Hair et al., 2003), and the preference-sensitive nature of the disease suggests that there are few decisions that would be considered wrong (Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007). In this study, decisional conflict referred to “uncertainty about the course of action [one should] take” (O’Connor, 1995, p. 25), as represented by five dimensions, which were established using factor analysis with the collected data: (a) informed treatment choice, (b) clarity of breast reconstruction choices, (c) satisfaction with treatment choices, (d) informational uncertainty, and (e) decisional support.

**Influence of the presence of patient navigators on decisional conflict.** The effect of a patient navigator as part of a cancer-care team led to hypothesized outcomes for all dimensions, but only one dimension, decisional support, revealed a significant mean differences between patients who had patient navigators and others who did not.

The implication of the outcome that patients who had a patient navigator on their cancer-care teams reported feeling more supported in their treatment decisions aligns with the primary purpose of patient navigators for providing informational, emotional, and tangible support to patients during decision-making. Receiving informational support is an important part of the experience patients should have when a patient navigator is a member of their cancer-care teams. Arguably, the more information a patient receives about options, the more they should feel that they made informed treatment choices.
The dimension of informed treatment choice focused on patients’ judgements of whether or not they had the right amount of information when making decisions about treatment. It would be reasonable to conclude that patients who felt that they received support while making decisions about treatment would also feel as though they received sufficient information during treatment decision-making and, subsequently, made an informed choice about treatment.

Empirically, a post hoc assessment using bivariate Pearson correlation was made to determine the relationship between these variables, and a positive significant relationship was detected ($r = .54, p < .01$). This result provides support for the implication that when cancer-care teams include patient navigators a patient’s feelings of support during the decision-making process are increased, which correlates positively to a patient’s feelings about having made an informed treatment choice.

Beyond informational support during decision-making, it is also important to consider how emotional support can affect a patient’s sense of support for their treatment decisions. Although the emotional side of decisional support was not assessed through quantitative items, qualitative results suggested that emotional support was important during decision-making and seemed to align with a patient feeling more supported in their treatment decisions.

So, [my husband and I] talked about it and ultimately that we would do [chemotherapy] because I was so young and so healthy and we thought I would have a good outcome from it and so we met again with [the oncologist]—he was very supportive in my decision. He felt that was a good decision that we made and he agreed with us and we decided on preventative chemo. (P10)

I talked to my husband [about my decision] . . . and, um, before the surgery we had a party, just the two of us. We don’t drink, so we had sparkling apple cider and we
took a couple of pictures of the girls and I hid them away, you know because if at first
I’m having a hard time dealing with it because I can look. Because honestly, I can’t
remember what it was like to have two now. (P4)

But I told [my daughter that] I don’t want [chemotherapy] no more. I wanted her
to understand that it’s my choice and I asked her, “Are you going to be ok with that.
You’re not going to hold it against me?” She said, “no mom, it’s your decision,” and she
saw the frustration I had with that one treatment. Because it does affect them.
Emotionally or whatever, it does affect them. (P7)

The importance of informed and supported decision-making is highlighted clearly in
these results, but one participant provided a clear statement to summarize the role of the cancer-
care team in this process.

The most important thing is to give women all their options before they make a decision.
You know I just think that surgeons . . . sort of . . . and maybe it’s particularly female
surgeons because they get it with the breasts, but I just feel like, you know, they are very
influential in their own beliefs. (P9)

Future research that specifically addresses the perceived magnitude and quality of
information, emotional, and tangible support when a patient navigator is on a cancer-care team
versus an experience when a patient navigator is not on a cancer-care team would help to show
how support varies with cancer-care team composition. Since breast cancer decision-making is
often described as preference-sensitive an important element of providing patient-centered care
is supporting a patient’s decision regardless of their preferred course of treatment. The results,
showing a significant increase in feelings of support while making decisions for treatment from
women who had a patient navigator on their cancer-care teams, suggest a more patient-centered approach to treatment and care.

*Influence of patient-centered communication on decisional conflict.* Patient-centered communication was a significant predictor of participants’ feelings that they had made an informed treatment decision, were clear about the available choices for breast reconstruction, were satisfied with their treatment decisions, were unsure about needing more information to make a decision, and were supported in the decision-making process. These results support previous research that suggests a positive influence of patient-centered communication on the patient experience (Mead, Bower, & Hann, 2002). Two examples in the interviews show the dichotomy of what happens when a patient experiences patient-centered communication, versus when a patient does not experience patient-centered communication. Both patients had a clear sense of what they wanted, but only one was able to convince the cancer-care team of her preferences.

So as far as my cancer team, they really didn’t have any input. When I went to see my breast surgeon, my husband and I walked in and she comes in, introduces herself, and she goes, “We’ll talk a little bit about breast cancer, we’ll discuss your pathology report, and then we’ll talk about options.” And I said, “that’s great, I don’t know that much about breast cancer. I said, as far as options, there are no options. I’m having a bilateral mastectomy, no reconstruction. Preferably, no chemo, preferably, no radiation, but that is going to depend on obviously what you find when the breasts are removed.” She didn’t try to pressure me at all to have reconstruction or anything. She said, “I do have to go over reconstruction with you.” I said, “I know, informed consent, but make it quick because it’s just not an option.” (P6)
I wanted to make sure that [the cancer] was gone and actually I requested that they take both and that way I would never have to worry about it. You know, I figured at 55, you know my husband and I . . . it’s not a big deal for us. I still wish they would have taken both because it’s exceptionally difficult to match—so I can’t wear sweaters or anything like that because one is way up by my chin and one is way down by my belly, so it’s very hard. They refused to do both because they said it was so small. They didn’t even want to do the mastectomy. And then afterwards, they said they were really glad because they would have had to do that anyway because it had spread. So I think we know as people, men and women, we know our bodies better than anyone else. I don’t think [I could have gotten the double mastectomy], I tried and tried. I had documentation on why [a double mastectomy] would be better and no. They said no. (P4)

Both of these anecdotes serve to show that cancer-care teams who provide patient-centered communication can better adjust the information and choices that are shared with patients. This, in turn, can make women feel as though their treatment choices are more supported by members of the cancer care team. All of this speaks to the preference-sensitive nature of breast cancer treatment decisions and the need for cancer-care teams to adjust communication accordingly for each patient.

A second means of assessing the strength of these relationships was to consider effect size, of which three—informed treatment choice, clarity of breast reconstruction choices, and satisfaction with treatment decisions—had medium effect sizes, while a participant’s feelings of needing more information to make decisions and support they received during treatment had small effect sizes. Within these relationships, there was one surprising result, that between patient-centered communication and informational uncertainty, which merits specific discussion.
The overall model where patient-centered communication was regressed on informational uncertainty revealed a significant and positive overall relationship, which was not predicted. However, when considering partial correlations between the individual dimensions of patient-centered communication and a participant’s feelings of uncertainty about their information needs, the relationships were greatly diminished, with small effect sizes and non-significant results. Although this result suggests that no real relationship may exist between dimensions, the result of the overall model should be addressed.

Results of the complete model suggest that the more patient-centered communication a participant experienced, the more informational uncertainty they felt. The items tapping this dimension of decisional conflict focused on the uncertainty about what to do with a treatment decision and whether or not the patient wanted more information about options. The quizzical issue with this result is that previous research has consistently indicated that information improves the cancer experience (Kerr, Engel, Schlesinger-Raab, Sauer, & Holzel, 2003; Roberts, Cox, Reintgen, Baile, & Gibertini, 1994), as well as helps to manage stress management during decision-making (Kreps, 2003; O’Connor, Legare, & Stacey, 2003). Therefore, alternative explanations must be explored; two are described in the following paragraphs.

