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# COMMUNICATION-PARTICIPATION BEHAVIOR DURING THE DELIVERY OF BREAST-CANCER CARE

by

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#### ABSTRACT OF THE DISSERTATION

Communication-participation behavior during the delivery of breast-cancer care

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This two-study dissertation examines the association between communicationparticipation behaviors and cancer patients' post-visit psychosocial health outcomes. Study one was a meta-analysis of 25 articles (including 10 distinct data sets) that examined the association between patient-provider communication and patients' postvisit satisfaction. The meta-analysis found that communication behaviors representing patient-centered care were significantly associated with patients' post-visit satisfaction. Study two was conducted to further explore the association between communicationparticipation behaviors and patients' post-visit psychosocial health outcomes. Communication-participation behaviors included: (1) surgeon partnership building; (2) surgeon supportive talk; (3) client assertive responses; (4) client question asking; and (5) client expression of concern (Street & Millay, 2001). Inductive/grounded thematic analysis (Strauss & Corbin, 1998) of these communication-participation behaviors produced six secondary communication-participation variables: (1) surgeon partnership building: question solicitation; (2) surgeon partnership building: other; (3) patient assertive responses: stating preferences; (4) patient assertive responses: challenging

surgeon; (5) patient question asking: self-initiated; and (6) patient question asking: prompted. Patients' psychosocial outcomes included: (1) illness uncertainty (Mishel, 1988); (2) mental adjustment to cancer (Watson et al., 1988); (3) patients' satisfaction with surgeons' visit communication; (4) patients' satisfaction with treatment plans; and (5) patients' intentions to adhere to treatment plans. Data were videotapes of treatmentdecision-making conversations between a single surgeon and 51 of his newly diagnosed female breast-cancer patients, as well as pre- and post-visit surveys. Major findings were that communication-participation behaviors were significantly associated with decreases in patients' uncertainty and increases in patients' adaptive coping styles. For example, increases in surgeon partnership building were associated with decreases in patients' unpredictability uncertainty from pre- to post visit; increases in patient assertive responses: stating preferences were associated with increases in patients' fighting spirit and decrease in anxious preoccupation from pre- to post visit; increases in patient assertive responses: challenging surgeon were associated with decreases in patients' fatalism from pre- to post visit. Communication-participation behaviors, and in particular patient question asking, were significantly, negatively associated with patients' satisfaction with treatment plans and patients' intentions to adhere to treatment plans. These findings, their implications, and directions for future research are discussed.

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# **DEDICATION**

To the greatest joys of my life, Peter and Irene Kokona

For your unconditional love and for never failing to believe in me

To my parents and grandparents

For showing me the way

and allowing me to believe that all things are possible

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# CHAPTER ONE: INTRODUCTION

Breast cancer is a national and international health problem (American Cancer Society; ACS, 2010). As of 2008, among American women, breast cancer is the second-highest, new-cancer diagnosis (after basal and squamous cell skin cancers), it is the most frequent cancer diagnosis, and it is the leading cause of cancer death (exceeded only by lung cancer) (ACS, 2010). About one in eight women will be diagnosed with breast cancer in their lifetime (American Cancer Society (ACS, 2010). Approximately 192,370 women were diagnosed with breast cancer in 2009 (ACS, 2010).

Breast cancer is among a consortium of diseases that does not have well-established risk factors, other than older age and being female (ACS, 2010; There are several speculative risk factors that have yet to be rigorously documented, such as the use of oral contraceptives, alcohol, and hormone therapy; ACS, 2010). Although breast cancer can be hereditary (i.e., those with a family history of breast cancer are more likely to be affected), approximately 90% of individuals with a positive diagnosis have no prior family history (ACS, 2010). For at least the above reasons, a diagnosis of breast cancer is frequently unexpected and associated with shock (Krause, 1991), fear (Lyons, Jacobson, Prescott, & Oswalt, 2002), and feelings of vulnerability (McWilliam, Brown, & Stewart, 2000).

Breast cancer takes a much greater toll on women's psychosocial health than it does their mortality (Hewitt, Herdman, & Holland, 2004); this is because, at least as a physical disease, breast cancer is highly treatable. Although mortality rates depend on cancer stage – i.e., those with more severe stages of cancer, such as stages 3 and 4, have reduced survival rates (57% for Stage 3 and 20% for Stage 4) – the five-year post-

diagnosis survival rates for stage 0-1 breast cancer is 100% and stage 2 is 86% (The vast majority of the population in the main dissertation study represent stages 0-2) (National Cancer Institute; NCI, 2010). Admittedly, cancer treatment (e.g., surgery and additional therapies, such as chemotherapy and/or radiation) has side effects (e.g., chest pain, diarrhea, hair loss, hot flashes, and fatigue) (Breastcancer.org, 2010), but these tend to subside relatively shortly after treatment.

On the other hand, as an illness (vs. disease; Friedson, 1973), breast cancer takes an enormous toll on women's psychosocial health and quality of life (Falagas et al., 2007; Hewitt et al., 2004). Americans fear cancer more than any other serious medical condition (NCI, 2007). Especially because positive diagnoses are often surprising (Krouse & Krouse, 1982), they launch patients into states of crisis (Krouse & Krouse, 1982). Following diagnosis, cancer patients report increases in anxiety and depression (Antoni et al., 2006; Gaston-Johansoon, Ohly, Fall-Dickson, Nanda, & Kennedy, 1999; Leedman & Ganz, 1999; McCaul et al., 1999; Schofield et al., 2003; Vahdaninia, Omidvari, & Montazeri, 2010), anger and sadness (Frank-Stromborg, Wright, Segalla, & Diekmann, 1984; McCaul et al., 1999), fear (including that of death, surgery, and the treatment process) (Frank-Stromborg et al., 1984; Lackey, Gates, & Brown, 2001; Lyons et al., 2002), hopelessness (Frank-Stromborg, et al., 1984), shock and disbelief, (Lyons et al., 2002), vulnerability (Lyons et al., 2002; McWilliams et al., 2000), distress (Chen et al., 1996; Leedman & Ganz, 1999; McCaul et al., 1999), uncertainty (Frank-Stromborg et al., 1984; Loveys & Klaich, 1991; Shaha, Cox, Talman, & Kelly, 2008), and rumination (Lyons et al., 2002). Relative to other types of cancer, women report that breast-cancer diagnoses are more unexpected and fear-inducing (Butow et al., 1996; Hilton, 1993). The

aforementioned negative psychosocial health effects appear to carry over into treatment and beyond, as diagnosis is also associated with reduced physical and mental quality of life (Falagas et al., 2007).

When women are diagnosed with breast cancer (which is typically occurs at a primary care visit), they almost always consult with surgeons because the first treatment step is typically the surgical removal of the malignant tumor(s) (i.e., the cancer). According to the *National Survey of Ambulatory Surgery*, in 2006, there were over 234,000 medical visits concerning malignant neoplasm of the breast with a surgeon, including both surgical procedures and non-surgical consultations (Cullen, Hall, & Golosinskiy, 2009). Also in 2006, 317,000 lumpectomies (surgical removal of the tumor) were performed on female breast-cancer patients. These figures do not include the volume of breast-cancer surgeries that required an in-patient status (e.g., mastectomy, or removal of the breast), which significantly increases the total number of breast cancer surgeries. Without discounting the complexity of breast surgery, women with stage 0-2 breast cancer have essentially two options, including lumpectomy with radiation or mastectomy. According to multiple 20-year longitudinal studies, the survival rates associated with these two treatment options are not significantly different (Fisher et al., 2002; Veronesi et al., 2002), suggesting that treatment-decision-making conversations are not simply about mortality, but rather are seeped in psychosocial issues revolving around patients' comfort levels, fear and uncertainty, body image, etc.

Given that women who are newly diagnosed with breast cancer are experiencing a wide variety of negative psychosocial health effects that carry over into treatment and beyond, and given that surgeons are one of the first specialists who these women visit

after diagnosis, this dissertation examines surgeon-patient communication as a mechanism for either ameliorating or exacerbating negative psychosocial health outcomes.

#### CHAPTER TWO: REVIEW OF LITERATURE

This chapter reviews prior research relevant to the present dissertation. This chapter begins by reviewing illness uncertainty (Mishel, 1988), mental adjustment to cancer (Watson et al., 1988), the rationale for video-taped data, patient centered-care, patients' satisfaction with surgeons' visit communication, patient satisfaction with treatment plan, and patient intention to adhere to the treatment plan.

## Illness Uncertainty

As noted above in the Introduction section, patients report that breast-cancer diagnoses are unexpected (Butow et al., 1996). At least for patients with relatively-new diagnoses (which are the population under examination in the main dissertation study), the general lack of breast-cancer symptoms, as well as the relevance of a new identity as a person with cancer (Mishel, 1988; Nelson, 1996), can bring patients to ask questions like: *How did this happen to me?*, *What's the best treatment for me?*, and *When can I resume my normal life?* (see Problematic Integration Theory, Babrow, 2001). Such questions are part of what is referred to as illness uncertainty.

Referring to uncertainty in general (i.e., not illness uncertainty, *per se*), Brashers (2001) noted that it "exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general" (p. 478). Of course, "uncertainty is central to the experience of illness" (Babrow & Mattson, 2003, p. 44). Referring to uncertainty specifically in the health-care context, Mishel (1988) defined illness uncertainty as "the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately

structure or categorize an event because of the lack of sufficient cues" (p. 225). A state of uncertainty can occur when individuals cannot interpret vague or unfamiliar information and cannot predict future outcomes (Mishel, 1984, Thompson & O'Hair, 2008). In a qualitative study concerning challenges with breast cancer (Hilton, 1993), uncertainty emerged as a dominant issue, one participant stating: "The worst part was the uncertainty!" (p. 89). Participants reported that uncertainty was constant throughout all phases of breast-cancer treatment, beginning with a suspicious lump or abnormal mammogram and continuing through post-treatment fear of recurrence (Hilton, 1993).

A number of different theories have dealt with the concept of uncertainty and its management, including uncertainty reduction theory (URT; Berger & Calabrese, 1975), uncertainty management theory (UMT; Brashers, 2001), problematic integration theory (PI; Babrow, 2001), and the theory of motivated information management (TMIM; Afifi & Weiner, 2004). A comprehensive review of the general notion of uncertainty and its management in all contexts is beyond the scope of this chapter, and has been dealt with elsewhere (Afifi & Weiner, 2004; Babrow, Kasch, & Ford, 1998). What follows is a review of illness uncertainty, specifically as described by Mishel's (1988) uncertainty in illness theory.

## *Uncertainty in Illness Theory (UIT)*

Mishel (1988, 1999) presented a model for explaining uncertainty in acute, and later chronic, illness. Mishel explained that illness uncertainty can stem from several sources, including: (1) the nature of the illness; (2) patients' perceptions of the future; (3) patients' concepts of self; and (4) lack of information. Uncertainty surrounding the *nature* of the illness refers to ambiguous characteristics of the illness itself, including its

symptoms, their origin, and their pattern of expression, as well as what novel bodily sensations mean after treatment (e.g., weight loss after cancer treatment) and their possible relationship to the illness (e.g., recurrence); this theoretical dimension of uncertainty was also discussed by Babrow, Hines, and Kasch (2000) and Babrow et al. (1998). Uncertainty surrounding patients' perceptions of the future refers to the predictability of recovery How long will I be in the hospital?), recurrence (e.g., What are the chances of my cancer returning?), and lifestyle (e.g., Will I be able to work again?) following treatment; this theoretical dimension of uncertainty was also discussed by Babrow et al., (1998, 2000). Uncertainty surrounding patients' concepts of self refers to how the illness and its treatment experience might/does alter the patients' self-concepts, such those surrounding physical fitness and body image; this theoretical dimension of uncertainty was also discussed by Babrow et al. (2000). Uncertainty surrounding lack of information refers to an inability to understand, and/or make sense of, component stages of an illness experience, such as treatment (e.g., What surgery do I get and why?, What is chemotherapy?, What are treatment risks?); this theoretical dimension of uncertainty was also discussed by Babrow et al., (1998, 2000). These four sources of uncertainty are likely to be relevant for the patient population examined in this dissertation, that being women newly diagnosed with breast cancer.

Uncertainty in illness theory explains that the primary antecedent to illness uncertainty is the *stimuli frame*, which is composed of the: (1) symptom pattern; (2) event familiarly; and (3) event congruence. *Symptom pattern* refers to the coherence, consistency, and patterning of symptoms and their triggers (e.g., *I get discomfort in my stomach immediately after eating*). Individuals assess patterns by examining the number,

intensity, duration, and frequency the symptoms. Note that, in the medical context under examination in the main dissertation study, symptom pattern may not be relevant because newly-diagnosed, early-stage breast cancer patients rarely experience breast-cancer symptoms (i.e., diagnoses are often made from regular screenings; ACS, 2010). Event familiarity refers to the understandability and predictability of regular events associated with illnesses, such as their composition, ordering, etc. (e.g., first breast surgery, then recovery, then chemotherapy, then breast reconstruction). Note that, for newly-diagnosed breast cancer patients who have yet to talk to surgeons, event familiarity is likely to be highly relevant; it will be low and highly conducive to uncertainty (Hewitt et al., 2004). Event congruence refers to the alignment between the expected occurrence of illness events and their actual occurrence (e.g. the alignment between anticipated and actual recovery time). For breast-cancer patients who have yet to undergo treatment, the relevance of event congruence immediately after treatment-decision-making conversations is likely to be low, insofar as patients have yet to experience actual events (e.g., actual surgery, chemotherapy, etc.). Uncertainty in illness theory argues that these three antecedents are negatively associated with uncertainty; high symptom patterning, high event familiarity, and high event congruence are associated with low illness uncertainty (Mishel, 1981; Mishel & Braden, 1988; Sheer & Cline, 1995). In sum, for newly diagnosed, early-stage breast cancer patients engaging in treatment-decisionmaking conversations, only event familiarity is likely to be relevant.

Uncertainty in illness theory (Mishel, 1988) argued that at least three *structure providers* affect patients' levels of uncertainty: (1) patients' levels of education; (2) patients' levels of social support; and (3) patients' experiences with credible authorities.

Level of education facilitates patients' understanding of illnesses, and allows patients to better place illnesses into context and thus assign them meaning. Mishel (1988) reported that individuals with less than a high school education experience greater illness uncertainty, including more difficulty understanding treatment plans. Social support is defined as "interpersonal transactions that include one or more of the following: the expression of positive affect of one person to another; the affirmation or endorsement of another's behaviors, perceptions, or expressed views; the giving of symbolic or material aid to another" (Mishel & Braden, 1987, p. 47-48). Specifically, Mishel and Braden (1987) found that, among a sample of women with gynecological cancer, social support was negatively associated with illness uncertainty. Nelson (1996) found that, among women with breast cancer, women rely on members of their social networks to provide optimism, as well as a chance to talk through illness uncertainty. Credible authorities are health-care providers whom patients rely on as sources of health/illness information. Patients' levels of confidence in health-care providers as trustworthy sources of information is negatively associated with illness uncertainty.

Uncertainty in illness theory (Mishel, 1988) described uncertainty as a neutral phenomenon that is not inherently bad or good (also see Babrow, 2001; Babrow & Mattson, 2003). The theory proposes that patients' levels of illness uncertainty are based on both recognizing uncertainty and appraising its polarity and implications (also see Uncertainty Management Theory, Brashers, 2001; Theory of Motivated Information Management, Afifi & Weiner, 2004). Although some patients might appraise illness uncertainty as being positive, the vast majority of research has found that patients appraise illness uncertainty as being negative, dangerous, and harmful (e.g., Mishel,

1988; Wonghongkul, Moore, Schneider, & Deimling, 2000). When this happens, patients tend to seek to reduce illness uncertainty by vigilance (constant monitoring of the situation), direct action (such as confronting the situation), and/or by information seeking (see Uncertainty Management Theory, Brashers, 2001; Brashers et al., 2000; Feltwell & Reis, 2004). Mishel (1988) noted that information seeking is the most common uncertainty-management response, and individuals tend to seek information by requesting information from health-care providers, family and friends, and individuals with similar health conditions (also see Mast, 1995). For this reason, patient question asking is centrally examined in the main dissertation study.

In the context of cancer, although patients' illness uncertainty decreases over time (particularly between the time of treatment selection and a few months after surgery; Hughes, 1993; Liu, Tang, Huang, & Chiou, 2006), illness uncertainty remains pervasive even five years post-surgery (Decker, Haase, & Bell, 2007). Decker et al. (2007) reported that, although illness uncertainty remains, over time, the stimuli of illness uncertainty changes; for example, newly diagnosed cancer patients report being uncertain about their future, whereas five years post-treatment, the same patients report being uncertain about unanswered questions.

## Illness Uncertainty and Outcomes

In the context of cancer, increased levels of illness uncertainty are associated with several deleterious psychosocial health outcomes, such as problems with psychological adjustment, (Christman, 1990; Germino et al., 1998; Mishel & Braden, 1987; Mishel, Hostetter, King, & Graham, 1984; Neville, 1998), tension, anger, depression, and fatigue (Stieglis et al., 2004), sadness and pessimism (Mishel et al., 1984), and symptom distress,

including pain, nausea, and insomnia (Phillips-Salimi, Kintner, Monahan, & Azzouz, 2007). Increased illness uncertainty is also associated with decreased quality of life (Padilla, Mishel, & Grant, 1992; Wallace, 2003), decreased optimism and motivation (Mishel et al., 1984), and the perception of low levels of social support (Germino et al., 1998; Neville, 1998). In a study of prostate cancer, Germino et al., (1998) found that increased illness uncertainty is associated with a decrease in the quality of patients' sexual relationships, and a decrease certain role behaviors, such as attending social events, shopping, running errands, keeping in touch with friends, and enjoying leisure time (Germino et al., 1998). In a study of gynecological cancer, Mishel et al. (1984) found that women with increased illness uncertainty reported increased difficulties with recreational and social activities. Exclusively among breast cancer patients and survivors, increased illness uncertainty is associated with increased anxiety, fear, depression, and hopelessness (Nelson, 1996; Wong & Bramwell, 1992), decreased hope (Wonghongkul et al., 2000), increased fatigue, both in treatment and into survivorship (Mast, 1998), decreased self-control in terms of suppressing thoughts of cancer (Dirksen, 2000), and a decreased quality of life, which involves health and functioning, socioeconomic status, psychological and spiritual health, and family relationships (Sammarco & Konecny, 2008).

#### **Cancer Coping**

Mental adjustment to cancer is defined as the "cognitive and behavioral responses the patient makes to the diagnosis of cancer" (Watson et al., 1988, p. 203). Note that the term 'mental adjustment to cancer' has been used interchangeably with 'coping' by Watson and colleagues (Watson et al., 1988; Greer, Morrey, & Watson, 1989), and

hereafter 'mental adjustment to cancer' is referred to as coping. Coping is a complex phenomenon, as individuals respond to cancer diagnoses in diverse ways. Dimensions of coping include: (1) fighting spirit, (2) helplessness-hopelessness, (3) anxious preoccupation, (4) cognitive avoidance, and (5) fatalism (Watson et al., 1988). Fighting spirit is defined as patients' "regarding cancer as a challenge and adopting a positive attitude" (Greer, 2000, p. 848). Helplessness-hopelessness is a response marked by depression, pessimistic attitudes, fear, and negative appraisals of the cancer diagnoses (Glese-Davis & Spiegel, 2003; Mishel et al., 1988). Anxious preoccupation is characterized by persistent anxiety and a pessimistic attitude and negatively evaluating any information or physical symptoms (Greer, 1991). Cognitive avoidance, also referred to as denial in some literature, is characterized by the constant redirecting of thoughts to avoid thinking about cancer and the preference for a passive role in treatment decisionmaking conversations (Shields et al., 2004; Watson et al., 1994). Fatalism, also referred to as stoic acceptance (e.g., Mishel et al., 1988), is characterized by patients' acknowledgement of the diagnosis, a "resigned" attitude toward the illness, emotional suppression, and a lack of desire to actively participate in information seeking or treatment decision-making (Cordova et al., 2003; Greer, 1991; Shields, Morrow, Griggs, Mallinger, Roscoe, Wade, et al., 2004).

Patients' ability to adjust to, or cope with, cancer (e.g., maintain hope, optimism, and a fighting spirit) can buffer them from ill psychosocial effects (Nezu, Nezu, & Felgoise, 2003). For example, patients' poor coping with cancer is associated with a decrease in patients' quality of life, including increased depression (Söllner et al., 1999), increased cancer-related worries concerning physical, emotional, and relational problems

(Grassi et al., 2004), increased sexual problems (Ferrero, Barreto, & Toledo, 1994), and decreased life satisfaction (Herbert, Zdaniuk, Schulz, & Scheier, 2009). Additionally, coping is negatively associated with patients' communication self-efficacy during medical interactions (Collie et al., 2005), and patients' global quality of health/physical functioning (Nordin & Glimelius, 1998).

Research has conflicting findings concerning coping styles and survival and recurrence among cancer patients (Greer, 1991; Petticrew, Bell, & Hunter, 2002; Watson, Haviland, Greer, Davidson, & Bliss, 1999). Greer (1991) concluded that, among nonmetastatic, early-stage cancer patients, coping style can affect cancer progression, such as helplessness-hopelessness being positively associated with recurrence and mortality. In a longitudinal study of 578 newly-diagnosed breast cancer patients, Watson et al. (1999) examined the effects of fighting spirit and helplessness-hopelessness on recurrence and survival and found a significant increase of recurrence and mortality among patients with high (vs. low) levels of helplessness-hopelessness. Osbourne et al. (2004) examined the effects of fighting spirit on mortality in 61 breast-cancer patients and found that fighting spirit was positively associated with survival 6-8 years following diagnosis. As a possible counterpoint to the above findings, Petticrew et al. (2002) conducted a (nonstatistical/non-meta-analytic) review of the literature examining fighting spirit and helplessness-hopelessness and found no association between these coping styles and mortality.

Watson and colleagues (1988, 1994) presented an internationally-validated approach for assessing cancer-patient's coping with cancer diagnoses. The Mental Adjustment to Cancer Scale (MAC, Watson et al.,, 1988) and the Mini-MAC (Watson et

al., 1994), a parsimonious version of the original scale, assess patients' cancer coping style (Watson et al., 1988, p. 203). The MAC measures the five dimensions of mental adjustment (noted above): fighting spirit, helplessness-hopelessness, anxious preoccupation, fatalism, and cognitive avoidance. The scale has been validated among cancer patients in Australia (Osborne, Elsworth, Kissane, Burke, & Hopper, 1999), China (Ho, Wong, Clan, Watson, & Tsui, 2003), England (Watson et al., 1988; Watson & Homewood, 2008), France (Cayrou, Dickes, Gauvain-Piquard, & Roge, 2003), Greece (Anagnostopoulos, Kokokotroni, Spanea, & Chryssochoou, 2006; Mystakidou et al., 2005), Italy (Grassi et al., 2005), and South Korea (Kang et al., 2008). These studies generally support the original dimensions. Helplessness-hopelessness and anxious preoccupation are consistently interpreted as negative or maladaptive adjustment styles, and fighting spirit is consistently interpreted as a positive/adaptive adjustment style (Anagnostopoulos et al., 2006; Cayrou et al, 2003; Ho et al., 2004; Watson et al., 1988; Watson & Homewood, 2008).

# Fighting Spirit

Fighting spirit, as noted above, is characterized by the patient's acceptance of the diagnosis, determination to overcome the cancer, increased level of internal locus of control (e.g., perception that patient can control the course of the disease), increased optimistic attitude, increased information-seeking behavior (e.g., question asking), and increased desire to participate in treatment decision-making (e.g., stating treatment preferences and contributing to the treatment decision; Grassi, Rosti, Lasalvia, & Marangolo, 1993; Greer, 1991; Link, Robbins, Mancuso, & Charlson, 2003). Social support is positively associated with fighting spirit (Grassi et al., 1993), and patients with

greater perceived social support exhibit greater fighting spirit, particularly if they count their physician as a member of their social support network (Akechi, Okamura, Yamwaki, & Uchitomi, 1998). Among general cancer patients (i.e., not exclusively breast cancer patients), increases in fighting spirit have been associated with decreases in anxiety and/or depression (Cayrou et al., 2003; Grassi et al., 2004; Ho et al., 2003, 2004; Kang et al., 2008; Link et al., 2003; Nordin, Berglung, Terje, & Glimelius, 1999; Nordin & Glielius, 1998; Schnoll, Mackinnan, Stolbach, & Lorman, 1995; Watson et al., 1994), emotional suppression and mood disturbance (Cordova et al., 2003), health distress (Ho et al., 2004), cancer worry, particularly worry concerning recurrence (Lampic et al., 1994), and psychological stress (Grassi et al., 2005). Increases in fighting spirit have been positively associated with increases in well-being (Lampic et al., 1994; Whitford, Oliver, & Peterson, 2008), emotional functioning and adjustment (Nordin & Glielius, 1998; Schnoll et al., 1995), and quality of life (Nordin & Glielius, 1998).

In studies of breast-cancer patients exclusively, increases in fighting spirit have been associated with decreases in anxiety and/or depression (Akechi et al., 2001; Schnoll, Harlow, Stolbach, & Brandt, 1998; Watson et al., 1991), decreases in emotional and psychological distress (Classen, Koopman, Angell, & Spiegel, 1996; Ferrero et al., 1994), and increases in medical-care satisfaction (Ferrero et al., 1994). Fighting spirit has been positively associated with improved energy and mental health (Anagnostopoulos et al., 2006), regimen adherence (Ayres et al., 1994), and quality of life (Levine & Targ, 2002; Schnoll et al., 1998).

### Helplessness-Hopelessness

Helplessness-hopelessness, as noted above, is characterized by a high external locus of control (i.e., a perception that one cannot control the course of the disease) and a pessimistic attitude in which the patient is consumed with fear and negatively appraises the cancer diagnosis (Grassi et al., 1993; Greer, 1991). Among general cancer patients, increased helplessness-hopelessness is associated with increased anxiety and/or depression (Bjorck, Hopp, & Jones, 1999; Cayrou et al., 2003; Grassi et al., 2004; Ho et al., 2003, 2004; Kang et al., 2008; Lampic et al., 1994; Nordin et al., 1999; Nordin & Glielius, 1998; Schnoll et al., 1995; Watson et al., 1988, 1994), distress (Ferrero et al., 1994; Ho et al., 2004; Schnoll et al., 1995), cancer-related worries, including worry concerning recurrence (Grassi et al., 2004; Lampic et al., 1994); anger, fatigue, confusion (Schnoll et al., 1995), post-traumatic stress syndrome (Kangas et al., 2005), acute stress disorder (Kangas et al., 2007), psychological stress (Grassi et al., 2005), and control over the emotions of anger and anxiety (Watson et al., 1991). Increases in helplessnesshopelessness are also associated with decreases in self-esteem (Bjorck et al., 1999), wellbeing (Lampic et al., 1994; Whitford et al., 2008), emotional functioning and adjustment (Nordin & Glielius, 1998; Schnoll et al., 1995), and quality of life (Nordin & Glielius, 1998).

In studies of breast-cancer patients exclusively, increases in helplessness-hopelessness are associated with increases in anxiety and/or depression (Akechi et al., 2001; Grabsch et al., 2006; Reuter et al., 2006; Schnoll et al., 1998; Watson et al., 1991), psychological distress (Ferrero et al., 1994), and post-traumatic stress disorder (Levine, Eckhardt, & Targ, 2005). Increases in helplessness-hopelessness are also associated with

decreases in quality of life (Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Schnoll et al., 1998), medical-care satisfaction (Ferrero et al., 1994), well-being (Levine & Targ, 2002), and emotional health, social functioning, vitality, and mental health (Anagnostopoulos et al., 2006).

#### Anxious Preoccupation

Anxious preoccupation, as noted previously, is characterized by anxiety and a pessimistic attitude that leads to negatively evaluating information or physical symptoms (Greer, 1991). In studies of general cancer patients, increases in anxious preoccupation has been associated with increases in anxiety and depression Bjorck et al., 1999; Cayrou et al., 2003; Grassi et al., 2004; Ho, Chan,& Ho, 2004; Ho et al., 2003; Kang et al., 2008, Lampic et al., 1994; Nordin et al., 1999; Nordin & Glielius, 1998; Schnoll et al., 1995; Watson et al., 1988; Watson et al., 1994), cancer-related worries concerning physical, emotional, and relational issues (Grassi et al., 2004; Lampic et al., 1994), distress (Ho et al., 2004; Schnoll et al., 1995), anger and confusion (Schnoll et al., 1995), post-traumatic stress syndrome (Kangas et al., 2005), and acute stress disorder (Kangas et al., 2007). Increases in anxious preoccupation are also associated with decreases in self-esteem (Bjorck et al., 1999), well-being (Lampic et al., 1994; Whitford et al., 2008), emotional functioning and adjustment (Nordin & Glielius, 1998; Schnoll et al., 1995), and quality of life (Nordin & Glielius, 1998).

In studies of breast-cancer patients exclusively, increases in anxious preoccupation are associated with increases in anxiety and/or depression (Akechi et al., 2001; Grabsch et al., 2006; Reuter et al., 2006; Schnoll et al., 1998; Watson et al., 1991), psychological distress (Ferrero et al., 1994), and post-traumatic stress disorder (Levine et

al., 2005). Increases in this coping style are also associated with decreases in emotional health, social functioning, vitality (energy levels), and mental health (Anagnostopoulos et al., 2006) spiritual well-being, (Levine & Targ, 2002), and quality of life (Schnoll et al., 1998).

### Cognitive Avoidance

Cognitive avoidance, as noted above, is characterized by the constant redirecting of thoughts to avoid thinking about cancer, and a preference for a passive role in treatment decision-making conversations (Shields et al., 2004; Watson et al., 1994). Cognitive avoidance is positively associated with social support (Grassi et al., 1993), such that increases in social support are associated with increases in cognitive avoidance. In studies of cancer patients, increases in cognitive avoidance are associated with increases in anxiety (Ho et al., 2003; Kang et al., 2008; Nordin et al., 1999; Watson et al., 1994), depression (Nordin et al., 1999), and acute stress disorder (Kangas et al., 2007).

In studies of breast-cancer patients exclusively, outcomes associated with cognitive avoidance sometimes disagree. However, most research supports the finding that increases in cognitive avoidance are associated with increases in negative psychosocial outcomes, such as depression (Reuter et al., 2006) and psychological distress (Ferrero et al., 1994). Increases in cognitive avoidance are also associated with decreases in quality of life (Cotton et al., 1999) and spiritual well-being (Levine & Targ, 2002). In contrast to the aforementioned findings, two positive/adaptive outcomes of increased cognitive avoidance are increased vitality (Anagnostopoulos et al., 2006) and decreased distress during hospitalization (Watson et al., 1984).

#### Fatalism

Fatalism, as noted above, is characterized by patient's acknowledgement of the diagnosis, its emotional suppression, and a lack of desire to actively participate in information seeking and treatment decision-making (Cordova et al., 2003; Greer, 1991; Shields et al., 2004). Increases in fatalism are positively associated with social support (Grassi et al., 1993). Most interpretations of fatalism categorize it as a positive/adaptive strategy, resulting in improved health outcomes (Anagnostopoulos et al., 2006; Ho et al., 2004; Waston & Homewood, 2008). In general cancer populations, increased fatalism is associated with decreased anxiety and depression (Ho et al., 2004; Kang et al., 2008), decreased distress (Ho et al., 2004), and increased well-being (Lampic et al., 1994).

In studies of breast-cancer patients exclusively, results are sometimes contradictory. For example, increases in fatalism have been significantly associated with both *increases* in anxiety, depression, and quality of life (Akechi et al., 2001; Cotton et al., 1999; Watson et al., 1991), and *decreases* in anxiety, depression, and quality of life (Ferrero et al., 1994; Reuter et al., 2006; Schnoll et al., 1998). Some studies have found that increases in fatalism are associated with increases in well-being (Levine & Targ, 2002) and improved mental health (Anagnostopoulos et al., 2006).

## Video-taped Data

There is evidence that physician-patient communication variables have independent effects on patient's psychosocial health outcomes (Stewart, 1995; Venetis Robinson, Turkiewicz, & Allen, 2009). The vast majority of psycho-oncological studies rely on reported, perceived, or anecdotal/experienced data (Beach & Anderson, 2003). For this reason, the National Academy of Sciences' Institute of Medicine's report on

Ensuring Quality Cancer Care (Institute of Medicine, 1999), identified an existing gulf between ideal cancer care and what we observe about its reality during visits. Research of physician-patient communication (not specified to only cancer patients) finds that participant self-reports on the occurrence of communication-participation behaviors are not significantly associated with their actual, audio-/video-taped occurrence during visits (DiMatteo, Robinson, Heritage, Tabbarah, & Fox, 2003; Street, 1992). For example, DiMatteo et al. (2003) found that patients' do not accurately report their own rates of question-asking, or physicians' rates of facilitative communication. Similarly, Street (1992) found that parents' perceptions of physicians' informativeness were not positively correlated with physicians' actual information-giving; rather, parents' perceptions were negatively associated with physicians' directive-giving.

Although videorecording is increasingly employed across the social and medical sciences (Gordon, Street, Sharf, Kelly, & Souchek, 2006; Pearce, Trumble, Arnold, Dwan, & Phillips, 2008; Pollak et al., 2007), researchers argue that the presence of a recording device, particularly video-recording machines, could alter the authenticity of the interaction (see Penner et al., 2007). However, physicians, patients, and their companions rarely orient to cameras during visits, and only a very small portion of the actual communication reflects orientation to the video-recording machine (Albrecht et al., 2005; Borgers et al., 1993; Penner et al., 2007). Furthermore, video-recording the visits provide greater opportunity for data analysis. In a comprehensive review of the literature on nonverbal communication during physician-patient visits, Robinson (2007) demonstrated that having access to videotapes (vs. only audiotapes) increases coding reliability and validity.

Because this dissertation is focusing on observed and quantifiable communication behaviors, the subsequent review of studies is limited to those of observed communication. Knowledge of actual (versus perceived) communication is needed for creation of concrete physician and/or patient training protocols.

#### Patient-Centered Care

Evolving models of medical practice: From biomedical to patient-centered Both providers' treatment of patients, and researchers' conceptions of the 'appropriate' provider-patient relationship, have evolved dramatically over the past few centuries (Foucault, 1973; Reiser, 1978). In the early 1700's, providers regarded patients as experts in terms of experiencing their own illness, for example allowing patients extended periods of time to present their illnesses in their own terms, and often in the context of their homes and family (Resier, 1978). However, throughout the 1800's, with the proliferation of diagnostic technologies (e.g., stethoscope, x-ray) (Reiser, 1978), coupled with the rise of a particular biomedical philosophy of the practice of medicine (discussed below; Engel, 1977), providers decreased their reliance on patients' perspectives on, and concerns about, their health/illness, and increased their focus on treating diseases as independent entities (see also Foucault, 1973; Mishler, 1981). Starting around the 1960s, researchers began to question the efficacy of the biomedical philosophy, favoring instead a biopsychosocial model of medicine (Engel, 1977) that centrally involved: (1) the inclusion of patients' perspectives, as well as the inclusion of patients' lifeworld concerns (Bensing, 2000; Mishler, 1981), in the diagnosis and treatment of disease, reflecting a shift away from terms such as 'disease' in favor of 'illness' (Friedson, 1973); and (2) patients' active (vs. passive; cf. Parsons, 1975)

participation in their healthcare, especially in their conversations with providers (Bensing, 2000; Engel, 1977; Roter & McNeilis, 2003). As McCormick wrote: "knowing the person who has the disease is as important as knowing the disease that person has" (1996, p. 668).

From the mid 1800's until at least the late 1980s (and perhaps even the late 1990s), the practice of provider-patient communication strongly reflected the 'biomedical model:' The style of healthcare in which diseases, and not individuals, are treated (Sharf & Vanderford, 2003). According to the biomedical model, diseases are independent entities from the host individuals and their life situations. Disease is conceptualized as a metaphorical breakdown in the body-machine, and the role of providers is to fix broken parts (Engel, 1977). Because diseases are considered to be independent entities, their diagnosis and treatment are generalizable across populations according to strict scientific methods (Sharf & Vanderford, 2003). As such, the biomedical model leaves little room for patients' personal identities, experiences (both instrumental and affective), and narratives (Engel, 1977; Reiser, 1978). When guided strictly by the biomedical model, providers have little incentive to consider patients' perspectives, to consider patients' lifeworld environments (e.g., social, economic, relational, religious, etc.) when diagnosing and treating disease (Engel, 1977; Mishler, 1981), to create personal/relational bonds with patients, or to facilitate patients' participation in their care (i.e., patients are relatively passive; Emanuel & Emanuel, 1992).

As an alternative to the biomedical model of medical practice, researchers have proposed a number of conceptually similar, albeit differently named, models, including the *biopsychosocial model* (Engel, 1977), *relationship-centered care* (Roter, 2000), and

patient-centered care (Beach & Inui, 2006; Bensing, 2000); hereafter the term 'patientcentered care' is adopted. Although patient-centered care recognizes biology/physiology as a primary concern (Babrow & Mattson, 2003), it adopts the position that: (1) it is necessary to understand (e.g., diagnose and treat) illness in the contexts of patients' lives, emotions, and psychology (Sharf & Vanderford, 2003); and (2) patients should be actively involved in their care (and particularly with clinical decision making), especially including being involved interactionally during visits with providers (Bensing, 2000). For example, McWhinney (1995) described three core values of patient-centered communication: (1) Providers must consider patients' needs, beliefs, and perspectives (e.g., providers should ask for patients' opinions, for example of treatment options); (2) Providers must work to build a partnership between themselves and patients (e.g., providers' should be compassionate, interpersonally sensitive, and actively listen); and (3) Providers should encourage patients' participation during medical visits, including participation in medical decision making (e.g., providers should solicit patients' questions and prompt patients to provide their views on treatment plans). For another example, Epstein et al. (2005) similarly operationalized patient-centered care as:

"(1) eliciting and understanding the patient's perspective—concerns, ideas, expectations, needs, feelings and functioning, (2) understanding the patient within his or her unique psychosocial context, (3) reaching a shared understanding of the problem and its treatment with the patient that is concordant with the patient's values, and (4) helping patients to share power and responsibility by involving them in choices to the degree that they wish" (p. 1517).

To summarize, two common themes across all patient-centered (vs. biomedical) models of medicine are: (1) whether by virtue of providers' enablement or patients' own initiatives, patients need to become active participants during visits so that their concerns and preferences can be voiced; and (2) providers need to treat patients as partners in medical decision-making (Bensing, 2000; Epstein et al., 2005; Lambert et al., 1997; McWhinney, 1995; Roter, 2000).

Admittedly, although patient-centered care espouses patients' participation, research has shown that patients' preferences for participating can vary, albeit in a limited fashion among specifiable populations (Street, Gordon, Ward, Krupat, & Kravitz, 2005; Thompson, Pitts, & Schwankovsky, 1993). For example, in the context of cancer, relative to younger patients, older patients tend to prefer less active roles in treatment-decision making (Benbassat, Pilpel, & Tidhar, 1998; Degner & Sloan, 1992; Maly et al., 2004). However, despite these findings, research overwhelmingly finds that a majority of breastcancer patients prefer an active role in treatment-decision making, including the option to make final treatment decisions for themselves with the guidance of providers (Bilodeau & Degner, 1996; Degner et al., 1997; Freedman, 2002; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002; Maly et al., 2004; Protiere et al., 2000). For example, Keating et al. (2002) found that, among post-surgical, pre-adjuvant therapy breast-cancer patients, 88% reported wanting some level of collaborative decision-making role. For another example, in the context of French breast cancer patients selecting adjuvant therapy, Protiere et al. (2000) found that only 12% of patients preferred that providers made treatment decisions on their own. Principles of patient-centered care would suggest that providers should solicit, and work with, patients' preferences for levels of participation.

Empirical Realizations of Patient-Centered Care: Patient Participation

With the exception of work by Street and his colleagues (e.g., Street, 1992; Street, Voigt, Geyer, Manning, & Swanson, 1995; Street & Millay, 2001) – which will be reviewed below – research on generalizable empirical realizations of the aforementioned models of patient-centered care have been relatively scarce. In an examination of 537 primary-care visits, Roter et al. (1997) documented five patterns of communication, which they labeled: narrowly biomedical, expanded biomedical, biopsychosocial, psychosocial, and consumerist. The biomedical patterns (combined), which accounted for 65% of all visits, were characterized by a relatively high volume of biomedical information-giving by providers and patients, a relatively high volume of provider question asking (i.e., provider-directed talk), and a relatively low volume of talk devoted to psychosocial topics by providers and patients. The biopsychosocial pattern, which accounted for 20% of all visits, was characterized by a relative balance in discussion of biomedical and psychosocial talk. Although providers' talk was more biomedical than psychosocial, patients' talk was equivalent. This pattern is also characterized by low volume of provider question asking (as compared to the biomedical pattern. The psychosocial pattern, which accounted for 7% of all visits, was characterized by providers' and patients' high volume of psychosocial talk and a low volume of question asking. In this pattern, providers' talk is equivalent between biomedical and psychosocial talk; patient talk is more psychosocial than biomedical. The *consumerist* pattern, which accounted for 8% of all visits, was characterized by a high volume of provider information giving and low volume of question asking, a high volume of patient question asking, and a low volume of psychosocial and social exchange by either participant.

Compared to all other patterns, patients involved in *psychosocial* interactions reported the highest levels of visit satisfaction.

Roter et al.'s (1997) patterns are relatively molar. As noted above, central to the infrastructure of most recommended models of medical practice – including the biopsychosocial model (Engel, 1977), patient-centered care (Roter, 2000), and relationship-centered care (Beach & Inui, 2006) – is communicative behaviors that facilitate or embody patients' 'participation.' Over the last 20 years, Street and his colleagues (Street, 1992; Street et al. 1995; Street & Millay, 2001) have identified, and developed a coding schema to analyze, communication behaviors that either facilitate or constitute patients' participation. According to Street and Millay (2001), there are two categories of behavior that represent providers' patient-centered care: partnership building and supportive talk. Providers' partnership building includes: (1) providers asking about or soliciting patients' feelings or preferences, especially regarding decisionmaking (e.g., How do you feel about this decision?);<sup>3</sup> (2) providers encouraging patients to participate in conversations, especially regarding decision-making (e.g., "You will have to make the final decision because this is your body"); (3) providers soliciting patients' questions, especially open-ended ones (e.g., "OK, do you have any questions or anything?"; Street & Millay, p. 69); and (4) providers affirming patients' opinions (e.g., Patient: "If you guys want me to keep coming for this, I will. But I do want to keep my doctor." Provider: "Yah, I think the important thing is to have a regular doctor that you consider your regular provider. I think that's very important" (Street & Millay, p. 69) and agreeing with patients' requests (e.g., Patient: "Can I get a refill?" Provider: "You sure can."). Providers' supportive talk includes efforts to reassure, support, or empathize with

patients (e.g., "Don't worry about the surgery. Everything is going to be all right."), including ones that legitimize patients' expressions of concerns and fears (e.g., Patient: "I'm so scared." Provider: "I understand.").

Separate from providers' facilitation of participation, Street and Millay (2001) define patients' participation as:

"the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction as well as the healthcare provider's belief and behaviors" (p. 62).

According to Street and Millay (2001), there are three categories of patient behavior that represent patient-centered participation: (1) asking questions, (2) making assertive utterances, and (3) expressing concerns. Asking questions includes any attempt to seek information (e.g., "Does smoking do that?"; Street & Millay, p. 63) or clarification, including the asking of direct questions, as in the prior example, and indirect questions (e.g., Patient: "So I guess that I should recover in the next couple of days"). Making assertive utterances includes patients' attempts to impose their opinions (Street & Millay, 2001), such as: (1) stating preferences or expressing wishes (e.g., "I really don't want anybody to x-ray it"; Street & Millay, p. 63); (2) disagreeing with providers (e.g., Doctor: "So let's go ahead and get this surgery done." Patient: "But I don't want to do it."); and (3) interrupting providers to make points (e.g., Doctor: "So another thing we could..." Patient: "I think that treatment is not the best option."). Expressing concerns includes patients sharing negative emotions with providers, such as fears, worries, and frustrations (e.g., "I'm afraid that I might not make it out of surgery").

## Theoretical Support for the Efficacy of Patient-Centered Care

Self-determination theory is one of human motivation, and argues that humans have three basic psychological needs that, when satisfied, lead to improved health: (1) autonomy; (2) relatedness; and (3) competence. *Autonomy* refers to the need for individuals to direct their own behavior (versus an external other forcing a particular behavior) (Ryan & Deci, 2000). *Relatedness* refers to the degree of attachment or connection (versus detachment or disconnection) to others (Ryan & Deci, 2000). *Competence* refers to one's perceived self-efficacy to complete a task (Ryan & Deci, 2000). There is research showing that patients' perceptions of positive interpersonal relationships with their cancer-care providers (e.g., relatedness) are positively associated with patients' reported levels of being active participants in treatment-decision making (Takayama & Yamazaki, 2004).

Self-determination theory argues that the aforementioned three basic psychological needs are affected by social elements, one primary one being interactions with healthcare providers. For example, patients can waiver between states of active involvement and passive presence (e.g., in treatment-decision-making conversations, patients can either engage providers by asking questions and offering opinions, or refrain from speaking). However, providers can engage in either autonomy-supportive or autonomy-controlling behaviors. Autonomy-supportive behavior is defined as "providers interacting with patients by taking full account of their perspectives, affording choice, offering information, encouraging self-initiation, providing rationale for recommended actions, and accepting the patients decision" (Williams et al., 2000, p. 81). In contrast, autonomy-controlling behavior is defined as providers 'pressuring' patients to "behave in

specific ways" (p. 81). Provider behaviors involving partnership building, particularly those that solicit patients' autonomy (e.g., soliciting patients' questions), can serve to increase at least patients' perceptions of autonomy. For another example, providers' supportive talk (Street & Millay, 2001) has the capacity to increase patients' perceptions of relatedness and competency.