One possible explanation for this result is that when people face outcomes that they feel are bad, such as death following a breast cancer diagnosis, an increase of uncertainty can help maintain hope that the negative outcome will not happen (Ford, Babrow, & Stohl, 1996). Perhaps what we see in these unexpected data between informational uncertainty and experienced patient-centered communication is that when cancer-care teams provide more patient-centered communication, patients feel a greater sense of uncertainty about negative outcomes and, therefore, more belief that a positive outcome is likely. Further support for this explanation is
seen when informational uncertainty is correlated with decisional support ($r = .33, p < .01$) and satisfaction with treatment choices ($r = .47, p < .01$). These relationships suggest that when patients feel uncertain about the information they have received, they are also feeling more supported and satisfied with their ultimate choice. One possible way to look at this, then, is that when there is uncertainty in the information about treatment choices, patients have few things to consider and can therefore feel less disagreement with what they experienced and what the other possibilities could have been. If this is true, an important implication for the decisional conflict literature is that the dimension of informational uncertainty seems to follow the predictions of UMT.

A second possible explanation for the unexpected direction is related to previous data about information overload following diagnosis (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004). Although more information can improve the breast cancer experience in the long-term (Vogel, Leonhart, & Helmes, 2009) and patients want more information throughout treatment (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004), there may be a point when it becomes too overwhelming. Two participants suggested that they were relieved when some treatment options were taken off the table for clinical reasons, making it easier for them to make a choice from fewer options. Meanwhile, two women felt that the amount of information they received may have been more than was necessary and it complicated the situation.

I got my results at the beginning and my course of treatment wasn’t any question—it was just you’re starting chemo and you’re starting it next week. It was helpful that there was a plan and I didn’t have to decide on the plan. It was just the plan that was going to happen and then you get more used to it, then you have less things to stress about and more things that you can decide about. (P5)
So at some point we decided, yes, I’m going to do reconstruction. I mean, conveniently there were a lot of choices that I didn’t have to even think about. Like some people can keep their nipples and I can’t because it’s a cancer in your milk duct, [so] you can’t keep that. It was a lot of that kind of [decision-making] taken out of my hands, which was good. (P8)

These excerpts help to explain the correlation that was seen in a post hoc analysis of the relationship between informational uncertainty and satisfaction with treatment choices \((r = .47, p < .01)\); women who have more uncertainty about information may feel that fewer treatment options made it easier to feel satisfied with the treatment decisions they made. Additionally, an analysis of the relationship between the participant feeling that they made an informed treatment choice and informational uncertainty revealed a significant positive correlation \((r = .39, p < .01)\). This also supports the notion that when there is less known about treatment choices you can feel more confident in how informed you were in your final decision.

Regardless of the explanation for why this relationship surfaced in the case of informational uncertainty and experienced patient-centered communication, there exists the responsibility of the cancer-care team to provide the magnitude of information that a patient desires. As Levenstein, McCracken, McWhinney, Stewart, and Brown (1986) pointed out, patients need providers who are sensitive to the feedback about the necessary communication each patient desires. In one example from the qualitative interviews, a participant stated that she was regularly asking her cancer-care team for information and explanations, which they were not providing.

She has a tendency to order a bunch of lab work without telling me what it is she’s looking at. Whether it’s because they don’t want to worry me or I don’t know . . . I just
don’t know why they don’t do that. Especially, I try to tell them, I’m a nurse, I’m interested in these kinds of things, I want to know. I get that some people would have more anxiety if they were told—oh, I’m looking for multi-myeloma, I’m looking for copper deficiency, but I try to tell them, I’m someone who wants to know. I’m into numbers, I’m into the science, I’m into the curiosity of it. I just get really turned off when I don’t get told. (P11)

This example provides support for the necessary practice of listening for patient’s informational needs and adjusting the providing patient-centered communication and information accordingly. The three other dimensions of decisional conflict (i.e., informed treatment choice, satisfaction with treatment choices, decisional support) showed the predicted outcomes when correlated with experienced patient-centered communication; for all three dimensions, the relationships were positive and statistically significant. Multiple regression analysis was used to test these relationships, such that all three dimensions of patient-centered communication—interpersonal sincerity, patient engagement, and individual confirmation—were entered as predictor variables. Thus, the partial correlations of each predictor with the criterion variable could be assessed to determine if a relationship was maintained when controlling for the other predictors.

As previously described, the partial correlations when informational uncertainty was the criterion variable resulted in non-significant results with very small effect sizes. The second criterion variable where relationships no longer existed with any of the predictor variables was that of decisional support. The remaining three criterion variables, informed treatment choice, clarity of the breast reconstruction choices, and satisfaction with treatment decisions maintained some significant relationships.
There were several unsurprising results because they aligned with the pertinent scholarly literature on patient-centered communication and decisional conflict during treatment decision-making. An interesting result was that all of these relationships were between the level of interpersonal trust participants felt in the cancer-care team and the feeling that they made an informed treatment choice, believing they were clear on the available breast reconstruction choices, and satisfied with treatment decisions. The strongest relationship was between participants’ feelings that they made informed treatment choices and the amount of trust patients felt in the interpersonal relationship with members of the cancer-care team, which accounted for nearly half of all of the variance in the overall model assessing the influence of patient-centered communication on participant’s feeling that they made an informed treatment choice. This suggests that the more trust a patient has in the cancer-care team, the more they will feel their decision was well informed. Similarly, communication of interpersonal trust by the cancer-care team also predicted that participants would have more clarity about their breast reconstruction options and feel satisfied with their treatment decisions overall.

The idea of trust is an important factor of conceptualizing patient-centered communication (Politi & Street, 2011), but it may also play a more critical practical role that providers can foster. The items that measured a participant’s level of interpersonal trust centered on questions regarding whether or not the participant felt that they were being told the truth verbally, but that nonverbal aspects of communication conveyed trust (e.g., looking the patient in the eye, acting friendly and warm, and listening attentively). These results suggest that interpersonal communication skills training for cancer-care team members could influence a patient’s overall trust and therefore make them feel more informed about their options and more satisfied with the treatment decisions.
One explanation for the more pronounced experience of a trusting and personal relationship with cancer-care team members when considering satisfaction with treatment choices could be that trustworthy and genuine providers give patients the feeling that all of the options applicable to their case were on the table and that the patient could feel satisfied with the choice that was made. One participant provided a story that suggested the way in which the provider communicated with her on an interpersonal level, made her feel more confident in her treatment choice.

When I first saw [my surgeon], my blood pressure was like 200/100, it was just outrageously high, I was crying I was really upset and she just kind of sat down and said, “you know, I know you’re fearful. You’re a nurse, so you see worse case scenarios, but I just want you to know that this is treatable. You will always be a cancer patient, but you won’t always have cancer.” Then she went on to tell me, “What is worrying you right now?” So she got the emotions out of the way, first–at that time I was worried about my kids, that I was going to die and leave my kids alone. I thought that that was really great the way she handled it. She got me calmed down, she got the emotions out of the way and then she said, “Ok, here’s what we can do; and then she explained the lumpectomy first and then she said, now some women opt for a mastectomy and we can certainly do that if you want. She was somewhat careful about giving her opinion–like what she thought I should do, but I sort of sensed that she thought I ought to go the lumpectomy, I don’t know why, it wasn’t anything in particular that she said. I know, that me myself I was saying, it sounds like the lumpectomy is the easiest way to go first and she kind of took a deep breath like she was kind of glad that I said that, you know. (P11.)
There was a fourth significant relationship discovered in partial correlation analyses; that of the relationship between the level of engagement a participant felt from the cancer-care team and a participant’s feelings of having made an informed treatment choice. This relationship was hypothesized to be positive, such that more engagement predicted more informed patients, but the results indicated a negative relationship ($r_p = -0.24$, $r_p^2 = 0.06$). This suggests that when participants experienced more engagement in their treatment experience, they also felt less informed about the available choices for the treatment. It should be noted, though, that the effect size of this relationship is quite small – explaining only 6% of the variance.

One explanation for why the relationship was negative relates to the debate regarding a patient’s preference for participating in decision-making. Some scholarly literature suggests that participating in the decision-making process can lead to distress and anxiety in patients (Butow, Dunn, Tattersall, & Jones, 1994; Pierce & Hicks, 2001). The negative relationship seen above suggests support for this argument. Hence, if patients are more engaged in the process, they may feel as though the results of their decision are their own doing. If the onus of the decision is on the patient, she may never feel as if she has sufficient information to make an effective choice. Support for this suggested explanation was evidenced in the comments of one participant.