The last 20 years has seen empirical support for the predictions of self-determination theory. Specifically, studies find that increases in providers' autonomy-supportive behavior are associated with improvements in patients' health outcomes, including increased glucose control in diabetic patients (Williams & Deci, 1996a; Williams, Freedman, & Deci, 1998), decreased rates of smoking (Williams & Deci, 1996b), increased weight loss among obese patients (Williams, Grow, Freedman, Ryan, & Deci, 1996), and increased adherence to medication among outpatients (Williams, Rodin, Ryan, Grolnick, & Deci, 1998). In a separate line of research, Deadman, Leinster, Ownes, Dewey, and Slade (2001) found that patients' reported levels of choice regarding treatment-decision making was positively associated with patients' reported levels of fighting spirit, and negatively associated with levels their of helplessness-hopelessness, avoidance, anxious preoccupation, and depression. Four months post-operation, patients who made the treatment decisions reported less fatalism and anxiety, and an increased sense of body image regarding both their body and breasts.

## Patient-Centered Care and Healthcare Outcomes

The predictions and findings associated with self-determination theory have been largely divorced from observed (i.e., taped) provider-patient communication behavior, but are reflected in separate lines of research focusing on patient-centered participation

behaviors. In a review of 21 studies of actual communication published between 1983 and 1993 that did not exclusively represent cancer care (in fact, only a small minority of these studies involved cancer care), Stewart (1995) found that greater patient participation is associated with improved healthcare outcomes. For example, one of the 21 studies (Kaplan, Greenfeld, & Ware, 1989) found patient participation during visits to be associated with improvements in patients' overall health, reductions in their functional limitations during follow-up visits, and decreases in the numbers of symptoms they experienced during chemotherapy (Kaplan et al., 1989). Stewart's (1995) review found that increased provider facilitation of patient participation, such as providers' soliciting patients' questions, was associated with improved patient symptom resolution and lower anxiety. Increases in patient-centered care have been associated with improvements in patients' emotional health and recovery from discomfort (Stewart et al., 2000).

In the context of cancer care, a variety of researchers have lamented that the associations between observed communication behaviors and healthcare outcomes is "one of the least developed areas of communication research" (Epstein & Street, 2007, p. 39; see also Arora, 2003, 2008). Of existing literature, increased levels of patients' participation – including asking questions, giving opinions, and expressing concerns – have been associated with breast-cancer-patients' beliefs that they made treatment decisions, and patients' willingness to take responsibility for such decisions (Street & Voigt, 1997). Increased levels of patients' participation have also been associated with decreases in breast-cancer patients' decisional regret (Step, Rose, Albert, Cheruvu, & Siminoff, 2009). Increased numbers of breast-cancer patients' questions has been associated with patients' post-visit breast-cancer knowledge (Siminoff, Ravdin,

Colabianchi, & Sanders Sturm, 2000). Of note, in potential conflict with the predictions of self-determination theory (Ryan & Deci, 2000), increases in the number of cancerpatients' questions has been associated with decreases in patients' satisfaction (Ishikawa, Takayama, Yamazaki, Seki, & Katumata, 2002; Ong, Visser, Lammes, & de Haes, 2000; Siminoff et al., 2000; Timmermans, van Zuuren, van der Maazen, Leer & Kraaimaat, 2007), patients' certainty that they made treatment decisions (Siminoff et al., 2000), increases in patients' doubts concerning treatment decisions (Timmermans et al., 2007), and decreases in patients' perceptions that interactions were collaborative (Takayama & Yamazaki, 2004).

Until the meta-analysis performed by the present author (Venetis et al., 2009), there was no *comparative* evidence that, in cancer care, patient-centered care is positively associated with beneficial health outcomes; this study was conducted as part of the present dissertation and is included in full as Chapter 3. In brief, Venetis et al.'s meta-analysis of 25 studies, representing 10 distinct data sets, found that patient-centered communication – which included both affective behavior and participation behavior – was significantly, positively associated with patients' post-visit patient satisfaction, which not only included patients' satisfaction with providers levels of collaboration, but also patients' satisfaction with their levels of control, involvement, and participation during visits. Although Venetis et al. also found that biomedical or instrumental communication (e.g., providers' giving medical information) was significantly, positively associated with satisfaction, they found that, compared to instrumental communication, patient-centered communication was significantly more strongly associated with satisfaction.

## Patients' Satisfaction with Visit Communication

Patients' satisfaction emerged as a variable of interest in the 1960s (e.g., Korsch, Gozzi, & Francis, 1968), and has been measured prolifically as a healthcare outcome for the ensuing five decades (Brown, Stewart, & Ryan, 2007). There are two predominant conceptualizations of patients' satisfaction. The first is patients' general-healthcare satisfaction, which is represented by measures such as the RAND Patient Satisfaction Questionnaire (PSQ; originally developed by Ware, Snyder, & Wright, 1976a, 1976b), and which assess the following aspects of patients' medical experiences: (1) general satisfaction with an entire healthcare experience that is not limited to experiences during visits; (2) medical-technical quality of care that is not limited to experiences during visits; (3) financial aspects of care; (4) access/availability/convenience of care; (5) time spent with providers; (6) providers' interpersonal manner; and (7) providers communication (RAND Health, 2010). Note that only the last three aspects are focused exclusively on provider-patient behaviors. The second conceptualization is patients' satisfaction with particular visits. This latter measure is almost always operationalized in terms of patients' evaluations of providers' communication behaviors (e.g., Brown, Boles, Mullooly, & Levinson, 1999). For this reason, it is the latter measure that is of most interest to communication scholars, and to the main dissertation study.

Patients' satisfaction with providers' communication has two robust dimensions, that with medical-technical behavior and that with affective-relational behavior (Ben-Sira, 1980). The medical-technical dimension refers to "technically based skills used in problem solving that comprise the base of the 'expertness' acquired through professional medical education and for which a physician is consulted" (Roter & Larson, 2002, p.

243); these behaviors include performing physical exams and procedures, gathering information through question asking, and educating patients (Roter & Larson, 2002). The affective-relational dimension refers to "those exchanges with explicit socio-emotional content related to the building of social and emotional rapport, for instance, the use of social amenities, empathy, concern, or reassurance" (Roter & Larson, 2002, p. 244), as well as exchanges contributing to patients' perceptions of being understood by providers (Roter & Larson, 2002). Although patients report that both dimensions are salient and important to medical care (Hall, Roter, & Katz, 1988), patients report that the affective dimension is a more substantial predictor of quality of care (Bensing & Dronkers, 1992; Ben-Sira, 1982; Buller & Buller, 1987; Griffith, Wilson, Langer, & Haist, 2003; Mechanic & Meyer, 2000). For example, pre-surgery breast cancer patients reported willingness to abandon the pre-consultation surgery choice for the surgeons' recommendations as long as patients perceived that surgeons were listening to their concerns and speaking openly and honestly (Henman, Butow, Brown, Boyle, & Tattersall; 2002). As in demonstrated in Chapter 3 of this dissertation, in the context of cancer care, providers' affective behavior is more strongly associated with patients' satisfaction than is providers' instrumental behavior.

The widespread and frequent employment of the variable *patients' visit* satisfaction can be explained, according to Kaplan et al. (1989), by its simplicity of application (as a relatively short, self-report measure), and its "logical and intuitive appeal as an appropriate indicator of effective physician-patient communication" (p. S111). Research has found that patients' visit satisfaction is a reliable indicator of the quality of providers' medical care (DiMatteo & Hays, 1980; Roter, Hall, & Katz, 1987;

Roter et al., 1997; Weaver, Ow, Walker & Degenhardt, 1993). Furthermore, visit satisfaction is a part of medical schools' communication-training objectives (Duffy, Gordon, Whelan, Coe-Kelly, & Frankel, 2004) and is used as an evaluative tool for determining physicians' salaries (Grumbach, Osmond, Vranizan, Jaffe, & Bindman, 1998). An exhaustive review of the associations between patients' visit satisfaction and healthcare outcomes *outside the context of cancer care* (e.g., primary care) is beyond the scope of this chapter, and is the topic of numerous review articles (Boudreaux & O'Hea, 2004; Cleary & McNeal, 1988; Mair & Whitten, 2000; Sitzia & Wood, 1997; Williams, Weinman, & Dale, 1998). In brief, though, research has found that patients' satisfaction with providers' communication (again, *in a range of contexts not including cancer care*) is associated with patients' treatment adherence (Glickman et al., 2010), trust in providers (Hall, Zheng, et al., 2002) and continuity of care (i.e., maintaining the same provider; Hall, Horgan, Stein, & Roter, 2002; Saultz & Albedaisi, 2004).

Again, *outside the context of cancer care*, there is convincing evidence that specific aspects of provider-patient communication are associated with patients' satisfaction with providers' communication. For example, patients' visit satisfaction has been positively associated with: (1) the thoroughness of providers' explanations and the amounts of information given by providers (Comstock, Hooper, Goodwin, & Goodwin, 1982; Jackson, Chamberlain, & Kroenke, 2001; Roter et al., 1987; Taylor & Benger, 2004); (2) the extent to which providers address patients' concerns (Jackson et al., 2001); (3) providers' provision of empathy (Comstock et al., 1982; Graugaard, Holgersen, & Finset, 2004); (4) providers' use of open- (vs. closed) ended questions when soliciting

patients problems (Robinson & Heritage, 2006); (5) providers asking for patients' opinions (Stewart, 1984); and (6) patients giving their opinions (Stewart, 1984).

Within the context of cancer care, patients' visit satisfaction has been positively associated with patients' improved quality of life when measured three years following diagnosis (Kerr, Engel, Schlesinger-Raab, & Holze, 2003), and negatively associated with patients' emotional distress three months following diagnosis (Butow et al., 1996), psychological morbidity three months following baseline (Shilling, Jenkins, & Fallowfield, 2003), and anxiety three months following baseline (Steptoe, Sutcliffe, Allen, & Coombes, 1991).

As in non-cancer-care contexts, within cancer care there is strong evidence that specific aspects of provider-patient communication are associated with patients' visit satisfaction. On the one hand, many of these findings mirror those generated in studies not involving cancer care. For example, among cancer patients, visit satisfaction is positively associated with: (1) providers' giving medical information (in cancer, Ong et al., 2000; non-cancer, Jackson et al., 2001); (2) providers asking open- (vs. closed) questions (Ishikawa et al., 2002a); (3) providers enacting verbal attentiveness and friendliness and discussing socio-emotional topics (Ong et al., 2000); (4) providers discussing patients' goals and fears (Siminoff et al., 2000); (5) providers enacting empathy during physical examination (Eide, Graugaard, Holdersen, & Finset, 2003); and (6) patient participation (Siminoff et al., 2000). On the other hand, some findings in cancer care have yet to be fully explained. For example, visit satisfaction has been *negatively* associated with the amount of instruction giving by providers (Ishikawa et al., 2002a), and *positively* associated with the provision of *less* detailed information. Perhaps

the most counterintuitive finding has been that cancer patients' visit satisfaction has been *negatively* associated with levels of patients' level of question asking (Ishikawa et al., 2002a; Ong et al., 2000; Siminoff et al., 2000).

## Patients' Satisfaction with Surgical Treatment Plans

Although literature has examined cancer-patients' satisfaction with treatment decision-making (e.g., Lantz et al., 2005; Moyer & Salovey, 1998), as well as cancerpatients' satisfaction with the results of treatment decisions (such as physical consequences of differing treatments; e.g., Al-Ghazai, Fallowfield, & Blamey, 2000; Lantz et al., 2005; Weiss, Wengert, Martinez, Sewall, & Kopp, 1996), there appears to be no research on cancer-patients' satisfaction with surgical-treatment plans discussed *prior* to actual surgery, such as those made with surgeons during treatment-decision-making conversations, which are the focus of the main dissertation study.

However, in a sample of breast and prostate cancer patients, several months following the treatment decision, most patients reported being satisfied with it (Davison, So, & Goldenberg, 2007; Weiss et al., 1996). For example, among prostate patients, one-year following surgical treatment, 92% reported that they 'made the right decision' and 89% reported that they would make the same decision again (Davison et al., 2007). A variable related to patients' satisfaction with treatment decisions is patients' *regret* with/about treatment decisions, including surgery and chemotherapy (e.g., Brehaut et al., 2003; Step, Siminoff, & Rose, 2009). *Decision regret* is defined as "a negative emotion associated with thinking about a past or future choice' (Connolly & Reb, 2005, p. S29), which is fostered over time (Connolly & Reb, 2005) and best assessed after treatment decisions are actualized (i.e., after actual surgery). Cancer patients' *decision regret* three

months post treatment decisions/procedures is negatively associated with patients' satisfaction with associated treatment plans (Brehaut et al., 2003; Lantz et al., 2005; Stryker, Wray, Emmons, Winer, & Demetri, 2006). Research among cancer patients finds that *decision regret* is associated with negative health outcomes (Brehaut et al., 2003; Davison et al., 2007). For example, among breast-cancer-surgery patients, three months following surgical-treatment decisions, *decision regret* was negatively associated with physical and psychological health, as well as general quality of life (Brehaut et al., 2003). Among prostate-cancer patients, one year following treatment decisions, *decision regret* was negatively associated with role and social functioning, and positively associated with pain and financial difficulty (Davison et al., 2007).

There is evidence that cancer-patients' satisfaction with surgical-treatment decisions (after actual surgery) is associated with provider-patient communication. For example, this type of satisfaction has been positively associated with women's perceptions that treatment-decision-making conversations facilitated their communication participation (Mandelblatt, Kreling, Figeuriedo, & Feng, 2006). This type of satisfaction has been associated with specific patient-centered communication behaviors, such as providers discussing psychosocial and emotional topics (e.g., patients' goals and fears; Siminoff et al., 2000; Step, Siminoff, et al., 2009).

Because, in the data examined for the present dissertation, patients have not yet undergone surgery, the analytic focus is on their satisfaction with proposed treatment plans (rather than on patients' satisfaction with, or regret about, actualized treatment decisions). Given the negative association between patients' satisfaction with treatment plans and decision regret (Brehaut et al., 2003; Lantz et al., 2005; Stryker et al., 2006), an

examination of patients' satisfaction with proposed treatment plans is a possible early index of patients' eventual satisfaction with treatment plans and associated decision regret.

# Intention to Adhere to Surgical-Treatment Plans

As far as the present author can determine, no prior study has measured patients' intentions to adhere to surgical-treatment plans immediately after surgical-treatmentdecision-making consultations. However, there are two rationales for doing so. First, whereas patients' satisfaction with surgeons' practice style (Brown et al., 1999) is a measure of patients' evaluations of the affective dimensions of surgeons' communication (Buller & Buller, 1987; Venetis et al., 2009), patients' intentions to adhere to surgicaltreatment plans is arguably a proxy measure for an outcome of satisfaction, specifically that with surgical-treatment-decision-making consultations themselves. Second, it is important to understand factors – and, specifically in the case of this dissertation, communication factors – that contribute to patients' non-adherence to surgeons' recommendations (Although, admittedly, patients' post-visit commitments can be modified in the ensuing hours, days, weeks, etc.). Siminoff, Fetting, and Abeloff (1989) found that 82% of breast-cancer-surgery decisions are made during surgical-treatmentdecision-making consultations. Minimally, non-adherence can lead to 'surgeon shopping' (Yuen, Leung, & Wong, 1987), which can potentially unnecessarily waste organizational resources (e.g., surgeons' time) and delay care; note that, in the case of breast-cancer treatment, surgeons' recommendations conform to professional guidelines 97% of the time (Landercasper, Dietrich, & Johnson, 2006), suggesting that patients who 'shop' do not commonly receive radically different recommendations. Maximally, the most

extreme form of non-adherence – that is, electing to not have any form of surgery – can increase patients' mortality rates (Eberhardt, Stamatis, & Stuschke, 2009; Wright, Hill, Lowy, & Fraser, 1970).

#### Summary

In review, the breast-cancer diagnosis is associated with myriad negative psychosocial health outcomes (Hewitt et al., 2004). The outcomes of interest in the main dissertation study include illness uncertainty, mental adjustment to cancer, patients' satisfaction with the visit communication, patients' satisfaction with surgical-treatment plans, and patients' intention to adhere to surgical-treatment plans. Research supports the claim that patient-centered communication, especially that which is associated with patients' participation, is associated with improved psychosocial outcomes (Stewart et al., 2000). This dissertation has two goals: (1) to confirm the claim that patient-centered care is positively associated with beneficial psychosocial health outcomes (i.e., the metaanalysis reported in Chapter 3 as Study 1), and (2) to examine the association between surgeon facilitation and patient participation behaviors on breast-cancer patients' outcomes as outlined above (i.e., the main dissertation study reported in Chapters 4-5). This main dissertation study is the first to accomplish the second goal in the pre-srugery context (cf., Brehaut et al., 2003; Davison et al., 2007; Lantz et al., 2005; Stryker et al., 2006).

Based on the above review of literature, the following research questions are proposed:

RQ1: Does prior research support the contention that patient-centered communication affects patients' psychosocial health outcomes in the cancer-care context?

- RQ2: Are the communication variables (a) patient participation, (b) companion participation, and (c) surgeon facilitation associated with a change in patients' illness uncertainty about cancer (pre-post visit)?
- RQ3: Are the communication variables (a) patient participation, (b) companion participation, and (c) surgeon facilitation associated with a change in patients' mental adjustment to cancer (i.e. cancer coping) (pre-post visit)?
- RQ4: Are the communication variables (a) patient participation, (b) companion participation, and (c) surgeon facilitation associated with patients' post-visit satisfaction with visit communication?
- RQ5: Are the communication variables (a) patient participation, (b) companion participation, and (c) surgeon facilitation associated with patients' post-visit satisfaction with treatment plans?
- RQ6: Are the communication variables (a) patient participation, (b) companion participation, and (c) surgeon facilitation associated with patients' post-visit intention to adhere to treatment plans?
- RQ7: Are the communication variables (a) patient participation, (b) companion participation, and (c) surgeon facilitation associated with the length of treatment-decision making conversations?

## CHAPTER THREE: STUDY ONE

## Prolegomenon

The study to be reported in this chapter addresses Research Question 1 and was conducted as a 'proof of concept/principle' for the analytic goal of the main dissertation study, which was to examine associations between communication behaviors and breastcancer patients' psychosocial health outcomes. The study reported in this chapter had the purpose of documenting that the findings of all previous comparable studies generally supported such an association. The present author was wholly responsible for the conception and design of the study reported in this chapter, as well as the acquisition of data; she was primarily responsible for the interpretation of data, as well as the drafting, revising, and editing of the manuscript. This study was published as Venetis, Robinson, Turkiewicz, and Allen (2009) in the journal Patient Education & Counseling. Dr. Jeffrey D. Robinson (Department of Communication, Portland State University, and dissertation chair) provided interpretive support, and Mike Allen and Katie LaPlant Turkiewicz (Department of Communication, University of Wisconsin-Milwaukee) were primarily responsible for the meta-analytic statistics. The present author would also like to thank the journal's guest editors Neeraj K. Arora, Ronald Epstein, Richard Street, and Phyllis Butow, as well as two anonymous reviewers, for extremely helpful feedback on a previous journal-submission draft. The study reported in this chapter is reproduced with full Copyright approval from *Patient Education & Counseling*.

An Evidence Base for Patient-Centered Cancer Care: A Meta-Analysis of Studies of
Observed Communication between Cancer Specialists and their Patients

Introduction

One unique contribution of health communication as a field of inquiry has been its focus on the health-related effects of observed (i.e., taped and coded, vs. self-reported) physician-patient communication variables (Stewart, 1995). In the last decade, with a worsening global cancer crisis (ACS, 2007), the physician-patient literature has been refocusing its attention from primary care delivered by general-practice physicians to cancer care delivered by specialists (e.g., oncologists). The current (and relatively small) pool of studies of observed cancer communication suffer from two limitations. First, similar to a critique made 20 years ago by Roter, Hall, and Katz (1988), different studies focus on different independent and dependent variables, and even similarly conceptualized (and labeled) variables tend to be differently operationalized. Second, studies suffer from reduced statistical power due to small sample sizes. Combined, these two limitations virtually prohibit empirically rigorous claims regarding the effects of particular communication behaviors on particular outcomes. Stated differently, these weaknesses stand as major barriers to achieving the goal of evidence-based medicine (Bensing, 2000). One solution to this problem is meta-analysis (Allen & Preiss, 1993; Hunter & Schmidt, 2004; Rosenthal & DiMatteo, 2001). In the context of studies of observed communication between cancer specialists and their patients, this paper uses meta-analysis to investigate whether or not patient-centered care is significantly

associated with patients' health outcomes. This paper begins by briefly describing the unique ecology of cancer care, and then reviews patient-centered-care communication.

## Cancer-care as a unique medical context

The diagnosis of cancer most commonly emerges from biopsies and imaging tests ordered by patients' primary-care physicians (e.g., internists), who then refer patients to specialists (e.g., oncologists). For this reason, studies of cancer-care communication between physicians and patients focus, almost exclusively, on visits that take place after patients are diagnosed with cancer (Most exceptions to this are qualitative/discursive analyses of the delivery of 'bad' cancer news; e.g., Maynard (2006). In at least three ways, visits between patients who have already been diagnosed with cancer and specialists represent a unique ecology (Street, 2003) for communication and its effects. First, there is evidence that, relative to primary-care physicians, specialists are less competent communicators (Bialor, Gimotty, Poses, & Fagan, 1997) and more resistant to changing their communication skills (Stewart et al., 2007). From cancer-patients' perspectives, cancer-care specialists need to improve patient-centered aspects of their communication (Maguire & Faulkner, 1988; McWilliam et al., 2000). Second, research has shown that the types of problems that get dealt with during medical visits – such as new acute problems (e.g., flu) and chronic-routine problems (e.g., diabetes) – differentially affects physicians' and patients' goals for visits, which differentially shapes the content and process of communication (Eide, Graugaard, Holgersen, & Finest, 2003). Relative to most types of primary-care visits, the goals of many cancer-care visits are different and more narrow. For example, many cancer-care visits are with various types of oncologists and have the goal of developing treatment plans; These visits emphasize

treatment information and decision making, and do not typically include a traditional problem presentation, history taking, physical examination, and diagnosis.

Third, relative to primary care, the psychosocial (vs. biomedical) dimension of illness (vs. disease) (Mishel, 1988) is more pronounced when the problem is cancer (Engel, 1977); That is, relative to acute problems in primary care (e.g., flu, back pain, etc.) (Epstein & Street, 2007), cancer presents patients with higher levels of uncertainty, anxiety, fear, frustration, and vulnerability. Akin to organizational communication generally (Farace, Monge, & Russell, 1977), physicians' and patients' discriminate between two underlying dimensions of communication: medical-technical (i.e., instrumental) and affective-relational (Bensing & Dronkers, 1992). The affectiverelational dimension is particularly salient to patients. For example, patients do not abide strictly by a rational-consumer model of medicine. That is, patients seldom evaluate physicians and their medical care/competence, nor do patients retain physicians, based solely on physicians' medical-technical skills and patients' health outcomes (Glassman & Glassman, 1981). Although patients base their evaluations of physicians' communicative competence on both the instrumental and affective dimensions, which are positively correlated (Ben-Sira, 1982; Cegala, McNeilis, McGee, & Jonas, 1995; Street & Buller, 1987), there is an accumulation of evidence that patients' evaluations of the quality of physicians' and their medical care are influenced more heavily by the affective dimension (Ben-Sira, 1982; Griffith, Wilson, Langer, & Haist, 2003; Mechanic & Meyer, 2000). In sum, the unique ecology of cancer-communication warrants an examination independent from that of primary care.

#### Patient-centered communication

It is well established that physicians' and patients' communication behaviors, generally speaking, have the potential to positively shape patients' post-visit health outcomes, such as their satisfaction and their physical and psychological quality of life (for review, see Stewart, 1995). Given that patients prioritize the affective-relational (vs. instrumental) dimension of communication (see above), one type of communication that has been shown to be strongly associated with patients' health outcomes is patientcentered communication, or that which attends to: (1) patients' affective states (e.g., fear, vulnerability, hopelessness, uncertainty); (2) patients' (vs. physicians') values, needs, and preferences, including psychosocial (vs. biomedical) content; and (3) patient empowerment in terms of having control over topical directions, decision making, etc. (Bensing, 2000; Dowsett et al., 2000; Epstein et al., 2005; Epstein & Street, 2007). Patient-centered communication is typically operationalized in two main ways: (1) Affective Behavior (Eide et al., 2003; Ong, de Haes, Hoos, & Lammes, 1995; Roter & Hall, 1992), including physicians' displays of empathy, concern, reassurance, etc.; and (2) Participation Behavior, including patients' questions and physicians' prompts for them (Gordon, Street, Sharf, & Souchek, 2006; Leighl, Gatterllari, Butow, Brown, & Tattersall, 2001; Street & Gordon, 2006, 2008; Street & Millay, 2001; Street & Voigt, 1997; Street, Voigt, Geyer, Manning, & Swanson, 1995).

In the context of cancer care, prior research consistently suggests that patient-centered communication is associated with a variety of types of patients' health outcomes. For example, communication behaviors that address the affective (vs. instrumental) dimension "positively" (e.g., reassurance) have been associated with

decreases in patients' requests for post-operative narcotics (Egbert, Battit, Welch, & Bartlett, 1964; Langer, Janis, & Wolfer, 1975) and increases in patients' levels of physical functioning, such as their levels of blood glucose and diastolic blood pressure (Kaplan et al., 1989). However, in the context of observed cancer communication, by far the most frequently studied health outcome has been patients' satisfaction-like constructs (e.g., satisfaction with physicians', their communication, information received, treatment decisions, etc.). Research suggests that patient-centered aspects of care are significantly, positively associated with patients' satisfaction (Arora, 2003), which is important in a variety of ways. For example, patients' satisfaction with oncologists is positively associated with patients' willingness to participate in breast-cancer clinical trials (Mancini et al., 2007) and adherence to medical recommendations (Bartlett et al., 1984; DiMatteo, 2004), and has become an important determinant of health-care services' and medical schools' communication-training objectives (Duffy et al., 2004). Patients' satisfaction with treatment decisions has been positively associated with patients' adherence to/continuance of treatment (Willis & Holmes-Rovner, 2003) and with their post-treatment quality of life (Brehaut et al., 2003; Stalmeirer et al., 2005). Patients' dissatisfaction with treatment decisions has been positively associated with their experimentation with alternative therapies (Allen, 2000).

One type of communication that is typically *not* considered to be patient-centered is *Instrumental Behavior* (Dowsett et al., 2000; Epstein et al., 2005; Epstein & Street, 2007; Ong et al., 2000), including physicians' question asking and patients' information giving. Importantly, *Instrumental Behavior* is medically necessary, and thus not

pejorative, and has also been found to be associated with patients' post-visit satisfaction (Roter et al., 1987).

This article uses meta-analysis (Allen & Preiss, 1993; Hunter & Schmidt, 2004; Rosenthal & DiMatteo, 2001) to answer three research questions pertaining to studies of observed (i.e., taped and coded) communication between cancer-specialists and their patients:

- RQ1: What is the association between patient-centered communication and satisfaction-like health outcomes?
- RQ2: What is the association between instrumental behavior and satisfaction-like health outcomes?
- RQ3: Are patient-centered communication and instrumental behavior significantly different in terms of their strength of association with satisfaction-like health outcomes?

## Method

## Literature Search

The article search began January 2007 and ended March 2009. The study pool for the meta-analysis was initially created utilizing the web-based search engines *PsychINFO*, *EbscoHost*, and *Medline* using combinations of the keywords *cancer*, *communication*, *oncologist*, *physician*, *patient*, *audio*, and *video*. In order to be included, articles had to have been reported in English, had to involve visits in which patients who were already diagnosed with cancer interacted with physicians (vs. nurses, etc.), had to involve the coding and quantification of taped communication behavior, and had to involve the statistical association of communication variables with either themselves or

post-visit health outcomes. Bibliographies of all first-pass articles were examined for additional applicable studies. Finally, we contacted the authors of all applicable studies and sought additional applicable *unpublished* studies (none were generated). The article search yielded 25 articles (which are denoted with asterisks in the References) representing 10 distinct data sets (Albrecht, Blanchard, Ruckdeschel, Coovert, & Strongbow, 1999; Brown, Butow, Dunn, & Tattersall, 2001; Butow et al., 1999; Butow, Brown, Cogar, & Tattersall, 2002; Butow, Dunn, Tattersall, & Jones, 1994; 1995; Eggly et al., 2006; Eide et al., 2003; 2004; Eide, Quera, Graugaard, & Finset, 2004; Gattellari, Butow, & Tattersall, 2001; Gordon et al., 2006; Ishikawa, Takayama, Yamzaki, Seki, & Katsumata, 2002; Ishikawa et al., 2002a; Leighl et al., 2001; Ong et al., 1998; 1999; 2000; Siminoff et al., 2000; Street & Gordon, 2006, 2008; Street & Millay, 2001; Street & Voigt, 1997; Street et al., 1995; Takayama, & Yamazaki, 2004). From each data set, we omitted variable relationships when authors did not report correlation data sufficient for a meta-analysis.

## Variable Coding

Each communication variable in every data set was coded, *a priori*, as representing either *Patient-Centered Communication* or *Instrumental Behavior*. Our variable *Patient-Centered Communication* was itself composed of two classes of variables: *Affective Behavior* and *Participation Behavior*. *Affective Behavior* (Ong et al., 1998) included physicians' displays of approval, empathy, concern, worry, reassurance, optimism, and positive affect, and both oncologists' and patients' social/informal talk (*Affective Behavior* was predominantly, but not exclusively, a physician-level variable). *Participation Behavior* (Gordon et al., 2006; Street & Gordon, 2006, 2008; Street &

Millay, 2001; Street & Voigt, 1997; Street et al., 1995) included both: (1) *Physician Facilitation*, which included physicians' communication behaviors that are specifically designed to promote patients' self-determined, communicative participation, such as prompting patients to ask questions and voice concerns, and soliciting patients' opinions; and (2) *Patient Participation*, which included patients' communication behaviors that initiate actions that solicit some type of response from physicians, such as patients' asking questions, voicing preferences and concerns, and giving opinions. Finally, our variable *Instrumental Behavior* (Ong et al., 1998) included physicians' question asking and counseling/direction giving, and both physicians' and patients' information giving.

For each communication variable in each data set, we coded each related health outcome, *a priori*, in terms of whether or not it represented a type of patients' *Satisfaction*. Our variable *Satisfaction* was composed of different types of 'satisfaction-like' constructs, not only including patients' satisfaction with visits generally, with specific aspects of visit communication (e.g., amount of information received; the treatment decision), and with physicians personally, but also with patients' perceptions of their levels of control, involvement, and participation during visits, and patients' perceptions of physicians' levels of collaboration. Four articles separately measured a different non-satisfaction-based health outcome, including patients' anxiety, coping, quality of life, and information recall; There was not a sufficient amount of data to meta-analytically study these outcomes.

## Statistical Analysis

Meta-analysis is a method of comparing findings of different studies. The problem with differences between the findings of individual studies is that inconsistent

findings (as determined by the significance test) can be the result of either random sampling error or systematic factors. Meta-analysis describes a set of techniques that take a series of data sets and seeks to combine their estimates for an average that reduces sampling error, and facilitates an examination of sources of variability in findings (Allen & Preiss, 1993; Hunter & Schmidt, 2004; Rosenthal & DiMatteo, 2001).

A meta-analysis consists of the following steps: (1) The conversion of individual data sets to a common metric; (2) The averaging of individual estimates to form an overall estimate; and (3) The consideration of sources of variability, and explanations for differences among study findings. The conversion of individual data sets to a common metric follows a series of expectations about the nature of statistical relations (Hunter & Schmidt, 2004). Some articles employed designs that generated appropriate information but are not included in this report because the format of the statistical reporting does not permit estimation of zero order relations. The use of multivariate statistics generates coefficients that could have been generated by any number of zero order correlation matrices. What this means is that generation of the underlying relationships is not possible and the data not recoverable for use in a meta-analysis (Hunter & Schmidt, 2004). The calculation of the average estimate uses a weighting system that reflects the sample size of the estimate. The weighting by sample size simply reflects the assumption that larger samples have less sampling error and are more accurate estimates than smaller samples (Allen & Preiss, 1993). Concern exists about the impact of using multiple effects from the same sample. This violation of independence of the estimates could impact the estimation of the mean effect or estimates of the variance or standard deviation of the

sample. A monte carlo simulation of the impact of such violations demonstrated that neither the mean or estimates of the variance or impacted by this problem (Tracz, 1985).

## Results

## Research question 1

Answering RQ 1, *Patient-Centered Communication* (which included the combination of *Affective Behavior* and *Participation Behavior*) was significantly, positively associated with patients' post-visit *Satisfaction* (which included a range of satisfaction-like measures): k = 38, N = 3467,  $average\ r = .143$ ,  $\chi^2 = 62.33$ , p < .05. Although *Affective Behavior* was itself significantly, positively associated with *Satisfaction*, k = 22, N = 2240,  $average\ r = .163$ ,  $\chi^2 = 47.1$ , p < .05, Participation *Behavior* was not: k = 16, N = 1227,  $average\ r = .107$ ,  $\chi^2 = 12.88$ , p > .05. Neither of the sub-components of *Participation Behavior* were themselves significantly associated with *Satisfaction*, including *Physician Facilitation*, k = 5, N = 562,  $average\ r = .067$ ,  $\chi^2 = 3.24$ , p > .05, and *Patient Participation*: k = 11, N = 665,  $average\ r = .141$ ,  $\chi^2 = 8.08$ , p > .05. However, these two sub-components were significantly, positively associated, k = 7, N = 269,  $average\ r = .101$ ,  $\chi^2 = 23.06$ , p < .05, suggesting a logical sequential relationship between physicians' prompts for patients' participation and its realization.

## Research question 2

Answering RQ 2, *Instrumental Behavior* was significantly, positively associated with patients' post-visit *Satisfaction* (which included a range of different types of satisfaction measures): k = 9, N = 911, average r = .076,  $\chi^2 = 29.8$ , p < .05.

## Research question 3

Answering RQ 3, *Patient-Centered Communication* (which included the combination of *Affective Behavior* and *Participation Behavior*) was significantly more strongly associated with patients' post-visit *Satisfaction* (which included a range of different types of satisfaction measures) than was *Instrumental Behavior*: z = 6.11, p < .05. *Affective Behavior* was itself significantly more strongly associated with *Satisfaction* than was both *Participation Behavior*, z = 2.62, p < .05, and *Instrumental Behavior*: z = 9.26, p < .05. *Participation Behavior* and *Instrumental Behavior* were not significantly different in terms of their strength of association with *Satisfaction*: z = 1.61, p > .05.

#### Discussion and Conclusion

#### Discussion

Ultimately, the goal of basic research on the relationship between physicians' and patients' communication behaviors, and the effects of such behaviors on patients' healthcare outcomes, is the implementation and testing of communication interventions toward the goal of improving patients' biopsychosocial wellness. Effectively changing health behavior necessitates a connection between scientific evidence and critical analysis (Allen, 1999). Making this a connection can be facilitated by meta-analysis (Allen & Burrell, 1996; Allen, Mabry, & McKelton, 1998).

This article examined studies of observed (i.e., taped and coded) communication between cancer specialists (e.g., oncologists) and their patients; It used meta-analysis to test the association between both *Patient-Centered Communication* and *Instrumental Behavior* and patients' post-visit health outcomes involving satisfaction-like constructs.

Both *Patient-Centered Communication* and *Instrumental Behavior* were significantly, positively associated with *Satisfaction*, and thus are essential to quality cancer care.

For the purposes of our meta-analysis, we operationalized *Patient-Centered*Communication as involving both Affective Behavior (e.g., physicians reassuring patients ()Ong et al., 1998), and Participation Behavior (e.g., physicians prompting patients to initiate actions, such as ask questions or express concerns, and patients initiating such actions (Gordon et al., 2006; Street & Gordon, 2006, 2008; Street & Millay, 2001; Street & Voigt, 1997; Street et al., 1995). We included Participation Behavior because it represents a key feature of patient-centered care, which is patient empowerment/control (Epstein et al., 2005; Epstein & Street, 2007). Although Affective Behavior was itself significantly associated with Satisfaction, Participation Behavior was not. However combining Participation Behavior with Affective Behavior significantly increased the effect on Satisfaction.

The lack of significant association between  $Participation\ Behavior$  and Satisfaction was somewhat surprising to the authors. Future research needs to continue to investigate the effects-pathways from  $Participation\ Behavior$  to health outcomes. For example, it is possible to conceptualize  $Participation\ Behavior$  as a patient-centered form of  $Instrumental\ Behavior$  because it typically leads to physicians' information giving. That is, regardless of how patients' initiating actions (e.g., questions) are realized (i.e., prompted by physicians or self-initiated by patients), they normatively solicit physicians' responses. In this sense,  $Participation\ Behavior$  involves either a three-part sequence (e.g., physician prompt  $\Rightarrow$  patient question  $\Rightarrow$  physician response) (Robinson, 2001) or a two-part sequence (e.g., patient question  $\Rightarrow$  physician response) (Ishikawa et al., 2002),

both of which ultimately lead to *Instrumental Behavior*. Research does not currently examine these sequential relationships.

Both Patient-Centered Communication (as a composite variable), and Affective Behavior (i.e., one sub-component of Patient-Centered Communication) had significantly stronger associations with Satisfaction than did Instrumental Behavior. Similar to findings in primary care (Ben-Sira, 1982; Griffith et al., 2003; Mechanic & Meyer, 2000), relative to Instrumental Behavior, patients' evaluations of the quality of cancerspecialists and their medical care appear to be influenced more heavily by Patient-Centered Communication and Affective Behavior.

#### Conclusion

In conclusion, this article provides an evidence base for the efficacy of patient-centered care. This article is limited in several ways, most stemming from the small amount of research on observed (i.e., taped and coded) communication behavior during cancer care and its relationship to healthcare outcomes. Much more research is needed in this area, and authors should endeavor to include, in publications, statistical data that accommodates meta-analysis (e.g., zero-order correlation matrices). The studies included in our meta-analysis were conducted in several different nations (Australia, Japan, the Netherlands, and the United States), and due to limited data, we were not able to study the possible affect of nationality on communication behavior or *Satisfaction*. We only focused on one type of health outcome involving patients' satisfaction with a variety of visit phenomena. Future communication research needs to broaden their focus on health outcomes beyond satisfaction-like constructs to those that would allow comparability with arguably more mainstream medical research, such as patient's anxiety and

depression (Brown et al., 1999; Zigmond & Snaith, 1983), mental adjustment to cancer (i.e., cancer coping, such as fatalism and helplessness-hopelessness; (Ong et al., 1999; Watson, Law, dos Santos, Greer, Baruch, & Bliss, 1994) and cancer uncertainty (Mishel, 1988). Finally, we were unable to test the effect of patients' *companions*' communication behavior (and their presence is common in cancer care) because too little companion data is currently reported.

## **Practice Implications**

Our findings suggest that cancer specialists (e.g., oncologists) need to attend continuing-medical-education courses dealing with improving their *Patient-Centered Communication*. Although, compared to general practitioners, it appears to be more difficult to train specialists (Stewart et al., 2007) there is a wealth of evidence that communication-training programs can significantly increase physicians' rates of patient-centered behaviors (Cegala & Broz, 2002; Fallowfield et al., 2002; Jenkins & Fallowfield, 2002; Maguire, Faulkner, Booth, Elliott, & Hellier, 1996).

## CHAPTER FOUR: STUDY TWO METHOD

The study one results were limited to patient satisfaction. As described in Chapter Two, patients experience a wide range of cancer-related psychosocial effects (Hewitt et al., 2004). In order assess the effects of communication-participation behavior on the patient psychosocial outcomes of illness uncertainty, mental adjustment to cancer (coping), and patient intention to adhere, as well as to further test the association to satisfaction, but specifically as visit satisfaction and treatment plan satisfaction, study two was conducted and is described below.

## **Cancer Population**

This study focuses on the association between aspects of surgeon-patient communication and patients' psychosocial health outcomes. Different types of cancer, and different stages of the cancer-care process, are associated with different types and levels of psychosocial health outcomes (Bloom et al., 1993; Decker, Haase, & Bell, 2007). Thus, in order to promote contextually rich explanations that have increased ecological validity, this study focuses exclusively on one specific cancer population: newly diagnosed women with breast cancer visiting surgeons (predominantly for the first time) to discuss treatment options and/or develop a treatment plan. Although this focus reduces generalizability across cancer types and stages of the cancer-care process, it is methodologically justified and is called 'observation selection' (Bollen, 1989).

## Study Site

Given this study's focus on newly diagnosed women with breast cancer, it was conducted at The Stacy Goldstein Breast Cancer Center, which is housed in The Cancer Institute of New Jersey (CINJ). CINJ is part of the University of Medicine and Dentistry

of New Jersey and Robert Wood Johnson University Hospital and Medical School. CINJ is one of the National Cancer Institute's 41 designated Comprehensive Cancer Centers, and the only one in New Jersey. The comprehensive designation is the highest rank given by the National Cancer Institute, and is achieved by meeting rigorous criteria for cancer care, research, prevention, and education. The Stacy Goldstein Breast Cancer Centerserves approximately 1,600 breast cancer patients annually across all facets of the cancercare process, including surgical, medical, and radiation oncology, clinical psychology, social work, and education. At the inception of this study, the Stacy Goldstein Breast Cancer Center employed two surgical oncologists who performed the majority of breast-cancer surgeries.

## **Participants**

This study involves three types of participants: surgical oncologists, their patients, and, when relevant, patients' companions.

## Surgical Oncologists

At the inception of this study, both surgical oncologists at the Stacy Goldstein Breast Cancer Center were recruited and agreed to participate; one surgeon was a male associate professor of medicine and the director of breast-care services, and the other surgeon was a female, assistant professor of medicine. However, just prior to data collection, the female surgeon left the facility for another position, and her replacement was not hired until after the termination of data collection. Thus, this study involves the single male surgeon. During the period of data collection, this surgeon conducted 95% of the breast surgeries at the breast center. He typically conducted the visit that were the

focus of the main dissertation study (i.e., treatment-decision making visits) on Tuesdays and Thursdays, and saw approximately four eligible patients per week.

#### **Breast-Cancer Patients**

Eighty-eight patients were asked to participate; 74 patients (84%) agreed, 14 patients (16%) declined, and one (01%) withdrew prior to videotaping. The 14 patients who declined reported doing so because they did not want to be videotaped (e.g., because of the personal/sensitive content of visits), felt too anxious, and/or did not want to fill out surveys. Of the 74 patients who agreed, 51 generated complete data sets, meaning that they filled out both the pre- and post-visit survey (which was necessary to calculate change scores for illness uncertainty and mental adjustment to cancer) and had their visit videotaped. Of the 23 incomplete data sets, 17 did not complete the pre- and/or post-visit survey, three did not yet have a positive cancer diagnosis (and remained hopeful that the biopsy would be negative), one patient was seen by multiple oncologists during the visit, and for one patient, the video ended during one visit. Because the primary outcome variables for this study are change scores (from pre- to post-visit), analyses are based on the 51 complete data sets.

# Companions

Based on previous research (Street & Gordon, 2008), companions (e.g., spouse, sister) are not a specific focus in the present study. Prior research (Street & Gordon, 2008) suggests that there are no significant differences between patients with and without companions with respect to patients' education, age, ethnicity, health status, and prior history with breast surgeons. A similar lack of differences was also found in this current dissertation research.<sup>4</sup> Street and Gordon also found that the presence of companions

does not significantly affect the: (a) surgeons' control of the conversational floor during visits; (b) surgeons' facilitative communication during visits (i.e., one aspect of communication participation); or (c) overall visit length. Street and Gordon also found that: (a) the presence of companions does not significantly affect the overall amount that patients talk during visits; and (b) the presence of companions does not significantly affect patients' levels of communication participation. Finally, Street and Gordon found that patients' post-visit satisfaction is not significantly associated with companions' level of communication participation.

However, companions are participants because they are an ecologically natural element of surgeon-patient visits; companions were recorded and their speech was coded. Of the 51 patients analyzed, 39 (76%) brought one or more companions. The number of companions ranged from 1-3 per patient (M = 1.02; median = 1), for a total of 52 companions. Thirty-nine (76%) patients were accompanied by one companion. Of these 39 patients, 11 patients (22% of total 51 patients) were accompanied by two companions, and two patients (4% of total 51 patients) were accompanied by three companions (see Table 2). Companions were husbands (n = 26), adult children (n = 12), parents (n = 5), friends (n = 5), siblings (n = 3), and other relatives (specifically, a sister-in-law; n = 1).

## Procedure

Prior to all data collection, a member of the research team introduced and explained the study to the surgeon and solicited his informed consent; he was not compensated for his participation.

The data collection procedure unfolded as follows. Prior to a given data-collection day, the research team consulted (by phone or in person) with the surgeon's staff in order

to determine the presence of eligible patients and, if present, their appointment times. A member of the research team arrived at the breast center 30 minutes prior to the first eligible appointment time, set up all recording equipment, and prepared/organized all consent and survey materials (see Appendices A-F). In the treatment-decision-making room, a small, wireless, digital videocamera was affixed in one of the ceiling corners. The camera had a wide-angle lens, allowing it to capture the entire room and all participants.

Eligible patients arrived to the clinic, checked in, and were briefly physically examined by the surgeon. Upon completion of the physical examination, the surgeon notified the patient that he (the surgeon) was participating in a research study in which the patient is eligible to participate; the surgeon ushered the patient (and their companions) into a treatment-decision-making room and alerted them that a member of the research staff would introduce and explain the study. A member of the research team then entered the treatment-decision-making room, introduced him/herself, introduced and explained the study, and finally solicited informed consent from the patient (see Appendix C) and, if relevant, all companions (see Appendix D). Patients were compensated \$20 in cash (companions were not compensated) (see Appendix E and F).