We were emotionally [focused] in our decision, but [the oncologist] was methodically researching things and everything else. So ultimately we felt like that was his decision and even though we were so disappointed, we kind of had to relent to him because, well, he’s the one that knows best because he’s the doctor. [H]e’s the one making my life decisions right now. [I]t was disappointing, but we had to give in because he was the one saving my life essentially. (P10)
The experience of this participant suggests that when a difficult decision was relented to the cancer-care team, she felt less burden to make that decision and more encouraged that the choice was an informed one. By better understanding the preferences of patients for engaging in the treatment experience and decision-making, cancer-care teams will be better able to gauge the level of engagement that patients experience.

Decisional conflict is a concept that has received limited attention in research when considering patient navigation as part of the overall cancer-care experience. The results of this study provide explanations for some hypothesized results, while also offering suggestions for where additional research on the concept would be helpful. For all of the relationships that emerged in the data, however, it remains important to remember that women are facing a great number of treatment decisions just after a terrifying diagnosis, communication can play an important role in helping to ease that strain. Through skills training and improved vigilance by the cancer-care team, patients may be able to manage their emotional and cognitive responses to decisions more effectively by receiving more effective patient-centered communication.

**Patient satisfaction.** Although the connection between the amount of patient-centered communication experienced by participants and patient satisfaction with the care experience has received a good deal of support in relevant commentaries (Aharony & Strasser, 1993; Mallinger, Griggs, & Shields, 2005; Roberts, Cox, Reintgen, Baile, & Gibertini, 1994), research into how patient navigators may influence patient satisfaction with the care experience is expanding. An additional boost of importance for the study of patient satisfaction with the care experience is that the NCI’s Patient Navigation Research Program (PNRP) identified it as a primary outcome for patient navigation (Jean-Pierre et al., 2011). The conceptualization and measures developed by the PNRP were employed in this study, which states that patient satisfaction refers to “the
extent to which patients’ healthcare experiences match their expectations” (Jean-Pierre et al., 2011, p. 854). As expected, patient satisfaction scores were higher in participants who had a patient navigator on their cancer-care teams, but the only significant result was in considering a patient’s satisfaction with cancer care. Also expected was the positive significant correlation between the amount of patient-centered communication participants experienced and patient satisfaction with the care experience. These results were also reinforced by interview data concerning how patient navigators contribute to more satisfaction in the care experience.

[The nurse navigator] was there and she wanted to help and she said call me if you have any questions, if you don’t understand your diagnosis, if you want me. She explained a few things on [my diagnosis report]. She did offer me more time because the surgeon was going to help me make the decision and she pretty much helped me understand the report and what exactly was on there. (P2)

[Tara: What did you like most about having a nurse navigator available to you?] Just knowing that I had someone to call, if I need to speak to someone regarding any health issues or any concerns that I had once I returned home. Knowing that she was going to point me in the right direction of [whom] I needed to speak to and what I needed to regarding whatever my concern was at that time. (P1)

Things would have gone much smoother if I had had the navigator from the beginning. If I had recognized all they could have done for me–I think it could have been easier. (P11)

More novel results were derived from the multiple regression analysis, which revealed that experienced patient-centered communication predicted increased patient satisfaction and was supported with a very large effect size. These results suggest important support for the
provision of patient-centered communication and the subsequently better experience for patients. Although this relationship was expected, the partial correlation suggested that this relationship was largely due to a participant’s experienced of interpersonal sincerity and feeling that they were engaged in the treatment process, which accounted for 72% of total variance explained by the overall model.

An observation growing from this research is that cancer-care centers would likely improve overall patient satisfaction with the care experience if they consistently offered a patient navigator to enhance the patient-centered communication experienced during care. One participant provided support for this notion.

It would be wonderful if everyone who was diagnosed was assigned a navigator? I mean I feel like that should just be like standard—wouldn’t that make sense? It would be nice to have one point person because I just ended up calling my oncologist a lot and her nurse would be like, “Oh, we don’t know what the answer to that is.” It would be nice if there was a point person that was just sort of there for your random questions, which would be good. I think that that would be nice. (P8)

There are likely many reasons why the presence of a patient navigator on a cancer care team might influence patient satisfaction with the care experience. One such explanation is related to immediacy and the idea that nonverbal behaviors that convey trust help patients to feel as though they have readily available access to the cancer-care team. Participants noted this during interviews with several comments concerning how nice it was to have a patient navigator to talk with whenever they felt a need or concern. For instance:

There was a nurse hotline at the breast cancer center that is manned by a nurse during the business day. You can call if you have any questions about anything or if something’s
happening and you’re having some kind of side effect and you want to ask about it. It made you feel like someone was there. (P5)

After I was released from the hospital, if I had any health issues, if I wasn’t feeling good, the nurse navigator was always there to talk to me. Give me some advice, some information about what I was feeling or if I should worry or be concerned. At the time I was dealing with certain issues, due to my surgeries and such. (P1)

Immediacy refers to nonverbal behavior that reduces the physical or psychological distance (Wanzer, Booth-Butterfield, & Gruber, 2004). There is support in prior scholarly literature for the improvement of patient satisfaction with the care experience due to the immediacy felt from patient-centered communication offered by the cancer-care team (Wanzer, Booth-Butterfield, & Gruber, 2004). This suggests the important role that patient navigators could play in providing a greater sense of immediacy for patients. When the cancer-care team provides greater immediacy, they are also allowing the patient to stay engaged in the process more easily, which has a significant positive relationship with feeling satisfied with the care experience. Thus, the care experience could be improved simply by allowing patients to have more access to the cancer-care team; something that could be accomplished with the use of patient navigators.

Even if immediacy does not come from the relationship with the cancer-care team, patients desire to have connections with people who can answer their questions, talk about problems, and support them when stress and anxiety arise. One prominent response of patients regarding informational and emotional support involved their use of the Internet. Following is a sample:
I Googled breast MRI and YouTube has some great videos. Some nice videos like this is what’s going to happen and then that’s exactly what happened so I wasn’t afraid when I got there, but it was still uncomfortable and weird. (P3)

I just did a lot of research on the Internet. I looked at John Hopkins, there’s a cancer treatment center in LA, a couple in Seattle. I went to different blogs to read what people were saying about different places. Because I knew this was a life-changing thing, I wanted to make sure I made the right decisions for me. (P4)

Some of the questions I had [for the survivor Facebook group] were about fertility because it is hard to get information and I was also seeing a nutritionist and so I would ask people food questions and stuff, because we could talk about it. They are just good support–like “I’m having my last chemo” and everyone’s all excited–and that was really good. (P8)

My friend said, “Ok, we’re going to find the best surgeons and the best oncologists and whatever we need to do.” So, she went online and she started researching and we found a surgeon that sounded like someone I wanted to talk to and as it turns out, she broke her arm the week before I was diagnosed, so she was not working. (P9)

However, a downside to the Internet use is that communication is, obviously, not filtered based on the preferences or needs of the patient; an important function of patient-centered communication.

I also went on the internet, which I quickly did not go on the internet much longer. Because it’s more . . . I don’t want to say factual, without any kind of compassion, but they did give statistics. Of course I was looking up stage 4 cancer and the information all makes it sound like you’re going to die. There’s too much negative stuff on the Internet
about stage 4 cancer. I learned from reading articles or books or things the nurse gave me. (P5)

My breast surgeon, when he did call with the diagnosis, he said, please stay off the Internet, but if you do want to do research, Komen.org is probably your best, safest bet to get any information off of. So, that was probably the only thing we did you for research was to go to their website and read all of the different treatment options and see what would be best for us. We felt comfortable with it, we felt it was enough given the timeline. (P10)

[Tara: How did you feel about having to find so much information on your own?]