If patients agreed to participate, they completed the paper-and-pencil, pre-visit survey (see Appendix A), which took approximately 15 minutes to complete. Because patients typically waited 20-30 minutes between the end of the physical examination and the beginning of the treatment-decision-making conversation, the pre-visit survey generally did not delay the surgeon's schedule. A member of the research team started the videocamera while the patient was completing the pre-visit survey and before the

surgeon entered the room. Cameras were turned on by research staff for two reasons.

First, physicians routinely forget to turn on cameras (Heritage, Robinson, Elliot, Beckett, & Wilkes, 2007; Robinson, 2003; Robinson, Krieger, Burke, Weber, & Osterling, 2008).

Second, the turning on of cameras by physicians draws patients' attention to cameras. A member of the research team collected the pre-visit survey when complete, and then informed the surgeon that the patient was 'ready.' No member of the research team was present in the rooms during treatment-decision-making visits.

After the surgeon completed the treatment-decision-making visit and left the room, the patient (and their companions) remained in the room while a member of the research team turned the camera off and administered the post-visit survey. When the patient completed the post-visit survey, they (and their companions) were thanked, patients were paid for their participation, and patients and companions were given copies of their signed consent forms. If patients declined payment (and only when they declined payment, so as to not bias their choice), they were offered the option of donating their \$20 to the *Susan Komen Foundation for the Cure* (a non-profit organization that supports breast cancer research); if so, patients were asked to sign a waiver form, and the money was donated. Only two of the 51 patients (3%) declined payment and elected to donate it.

The researcher stayed at the office through the last eligible patient. All equipment was removed at the end of each day. Equipment cleanup required less than five minutes.

Data Processing, Entering, and Cleaning

## Survey Data

Survey data was entered by hand into an Excel spreadsheet. Once all data collection had ended, the excel document was converted into an SPSS 17.0 file. Data

were screened for missing data, which was treated in two ways. First, if less than 5% of data were missing for a particular variable, a process of mean substitution was employed using SPSS software (Tabachnick & Fidell, 2007). Second, if most/all items of a particular measurement scale were left blank, and if missing data were not randomly distributed (Tabachnick & Fidell, 2007), then that measurement scale was removed from analysis; This was only the case for the *Patient Perceived Similarity to Surgeon* scale (Street, O'Malley, Cooper, & Haidet, 2008).

For measurement scales in the pre-visit and post-visit surveys, confirmatory and exploratory analyses were performed, as appropriate (and are described below). Only factors with eigenvalues of 1.0 and greater were retained, and only items with primary factor loadings of .60 and greater were retained (Tabachnick & Fidell, 2007). When necessary, items were rescored so that greater values indicated more of a given variable. Where appropriate, composite scores were created by averaging responses to individual items; greater values indicated more of a given variable. All measures were tested for normality and multivariate outliers. The measurement scales of patients' intentions to adhere to treatment plans and patients' satisfaction with visit communication, which had skewness above 2.0, were dichotomized (This process is described below for each variable). In certain instances, the pre-visit and post-visit values of common variables (e.g., illness uncertainty and mental adjustment to cancer) exceeded parameters of normality; however, because the variable of analysis was a change score, if the change score achieved normality (and skewness was below 2.0), no transformations were performed. All change scores achieved normality.

Several potential covariates were measured in the surveys (see below). However, because the inclusion of a particular covariate in one regression analysis requires that the same covariate be entered into other regression analyses in order to produce comparability among results, and because no single covariate was consistently significantly associated with any of the focal communication variables (i.e., the independent variables, none of the potential covariates were included in the primary or secondary regression analyses (K. Greene, personal communication, May 7, 2010). This analytic decision was supported by a power analysis (computed using GPower3.0.10 software), which found that, with a sample size of 51 with a power of .85 the number of independent variables cannot exceed five. For an analysis of covariates, readers are directed to post-hoc tertiary analyses.

#### Video Data

The videotape of each visit was transformed into a digitized and compressed computer movie file. All videos were burned onto two DVDs and stored on an external hard drive. Interaction data were coded by watching and listening to videos (see below for coding procedures). Because the coding process did not require the reading of transcripts (Street Behavior Coding Guide; R. L. Street, personal communication, March 15, 2009), transcripts were not exhaustively produced. Rather, interaction data were selectively transcribed after coding for the purpose of qualitatively refining the communication variables used in the primary analysis (see below for a description of the secondary analysis).

#### Variables/Measurement Instruments

#### *Pre-visit survey*

The pre-visit survey included measures of two central dependent variables, including *patients' illness uncertainty* and *mental adjustment to cancer* (i.e., cancer coping), as well as patients' levels of *religious-service attendance*, *perceived social support*, and demographics (see Appendix A for a copy of the pre-visit survey).

Illness Uncertainty

Illness uncertainty about cancer was measured with a modified version of Mishel's widely-used and psychometrically tested *Illness-Uncertainty Scale* (Community Form). Mishel's original 23-item scale had to be modified because some items were not salient to (or relevant for) the present patient population (i.e., newly diagnosed breastcancer patients). The following types of items were removed from the original scale: (1) Items related to symptoms, because the present patient population is typically asymptomatic (e.g., My symptoms continue to change unpredictably); (2) Items related to illness progression and treatment success, because the present patient population is at the very beginning of the treatment experience (e.g., I am unsure if my illness is getting better or worse); and (3) Items related to communication with health-care providers, because a large portion of the present patient population was not expected to have yet interacted with a relevant cancer specialist (e.g., I understand everything explained to me). When relevant, the term "illness" was replaced with "cancer." The modified scale included the following items: (1) "I don't know what is wrong with me," (2) "I have a lot of questions without answers," (3) "It is unclear how bad my pain will be, (4) "The purpose of treatment is clear to me," (5) "I can predict how long my cancer will last," (6)

"My treatment is too complex to figure out," (7) "Because of the unpredictability of my cancer, I cannot plan for the future," (8) "It is not clear what is going to happen to me," (9) "I can generally predict the course of my cancer," (10) "I have not been given a specific diagnosis," (11) "The seriousness of my cancer has been determined," (12) "The explanations I've been given about my cancer seem hazy to me," (13) "I have been given many differing opinions about what is wrong with me," (14) "I usually know if I am going to have a good or bad day," (15) "The results of my tests are inconsistent," (16) "The effectiveness of the treatment is undetermined," (17) "I'm certain they will not find anything else wrong with me," and (18) "The treatment I will receive has a known probability of success." Items were formatted using a five-point Likert-type scale. Mishel's original scale is supposed to represent a single-factor. However, a factor analysis revealed two factors (see Tables 6 and 7). The first factor was named 'ambiguity uncertainty' and contained six items: (1) "I have a lot of questions without answers" (recoded); (2) "My treatment is too complex to figure out" (recoded); (3) "Because of the unpredictability of my cancer, I cannot plan for the future" (recoded); (4) "It is not clear what is going to happen to me" (recoded); (5) "The explanations I've been given about my cancer seem hazy to me" (recoded); and (6) "The results of my tests are inconsistent" (recoded). The resulting factor had an eigenvalue of 3.30 and accounted for 54.98% of the variance. Variable statistics for the pre-visit measure include: M = 2.16, SD = .77,  $\alpha$ =.83, variance =.59, skewness =.56, kurtosis =-.26 (see Table 6). The second factor was named 'unpredictability uncertainty' and contained two items: (1) "I can predict how long my cancer will last;" and (2) "I can generally predict the course of my cancer." The resulting factor had an eigenvalue of 1.48 and accounted for 74.17% of the variance.

Variable statistics for the pre-visit measure include: M = 3.50, SD = .88,  $\alpha = .65$ , variance = .78, skewness = -.11, kurtosis = -.53 (see Table 7). Factor analyses and reliability testing were computed with the pre-visit measures, and the structure of the pre-visit variable was maintained for the corresponding post-visit variable.

Mental Adjustment to Cancer (i.e., Cancer Coping)

Cancer coping was measured with the widely-used and psychometrically tested *Mini-Mental Adjustment to Cancer Scale* (Mini-MAC; Watson et al., 1994). This scale includes five subscales: *fighting spirit*, *helplessness-hopelessness*, *anxious preoccupation*, *cognitive avoidance*, and *fatalism* (described below). For all subscales, items were formatted using a six-point Likert-type scale. All factor analyses and reliability testing were computed with the pre-visit measures, and the structure of the pre-visit variable was maintained for the corresponding post-visit variable.

Fighting spirit. The original Mini-MAC's scale for fighting spirit contains four items: (1) "I am determined to beat this disease," (2) "I see my illness as a challenge," (3) "I try to fight the illness," and (4) "I am very optimistic." These items were subjected to a confirmatory factor analysis. Two of the four items were retained: (1) "I am determined to beat this cancer" and (2) "I am very optimistic" (see Table 8). The resulting factor had an eigenvalue of 1.40 and accounted for 70.01% of the variance. Variable statistics for the pre-visit measure include: M = 5.36, SD = .85,  $\alpha = .56$ , variance = .72, skewness = -1.65, kurtosis = 2.62.

Helplessness-hopelessness. The original Mini-MAC's scale for helplessness-hopelessness contains eight items: (1) "I feel like giving up," (2) "I feel that life is hopeless," (3) "I feel completely at a loss about what to do," (4) "I can't handle it," (5) "I

feel there is nothing I can do to help myself," (6) "I think it is the end of the world," (7) "I can't cope," and (8) "I am not very hopeful about the future." These items were subjected to a confirmatory factor analysis, and five items were retained: (1) "I feel like giving up," (2) "I feel completely at a loss about what to do," (3) "I feel there is nothing I can do to help myself," (4) "I feel like it's the end of the world," and (5) "I can't cope" (see Table 9). The resulting factor had an eigenvalue of 2.98 and accounted for 59.60% of the variance. Variable statistics for the pre-visit measure include M = 1.44, SD = .78,  $\alpha = .80$ , variance = .61, skewness = 2.44, kurtosis = 7.0.

Anxious preoccupation. The original Mini-MAC's scale for anxious preoccupation contains eight items: (1) "I am upset about having cancer," (2) "It is a devastating feeling," (3) "I suffer great anxiety about it," (4) "I am a little frightened," (5) "I worry about the cancer returning or getting worse," (6) "I feel very angry about what has happened to me," (7) "I have difficulty in believing that this happened to me," and (8) "I am apprehensive." These items were subjected to a confirmatory factor analysis, and six items were retained: (1) "I am upset about having cancer," (2) "I feel devastated about having cancer," (3) "I suffer great anxiety about the cancer," (4) "I am a little frightened," (5) "I feel very angry about what has happened to me," and (6) "I am apprehensive" (see Table 10). The resulting factor had an eigenvalue of 3.53 and accounted for 58.89% of the variance. Variable statistics for the pre-visit measure include M = 3.14, SD = 1.27,  $\alpha = .87$ , variance = 1.61, skewness = .61, kurtosis = -.74.

Cognitive avoidance. The original Mini-MAC's scale for cognitive avoidance contains four items: (1) "I make a positive effort not to think about my illness," (2) "Not thinking about me helps me cope," (3) "I deliberately push all thoughts of cancer out of

my mind," and (4) "I distract myself when thoughts about my illness come into my head." These items were subjected to a confirmatory factor analysis, and all four items were retained (see Table 11). The resulting factor had an eigenvalue of 2.69 and accounted for 67.24% of the variance. Variable statistics for the pre-visit measure include M = 3.33, SD = 1.40,  $\alpha = .85$ , variance = 1.97, skewness = .06, kurtosis = -1.12.

Fatalism. The original Mini-MAC's scale for fatalism contains five items: (1) "I've had a good life; what's left is bonus," (2) "I've put myself in hands of God," (3) "Since my cancer diagnosis I now realize how precious life is and I'm making the best of it," (4) "I count my blessings," and (5) "At the moment I take one day at a time." These items were subjected to a confirmatory factor analysis, and three items were retained: (1) "I've had a good life; what's left is bonus," (2) "I've put myself in the hands of God," and (3) "I count my blessings" (see Table 12). The resulting factor had an eigenvalue of 1.64 and accounted for 54.65% of the variance. Variable statistics for the pre-visit measure include M = 4.31, SD = 1.30,  $\alpha = .59$ , variance = 1.69, skewness = -.49, kurtosis = -.41. Religious-Service Attendance

Patients' levels of religious-service attendance are positively associated with their ability to cope with cancer (Bowie, Sydnor, Granot, & Pargament, 2005). Religious-service attendance was measured with a widely-used, single-item measure (Idler, et al., 2003): "Prior to your cancer diagnosis, how often did you attend religious services?" Responses ranged from (1) *never* to (9) *several times a week* (see Table 1). Responses included: never (n = 9; 18%) less than once a year (n = 3; 6%), about once or twice a year (n = 8; 16%), several times a year (n = 9; 18%), about once a month (n = 2; 4%), 2-3 times a year (n = 2; 4%), nearly every week (n = 5; 10%), every week (n = 11; 22%),

and several times a week (n = 1; 2%). Following prior research (Strawbridge, Cohen, Shema, & Kaplan, 1997), this variable was dichotomized into every week or more (i.e., 'frequent' attendees; n = 12; 24%) and less than every week (i.e., 'infrequent' attendees; n = 38; 76%).

## Patients' Perceived Social Support

Patients' perceived social support has been found to be positively associated with their mental adjustment to cancer (Manne et al., 2003; Söllner et al., 1999). This variable was measured with the widely-used and psychometrically tested Berlin Social-Support Scale (Zigmond & Snaith, 1983). The original Perceived Social Support scale contains eight items: (1) "There are some people who truly like me," (2) "Whenever I am not feeling well, other people show me that they are fond of me," (3) "Whenever I am sad, there are people who cheer me up," (4) "There is always someone there for me when I need comforting," (5) "I know some people upon whom I can always rely," (6) "When I am worried, there is someone who helps me," (7) "There are people who offer me help when I need it," and (8) "When everything becomes too much for me to handle, others are there to help me." Items were formatted using a four-point Likert-type scale. These items were subjected to a confirmatory factor analysis and six items were retained: (1) "Whenever I am sad, there are people who cheer me up," (2) "There is always someone there for me when I need comforting," (3) "I know some people upon whom I can always rely," (4) "When I am worried, there is someone who helps me," (5) "There are people who offer me help when I need it," and (6) "When everything becomes too much for me to handle, others are there to help me" (see Table 16). The resulting factor had an eigenvalue of 3.79 and accounted for 63.14% of the variance. Variable statistics include

M = 3.8, SD = .38,  $\alpha = .87$ , variance = .15, skewness = -2.46, kurtosis = 6.3. Because the composite was negatively skewed, and because of the extreme ceiling effect (with patients reporting high levels of support), the composite was dichotomized, such that lower values of perceived social support (0-3) were recoded as 0 (i.e., *moderate social support*), and the highest value of perceived social support (4) was recoded as 1 (i.e., *high social support*). The resulting variable statistics include M = .83, SD = .28, variance = .08. Eighteen patients (35%) reported moderate perceived social support and 32 patients (63%) reported high perceived social support.

# Demographics

Data were collected on patients' age, education, household income, ethnicity, and marital status (all patients were female). Patient age was a continuous variable. Education level, following prior research (Melmed, Kwan, Reid, & Litwin, 2002), was dichotomized into 'less than B.A.' (n = 22; 43%) and 'B.A or more' (n = 29; 57%). Household income (for those who reported; n = 46), following prior research that dichotomized income by state median (Robinson et al., 2002), was dichotomized into \$0-\$75,000 (n = 21; 46%) and \$76,000-\$200,000+ (n = 25; 54%). Ethnicity, following prior research (Wilhelm-Leen, Hall, de Boer, & Chertow, 2010), was dichotomized into 'white' (n = 41; 80%) and 'non-white' (n = 10; 20%). Patient marital status, following prior research (Nakata, Takahashi, Otsuka, & Swanson, 2010), was dichotomized into 'single' (n = 19; 37%) and 'married' (n = 32; 63%) (see Table 2).

## Post-visit survey

The post-visit survey asked patients about *patients' mental adjustment to cancer*, illness uncertainty about cancer, prior history with this surgeon, prior history with any

breast surgeon, patients' satisfaction with visit communication, patients' satisfaction with treatment plans, and patients' intention to adhere to treatment plans (see Appendix B for a copy of the post-visit survey).

Patients' Prior History with Breast Surgeon

Because patients' prior histories with physicians is positively associated with patients' post-visit satisfaction with physicians (Weinberg, Greene, & Mamlin, 1981), patients were asked to answer the single item: "Is this the first time that you have had an appointment with this particular doctor?" Forty two patients (82%) reported no prior history, while nine patients (18%) reported a prior history.

Patients' Prior History with any Breast Surgeon

Because patients' scores on the study's main outcome variables – i.e., mental adjustment to cancer (e.g., coping), illness uncertainty, satisfaction with treatment plan, satisfaction with physician, and intention to adhere to treatment plan – may have been affected by whether or not patients had previously discussed treatment for their breast cancer, patients were asked to answer the following single item: "Is this the first breast surgeon that you have spoken to about your treatment decision?" 33 patients (65%) reported 'first conversation,' while 18 patients (35%) reported 'non-first conversation.' *Patients' Satisfaction with Visit Communication* 

Patients' satisfaction with surgeons' visit communication was measured with Brown's Art of Medicine Scale (Brown et al., 1999). The items were tailored to reflect patients' satisfaction with the breast surgeon she had just seen. Items were formatted using a nine-point Likert-type scale. The original Art of Medicine scale contains eight items: (1) "How courteous and respectful was the doctor," (2) "How well did the doctor

understand your problem," (3) "How well did the doctor explain to you what he or she was doing and why," (4) "Did the doctor use words that were easy for you to understand," (5) "How well did the doctor listen to your concerns and questions," (6) "Did the doctor spend enough time with you," (7) "How much confidence do you have in the doctor's ability or competence," and (8) "Overall, how satisfied are you with the service that you received from the doctor?" These items were subjected to a confirmatory factor analysis, and all eight items were retained, M = 8.80, SD = .45,  $\alpha = .90$ , variance = .21, skewness = -2.13, kurtosis = 3.63 (see Table 2). The resulting factor had an eigenvalue of 5.14 and accounted for 64.27% of the variance. Because the composite was negatively skewed, and because of the ceiling effect (with patients reporting high levels of satisfaction), the composite was dichotomized such that lower values of satisfaction (0 to 8.9) were recoded as 0 indicating that the patient was 'less than fully satisfied,' and the highest value of satisfaction (9) was recoded as 1 indicating that the patient was 'fully satisfied' (i.e., all items were responded to with a 9). The resulting variable statistics include M = .84, SD = .28, variance = .08. Twenty-one patients (41%) reported moderate satisfaction and 30 patients (59%) reported high satisfaction.

## Illness Uncertainty about Cancer

As stated above, all factor analyses and reliability testing were computed with the pre-visit measures, and the structure of the pre-visit variable was maintained for the corresponding post-visit variable (Wright, 2003). A confirmatory factor analysis was computed on the eight post-visit *ambiguity uncertainty* items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 6). The resulting factor had an eigenvalue of 3.05 and accounted for 50.90% of the variance. Variable

statistics for the post-visit measure include M = 1.68, SD = .53,  $\alpha = .80$ , variance = .28, skewness = 1.11, kurtosis = 2.60. A confirmatory factor analysis was computed on the two post-visit *unpredictability uncertainty* items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 7). The resulting factor had an eigenvalue of 1.55 and accounted for 77.45% of the variance. Variable statistics for the post-visit measure include M = 3.20, SD = .93,  $\alpha = .70$ , variance = .88, skewness = .28, kurtosis = -.21.

Mental Adjustment to Cancer (i.e., Cancer Coping)

As stated above, all factor analyses and reliability testing were computed with the pre-visit measures, and the structure of the pre-visit variable was maintained for the corresponding post-visit variable (Wright, 2003).

Fighting spirit. A confirmatory factor analysis was computed on the two post-visit fighting spirit items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 8). The resulting factor had an eigenvalue of 1.34 and accounted for 66.70% of the variance. Variable statistics for the post-visit measure include M = 5.62, SD = .61,  $\alpha = .56$ , variance = .37, skewness = -1.74, kurtosis = 2.54.

Helplessness-hopelessness. A confirmatory factor analysis was computed on the five post-visit helplessness-hopelessness items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 9). The resulting factor had an eigenvalue of 3.52 and accounted for 70.36% of the variance. Variable statistics for the post-visit measure include M = 1.26, SD = .60,  $\alpha = .87$ , variance = .35, skewness = 2.5, kurtosis = 5.54.

Anxious preoccupation. A confirmatory factor analysis was computed on the six post-visit anxious preoccupation items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 10). The resulting factor had an eigenvalue of 4.14 and accounted for 68.94% of the variance. Variable statistics for the post-visit measure include M = 2.98, SD = 1.29,  $\alpha = .91$  variance = 1.67, skewness = .72, kurtosis = -.39.

Cognitive avoidance. A confirmatory factor analysis was computed on the four post-visit cognitive avoidance items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 11). The resulting factor had an eigenvalue of 3.23 and accounted for 80.86% of the variance. Variable statistics for the post-visit measure include M = 3.16, SD = 1.60,  $\alpha = .92$ , variance = 2.57, skewness = .13, kurtosis = -1.24.

Fatalism. A confirmatory factor analysis was computed on the three post-visit fatalism items that were identified in the pre-visit survey as comprising a coherent and reliable factor (see Table 12). The resulting factor had an eigenvalue of 1.69 and accounted for 56.26% of the variance. Variable statistics for the post-visit measure include M = 4.22, SD = 1.26,  $\alpha = .55$ , variance = 1.60, skewness = -.37, kurtosis = -.32. Patients' Satisfaction with Treatment Plans

Patients' satisfaction with treatment plans was measured using a modified version of the Decision Attitude Scale (Sainfort & Booske, 2000). Items were formatted using a 1-5 Likert-type scale. The original Decision Attitude Scale captures one dimension of satisfaction, but it also contains three underlying structures. Items from two structures, *Satisfaction with Choice* and *Satisfaction with Adequacy of Information* were used. When

relevant, the term "choice" was replaced with "treatment plan." Seven of the Decision Attitude Scale items were used: (1) "The treatment plan is sound," (2) "I understand the treatment plan," (3) "It would be useful to consult with another doctor about the treatment plan," (4) "I am comfortable with the treatment plan," (5) "More information about the treatment plan would be helpful," (6) "The treatment plan is the right one for my situation," and (7) "I am satisfied with the treatment plan." These items were subjected to a exploratory factor analysis and six items were retained as one factor: (1) "The treatment plan is sound," (2) "I understand the treatment plan," (3) "It would be useful to consult with another doctor about the treatment plan" (recoded), (4) "I am comfortable with the treatment plan," (5) "The treatment plan is the right one for my situation," and (6) "I am satisfied with the treatment plan" (see Table 14). The resulting factor had an eigenvalue of 3.24 and accounted for 64.80% of the variance. Variable statistics include M = 4.24, SD = .67,  $\alpha = 0.82$ , variance = .45, skewness = -.59, kurtosis = -.61.

## Patients' Intentions to Adhere to Treatment Plans

Patients' intentions to adhere to treatment plans was measured with three items: (1) "I am committed to following the treatment plan," (2) "I intend to follow the treatment plan," and (3) "How likely are you to follow the treatment plan?" Items were formatted using a five-point Likert-type scale. These items were subjected to an exploratory factor analysis and all three items were retained (see Table 15). The resulting factor had an eigenvalue of 2.30, accounting for 76.33% of the variance. Variable statistics include M = 4.67, SD = .59,  $\alpha = .82$ , variance = .34, skewness = -2.0, kurtosis = 3.14. Because the composite was negatively skewed, and because most patients reported

high levels of intention to adhere, the composite was dichotomized such that lower values (1 to 4.9) were recoded as 0, indicating that patients were 'less than fully committed,' and that the highest value (5) was recoded as 1, indicating that patients were 'fully committed.' The resulting variable statistics include M = .77, SD = .36, variance = .13. Seventeen patients (34%) were 'less than fully committed' and 33 patients (66%) were 'fully committed' to adhere to treatment plans.

## Change scores

A central goal of this study was to examine how visit communication is associated with changes in different aspects of patients' psychosocial health from pre-visit to post visit. The variables *illness uncertainty* and *mental adjustment to cancer* were measured in both pre- and post-visit surveys. Change scores were derived by subtracting post-visit scores from pre-visit scores (Allison, 1990). For the deleterious, or maladaptive, variables of *helplessness-hopelessness*, *anxious preoccupation*, *cognitive avoidance*, *fatalism*, *ambiguity uncertainty*, and *unpredictability uncertainty*, the change-score mean was positive (see below), indicating that patients generally reported experiencing lesser amounts of the these variables after treatment-decision-making conversations. On the other hand, for the adaptive variable of *fighting spirit*, the change-score mean was negative (see below), indicating that patients generally reported experiencing greater amounts of this variable after treatment-decision-making conversations.

Variable statistics for *ambiguity-uncertainty change* include M = .41, SD = .60, variance = .30, skewness = 1.18, kurtosis = 1.67. The positive direction of the change score indicates that patients left the treatment-decision-making conversations with a *decreased* sense of *ambiguity uncertainty*. Variable statistics for *unpredictability*-

uncertainty change include M = .51, SD = .98, variance = .96, skewness = -.13, kurtosis = .52. The positive direction of the change score indicates that patients left the treatmentdecision-making conversation with a decreased sense of unpredictability uncertainty. Variable statistics for fighting-spirit change include M = -.27, SD = .75, variance = .56, skewness = -.65, kurtosis = 4.60. The negative direction of the change score indicates that patients left treatment-decision-making conversations with an *increased* sense of *fighting* spirit. Variable statistics for helplessness-hopelessness change include M = .18, SD = .47, variance = .22, skewness = 1.84, kurtosis = 4.50. The positive direction of the change score indicates that patients left treatment-decision-making conversations with a decreased sense of helplessness-hopelessness. Variable statistics for anxiouspreoccupation change include M = .16, SD = .79, variance = .62, skewness = .43, kurtosis = 3.08. The positive direction of the change score indicates that patients left treatmentdecision-making conversations with a decreased sense of anxious preoccupation. Variable statistics for *cognitive avoidance change* include M = .16, SD = .86, variance = .74, skewness = .64, kurtosis = 1.89. The positive direction of the change score indicates that patients left treatment-decision-making conversations with a decreased sense of cognitive avoidance. Variable statistics for fatalism change include M = .11, SD = .86, variance = .74, skewness = -.42, kurtosis = 2.98. The positive direction of the change score indicates that patients left treatment-decision-making conversations with a decreased sense of fatalism.

Visit-Level Communication Variables Coded from Videotapes

Using the schema established by Street and Millay (2001), videotapes of treatment-decision-making conversations were initially coded for five communication

variables that embodied or facilitated patients' communicative 'participation.' The five communication variables were: (1) *surgeon supportive talk*, (2) *surgeon partnership building*, (3) *client question asking*, (4) *client assertive response*, and (5) *client expression of concern* (see descriptions below). (For a more detailed conceptualization of participation, see Introduction; for operationalizations and distributional statistics, see below). Variables 1 and 2 were coded for surgeons, and variables 3-5 were coded for both patients and patients' companions.

## The coding process

Undergraduate coders (who were trained to be reliable; see below) watched digitized videotapes on computers, with the ability to stop, rewind, and replay as necessary. When coders identified one of the five communication variables, they recorded the digital timecode at which the event occurred and transcribed the 'utterance' that represented the variable. Utterances are units of talk that serve as complete thoughts with both a subject and verb (Street coding scheme, 2009); they can appear as multiple predicates, independent clauses, a single sentence, or series of sentences (Stiles, 1992). Coders then designated the utterance as representing one of the five communication variables. Additionally, coders designated *question-asking* utterances as being either 'solicited by other' (e.g., asked for by the surgeon: *Do you have any questions for me?*) or 'self-initiated' (i.e., asked without being prompted). Each video was coded independently by three coders: the results of two coders were compared with each other, and the third coder was used to resolve coding discrepancies. All communication variables involve frequency counts and thus constitute ratio data.

Coder training and interrater reliability

Coders were six undergraduate Communication majors at Rutgers University (two men; four women), all of whom were either a junior or senior with a 2.5 or higher cumulative grade-point average who had completed the course Research Methods with a grade of 'B' or higher. Coders were 'blinded' to the study research questions. Coders were trained on video data that were collected for this study but that were not included in the main analyses due to the absence of complete, corresponding pre- and post-visit questionnaire data (described previously). Coders completed three, separate four-hour training sessions over the course of three weeks, with a one-hour coding homework assignment following each session, including the last session. The six coders were paired, but coded independently without knowing the identity of their coding 'partner.' At the end of the training period, the Scott's pi  $(\pi)$  statistic was calculated in order to determine intercoder reliability (using ReCal2 0.1 software located at dfreelon.org): Set A:  $\pi = .78$ ; Set B:  $\pi = .73$ ; and Set C:  $\pi = .73$ ; Overall M = .75. Having attained sufficient intercoder reliability (Lombard, 2010), the coding pairs continued to code one-third of the 51 core cases. Across a total of 1,601 coding decisions (ranging from 9-78 coding decisions per visit; M = 31.39; median = 28; SD = 18.24; var. = 332.80), reliabilities were: Set A:  $\pi =$ .77; Set B:  $\pi$  = .77; and Set C:  $\pi$  = .77; M = .77; Overall M = .77. The author examined all coding decisions to ensure face validity and made final decisions in cases of coding discrepancies.

Definitions and examples of the communication variables

This section defines, and provides examples of, the communication variables used in analyses. As discussed below, the primary regression analyses were designed to

involve the communication variables originally identified by Street and Millay (2001): (1) surgeon supportive talk, (2) surgeon partnership building, (3) client question asking, (4) client assertive response, and (5) client expression of concern. However, in order to potentially advance the ecological validity of these variables, all instances of each variable were subjected to an inductive/grounded thematic analysis (Strauss & Corbin, 1998) in order to discover the possible existence of robust sub-categories (the determination of which would also aid the development of future communication training/intervention efforts). The secondary regression analyses were designed to involve any emergent sub-variables. All variables are defined below with examples.

Surgeon supportive talk. As defined by Street and Millay (2001), provider supportive talk includes "statements of reassurance, support, empathy, and other verbal displays of interpersonal sensitivity" (p. 66). In the present data, surgeon partnership building was exemplified by Examples 1-2. Example 1 was taken approximately 25 minutes into the visit. At line 1, the surgeon has just completed explaining how the patient should move forward with her treatment, including scheduling two biopsies and the main surgery. The focus is on the surgeon's talk at lines 05-13.

Example 1: Surgeon Supportive Talk I (Patient 5, 24:36)

01 PAT: Alright, it's uh, you know, jus' wanna get the

02 answers, get go[ing]

03 DOC: [Yeah]

04 PAT: You know?

05 DOC: Yeah. You're on exactly the correct time frame.

06 You're not in any way behind schedule so I want to

```
07
         really stress that that you are uhm right exactly
80
         where you're supposed to be. [So ] you've got
09 PAT:
                                      [Okay]
10 DOC:
         your first opinion,
         you got your second opin[ion
11 DOC:
                                          1
12 PAT:
                                  [Uh hunh]
13 DOC:
         The plan [is ] slowly coming together for you.
14 PAT:
                   [Right]
         Okay, okay.
15 PAT:
```

At lines 5-13, the surgeon reassures and encourages the patient regarding her treatment and its timeline.

Example 2 was taken approximately 27 minutes into the visit. Leading up to line 1, the surgeon has explained surgical treatment logistics. At line 1, the patient requests clarification about an aspect of a partial mastectomy. After the surgeon confirms this at lines 02-03, the patient becomes visibly upset and pauses for over four seconds at line 04. At lines 8-9, with a 'choked up' voice, the patient expresses concerns about losing her nipple. The focus is on the surgeon's talk at lines 10-11.

```
Example 2: Surgeon Supportive Talk II(Patient 11, 26:49)

01 PAT: But that's for the part[ial ]

02 DOC: [Right.] That's for the

03 partial mastectomy with the sentinel node. Yeah.

04 PAT: (4.2). Uhh. I don't know why (.8) but I just don't

05 want in my (breast) ((note: what she says is
```

- 06 unclear but she grabs her breast))
- 07 DOC: Mm hmm.
- 08 PAT: And yet losing the nipple bothers me. I don't know
- 09 why.
- 10 DOC: Well it's a very important part of the breast. I
- 11 mean tha- tha- that would be bothersome.
- 12 PAT: (3.8) As far as the shape of my breast, I've always
- had small breasts. I guess I don't really care.
- 14 (1.0) But then when I think of (1.2) just one scar
- 15 that seems so (2.2) bad.

At lines10-11, the surgeon reassures and sympathizes with the patient. *Surgeon supportive talk* only occurred in 5 of 51 cases (9%). Due to its low frequency, *surgeon supportive talk* was excluded as a variable from all regression analyses. This is not to imply that the surgical oncologist was not emotionally supportive of his patients or did not attempt to comfort them. Note that, in this context, the provision of information, which the surgeon did extensively, is a form of support (see Raupach & Hiller, 2002). Further, only direct/explicit statements of support were coded, rather than support conveyed indirectly/implicitly, for example through nonverbal cues.

Surgeon partnership building. As defined by Street and Millay (2001), provider partnership building involves "communicative acts that encourage patients to discuss their opinions, express feelings, ask questions, and participate in decision making" (p. 66). In the present data, see Examples 3-4.

Example 3 was taken approximately 20 minutes into the visit. The surgeon has just recommended that the patient have a mastectomy to remove the affected breast, and have a magnetic-resonance-image test (MRI) to determine if there is cancer in the other breast. If there is cancer in both breasts, then the surgeon will recommend a bilateral mastectomy (i.e., the removal of both breasts). At lines 01-03, the husband (identified as 'HUS' in the transcript) asks if his wife is able to have a bilateral mastectomy even if there is no cancer in the second breast (i.e., The patient and her husband are interested in a surgery that is more invasive than potentially warranted). Participants in this example include the surgeon (identified as 'DOC'), the patient (identified as 'PAT') and the husband. The focus is the surgeon's talk at line 04.

Example 3: Surgeon Partnership Building (Patient 902, Video A, 19:36)

```
01 HUS:
         If we find out that there is no breast cancer but
02
         still want to do the bilateral that's still an
03
         option?
04 DOC:
         Yeah, uhm now let me ask you why though.
05 PAT:
         This is not- this is nothing good
06
         [coming out of this.
                                  1
07 HUS:
         [She's just gonna worry.]
         There's nothing good coming [out of this.]
08 PAT:
09 DOC:
                                      [So it's
                                                    1
10
         primarily for your worry or your concern [level. ]
11 PAT:
                                                    [There's]
```

- nothing good coming out of it. It's painful, (.2)
- it's oozing stuff, I- I-
- 14 DOC: When you say oozing stuff do you mean stuff is
- coming out of the nipples?
- 16 PAT: Yes.

At line 04, the surgeon enquires into the patient's and husband's rational for wanting a bilateral mastectomy (if the other breast is cancer free); here, the surgeon is soliciting their perspectives/opinions, especially as they relate to treatment decision making.

Example 4 was taken approximately 23 minutes into the visit. The surgeon, patient, and husband have been discussing the recovery time associated with varying treatment and reconstruction options. The focus is on the surgeon's talk at line 15.

Example 2: Surgeon Question Solicitation I (Patient 1,

# 23:00)

- 01 DOC: So (x) so you could probably do that
- 02 HUS: Not a lot of movements
- 03 PAT: [Yeah I mean yeah]
- 04 DOC: [A week so you co]uld probably do that a week
- 05 after nipple (x) reconstructio[n]
- 06 PAT: [O]ka[y]
- 07 DOC: [B]ut you
- 08 couldn't do that for uhh eight weeks after let's
- op say (x) mastectomy with (x) tranflap lower abdomen

```
10 PAT: Oka[y]

11 DOC: [f]lap ( up here) so figure about eight

12 weeks for that
```

13 PAT: Okay (X) Okay.

14 PAT: Okay (X)

02

# 15 DOC: You have any other questions right now?

16 PAT: I'm trying to think I should've written them down

At line 15, the surgeon solicits patient (and companion) questions, encouraging them to participate in the visit. *Surgeon partnership building* occurred in every visit (n = 51 cases; 100%) (M = 2.65; SD = 1.11; variance = 1.23, ranging from 1 to 6 instances per case; skewness = .84; kurtosis = .60).

An inductive/grounded thematic analysis (Strauss & Corbin, 1998) of *surgeon* partnership building revealed that it has one distinct and robust sub-category involving the specific behavior of soliciting questions, as shown in Example 4 (above). As such, in secondary analyses, *surgeon partnership building* was separated into two variables: (1) *surgeon partnership building: question solicitation*; and (2) *surgeon partnership building: other*.

For another example of *surgeon partnership building: question solicitation*, see Example 5, which was taken approximately eight minutes into the visit. At lines 1-9, the surgeon is explaining post-surgical treatment. The focus is the surgeon's talk at line 11.

Example 5: Surgeon Question Solicitation II, Video 2 (7:30)

Old DOC: If you were going the partial breast radiation

that would happen before the chemotherapy

- 03 PAT: Uh hunh
- 04 DOC: And then you would finish up with about nine
- 05 months' worth of medication called herceptin
- 06 PAT: Mm
- 07 DOC: that gets given to you once every three weeks and
- 08 the whole treatment extends over the course of a
- 09 year
- 10 PAT: (X) okay.

## 11 DOC: So what questions can I answer for ya

- 12 PAT: (x) Uhm (x) during the course of the full um year
- 13 (x) you would be basically guiding me right
- 14 DOC: well your gunna have a team [okay]
- 15 PAT: [yeah] yeah
- 16 DOC: so I'm I'm take care of the surgical part

At line 11 the surgeon solicits patient (and companion) questions, encouraging them to participate in the visit. This variable *surgeon partnership building: question* solicitation occurred in 42 of the 51 cases (82%) (M = 1.45, SD = 1.06, variance = 1.13, ranging from 1 to 5 instances, skewness = .76, kurtosis = 1.05).

The remaining *surgeon partnership building* behaviors were grouped into a subvariable called *surgeon partnership building: other*; this sub-variable included all other forms of *surgeon partnership building*, such as that in Extract 3 (above). For another example of *surgeon partnership building: other*, see Extract 6, which occurred approximately 23 minutes into the visit. The patient and her husband have just said that they 'can't think of any questions to ask.' The focus is on the surgeon's talk at lines 4-12.

Example 6: Surgeon Partnership Building: Other I (Video 1, 23:28)

- 01 DOC: I typically will look at my email everyday
- 02 sometimes every other day
- 03 PAT: Mm [hm]
- 04 DOC: But if you sent me an email on a Monday (x) you
- 05 might hear back from me on Wednes[da]y or Thursday
- 06 PAT: [Mm]
- 07 DOC: (x) so I'm certainly happy to shoot me some
- 08 questions
- 09 PAT: Ok[ay]
- 10 DOC: [An]d then I can respond to them so just because
- 11 (x) we're not sitting here together doesn't mean
- that the discussion i[sn't](x) continuing
- 13 PAT: [Right]
- 14 PAT: Ok[ay]

At lines 4-12, the surgeon attempts to build a partnership by encouraging the patient's participation in future email interactions.

For a final example of *surgeon partnership building: other*, see Extract 7, which occurred approximately 32 minutes into the visit. The surgeon has just made his treatment recommendation of a lumpectomy with radiation, and the patient has just asked if he would still be willing to do the surgery if she declined radiation. The focus is the surgeon's talk at lines 16-17.

```
Example 7: Surgeon Partnership Building: Other II (Video
53, 31:30)
01 DOC: So, If you ask me to do an operation that is not an
02
        appropriate operation, I'm not obligated to do the
03
        wrong thing for you. I would have to say well I'm
04
        sorry that's that's outside the realm of what would
05
       be uh the appropriate operation for your problem.
06
        You're gunna have to find someone else to do that
07
        for you.
08 Pat: Mm [hm]
09 DOC:
           [Ya] probably could but I think it would be
10
        difficult to find who was a breast cancer
11
        special[ist ]
12 PAT:
               [Right]
13 DOC: who would agree to do the wrong surgery for you
14 PAT: Right.
15 PAT: (.2) So[o]
               [Te] tell me about what your concerns are
16 DOC:
        about the lymph node map[ing].
17
18 PAT:
                                 [Uuh] It's not it's not the
```

lymph node mapping I should I should of I guess

lymph node mapping.

said it differently. My (.2) I'm willing to do the

19

20

21

- 22 DOC: Mm hm
- 23 PAT: And a lumpectomy. Because of my history, I've been
- there, done that and don't want to do it again with
- 25 radiation and chemotherapy.

At lines 16-17, inquires into, and encourages the patient to talk about, her opinions/preferences regarding radiation. The variable *surgeon partnership building:* other occurred in n = 47 out of 51 (92%) cases (M = 1.20, SD = .63, variance = .40, ranging from 1 to 3 instances, skewness = .81, kurtosis = 1.53).

Patient/companion assertive responses. As defined by Street and Millay (2001), patient assertive responses include "utterances in which the patient expresses his or her rights, beliefs, interests, and desires as in offering an opinion, stating preferences, making suggestions or recommendations disagreeing, or interrupting" (Street & Millay, 2001, p. 63). For instance, see Example 8, which was taken approximately five minutes into the visit. The surgeon has just talked about treatment and reconstruction options. Based on her current breast cancer, she could either have a mastectomy (removal of a single breast) or a bilaterial mastectomy (removal of both breasts). The focus is the patient's talk at lines 10-14.

Example 8: Patient Assertive Responses I (Video 1, 5:25)

- 01 DOC: And because if you're gonna go for a breast
- 02 reconstruction on this side
- 03 PAT: Mm hm
- 04 DOC: Sometimes you'll get the best symmetry
- 05 PAT: Mmm

- 06 DOC: If both of the breasts are reconstructed breasts
- 07 rather than trying to match this (x) to that.
- 08 PAT: Right
- 09 DOC: Does that (x) make sense?
- 10 PAT: Yeah (x) well as I said to you on the phone if
- 11 you're gonna do one might as well do em bo[th]
- 12 DOC: [We]11
- I mean yeah you I mean you said that but that's
- 14 PAT: It doesn't make any sense not to
- 15 DOC: And that's and that's very it's very logical

At lines 10-14, the patient asserts her treatment preference. For another instance, see Example 9, was occurred approximately 12 minutes into the visit. Here, the surgeon is explaining a surgical process. The focus is the patient's talk at line 14.

## Example 9: Patient Assertive Responses II (Video 36, 11:20)

- 01 DOC: So now there's a cavity in your breast (.2) that
- 02 has fluid in it, and that cavity will be there for
- 03 a month to a month and a half.
- 04 PAT: Ok[ay]
- 05 DOC: [And] then ugh a week or two later I take you
- 06 back to the operating room
- 07 PAT: Mm[hm]
- 08 DOC: [And] it's not s-not that we're going to do any
- 09 cutting but I want to be able to sedate you, and I

- 10 want the area to be very sterile. And we can then
- 11 uh numb up the skin and place the little (.2) uhm
- 12 PAT: Am I [asleep]?
- 13 DOC: [tube ] ugh you're sedated.

#### 14 PAT: Asleep.

- 15 DOC: Ugh, not general anesthesia. You don't need general
- 16 anesthesia, okay. This was originally designed as
- something that could potentially be done in a
- 18 doctor's office.

At line 14, the patient explicitly corrects the surgeon, which is the giving of an opinion in a disaffiliative manner. The variable *patient assertive response* occurred in 36 out of 51 cases (71%); M = 2.08, SD = 1.99, variance = 4.00, ranging from 1 to 8 instances, skewness = .30, kurtosis = .29). By contrast, the variable *companion assertive response* only occurred in 16 out of 51 cases (31%); M = .59, SD = 1.08, variance = 1.17, ranging from 1 to 5 instances, skewness = 2.29, kurtosis = 5.86. Due to its low frequency, it was not retained in regression analyses.

An inductive/grounded thematic analysis (Strauss & Corbin, 1998) of *patient* assertive response revealed that it contained two distinct and robust subcategories involving, on the one hand, patients stating treatment preferences, and on the other, patients disagreeing with and/or challenging the surgeon. These variables were called: (1) patient assertive responses: stating preferences; and (2) patient assertive responses: challenging the surgeon.

The variable *patient assertive responses: stating preferences* involves patients informing the surgeon of particular treatment and/or reconstruction preferences. An instance of this variable was seen in Example 8 (above). For another instance, see Example 10, which occurs approximately 32 minutes into the video (and is drawn from the same visit as was Example 7, above). At lines 1-2, the surgeon solicits the patients' concerns about 'lymph node mapping.' The focus is on the second part of the patient's answer at lines 08-10.

Example 10: Patient Assertive Responses: Stating

## Preferences I (Video 53, 31:58)

- 01 DOC: [Te] tell me about what your concerns are
- 02 about the lymph node map[ing].
- 03 PAT: [Uuh] It's not it's not the
- 04 lymph node mapping I should I should of I guess
- 05 said it differently. My (.2) I'm willing to do the
- 06 lymph node mapping.
- 07 DOC: Mm hm
- 08 PAT: And a lumpectomy. Because of my history, I've been
- 09 there, done that and don't want to do it again with
- 10 radiation and chemotherapy.
- 11 DOC: Okay. (.2) So here's so here's what I would
- recommend then. (.2) Let's say we do the lumpectomy
- and the sentinel node mapping and we find out the
- 14 stage of your cancer.

At lines 08-10, the patient explicitly states her treatment preference of not wanting radiation and chemotherapy.