I found it very frustrating. My medical team, my cancer team, they really should have been my Dr. Google, they should have been my internet. They added so much stress to me that was really . . . unfair. (P11)

In many cases, participants who used online resources suggested that there were downsides to this channel, which implies that there is likely an important role for both online and in-person navigation and support. In the final section of this discussion, a recommendation is made for future research about how technology may impact the patient experience. Regardless of where patients seek support and communication, they desire to have easy and quick access. In this study, empirical support is found for the influence of cancer-care teams that include patient navigators and patient satisfaction with the care experience. More research that assesses feelings of immediacy during breast cancer treatment decision-making can help to better understand the outcomes experienced by patients.

The second dimension of patient satisfaction, perceived inclusion in treatment decision-making, was significantly related to increased patient-centered communication. Although this
result is not surprising, partial correlations revealed only one significant relationship, which was between interpersonal sincerity and perceived inclusion in treatment decision-making. One explanation for this result could be that patients felt their cancer-care teams showed a genuine interest in them as patients and felt that they could share their preferences for treatment openly. Feeling trust in the cancer-care team was something that several participants suggested as a crucial element of a positive experience.

Find someone that you trust. This is your life and you want to make sure that you feel comfortable, that you rely on them. I’ve talked to so many women who say, “I’ve got this doctor and I don’t really like him. I say, “You don’t have to stay with him. Find someone that you feel comfortable with and that you trust.” I mean this is your life. There’s a doctor out there for everybody, you don’t have to stick with just one person if you’re not comfortable with them. (P1)

I did feel a lot of trust in [my cancer team]. Absolutely. The oncologist had us come into his office and he brought up his computer and showed us all of the [options] that I could have–what were the benefits and the negatives. And he explained them all to me and I felt really good with that. Because it gave me the choice instead of the doctor saying, this is the one you’re going to do. (P4)

Further investigation of decision-making preferences and style would help to expand these data. Some qualitative responses suggested that patients generally felt included in decision-making about treatment, while others felt as though members of the cancer-care team made the decisions.
I felt like I was in control the whole time, but for some reason I just really trust their choices, so I kind of when exactly with what they had planned out . . . mapped out for me. (P1)

I feel as though the oncologist had the final decision because he was the one that was driving my treatment and so since we felt like we didn’t know as much as he did. Obviously we had only just gone through a crash course in breast cancer. (P10)

I made the decision and it’s something that I have to live with and it’s going to be 4 years coming up. (P7)

A woman has to choose what it best for her; whether that’s bilateral mastectomy or whether it’s just having a single mastectomy with no reconstruction, no matter what they do, it has to be her choice. (P6)

I would say that I did not make this decision . . . I mean [the surgeon] didn’t say, “This is what you have to do,” but she didn’t present other possibilities. I didn’t feel as though I had a choice in terms of the way the treatment went. I felt like I was sort of railroaded along. (P9)

Regardless of who made the final decision, it was important that treatment options were presented and discussed with patients. The experiences of participants varied widely on what actually occurred with treatment, but the general consensus was that all options should be offered to patients.

At my very first meeting with the surgeon, I would have liked her to have present other options . . . other than lumpectomy, chemo, radiation. And at least we should have talked about what could happen, but I never felt like I got that information. I sort of felt like I
was being smacked with what was happening as it was happening, but no body ever said this could happen in advance. So I think that that was a problem. (P9)

I had several options and my oncologists, who were wonderful. I love my oncologist, she really laid out my options for treatment really very well in ways that made a lot of sense. (P8)

Patient satisfaction with the care experience is a variable that continues to receive attention in research and in practice. With policy guidelines for hospitals shifting to emphasize its use, there is a research need to help provide explanations for how improvements can be made. The connections between how much patient-centered communication patients experience and patient satisfaction with the care experience seem clear, now it is just a matter of implementing programs and empowering staff to practice the skills necessary to influence satisfaction with effective communication.

Pragmatic Implications for Breast Cancer Communication

Several important implications for improving communication with breast cancer patients can be gleaned from these results. Already in this discussion, I have discussed implications that suggest, the theoretical significance, the practical importance of patient navigators on the cancer-care team, and the feelings of immediacy that seem to arise in patients who have a patient navigator as part of their cancer-care team. In addition, the following implications are discussed in this section: (a) creating consistency in patient navigation research and practice, (b) improved communication about the timeframe necessary for breast cancer decision-making, and (c) the need for improved survivor support.

Creating consistency in patient navigation research and practice. Although there were mixed responses and mixed experiences by participants, there is a strong desire and need
for access to patient navigators during breast cancer treatment. Additionally, the functions of the patient navigator seem clear in the eyes of participants, such that effectively implemented patient navigation programs could greatly benefit to patients.

The cancer navigator is someone who talks to patients who are newly diagnosed with cancer and gets them resources that they need. Like in my case, this navigator gave me a wig, she told me about the support groups that I could go to. Basically if there were any kind of resources out there, she would help me get them. She was the one that told me about the [local organization]. They would give free acupuncture, massage, energy healing, sound healing, laughter yoga, meditation classes, art classes. (P11)

They set me up with a nurse navigator who made all of my initial appointments for me. I had a navigator who made all of my appointments for me and then after that, I didn’t really have someone who I would call a navigator, there was a nurse who gave me the initial . . . it was like a training, kind of an education about the treatments I was going to be going through. (P5)

The current challenge is that there is no clear and consistent role, title, or background for patient navigators. Better “patient-patient navigator communication” about the functions a patient navigator can provide would help to reduce situations where available navigators are ineffective for patients. Additionally, a national credential for navigators would ensure that patients would find similar backgrounds and training of navigators in different health systems. One group, the American Academy of Oncology Nurse and Patient Navigators (AONN), is working to implement certifications for practicing registered nurses to gain a better understanding of the needs and functions of a navigator and taking a qualifying exam before setting out to help patients as navigators (Academy of Oncology Nurse and Patient Navigators,
The fact that the Academy’s name includes two titles that are often used for patient navigators also points out part of the challenge in streamlining and creating consistency. A theoretical implication is that a better credentialing process and a stronger sense from patient navigators about the role they play, may result in more pronounced patient-centered communication being provided to patients. The efficiency and function of a cancer-care team is important for the members on the team, but also patients. One patient experienced this type of smooth integration of the cancer-care team and it contributed to a positive experience.

The team worked very well with one another. [T]he patient navigator was great. For what you had to go through, it was a really good experience. (P4)

Another participant’s comment about the integration and collaboration of her cancer-care team suggests that patient navigation could play an important part of having a positive patient experience. Although she did not use a patient navigator, she did agree that if providers do not work well together a patient navigator could help to enhance the quality of the cancer-care team.

I think that had my doctors not worked so well together, I would have definitely wanted a case manager or somebody to help me make those decisions. [A]ll of my doctors were working together and they all worked together on a regular basis, so I think that that helped move the process along because they all do communicate so frequently and work together so well. But, had that not been the case I think I would have definitely benefitted from and wanted a case manager or navigator . . . somebody to help me make those decisions. (P10)

The patient navigator could also help to manage the process of providing patients with a greater sense of what to expect by sharing experiences from other women and spending great lengths to discuss information and address questions. The patient navigator could be positioned
more as someone to talk at length about all of the possible side effects or scenarios the patient wishes to discuss.

So we kind of knew the broad things to expect, but stuff like weight gain, I wasn’t told to expect that. Especially as a young women, that’s something that I was pretty self-conscious about and I would have liked to have known up front. And when I brought it up to him, he kind of just brushed it off and I think that maybe they don’t’ see that as a big deal to us because you know, you’re surviving, you’re tolerating the chemo well, we’re not really worried that you’re gaining weight. But that’s something that . . . especially to a young women. I had acne breakouts because of the steroids that they prescribed. I would kind of liked to known what was normal and that that was going to happen. You know, it’s a hard thing to be a young women and go through a double mastectomy and then be bald because of chemo and you have all of these other side effects on top of that. [I]t’s kind of a lot to your self-esteem all at once. I think that, maybe knowing more of what to expect from chemo or from the entire treatment process would have helped me a little bit better. (P10)

The experience of unexpected side effects was a common theme in qualitative interview transcripts. Patients overwhelmingly suggested that they wished a warning had been issued in advance so that when things came up, they were ready for it.