For another instance of patient assertive responses: stating preferences, see Example 11, which occurs approximately nine minutes into the visit. Here, the surgeon is explaining options for breast reconstruction. The focus is on the patient's talk at line 08.

```
Example 11: Patient Assertive Responses: Stating
Preferences II (Video 25,8:50)
01 DOC: Now for reconstruction, there are two general
02
        ways to do it.
03 PAT: Mmhm.
04 DOC: One is to use your own tissue
05 PAT: Mmhm
06 DOC: And one is to use expanders or implants
08 PAT: I'm totally against expanders and my own tissue.
09 DOC: Say say that again. You're you're
        ((Patient and husband start laughing))
10 PAT: In reading about the three meth[ods ]
11 DOC:
                                        [Right]
12 PAT: I have canceled out the expander
13 DOC: Okay
14 PAT: because I think the idea of having to be inflated
15
        every month or three months or whatever sounds
```

16

gruesome to me

17 DOC: Right.

At line 8, the patient explicitly expresses her preference to not have 'expanders,' and to not use her own tissue, during reconstruction. The variable *patient assertive* responses: stating preferences occurred in 30 out of 51 cases (59%); M = 1.27, SD = 1.46, variance = 2.12, ranging from 1 to 6 instances, skewness = 1.24, kurtosis = 1.36).

Different from the variable *patient assertive responses: stating preferences* is that of *patient assertive responses: challenging the surgeon*, which involves patients' correcting, disagreeing with, or challenging the surgeon. An instance of this was already presented as Example 9 (above). For another instance, see Example 12, which occurs approximately 23 minutes into the visit. At lines 1-2, the surgeon refers to getting biopsy results in a week (vs. a day), with the explanation that the patient's cancer is 'not an emergency.' The focus is the patient's talk at line 05.

Example 12: Patient Assertive Responses: Challenging the Surgeon I (Video 4, 23:36)

01 DOC: So that's a that's the time frame it's not an

02 emergency

03 DAU: Mmm

04 DOC: Okay

#### 05 PAT: In their minds

06 DOC: In their minds yeah and ya know an emergency is

07 (x) one hour is the difference between life and

08 death (x) O[kay]

09 PAT: [Okay]

10 DOC: So it's clearly not an emergency (x) it's

11 something urgent urgent things occur and unfold

12 over the course of a week or two

At line 05, the patient challenges the surgeon's characterization of her cancer as 'not an emergency' by adding the qualification, "In their minds," implying that her cancer represents an urgent matter to her.

For another instance, see Example 13, which occurs approximately 10 minutes into the visit. Prior to this example, the surgeon has proposed to retain the patient's nipple-areola complex during surgery. However, the patient has stated that she has a 'low tolerance for risk,' and wants her nipple areola-complex removed. At lines 1-14, the surgeon attempts to persuade the patient to retain her nipple areola-complex, using a caraccident metaphor to describe risk. The focus is the patient's talk at lines 15-18.

Example 13: Patient Assertive Responses: Challenging
Surgeon II (Video 18, 9:50)

01 DOC: Let's say you had to make a choice between two 02 activities. One being doing this operation and the 03 other being our never going to drive in a car again, (.2) for the rest of your life. And you look 04 05 at the risk of driving in a car or the risk of 06 death of having the nipples versus not having the 07 nipples. I suspect that driving a car is the more 80 dangerous activity. So, if your goal because 09 that's 1.5% lifetime death rate in car accidents

```
10
        and so so if you had to say I'd choose one or the
        other and if I wanted to choose the one that would
11
12
        expand my lifespan on average longer you would
13
        choose not to drive the car. So the amount of
14
        benefit [is ] very [ sm]all
15 PAT:
                [It's] differ[ent]
16 PAT: It's different when you're faced with cancer
        though. It really is because it's like you're
17
18
        presented with your mortality.
19 DOC: Right, well people die in car acid[ents]
20 PAT:
                                            ſΙ
                                                 | know but
21
         it's you know what [I haven't] it's not a fatal
22 DOC:
                            [right
         disease, a possibly fatal disease. That's where
23 PAT:
24
         I'm at with it.
```

At lines 16-18, the patient disagrees with the surgeon, rejecting his metaphor. The variable *patient assertive responses: challenging the surgeon* occurred in 18 cases (35%); M = .61, SD = 1.04, variance = 1.08, ranging from 1 to 5 instances, skewness = 2.20, kurtosis = 5.70).

Patient/companion question asking. As defined by Street and Millay (2001), question asking involves "utterances in interrogative form intended to seek information and clarification" (p. 63). For instance, see Example 14, which occurs approximately nine

minutes into the visit. At lines 1-6, the surgeon concludes a discussion about getting second opinions. The focus is the patient's talk at lines 07-11.

## Example 14: Patient Question Asking I (Video 1, 8:50)

01 DOC: I always let people (x) know that there's kind of a

02 gradation of different t[ypes] of places

03 PAT: [Mm hm]

04 DOC: To get second opinions

05 PAT: O[kay]

06 DOC: [Fro]m(x) okay

07 PAT: (X) Now I guess my questions (x) uhm I kinda

08 figured that the whole thing was gonna have to go

09 [inclu]ding the nipple

10 DOC: [Right]

11 PAT: You're saying that the nipple would be (x) saved?

12 DOC: No it would not

At lines 07-11, after the surgeon concludes his discussion, and of her own initiative, the patient asks a question about whether or not her nipple will be saved during the surgery.

For another instance, see Example 15, which occurs approximately 18 minutes into the visit. At lines 1-2, the surgeon concludes a discussion about surgery options. The focus is the patients' talk at lines 04-06.

Example 15: Patient Question Asking II (Video 38b, 18:25)

01 DOC: So If you were scheduled for a lumpectomy

- 02 you get a lumpectomy.
- 03 HUS: Okay. I didn't know.
- 04 PAT: Since radiation was never discussed in the other
- 05 visit, is it, really I don't understand what's
- 06 involved with radiation [I don't know].
- 07 DOC: [Do you want ] to talk with
- one of our radiation oncologists a little bit?
- 09 PAT: That would be fine.

At 04-06, after the surgeon concludes his discussion, and of her own initiative, the patient begins to ask a direct question about radiation, "is it..." (line 5), and then asks her question indirectly by claiming a lack of knowledge about radiation. Note that the surgeon understands this as a question when he offers, at lines 07-08, to set up an appointment for the patient to speak with a radiation oncologist. The variable *patient* question asking occurred in 49 out of 51 cases (96%); M = 11.92, SD = 8.18, variance = 66.43, ranging from 1 to 32 instances, skewness = .71, kurtosis = -.12). The variable companion question asking occurred in 35 out of 51 cases (69%); M = 5.20, SD = 6.29, variance = 39.56, ranging from 1 to 20 instances, skewness = 1.24, kurtosis = .37).

An inductive/grounded thematic analysis (Strauss & Corbin, 1998) of *patient* question asking revealed that it contained two distinct and robust subcategories involving, on the one hand, patients asking questions when they were explicitly solicited by the surgeon, and on the other, patients asking questions of their own initiative. These variables were called: (1) patient question asking: self-initiated; and (2) patient question

asking: prompted. (This distinction did not emerge within the variable companion question asking because the surgeon typically did not address companions).

Examples 14 and 15 (above) were both of the variable *patient question asking: self-initiated.* For a final instance, see Example 16, which occurs approximately 16 minutes into the visit. At lines 01-14, the surgeon explains that, based on the patient's cancer, the recommended treatment is a partial mastectomy. The focus is on the patient's talk at line 15. Note that a 'HER2 receptor' is a growth-promoting protein is that associated with breast cancer recurrence, and thus with a worse prognosis.

# Example 16: Patient Question Asking: Self-Initiated I (Video 4, 16:10)

01 DOC: Follow it up with the radiation therapy and then do 02 a nipple areola reconstruction a year later (x) and the end result would be that the uh left breast 0.3 04 would be a little bit smaller you could even so if 05 I mean if there was a ( ) if there was a enough 06 of a difference in size that you were noticing like 07 you couldn't get a bra that fit properly you could always go back and put a small implant behind it 08 09 you could reduce the other side I mean there's a 10 bunch of different things you can do ta you know 11 kinda tweak the appearance a little bit (x) but I 12 think in terms of treating the cancer (x) the way 13 to go is probably with the partial mastectomy and

14 the sentinel node

15 PAT: What about the HER2 receptor?

16 DOC: Okay so we don't know that yet

17 PAT: Right

At line 15, without prompting, the patient takes the interactional initiative, changes the topic, and asks a question about the 'HER2 receptor.' The variable *patient* question asking: self-initiated occurred in 49 of 51 cases (96%); M = 11.08, SD = 8.02, variance = 64.35, ranging from 1 to 32 instances, skewness = .78, kurtosis = -.07.

The variable *patient question asking: prompted* refers to questions asked in direct response to the surgeon's solicitation of questions. Relative to the variable *patient question asking: self-initiated*, which involves high patient initiative, the variable *patient question asking: prompted* involves lower interactional initiative. There is, of course, a direct linkage between the variable *patient question asking: prompted* and its interactional precursor, that being the variable *surgeon partnership building: question solicitation* (see above). An instance of the variable *patient question asking: prompted* was already displayed in Example 5 at lines 12-13 (above), which is reproduced in reduced form below as Example 17. At line 01, the surgeon solicits questions. The focus is the patient's talk at lines 02-03.

Example 17: Patient Question Asking: Prompted I Video 2

(7:30)

01 DOC: So what questions can I answer for ya

02 PAT: (x) Uhm (x) during the course of the full um year

03 (x) you would be basically guiding me right?

04 DOC: well your gunna have a team okay

At lines 02-03, the patient responds to the surgeon's solicitation (at line 01) with a question regarding the surgeon's post-surgery involvement in treatment.

For another instance, see Example 18, which occurs approximately 23 minutes into the visit. At line 01, the surgeon concludes a discussion about 'good' breast surgeons in Manhattan, New York. The focus is the patient's talk at lines 06-07.

```
Example 18: Patient Question Asking: Prompted II (Video 3,
23:05)
01 DOC: So, a number of different good places to go.
02 PAT: Okay.
03 DOC: Okay.
04 PAT: Okay.
05 DOC: Do you have any other questions?
06 PAT: Uhm, if I need to do this surgery, uhm what's the
07
        [timef]
08 DOC: [timeframe]?
09 PAT: Right.
10 DOC: It's not an emergency.
11 PAT: Okay.
25 DOC: You could do this in two months and I wouldn't be
26
        concerned.
27 PAT: Okay.
```

At lines 06-07, in response to the surgeon's solicitation (at line 5), the patient asks a question about the timeframe of her surgery. The variable *patient question asking:* 

prompted occurred in 24 out of 51 cases (48%); M = .61, SD = .77, variance = .60, ranging from 1 to 3 instances, skewness = 1.36, kurtosis = 1.83). Because the variables surgeon partnership building: question solicitation and patient question asking: prompted are naturally sequenced, it is potentially conflationary to include both in a single regression analysis (at least in cases where surgeons' solicitations actually do generate patients' questions). Because of this, and because patients' self-initiated questions occurred much more frequently than patients' prompted questions, the decision was made to only include the former (i.e., patients' self-initiated questions) in the secondary regression analyses.

Patient/companion expression of concern. As defined by Street and Millay (2001), expression of concern includes "utterances in which the patient expresses worry, anxiety, fear, anger, frustration, and other forms of negative affect or emotions" (p. 63). For one instance, see Example 19, which was already displayed in Example 2 (above). At line 01, the patient requests clarification regarding a partial (vs. full) mastectomy, which the surgeon answers at lines 02-03. The focus is the patient's talk at lines 04-09.

Example 19: Patient Expression of Concern (Patient 11, 26:49)

```
01 PAT: But that's for the part[ial]

02 DOC: [Right.] That's for the

03 partial mastectomy with the sentinel node. Yeah.

04 PAT: (4.2). Uhh. I don't know why (.8) but I just don't

05 want in my (breast) ((note: what she says is

06 unclear but she grabs her breast))
```

07 DOC: Mm hmm.

08 PAT: And yet losing the nipple bothers me. I don't know 09 why.

10 DOC: Well it's a very important part of the breast.

At lines 04-09, the patient expresses her concerns regarding losing her nipple. The variable *patient expression of concern* only occurred in 13 out of 51 cases (25%). Due to its low frequency, it was not retained in regression analyses. The variable *companion* expression of concern occurred in 0 cases (0%), and was similarly excluded from regression analyses.

Summary of Communication Variables included in Regression Analysis

In sum, the communication-participation variables retained for the primary regression analyses were: surgeon partnership building, patient assertive response, patient question asking, and companion question asking. The communication-participation variables retained for the secondary regression analyses were: surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive response: stating preferences, patient assertive response: challenging surgeon, and patient question asking: self-initiated.

Length of Visit

Calculating the length of medical visits is a common practice among studies utilizing audio- and/or video-recorded data (Borgers et al., 1993; Eggly et al., 2006; Eide et al., 2003; Ishikawa et al., 2002b; Street & Gordon, 2008). Length of visit has been found to be significantly associated with increased patient question asking (Butow et al., 2002; Eggly et al., 2006). The length of the treatment-decision-making conversation

began with the time that surgeon entered the consultation room until the time that he exited and the medical visit was completed. *Length of visit* ranged from 10-60 minutes, M = 27.35 minutes, median = 25 minutes, SD = 11.08, variance = 122.8, skewness = .98, kurtosis = .73.

#### CHAPTER FIVE: STUDY TWO RESULTS

#### RESULTS

### Frequencies and Distributions

Data were collected on patients' age, education, household income, ethnicity, and marital status; sex was not solicited because all patients were female (see Table 2). Patients' ages ranged from 30 to 78 (M = 53.88, median = 54, SD = 11.35); age was a continuous variable. Education included: High School or less (n = 14; 2%), two-year college degree (e.g., AA (n = 8; 16%), B.A. degree (n = 19; 37%), and post-graduate degree (e.g., M.A., Ph.D.) (n = 10; 20%). Following prior research (Melmed, Kwan, Reid, & Litwin, 2002), education was dichotomized into 'less than B.A' (n = 22; 43%)and 'B.A. or more' (n = 29, 57%). Household income (for those who reported; n = 46) included: \$30,000 or less (n = 9, 20%), \$30,000-60,000 (n = 4, 9%), \$60,000-75,000 (n = 4, 9%)= 8; 17%), \$75,000-\$100,000 (n = 1; 2%), \$100,000-125,000 (n = 9; 20%), \$125,000-150,000 (n = 7; 15%), \$150,000-200,000 (n = 3; 6%),and more than \$200,000 (n = 5;11%). Following prior research, household income was dichotomized in terms of state median income (Robinson et al., 2002); In 2008, the New Jersey median income was \$70,347 (U.S. Census Bureau, 2010), and thus household income was dichotomized into 0-75,000 (n = 21, 46%) and 76,000 and up (n = 25, 54%). Regarding ethnicity, patients were 80% white, 8% African-American, 8% Asian, and 4% Hispanic; this distribution closely matched that of the Cancer Institute of New Jersey's 2008 total breast-cancer population, which was 83% white, 9% African-American, 4% Asian, and 7% Hispanic (including 4% 'other'). Following prior research (Wilhelm-Leen, Hall, de Boer, & Chertow, 2010), ethnicity was dichotomized into white (n = 41; 80%) and nonwhite (n = 10; 20%). Marital status included single and never married (n = 4; 8%), single and divorced/widowed (n = 15; 29%), and married (n = 32; 63%). Following prior research (Nakata, Takahashi, Otsuka, & Swanson, 2010), this variable was dichotomized into single (n = 19; 37%) and married (n = 32; 63%).

#### Analysis

A series of multiple linear regressions, logistic regressions, correlations, and frequencies were used to analyze hypotheses and research questions. The level of significance was set at p < .05 for all tests (Tabachnick & Fidell, 2007). Correlations were computed among independent variables to test for multicollinearity. With one exception, none of the independent variables were intercorrelated at r = .70 or higher, which warranted their possible inclusion in statistical models (Tabachnick & Fidell, 2007). The single exception was the correlation between *length of visit* and *question asking*, including both *patient question asking* (r = .73, p < .001) and *companion question asking* (r = .68, p < .001). Because *patient question asking*, as a form of communication-participation, was a primary variable of interest, the decision was made to omit *length of visit* as an independent variable. See Tables 3-5 for zero-order correlation matrices.

In the remainder of this chapter, regression analyses are divided into *primary*, *secondary*, and *tertiary* analyses (Secondary and tertiary analyses were post-hoc).

Primary analyses included the communication variables (as independent variables) that were coded according to Streets' schema (Street & Millay, 2001) and that subsequently qualified as statistically viable variables for inclusion (see Methods); these variables included: *surgeon partnership building*, *patient assertive responses*, *patient question asking*, and *companion question asking*. In order to better understand and explain how

communication behaviors were associated with patient outcomes, post-hoc secondary analyses were performed. As noted in the Methods chapter (Chapter 4), secondary analyses included the following communication variables (as independent variables): surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. Tertiary analyses explored the possible relevance of non-communication independent variables (see Methods chapter). Variables included in tertiary analyses were selected using a data reduction method of including into the model all potential covariates and independent variables (i.e., communication variables) that have an association with the dependent variable of .20 and greater (Hosmer & Lemeshow, 1989). For each research question, primary, secondary, and tertiary analyses are presented in order.

Because data represented a single surgeon, and because physicians tend to have relatively uniform practice styles (Cegala, Street, & Clinch, 2007; Street, 1991), it is assumed that that variance can be explained by independent variables can be accounted for in terms of patient- and companion-level variables.

RQ2: Communication-Participation and Illness Uncertainty about Cancer Change

Research Question 2 asked if the communication variables of (a) patient

participation, (b) companion participation, and (c) surgeon facilitation are associated with

a change in patients' illness uncertainty about cancer (pre-post visit). As noted in the

Methods chapter, the dependent variables were ambiguity-uncertainty change and

unpredictability-uncertainty change.

#### Ambiguity-Uncertainty Change

Primary analysis. A standardized multiple regression analysis was performed using the dependent variable ambiguity-uncertainty change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not account for a significant amount of variance of ambiguity-uncertainty change, F(4, 46) = .30, p = .88, adj.  $R^2 = -.06$ . In terms of individual relationships between the independent variables and ambiguity-uncertainty change, no independent variable was significantly associated with ambiguity-uncertainty change: surgeon partnership building (t = -.34, p = .73), patient assertive responses (t = .51, p = .61), patient question asking (t = -.79, p = .44), and companion question asking (t = .01, p = .99).

Secondary analysis. A standardized multiple regression analysis was performed using the dependent variable ambiguity-uncertainty change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of ambiguity-uncertainty change, F(5, 45) = .36, p = .88, adj.  $R^2 = -.07$ . In terms of individual relationships between the independent variables and ambiguity uncertainty change, no independent variable was significantly associated with cognitive-avoidance change: surgeon partnership building: question solicitation (t = -.08, p = .94), surgeon partnership building: other (t = -.41, t = .68), patient assertive responses: stating

preferences (t = -.48, p = .63), patient assertive responses: challenging surgeon (t = .81, p = .43), and patient question asking: self-initiated (t = -.95, p = .35).

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable ambiguity-uncertainty change and the independent variables of perceived social support, religiosity, and prior history with any breast surgeon. The regression analysis revealed that the model did not account for a significant amount of variance of ambiguity-uncertainty change, F(3, 45) = 1.23, p = .31, adj.  $R^2 = .01$ . In terms of individual relationships between the independent variables and ambiguity-uncertainty change, none of the independent variables were significantly associated with ambiguity-uncertainty change: religiosity (t = -.95, p = .36), history with any breast surgeon (t = 1.34, t = 0.19), and perceived social support (t = -.57, t = 0.57).

Unpredictability-Uncertainty Change

Primary analysis. A standardized multiple regression analysis was performed with the dependent variable unpredictability-uncertainty change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not account for a significant amount of variance of unpredictability-uncertainty change, F(4, 46) = 1.32, p = .28, adj.  $R^2 = .03$ . However, in terms of individual relationships with the independent variables and unpredictability-uncertainty change, surgeon partnership building (t = 2.22, p = .03,  $\beta = .32$ ) was significantly associated with unpredictability-uncertainty change. No other variable was significantly associated with the change: patient assertive responses (t = -.40, p = .69), patient question asking (t = .65, t = .52), and companion question asking (t = -.35, t = .73). In sum, greater amounts of

surgeon partnership building such as "Do you have any other questions right now?" during treatment-decision-making conversations was associated with patients' leaving visits with decreased *unpredictability uncertainty*.

Secondary analysis. A standardized multiple regression analysis was performed with the dependent variable unpredictability-uncertainty change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of unpredictability-uncertainty change, F(5, 45) = 1.35, p = .26, adj.  $R^2 = .03$ . However, in terms of individual relationships between the independent variables and unpredictability-uncertainty change, when controlling for all other independent variables, surgeon partnership building: question solicitation (t = 2.48, p = .02,  $\beta = .36$ ) was significantly associated with unpredictability-uncertainty change. No other independent variable was significantly associated with the change: surgeon partnership building: other (t = .83, p = .41), patient assertive responses: stating preferences (t = .48, p = .63), patient assertive responses: challenging surgeon (t = .98, p = .33), and patient question asking: self-initiated (t = .10, p = .92). In sum, greater surgeon partnership building: question solicitation -- such as "So what questions can I answer for you?" during the treatment-decision-making conversation was associated with leaving visits with decreased unpredictability uncertainty.

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable *unpredictability-uncertainty change* and the independent

variable of *surgeon partnership building: question solicitation*. The regression analysis revealed that the model *did* account for a significant amount of variance of *unpredictability-uncertainty change*, F(1, 49) = 5.32, p = .03, adj.  $R^2 = .08$ . In terms of individual relationships between the independent variables and *unpredictability-uncertainty change*, *surgeon partnership building; question solicitation was significantly associated* ( $\beta = .31$ , t = .42, p = .03). In sum, greater *surgeon partnership building: question solicitation ---* such as "So what questions can I answer for you?" during the treatment-decision-making conversation was associated with leaving visits with decreased *unpredictability uncertainty*.

Research Question 3 asked if the communication variables of (a) patient participation, (b) companion participation, and (c) surgeon facilitation are associated with a change in patients' mental adjustment to cancer (pre-post visit). The dependent variables, as noted in the Methods section (Chapter 4), include *fighting spirit*, helplessness-hopelessness, anxious preoccupation, cognitive avoidance, and fatalism. Fighting-Spirit Change

Primary analysis. A standardized multiple regression analysis was performed using the dependent variable fighting-spirit change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not account for a significant amount of variance of fighting-spirit change, F(4, 45) = 1.38, p = .26, adj.  $R^2 = .03$ . In terms of individual relationships between the independent variables and fighting-spirit change, no independent variable was significantly associated

with fighting-spirit change: surgeon partnership building (t = -.68, p = .50), patient assertive responses (t = -.97, p = .34), patient question asking (t = -1.10, p = .28), and companion question asking (t = .76, p = .45).