Have them give you the facts right away. Like, ok, we’re going to this, but it could change because of this and that. I felt like I was lied to because they didn’t say, maybe we’ll do chemo[therapy]. [T]hey just said no chemo and no radiation because we’re going to take both breasts. I like [my oncologist], but I just got a little angry like I was lied to. So if they’re straightforward like, “Ok we’re going to give you this and this. Then
you know and you won’t feel like [gasp] and angry.” Give you the facts right there and then of what could happen, you know. Inform you of the possibilities of you having this or that. Because it does happen. (P7)

Additionally, navigators could be a source of emotional support for patients who are not getting it at home, which could help to improve the patient’s overall sense of satisfaction with the care experience.

[I] talked to some family members and they were very opposed [to a mastectomy]. Most people can’t understand why you would choose to do that. My sister, she said, “You don’t want to do that. You’re going to be a freak. Your husband won’t want to be with you anymore.” I said, you know, “We’ve already decided and he said it was ok.” I had people say it would make me less than a female. I would never be able to wear a V-neck or any kind of low-cut. (P4)

No, [my husband] was good about going to my treatments with me. Taking me, picking me up, but he was very very bad about helping me with any decisions. He was not a good support system whatsoever. (P1)

Where patients felt patient navigators should have less involvement was in providing the initial communication about options for treatment. Qualitative responses revealed that patients wanted to hear this information from the physicians on cancer-care teams (e.g., oncologist, surgeon, radiologist). Meanwhile, participants suggested that the patient navigator would provide clarity and review of the information.

I want to hear [information] from the doctor. I want to hear it out of their mouth. It’s a comforting thing. Ok, my doctor said this and this–to me, I want to hear it from them. I
think he calls the shots and everyone under him follows his direction. I still want the one-on-one with the doctor. (P7)

I felt more confident talking to [my oncologist and surgeon] versus [the nurse navigator] about treatment options. They were able to set my mind at ease. They were so good at telling me different choices that I had; what was going to be a better treatment for me. The question that you always want to make sure that you talk to somebody that you really feel comfortable with. They were the ones that really knew—I mean, I kind of put my life in their hands. (P1)

[The patient navigator’s] role was to help me cope with the treatment of cancer and have one more person to talk to about things and bounce things off of. And to ask questions. They were very medically savvy and I could ask about the different medications I was on. (P4)

The navigator pretty much gave me the same information that had already been given to me. She did offer me that more time because the surgeon was going to help me make the decision and she pretty much helped me understand the report and what exactly was on there. (P2)

These responses imply that patients feel the role of a patient navigator is one of secondary information sharing and review, with a focus on recommendations for tangible patient resources. These data are consistent with recommendations by Swanson and Koch (2010), who suggested that patient navigators provide supplemental information to limit confusion and improve team efficiency.

The results of this study suggest a balance is necessary for the amount of information that should be shared with patients—some patients desire to know as much as possible, while others
wish to simplify. By improved certification and education of patient navigators about how to
gauge the level of information desired by patients and provide effective communication
accordingly, there could be improvements in the magnitude of patient-centered communication
experienced by patients, efficiency of the cancer-care team, and overall improved health
outcomes. The practical caveat to placing emotional and informational support responsibilities
on patient navigators is the necessary caseload for each navigator. The emotional toll faced by
patient navigators who must regularly communicate information, options, and support for such
serious and traumatic issue could result in navigators facing their own emotional stress and
subsequent support needs. Further research about emotional support needs of patient navigators
may help to improve certification programs and contribute to longevity in the career.

**Timeframe for diagnosis.** A second implication for breast cancer communication relates
to the timeframe in which women are making decisions about treatment. Prior research suggests
that treatment begins between 10 and 14 days following diagnosis (Harcourt et al., 2003). The
participants in this study, however, suggested that communication could be improved by
suggesting to patients that they have time to process the information and gather their thoughts.
The undertone of the comments typically suggested that participants think back and, in hindsight,
feel they did not need to make and implement treatment decisions so quickly. Having a more
extended timeframe for decision-making may allow for a clearer perspective for patients about
what they wanted from treatment. Several anecdotes from the qualitative transcripts shared this
sentiment.

It’s funny, when you get diagnosed, you feel like obviously something should happen
tomorrow—we should fix it immediately, so there’s obviously lag time where you’re just
[impatient tapping on table] . . . what am I doing? I should be doing something. [L]ike
here you are, we found it, we’re going to work on it, but it doesn’t have to happen tomorrow. I mean, I knew several people who were in surgery within days because they were like get it out, let’s do it, do surgery now and it’s like . . . I think there’s definitely a benefit to taking a few breaths, figuring out what you really want and how you want it to go and feeling really comfortable in your decisions, instead of panicking and doing whatever. (P8)

I rushed through it, because, I was worried about getting back to work, I was worried about losing my job, which was part of the reason why I rushed through it as well. And in retrospective I really didn’t need to rush through it. I think I would have had a much different experience if I had just taken a couple deep breaths and went through it calmly. (P11)

Although survivors feel that the time frame can be extended, providers seem to consistently stress that immediate action is necessary. In the example of the woman who was told by the physician that she needed to act quickly, the emotional ploy of suggesting, “who would take care of [her] husband,” put undue discomfort on her and perpetuates the belief that patients must act immediately after diagnosis. This story suggests that not only are women panicking to address the disease and “get it out of their body,” but providers may also be pushing women to act quickly, when in many cases a small amount of extra time would make the decision-making process more effective and not likely affect the long-term survival rate. What could be gained in communicating a thoughtfully longer decision-making period is less anxiety following diagnosis and an improvement in long-term satisfaction with the care experience–and satisfaction with the decision itself.
**Survivor support.** The trauma faced by cancer patients is well-established (Brown, Stewart, & McWilliam, 1999); because of these results, efforts have been made to research and suggest communication practices that help with the sharing of bad news and cancer diagnoses (Fallowfield & Jenkins, 2004). What has been less studied is the communication of what may seem like good news—sharing that treatment is nearly finished. This news is actually met with a great deal of stress and fear by patients. In fact, participants suggested that finishing treatment might be as traumatic as being diagnosed and beginning treatment, which echoes data from previous research (Korber, Padula, Gray, & Powell, 2011).

Although the completion of treatment can be a time of happiness, excitement and gratitude, there are undertones of stress and anxiety about recurrence that nearly all interview participants suggested. This constant fear of something happening when they least expect it puts a large amount of emotional strain on survivors that could ultimately impact their health and quality of life.

I’m still a little nervous. I guess, the statistics of it coming back are pretty small, but that window is only 5 or 10 years. So does that mean that it could come back in the same breast? The thing is, it’s not because the breast was infected, right? The one time I had cancer. There’s something in my body that’s mutating my genes or my cells that causing the cancer. So now I’m thinking that it’s related to how I’m living. (P2)

I was just cleared by the oncologist. [M]y tumor markers are clear, no expectation of it coming back, but we wait every day for the other shoe to drop. (P9)

I mean, you know, I still have those fear moments. Especially when I’m with my daughter. Like what if . . . what if it comes back, what if whatever. But overall, I think
it’s definitely helped me appreciate being alive and you see people who complain about getting old and I’m just like–can’t wait! It’s awesome! (P8)

The trauma and possibility that they could succumb to breast cancer often changes the perspective of survivors. Providing services that help to address the trauma faced at diagnosis, during treatment, at the completion of treatment, and then during survivorship may be able to help patients to integrate back into a routine that fits their new perspective in a productive way.

Some women stated that they were forever changed following breast cancer treatment, which suggests that survivors may benefit from talking with women who have had similar experiences and understand the experience first hand.

It’s just a new normal. I have found that, fundamentally, I’m not the same person I was before cancer and that was one of the things that the therapist and I talked about. I just kept thinking my work wasn’t that important. We don’t work in cancer we weren’t saving people’s lives, it wasn’t a big deal and it was adding so much stress. [The therapist] is like it’s okay to have a different outlook. I just feel like it makes you different and you come out of it different because you look different, and you feel different, and your outlook on things is different, your perspective on things is different, and I’m still trying to figure everything out. (P3)

It may sound cliché but it really does change you and it changes your outlook on things and I used to think about far into the future and now I’m more worried about what’s right now. (P5)

The provision of survivor programs that provide emotional and informational support to patients after they are finished with care is an area of research and practice that deserves a great deal of attention. Although rates of breast cancer diagnosis remains high and research on the
process of treatment deserves continued support, it is the experience after a patient is finished where she often feels completely on her own. Long-term retrospective studies of breast cancer patients may help to show how the effects of the emotional trauma persist and suggest areas where programs could help patients reach a productive and safe emotional space; thereby improving the health of breast cancer survivors.

**Limitations**

As with all research there are limitations in this study that may distort the actual influence of a variable on the defined outcomes. In the following section, I will address several limitations that may have affected results, including recruitment procedures, demographic representation, sample size, variable measurement, and research protocol.

The first limitation that may have had an impact on the results was the retrospective, cross-sectional study design. Since participants were eligible to participate up to three years following the completion of active breast cancer treatment, there could be recall bias that impacted their responses. The results of this study may be impacted because events that have occurred since participants completed breast cancer treatment may influence their perceptions of their breast cancer decision-making experience. A longitudinal design that recruits patients at the time of diagnosis and follows them through the actual decision-making process in real-time would be better able to capture the perspectives of patients without recall bias and with less influence from other outside factors.

The second limitation of this study was the way in which participants were recruited. Two of the most fruitful means of participant recruitment included Facebook groups for breast cancer survivors and charity walks supporting breast cancer research and celebrating survivors. These venues inherently draw survivors who are interested in remaining active in the breast
cancer survivor community, which is likely not be representative of all survivors. This limitation may have affected the results in this study because women who remain connected to the breast cancer community may have had a treatment experience that was in some way different than women who do not remain connected to the breast cancer community. If that level of connection to the breast cancer community is in some way connected to reflections about the treatment decision-making process, then results would not be generalizable.

A third limitation of this study was the relatively homogeneous demographic profile of participants. Specifically, the sample was predominantly Caucasian, which limits the perspectives that were captured for women of varying racial and ethnic backgrounds. The influence that this limitation may have on the results is in generalizability to women of all racial backgrounds. The role of the patient navigator was initially implemented to serve communities of color and to address cultural divides between physicians and patients (Freeman, 2006). By not having a representative sample of demographic backgrounds, interpretation of the results from the historical perspective about a patient navigator’s role is limited.

Another important limitation that should be mentioned is that of sample size; specifically, the sample size captured for each of the groups (e.g., PN present vs. PN not present). As determined in the power analysis, a minimum of 80 participants in each group was necessary for sufficient power. Unfortunately, that sample could not be obtained. In this study, there was nearly sufficient sample in the “PN present” group (n = 78), but not in the “PN not present” group (n = 46). Some of the previously reported analyses failed to reject the null, which could be due to limited power in the sample, rather than a specific lack of conceptual interaction. One dimension, clarity in breast reconstruction choice, received far fewer responses than other dimensions of decisional conflict because the items required that the participant have considered
breast reconstruction in order to answer (PN present, n = 55; PN not present, n = 36). This limitation may result in some mechanisms and factors showing results that approach statistical significance could mean that an influence is present, but could not be detected in this study’s sample.

The measures used for this research were derived from previous research, which revealed support for their methodological use (Jean-Pierre et al., 2011; Mallinger, Griggs, & Shields, 2005; O’Connor, 1995; Safran et al., 1998; Takayama, Yamazaki, & Katsumata, 2001), but with any self-report measure, there come limitations in how representative a scale is of the actual construct. For all of the variables in the study, greater refinement of the question text could help to reduce skips, limit redundancy, and provide more valid measures of the concepts. For instance, redundancy in the decisional conflict items was first mentioned in pilot testing and great effort was taken to reduce it as much as possible. However, with breast cancer necessitating many treatment options, it is difficult to reduce the scale very much. Therefore the limitations in measures could mean that constructs other than those intended were assessed and the interpretation of results would not accurately represent the breast cancer decision-making process.

**Recommendations for Future Research**

With any scientific study, new ideas emerge about how research can be pursued to better understand the influences of interest. Given the results of this research, I recommend three areas of continued study: (a) communication about fertility preservation for young breast cancer patients, (b) the implementation of technology as a means of improving emotional support for survivors, and (c) the assessment of tumor boards as a means of influencing the patient experience.
Fertility preservation and decision-making. Two interview participants discussed the issue of fertility and breast cancer treatment with both of them having similar stories about their treatment decision-making. One woman learned that she was pregnant while making treatment decisions and communication she received about how to manage the pregnancy and her treatment likely added a great deal of trauma.

When I found out I was pregnant, [my oncologist’s nurse practitioner] was like, “Well, [your oncologist] and everyone suggests that you terminate the pregnancy.” [She said] that was the overall consensus. And then when I actually met with my oncologist, she said like flat out to me, “I hope that nothing that I’ve said indicates to you that I would suggest that you terminate your pregnancy.” And I was like, “Well, nothing you said to me indicated that but, something that someone else said to me indicated that you had said exactly that.” (P8)

The other woman had just had a miscarriage within a few weeks of before being diagnosed and felt that discussing options to preserve fertility were important to her. However, providers did not acknowledge her concerns and adjust communication accordingly.

We went back and forth for a while; [our fertility plan] was a debate. [The oncologist] ultimately . . . didn’t know enough at the time and we were still in that kind of scared and overwhelmed phase and we talked with our doctor and stuff, but he said we should do the treatment . . . we were going to listen to him because we felt that he knew a lot more than we did. But looking back now and all the research that I’ve done I feel like he may have just been also just scared as we were and he didn’t have enough information at the time to make an informed decision either way. (P10)
In both of these instances, communication about fertility options was not handled using patient-centered communication. Each patient expressed her concerns about fertility, but received little information or misinformation from the cancer-care team.

So I ran into a lot of negative information and non-information . . . some doctors didn’t have a lot of information yet or some of them were kind of sheltered about it and so I spent a lot of my time over the last couple of years researching that and doing a lot of researching and reaching out to specialists across the country, different oncologists at the large cancer centers, trying to figure out–is there more information on it. The good news is that there is a lot more being done and it isn’t such a gray area. (P10)

The other thing that she told me was that after chemo I would be post-menopausal and wouldn’t be able to have children. [T]his is something that I had never heard before. I didn’t know that much about chemo or anything, so I was devastated about that. It was just like a whole other disaster. My daughter was 10 months at that point, so we had been planning to start trying again around a year, so that was really horrible. And it was really interesting because in my age group, only about 20% of women actually become post-menopausal . . . so that was completely inaccurate as well, so that was not awesome . . . it was kind of a crappy way to start the journey. (P8)

Research that considers the experience of young breast cancer patients and the communication about fertility options would help to address the special needs of these patients. Perhaps part of the credential process of patient navigators could include a section on the special needs of young women looking for options with fertility. No matter the direction, though, use of the information offered during breast cancer treatment decision-making should include the recognition of family planning as an important value for some women.
**Technology tools for emotional support.** Building on the feedback that many patients desire support services after they have finished treatment, research on how an interactive online support group may be able to provide the immediacy that patients desire and the emotional support to help them address the trauma of breast cancer treatment. One way that the emotional needs of patients could be met is through online support groups that are moderated by live patient navigators in various locations across the country. By having the support groups online, one could better address the individual and specific needs of patients so that they get the support they need. As was suggested by one patient, finding more programs specific to her needs as a young breast cancer survivor.

I wish that they had offered information tailored to my needs. For instance, I went to this chemo preparation course that was given by a nurse at the cancer center. And it was a very broad . . . kind of a crash-course about what to expect from chemo, but it was not specific to my chemo. For instance, they were telling us to eat lots of fatty foods and keep up with your diet and make sure you don’t lose a lot of weight, but my type of chemo consequently makes you put on weight. So there were things that I thought should have been tailored better to your breast cancer chemo . . . you know, young cancer patients . . . it was all just very overarching and broad, so I wished that they had more specific programs. (P10)

The benefit of doing a program online extends beyond an ability to offer highly specific groups based on a patient's individual situation, it could limit the costs of survivor programs. By having patient navigators moderate groups online, the individual hospital systems are able to better address costs because structure needs are not required. Finally, emotional support and patient healing could be enhanced over more traditional Facebook-style support groups because
the patient navigator would be able to help patients as they work through difficult issues like the
death of a fellow survivor.

Some days I want to not be in [the survivor Facebook group] anymore because people
have bad news and we went through a month where like 4 women died and it was just
like, this is just terrifying. [A]nd it’s like I don’t want to think about it, but I don’t want to
not . . . I mean these have been people who have been supporting me. It’s a weird club to
be a part of. (P8)

Addressing the emotional concerns of breast cancer patients was a common theme as the
missing piece in comprehensive breast cancer care. Both patients who received inadequate
communication and information from providers and those who reported receiving excellent
communication suggested that emotional needs were not entirely addressed. An online-based
support group that is moderated by patient navigators could provide a more tailored experience
with a sense of informational and emotional immediacy that is missing in other online groups.

**Influence of provider group decision-making on patients.** Several participants
mentioned that their oncologist had discussed their treatment plan at a “tumor board.” Tumor
board conferences provide an opportunity for physicians, nurses, and other care providers from
diverse disciplines to “assemble and discuss specific cases and to guide care” (Petty & Vetto,
1997, p. 97). One person suggested that by having her diagnosis discussed by the tumor board,
she felt that it allowed her physicians to make the best choices possible for her situation.

[I] felt like if it was my day to be talked about, then all the people who were treating me
were there and they were agreeing on what should be done for me. It reassured me that
they were . . . that it was like a discussion. [T]he impression that I have was that there
were options that you could have with my case, but at least the options that were
available to me were talked about and it reassured me that they were coming up and agreeing on the best option for me. (P5)

Future research could consider both the patient and provider perspective of communication related to tumor boards. The patient perspective this practice could influence feelings of decisional conflict and trust in providers, while also helping patients to feel as though all possible options have been considered. From a provider perspective the tumor board brings physicians together as a group and the dynamic could improve patient-centered care and communication. By having the social influence of other providers, physicians may feel more inclined to dig deeper into patients’ perspectives and preferences concerning treatment. These group dynamics could also serve to create greater cohesiveness in the cancer-care team if providers, like patient navigators, were also included. Having that perspective may give the cancer-care team a more whole-person view of the patient, her values, beliefs, concerns, and preferences.

Overall, there is a need for continued research on the breast cancer experience and particularly in decision-making about treatment options. Patients are facing an incredibly traumatic event that could be improved greatly by communication; something we have known, but still do not completely understand.
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APPENDIX A

Patient-centered communication items from the Perceived Physician’s Communication Style Scale (PPCS; Takayama, Yamazaki, & Katsumata, 2001) and the Primary Care Assessment Survey (PCAS; Mallinger, Griggs, & Shields, 2005; Safran et al., 1998). Scale: 1 = “strongly disagree”; 2 = “disagree”; 3 = “neither agree nor disagree”; 4 = “agree”; 5 = “strongly agree”

1. My cancer care team regularly asked whether I had any opinions about my cancer treatment.
2. My cancer care team regularly confirmed that I understood the explanations they provided about my breast cancer treatment.
3. My cancer care team was friendly and warm.
4. My cancer care team was my main source of information about my breast cancer treatment options.
5. My cancer care team showed a good understanding of my past health history.
6. My cancer care team gave me a chance to ask questions.
7. My cancer care team looked me in the eye when speaking to me.
8. My cancer care team missed important information, even though I provided it to them.\(^a\)
9. During my appointments, my cancer care team waited to hear about all my problems and concerns.
10. My cancer care team encouraged me to tell them everything I thought was important about my cancer treatment.
11. My cancer care team listened to my questions attentively.
12. My cancer care team provided clear explanations about my breast cancer treatment options.
13. My cancer care team asked thorough questions about how I was feeling during my breast cancer treatment.
15. My cancer care team showed a good understanding about me as a person, my values, and beliefs.
16. My cancer care team showed a good understanding of my responsibilities at home, work, or school.
17. My cancer care team showed a good understanding about my concerns.
18. All things considered, I trusted my cancer care team.
19. I felt like I could tell my cancer care team anything.
20. My cancer care team always told me the truth about my health, even if it was bad news.

Note: PPCS dimensions and corresponding items: Communication = 12-14; Contextual knowledge = 15-17; Trust = 18-20. PCAS dimensions and corresponding items: Facilitative = 1, 2; Patient-centered = 3-5; Acceptive = 6-8; Attentive = 9-11

\(^a\) Indicates item was reverse coded
APPENDIX B

Decisional conflict items from the Decisional Conflict Scale (O’Connor, 1995). Scale: 1 = “strongly disagree”; 2 = “disagree”; 3 = “neither agree nor disagree”; 4 = “agree”; 5 = “strongly agree”

1. I was unsure what to do in the decision about my breast cancer treatment.
2. It was clear to me which breast cancer treatment was the best choice for me.
3. I was unsure what to do in the decision about my breast cancer surgery.
4. It was clear to me which breast cancer surgery was the best choice for me.
5. The decision about whether or not to have breast reconstruction was difficult for me to make.\(^a\)
6. There was a clear choice that was best for me when deciding whether or not I should have reconstruction.
7. I was aware of the choices available to me for my breast cancer treatment.
8. I feel that I knew the benefits for each of the breast cancer treatment options.
9. I feel that I knew the risks for each of the breast cancer treatment options.
10. I wanted more advice and information about breast cancer treatment choices.
11. I had the right amount of support from others when making decisions about my breast cancer treatment.
12. I was aware of the choices available to me for my breast cancer surgery.
13. I feel that I knew the benefits for each of the breast cancer surgery options.
14. I feel that I knew the risks for each of the breast cancer surgery options.
15. I needed more advice and information about breast cancer surgery choices.
16. I had the right amount of support from others when making decisions about my breast cancer surgery.
17. I was aware of the choices available to me for breast reconstruction.
18. I feel I knew the emotional benefits of breast reconstruction.
19. I feel that I knew the emotional risks of breast reconstruction.
20. I wanted more advice and information about breast reconstruction options.
21. I felt pressure from others while making decisions about whether or not to have breast reconstruction.
22. I felt that I made an informed choice about my breast cancer treatment.
23. I am satisfied with the choices that were made for my breast cancer treatment.
24. I would make the same treatment choices if I had to do it all over again.
25. I felt that I made an informed choice about my breast cancer surgery.
26. I am satisfied with the choices that were made about the type of breast cancer surgery I had.
27. I would make the same surgery choices if I had to do it all over again.
28. I felt that I made an informed choice about whether or not to have breast reconstruction.
29. I am satisfied with the choices that were made about whether or not to have breast reconstruction.

Note: Dimensions and corresponding items: Decision uncertainty = 1-6; Factors contributing to uncertainty = 7-21; Perceived effectiveness of decision-making = 22-29
\(^a\) Indicates item was reverse coded
APPENDIX C

Patient satisfaction items from the Patient Satisfaction with Cancer Care Scale (PSCC; Jean-Pierre et al., 2011). Scale: 1 = “strongly disagree”; 2 = “disagree”; 3 = “neither agree nor disagree”; 4 = “agree”; 5 = “strongly agree”

1. I received the right amount of support from my cancer care team.
2. My questions were answered to my satisfaction.
3. My cancer care team treated me with courtesy and respect.
4. My cancer care team gave me the advice that I needed to better manage my physical health during cancer treatment.
5. My cancer care team gave me the advice that I needed to better manage my emotional health during cancer treatment.
6. My cancer care team kept me updated about what the next step in my treatment process would be.
7. Making an appointment to see the members of my cancer care team was easy.
8. I received high-quality care from my cancer care team.
9. I understood my illness better because of my cancer care team.
10. I felt that I was included in decisions about my breast cancer treatment.
11. I felt that I was included in decisions about my breast cancer surgery.
12. I was included in decisions about breast reconstruction.
APPENDIX D

Interview guide and sample questions used for semi-structured interviews.

[Main Question #1]
I’m interested in your thoughts on you and your patient navigator communicated during your breast cancer diagnosis and treatment.
[Optional prompts to begin conversation:]
• Tell me about when your patient navigator was brought into your cancer care team. How was their role described to you – what did the patient navigator say they were there to help you with?
• Tell me about your patient navigator and what role they played in your breast cancer treatment experience.
• Describe one or two of the most helpful or beneficial conversations you had with your patient navigator.
[Possible follow-up questions and probes]
• In what ways did your patient navigator help you deal with emotional challenges of treatment?
• How did your patient navigator help to make you feel like you were an important part in your cancer treatment?
• Tell me about the resources you used while going through breast cancer treatment. How did your patient navigator help you find these resources?
• Describe the qualities of a patient navigator that might help women have a better breast cancer treatment experience.

[Main Question #2]
Now I’d like to hear more about the decisions you had to make for your breast cancer treatment and the role your patient navigator played in this process. Tell me about the different treatment decisions you had to make – how did your cancer care team help you as you considered the different options?
[Possible follow-up questions and probes]
• In what ways did your patient navigator help you make decisions during treatment?
• What could your patient navigator have done or said differently to help support you more in those decisions?

[Main Question #3]
This last section of questions is focused on understanding how your patient navigator and the rest of your cancer care team interacted during your diagnosis and treatment. Describe the integration of your cancer care team – how was information passed from one member to another?
[Possible follow-up questions and probes]
• How did your patient navigator fit into your cancer care team?
• Tell me about the amount of trust you felt in your patient navigator.
• Considering all the members on your cancer care team, who seemed most accessible and why? Who seemed most credible and why? Who seemed to understand you best and why?
**APPENDIX E**

Bivariate correlations between items used to measure patient-centered communication (\(n = 118\)-124).

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Note. As a means of conserving space, item text is included in Appendix A. Bold text indicates \(p < .05\).
APPENDIX F

Bivariate correlations between items of the Decisional Conflict Scale (n = 73-86).

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Note. As a means of conserving space, item text is included in Appendix B. Bold text indicates $p < .05$. 
# Appendix G

Bivariate correlations between items in the PSCC scale \((n = 74-124)\)

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Note. As a means of conserving space, item text is included in Appendix C.

*p < .05

**p < .01
Appendix H

Modified hypotheses based on exploratory and confirmatory factor analyses for the revised dimensions of decisional conflict, patient satisfaction, and patient-centered communication

**H1:** Participants who had a PN, as a member of their cancer-care teams, will report experiencing more patient-centered communication than participants who did not have a PN as a member of their cancer-care teams.

**H1a:** Participants who had a PN, as a member of their cancer-care teams, will report experiencing more interpersonal sincerity when communicating with their cancer-care teams than participants who did not have a PN as a member of their cancer-care teams.

**H1b:** Participants who had a PN, as a member of their cancer-care teams, will report experiencing more perceived patient engagement with their cancer-care teams than participants who did not have a PN as a member of their cancer-care teams.

**H1c:** Participants who had a PN, as a member of their cancer-care teams, will report experiencing more individual confirmation from their cancer-care teams than participants who did not have a PN as a member of their cancer-care teams.

**H2:** Participants who had a PN as a member of their cancer-care teams will score significantly lower on measures of decisional conflict than participants who did not have a PN as a member of their cancer-care teams.

**H2a:** Participants who had a PN as a member of their cancer-care teams will score significantly higher on informed treatment choice than participants who did not have a PN as a member of their cancer-care teams.

**H2b:** Participants who had a PN as a member of their cancer-care teams will score significantly higher on clarity of breast reconstruction choices than participants who did not have a PN as a member of their cancer-care teams.

**H2c:** Participants who had a PN as a member of their cancer-care teams will score significantly higher on satisfaction with treatment choices than participants who did not have a PN as a member of their cancer-care teams.

**H2d:** Participants who had a PN as a member of their cancer-care teams will score significantly lower on feelings of informational uncertainty than participants who did not have a PN as a member of their cancer-care teams.

**H2e:** Participants who had a PN as a member of their cancer-care teams will score significantly higher on perceived decisional support than participants who did not have a PN as a member of their cancer-care teams.

**H3:** Patient-centered communication will have a significant negative relationship to the reported amount of decisional conflict of female breast cancer patients.

**H3a:** Patient-centered communication will have a significant positive relationship with perceptions of having made an informed treatment choice.

**H3a1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant positive relationship with perceptions of having made an informed treatment choice.

**H3a2** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will
have a significant positive relationship with perceptions of having made an informed treatment choice.

**H3a3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant positive relationship with perceptions of having made an informed treatment choice.

**H3b:** Patient-centered communication will have a significant positive relationship with the clarity of breast reconstruction choices.

**H3b1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant positive relationship with the clarity of breast reconstruction choices.

**H3b2:** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will have a significant positive relationship with the clarity of breast reconstruction choices.

**H3b3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant positive relationship with the clarity of breast reconstruction choices.

**H3c:** Patient-centered communication will have a significant positive relationship with a participant’s satisfaction with treatment choices.

**H3c1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant positive relationship with a participant’s satisfaction with treatment choices.

**H3c2:** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will have a significant positive relationship with a participant’s satisfaction with treatment choices.

**H3c3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant positive relationship with a participant’s satisfaction with treatment choices.

**H3d:** Patient-centered communication will have a significant negative relationship with informational uncertainty.

**H3d1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant negative relationship with informational uncertainty.

**H3d2:** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will have a significant negative relationship with informational uncertainty.

**H3d3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant negative relationship with informational uncertainty.

**H3e:** Patient-centered communication will have a significant positive relationship with decisional support.
**H3e1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant positive relationship with decisional support.

**H3e2:** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will have a significant positive relationship with decisional support.

**H3e3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant positive relationship with decisional support.

**H4:** Participants who had a patient navigator as part of their cancer-care teams will report experiencing more patient satisfaction with the care experience than participants who did not have a patient navigator as part of their cancer-care teams.

**H4a:** Participants who had a patient navigator as part of their cancer-care teams will score significantly higher on perceived patient satisfaction with care experience than participants who did not have a patient navigator as part of their cancer-care teams.

**H4b:** Participants who had a patient navigator as part of their cancer-care teams will score significantly higher on perceived inclusion in treatment decision-making than participants who did not have a patient navigator as part of their cancer-care teams.

**H5:** Patient-centered communication will have a positive relationship to patient satisfaction with the cancer care experience.

**H5a:** Patient-centered communication will have a significant positive relationship with patient satisfaction with the care experience.

**H5a1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant positive relationship with patient satisfaction with the care experience.

**H5a2:** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will have a significant positive relationship with patient satisfaction with the care experience.

**H5a3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant positive relationship with patient satisfaction with the care experience.

**H5b:** Patient-centered communication will have a significant positive relationship with perceived inclusion in treatment decision-making.

**H5b1:** The experienced amount of interpersonal sincerity felt by patients from their cancer-care teams, when controlling for patient engagement and individual confirmation, will have a significant positive relationship with perceived inclusion in treatment decision-making.

**H5b2:** The experienced amount of patient engagement felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and individual confirmation, will have a significant positive relationship with perceived inclusion in treatment decision-making.

**H5b3:** The experienced amount of individual confirmation felt by patients from their cancer-care teams, when controlling for interpersonal sincerity and patient engagement, will have a significant positive relationship with perceived inclusion in treatment decision-making.
CURRICULUM VITAE

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