Secondary analysis. A standardized multiple regression analysis was performed using the dependent variable fighting-spirit change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did significantly predict fighting-spirit change, F(5, 44) = 2.46, p = .05, adj.  $R^2$ = .13. However, in terms of individual relationships between the independent variables and fighting-spirit change, when controlling for all other independent variables, only patient assertive responses: stating preferences was significantly, negatively associated with fighting-spirit change (t = -2.72, p = .01,  $\beta = -.40$ ). No other independent variables were significantly associated with fighting-spirit change: surgeon partnership building: question solicitation (t = .003, p = .98), surgeon partnership building: other (t = -.11, p = .98) .99), patient assertive responses: challenging surgeon (t = 1.12, p = .27), and patient question asking: self-initiated (t = -1.46, p = .15). In particular, patients asserting their treatment preferences during treatment-decision-making visits – such as "Because of my history, I've been there, done that and don't want to do it again with radiation and chemotherapy" – was significantly associated with patients leaving visits with increased fighting spirit.

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable *fighting-spirit change* and the independent variables

religiosity, perceived social support, patient assertive responses: stating preferences, and patient question asking: self-initiated. The regression analysis revealed that the model did account for a significant amount of variance of fighting-spirit change, F(4, 43) = 4.59, p = .01, adj.  $R^2 = .23$ . In terms of individual relationships between the independent variables and of fighting-spirit change, perceived social support ( $\beta = .29$ , t = 2.10, p = .04) and patient assertive responses: stating preferences ( $\beta = .29$ , t = -2.09, p = .04) were significantly associated. Religiosity (t = 1.19, p = .24) and patient question asking: self-initiated (t = -1.00, p = .33) were not significantly associated with fighting-spirit change. In particular, patients asserting their treatment preferences during treatment-decision-making visits – such as "Because of my history, I've been there, done that and don't want to do it again with radiation and chemotherapy" – was significantly associated with patients leaving visits with increased fighting spirit. However, increases in perceived social support were associated with patients leaving visits with less fighting spirit.

Primary analysis. A standardized multiple regression analysis was performed using the dependent variable helplessness-hopelessness change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not account for a significant amount of variance of helplessness-hopelessness change, F(4, 46) = .49, p = .74, adj.  $R^2 = -.04$ . In terms of individual relationships between the independent variables and helplessness-hopelessness change, no independent variable was significantly associated with helplessness-hopelessness change: surgeon partnership

building (t = -.55, p = .58), patient assertive responses (t = -.42, p = .67), patient question asking (t = -.71, p = .48), and companion question asking (t = .68, p = .50).

Secondary analysis. A standardized multiple regression analysis was performed using the dependent variable helplessness-hopelessness change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of helplessness-hopelessness change, F(5, 45) = .49, p = .72, adj.  $R^2 = .04$ . In terms of individual relationships between the independent variables and helplessness-hopelessness change, no independent variable was significantly associated with helplessness-hopelessness change: surgeon partnership building: question solicitation (t = .03, p = .98), surgeon partnership building: other (t = -1.18, p = .24), patient assertive responses: stating preferences (t = .35, p = .73), patient assertive responses: challenging surgeon (t = .59, t = .56), and patient question asking: self-initiated (t = .42, t = .68).

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable helplessness-hopelessness change and the independent variables ethnicity and income. The regression analysis revealed that the model did not account for a significant amount of variance of helplessness-hopelessness change, F(2, 43) = 2.63, p = .08, adj.  $R^2 = .07$ . In terms of individual relationships between the independent variables and helplessness-hopelessness change, no independent variable

significantly was significantly associated with *helplessness-hopelessness change*: *ethnicity* (t = -1.41, p = .17) and *income* (t = -1.47, p = .15). *Anxious-Preoccupation Change* 

Primary analysis. A standardized multiple regression analysis was performed using the dependent variable anxious-preoccupation change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not account for a significant amount of variance of anxious-preoccupation change, F(4, 45) = 2.38, p = .06, adj.  $R^2 = .10$ . In terms of individual relationships between the independent variables, no independent variable was significantly associated with anxious-preoccupation change: surgeon partnership building (t = .01, p = .99), patient assertive responses (t = 1.83, p = .07), patient question asking (t = .12, p = .90), and companion question asking (t = 1.90, p = .06).

Secondary analysis. A standardized multiple regression analysis was performed using the dependent variable anxious-preoccupation change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of anxious-preoccupation change, F(5, 44) = 1.36, p = .26, adj.  $R^2 = .04$ . In terms of individual relationships between the independent variables, no independent variable was significantly associated with anxious-preoccupation change: surgeon partnership building: question solicitation (t = .37, p = .72), surgeon partnership

building: other (t = .003, p = .99), patient assertive responses: stating preferences (t = 1.28, p = .21), patient assertive responses: challenging surgeon (t = .37, p = .72), and patient question asking: self-initiated (t = 1.53, p = .13).

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable anxious-preoccupation change and the independent variables education, patient assertive responses: stating preferences, patient question asking: self-initiated, and companion question asking. The regression analysis revealed that the model did account for a significant amount of variance of anxious-preoccupation change, F(4, 45) = 2.86, p = .04, adj.  $R^2 = .13$ . In terms of individual relationships between the independent variables and of anxious-preoccupation change, patient assertive responses: stating preferences ( $\beta = .32$ , t = 2.15, p = .04) was significantly associated, and education (t = .36, p = .72), patient question asking: self-initiated (t = .41, p = .68), and companion question asking (t = 1.85, p = .07) were not significantly associated with anxious-preoccupation change. In sum, patients asserting their treatment preferences during treatment-decision-making visits – such as "Because of my history, I've been there, done that and don't want to do it again with radiation and chemotherapy" – was significantly associated with patients leaving visits with decreased *anxious* preoccupation.

## Cognitive-Avoidance Change

Primary analysis. A standardized multiple regression analysis was performed using the dependent variable cognitive-avoidance change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not

account for a significant amount of variance of *cognitive-avoidance change*, F(4, 46) = .46, p = .76, adj.  $R^2 = -.05$ . In terms of individual relationships between the independent variables and *cognitive-avoidance change*, no independent variable was significantly associated with *cognitive-avoidance change*: *surgeon partnership building* (t = .80, p = .43), *patient assertive responses* (t = -.82, p = .42), *patient question asking* (t = 1.14, p = .26), and *companion question asking* (t = -.68, p = .50).

Secondary analysis. A standardized multiple regression analysis was performed using the dependent variable cognitive-avoidance change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of cognitive-avoidance change, F(5, 45) = 1.40, p = .24, adj.  $R^2 = .04$ . In terms of individual relationships between the independent variables and cognitive-avoidance change, no independent variable was significantly associated with cognitive-avoidance change: surgeon partnership building: question solicitation (t = 1.52, p = .14), surgeon partnership building: other (t = -.25, p = .81), patient assertive responses: stating preferences (t = -1.06, p = .30), patient assertive responses: challenging surgeon (t = 1.77, p = .08), and patient question asking: self-initiated (t = .07, t = .94).

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable cognitive-avoidance change and the independent variables religiosity, surgeon partnership building: question solicitation, and patient assertive responses: challenging surgeon. The regression analysis revealed that the model did

account for a significant amount of variance of *cognitive-avoidance change*, F(3, 46) = 2.85, p = .05, adj.  $R^2 = .10$ . In terms of individual relationships between the independent variables and of *cognitive-avoidance change*, none of the variables were significantly associated: *religiosity* (t = -1.64, p = .11), *surgeon partnership building: question* solicitation (t = 1.57, p = .12), and patient assertive responses: challenging surgeon (t = 1.44, p = .16).

#### Fatalism Change

Primary analysis. A standardized multiple regression analysis was performed using the dependent variable fatalism change and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did not account for a significant amount of variance of fatalism change, F(4, 44) = .32, p = .86, adj.  $R^2 = -.06$ . In terms of individual relationships between the independent variables and fatalism change, no independent variable was significantly associated with fatalism change: surgeon partnership building (t = .71, p = .48), patient assertive responses (t = .15, p = .88), patient question asking (t = .35, p = .73), and companion question asking (t = .32, p = .75).

Secondary analysis. A standardized multiple regression analysis was performed using the dependent variable fatalism change and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of fatalism change, F(5,

43) = .2.10, p = .08, adj.  $R^2$  = .10. However, in terms of individual relationships between the independent variables and *fatalism change*, when controlling for all other independent variables, *patient assertive responses: challenging surgeon* was significantly associated with *fatalism change* (t = 2.72, p = .01,  $\beta$  = .43). No other independent variable was significantly associated with the change: *surgeon partnership building: question solicitation* (t = 1.30, p = .20), *surgeon partnership building: other* (t = .81, p = .43), *patient assertive responses: stating preferences* (t = -1.57, p = .12), and *patient question asking: self-initiated* (t = -.32, p = .75). In particular, greater *patient assertive responses: challenging surgeon* -- such as "It's different when you're faced with cancer though; it really is because it's like you're presented with your mortality" during the treatment-decision-making conversation was associated with leaving visits with decreased *fatalism*.

Tertiary analysis. A standardized multiple regression analysis was performed using the dependent variable fatalism change and the independent variables patient assertive responses: challenging surgeon and patient question asking: prompted. The regression analysis revealed that the model did account for a significant amount of variance of fatalism change, F(2, 46) = 8.08, p = .01, adj.  $R^2 = .23$ . In terms of individual relationships between the independent variables and of fatalism change, both of the variables were significantly associated: patient assertive responses: challenging surgeon ( $\beta = .36$ , t = 2.87, p = .01) and patient question asking: prompted ( $\beta = .39$ , t = 3.03, p = .01). In particular, greater patient assertive responses: challenging surgeon -- such as "It's different when you're faced with cancer though; it really is because it's like you're presented with your mortality" during the treatment-decision-making conversation was associated with leaving visits with decreased fatalism. Additionally, greater patient

*question asking: prompted*—such as in response to the surgeons' questions "Do you have any other questions for me?", patients' respond "Uhm, if I need this surgery, what's the timeframe?" during the treatment-decision-making conversation was associated with leaving visits with decreased *fatalism*.

RQ4: Communication-Participation and Patient Satisfaction with Visit Communication

Research Question 4 asked if the communication variables of (a) patient

participation, (b) companion participation, and (c) surgeon facilitation are associated with

a change in patients' satisfaction with the visit communication. The dependent variable,

as noted in the method section, is patients' satisfaction visit communication.

Primary analysis. A logistic regression analysis was performed using the dependent variable patients' satisfaction with visit communication (less than fully satisfied n = 21, fully satisfied n = 30) and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. A test of the full model was not significant,  $R^2 = .16$ ,  $\chi^2$  (4, N = 51) = 6.52, p = .16, indicating that, as a set, the predictors did not distinguish between those patients who were less than fully satisfied and those who were fully satisfied with the surgeon. The model was able correctly to classify 48% of those who were less than fully satisfied with the surgeon and 80% of those who were fully satisfied with the surgeon, for an overall success rate of 67%.

According to the Wald criterion, no independent variable was significantly associated with *patients' satisfaction with visit communication: surgeon partnership* building  $(\chi^2 (1, N = 51) = .10, p = .78, \text{ odds ratio} = .92)$ , patient assertive responses  $(\chi^2 (1, N = 51) = 1.72, p = .19, \text{ odds ratio} = .79)$ , patient question asking  $(\chi^2 (1, N = 51) = .19, \text{ odds ratio} = .79)$ 

1.11, p = .29, odds ratio = .95), or *companion question asking* ( $\chi^2$  (1, N = 51) = .25, p = .62, odds ratio = 1.03).

Secondary analysis. A logistic regression analysis was performed using the dependent variable patients' satisfaction with visit communication (less than fully satisfied n = 21, fully satisfied n = 30) and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. A test of the full model was not significant,  $R^2 = .17$ ,  $\chi^2$  (5, N = 51) = 7.03, p = .22, indicating that, as a set, the predictors did not distinguish between those patients who were less than fully satisfied and those who were fully satisfied with the surgeon. The model was able correctly to classify 43% of those who were less than fully satisfied with the surgeon and 73% of those who were fully satisfied with the surgeon, for an overall success rate of 61%.

According to the Wald criterion, no independent variable was significantly associated with *patients' satisfaction with visit communication: surgeon partnership* building: question solicitation ( $\chi^2$  (1, N=51) = .05, p=.83, odds ratio = .94), surgeon partnership building: other ( $\chi^2$  (1, N=51) = .10, p=.76, odds ratio = .85), patient assertive responses: stating preferences ( $\chi^2$  (1, N=51) = 1.14, p=.29, odds ratio = .79), patient assertive responses: challenging surgeon ( $\chi^2$  (1, N=51) = 1.83, p=.18, odds ratio = .62), or patient question asking: self-initiated ( $\chi^2$  (1, N=51) = .94, p=.34, odds ratio = .96).

Tertiary analysis. A logistic regression analysis was performed using the dependent variable patients' satisfaction with visit communication (less than fully

satisfied n = 21, fully satisfied n = 30) and the independent variables of *patient assertive* responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. A test of the full model was not significant,  $R^2 = .17$ ,  $\chi^2(3, N = 51) = 6.91$ , p = .08, indicating that, as a set, the predictors did not distinguish between those patients who were less than fully satisfied and those who were fully satisfied with the surgeon. The model was able correctly to classify 38% of those who were less than fully satisfied with the surgeon and 77% of those who were fully satisfied with the surgeon, for an overall success rate of 61%.

According to the Wald criterion, none of the independent variables were significantly associated with *patients' satisfaction with visit communication: patient* assertive responses: stating preference ( $\chi^2$  (1, N = 51) = 1.48, p = .22, odds ratio = .77), patient assertive responses: challenging surgeon ( $\chi^2$  (1, N = 51) = 1.74, p = .19, odds ratio = .62), or patient question asking: self-initiated ( $\chi^2$  (1, N = 51) = .92, p = .34, odds ratio = .96).

RQ5: Communication-Participation and Patients' Satisfaction with Treatment Plans

Research Question 5 asked if the communication variables of (a) patient

participation, (b) companion participation, and (c) surgeon facilitation are associated with

patients' satisfaction with treatment plans. The dependent variable, as noted in the

method section, is patients' satisfaction with treatment plans.

Primary analysis. A standardized multiple regression analysis was performed with the dependent variable patients' satisfaction with treatment plans and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed

that the model did not account for a significant amount of variance of *patients'* satisfaction with treatment plans, F(4, 45) = 2.15, p = .09, adj.  $R^2 = .09$ . However, in terms of individual relationships between the independent variables and patients' satisfaction with treatment plans, patient question asking  $(t = -2.08, p = .04, \beta = -.39)$  was significantly, negatively associated with patients' satisfaction with treatment plans. No other independent variable was significantly associated with patients' satisfaction with treatment plans: surgeon partnership building (t = 1.33, p = .18), patient assertive responses (t = .06, p = .80), and companion question asking (t = .46, p = .65). In particular, the more patients asked questions during visits -- such as "You're saying that the nipple would be saved?", the less they reported being completely satisfied with treatment plans.

Secondary analysis. A standardized multiple regression analysis was performed with the dependent variable patients' satisfaction with treatment plans and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did not account for a significant amount of variance of patients' satisfaction with treatment plans, F(5, 44) = 1.61, p = .18, adj.  $R^2 = .06$ . However, in terms of individual relationships between the independent variables and patients' satisfaction with treatment plans, patient question asking: self-initiated ( $t = -2.15, p = .04, \beta = -.34$ ) was negatively significantly associated with patients' satisfaction with treatment plans. No other independent variable was significantly associated with patients' satisfaction with treatment plans: surgeon partnership building: question

solicitation (t = 1.40, p = .17), surgeon partnership building: other (t = .46, p = .65), patient assertive responses: stating preferences (t = -.38, p = .71), and patient assertive responses: challenging surgeon (t = .12, p = .91). In particular, the more patients asked self-initiated questions during visits -- such as "What about the HER2 receptor", the less they reported being completely satisfied with treatment plans. Comparison of the primary and secondary patients' satisfaction with treatment plans analyses suggests that although patient question asking decreased patients' satisfaction with treatment plans, patient question asking: self-initiated, and not patient question asking: prompted (not included in the analysis as described in methods section), contributed to this decrease in patients' satisfaction with treatment plans.

Tertiary analysis. A standardized multiple regression analysis was performed with the dependent variable patients' satisfaction with treatment plans and the independent variables of age, perceived social support, history with any breast surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did account for a significant amount of variance of patients' satisfaction with treatment plans, F(4, 44) = 3.70, p = .01, adj.  $R^2 = .18$ . In terms of individual relationships between the independent variables and of patients' satisfaction with treatment plans, none of the variables were significantly associated: age (t = 1.92, p = .06), perceived social support (t = 1.82, t = 0.08), history with any breast surgeon (t = -.30, t = 0.77), and patient question asking: self-initiated (t = -.178, t = 0.08).

# RQ6: Communication-Participation and Patients' Intention to Adhere to Treatment Plans

Research Question 6 asked if the communication variables of (a) patient participation, (b) companion participation, and (c) surgeon facilitation are associated with a change in *patients' intention to adhere to treatment plans*. The dependent variable, as noted in the method section, is *patients' intention to adhere to treatment plans*.

Primary analysis. A logistic regression analysis was performed using the dependent variable patients' intention to adhere to treatment plans (less than fully committed n = 17, fully committed n = 33) and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. A test of the full model was significant,  $R^2 = .23$ ,  $\chi^2$  (4, N = 51) = 9.11, p = .05, indicating that, as a set, the predictors did distinguish between patients that were less than fully committed and fully committed to adhere to the treatment plans. The model was able correctly to classify 47% of those who were less than fully committed and 97% of those who were fully committed to adhere to the treatment plans, for an overall success rate of 80%.

According to the Wald criterion, only patient question asking was significantly, negatively associated with patients' intention to adhere to treatment plans,  $\beta = -.14$ ,  $\chi^2$  (1, N = 51) = 5.19, p = .02, odds ratio = .87. No other independent variable was significantly associated with patients' intention to adhere to treatment plans: surgeon partnership building ( $\chi^2$  (1, N = 51) = .03, p = .89, odds ratio = 1.05), patient assertive responses ( $\chi^2$  (1, N = 51) = .03, p = .87, odds ratio = 1.03), or companion question asking ( $\chi^2$  (1, N = 51) = .36, p = .55, odds ratio = 1.04). In sum, the more patients asked questions during

visits -- such as "You're saying that the nipple would be saved?", the less they reported being fully committed to intend to adhere to the treatment plans.

Secondary analysis. A logistic regression analysis was performed using the dependent variable patients' intention to adhere to treatment plans (less than fully committed n = 17, fully committed n = 33) and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. A test of the full model was significant,  $R^2 = .28$ ,  $\chi^2$  (5, N = 51) = 11.33, p = .05, indicating that, as a set, the predictors did distinguish between patients who were less than fully committed and were fully committed to intend to adhere to the treatment plans. The model was able correctly to classify 65% of those who were less than fully committed to intend to adhere to the treatment plans and 88% of those who were fully committed to intend to adhere to the treatment plans, for an overall success rate of 80%.

According to the Wald criterion, only patient question asking: self-initiated was significantly, negatively associated with patients' intention to adhere to the treatment plans,  $\beta = -.14$ ,  $\chi^2(1, N = 51) = 7.91$ , p = .01, odds ratio = .87. No other independent variable was significantly associated with patients' intention to adhere to treatment plans: surgeon partnership building: question solicitation ( $\chi^2(1, N = 51) = .22$ , p = .64, odds ratio = 1.17), surgeon partnership building: other ( $\chi^2(1, N = 51) = .06$ , p = .82, odds ratio = 1.14), patient assertive responses: stating preferences ( $\chi^2(1, N = 51) = .90$ , p = .34, odds ratio = .80), or patient assertive responses: challenging surgeon ( $\chi^2(1, N = 51) = .90$ ,  $\chi^2(1, N = 51)$   $\chi^2(1, N = 5$ 

questions during visits -- such as "What about the HER2 receptor?", the less they reported being fully committed to intend to adhere to the treatment plans.

Tertiary analysis. A logistic regression analysis was performed using the dependent variable patients' intention to adhere to treatment plans (less than fully committed n = 17, fully committed n = 33) and the independent variables of education and patient question asking: self-initiated. A test of the full model was significant,  $R^2 = .22$ ,  $\chi^2(2, N = 51) = 8.94$ , p = .01, indicating that, as a set, the predictors did distinguish between those patients who were less than fully committed and those who were fully committed to the treatment plan. The model was able correctly to classify 47% of those who were less than fully committed to the treatment plan and 97% of those who were fully committed to the treatment plan, for an overall success rate of 80%.

According to the Wald criterion, the only *patient question asking: self-initiated* was significantly, negatively associated with *patients' intention to adhere to treatment* plans,  $\beta = -.12$ ,  $\chi^2(1, N = 51) = 5.81$ , p = .02, odds ratio = .88). *Education* ( $\chi^2(1, N = 51) = .03$ , p = .87, odds ratio = 1.14) was not significantly related to *patients' intention to adhere to treatment plans*. In sum, the more patients asked self-initiated questions during visits -- such as "What about the HER2 receptor?", the less they reported being fully committed to intend to adhere to the treatment plans.

## RQ7: Communication-Participation and Length of Visit

Research Question 7 asked if the communication variables of (a) patient participation, (b) companion participation, and (c) surgeon facilitation are associated with the *length of visit*. The dependent variable, as noted in the method section, is *length of visit*.

Primary analysis. A standardized multiple regression analysis was performed with the dependent variable length of visit and the independent variables of surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The regression analysis revealed that the model did account for a significant amount of variance of length of visit, F(4, 46) = 24.65, p = .001, adj.  $R^2 = .65$ . In terms of individual relationships between the independent variables and length of visit, patient question asking (t = 4.10, p = .001,  $\beta = .64$ ) and companion question asking (t = 4.21, t = .001, t = .001,

Secondary analysis. A standardized multiple regression analysis was performed with the dependent variable length of visit and the independent variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenging surgeon, and patient question asking: self-initiated. The regression analysis revealed that the model did account for a significant amount of variance of length of visit, F(5, 45) = 12.43, p = .001, adj.  $R^2 = .53$ . In terms of individual relationships between the independent variables and length of visit, surgeon partnership building: question solicitation (t = 2.03, p = .05,  $\beta = .21$ ) and patient question asking: self-initiated (t = 7.29, t = .001, t = .79) were significantly associated with length of visit. No other independent variable was significantly associated with length of visit: surgeon partnership building:

other (t = 1.20, p = .24), patient assertive responses: stating preferences (t = -1.41, p = .17), and patient assertive responses: challenging surgeon (t = -.91, p = .37). In particular, the more surgeons solicited questions from patients and the more patients asked self-initiated questions during visits -- such as "What about the HER2 receptor?", the longer the visits.

Tertiary analysis. A standardized multiple regression analysis was performed with the dependent variable *length of visit* and the independent variables of *age*, *income*, education, marital status, patient question asking: self-initiated, patient question asking: prompted, and companion question asking. Please note, due to the inclusion of seven independent variables, this regression analysis was under-powered. The regression analysis revealed that the model did account for a significant amount of variance of length of visit, F(7, 38) = 13.92, p = .01, adj.  $R^2 = .67$ . In terms of individual relationships between the independent variables and of length of visit, patient question asking: selfinitiated ( $\beta = .41$ , t = 3.20, p = .01) and companion question asking ( $\beta = .39$ , t = 3.60, p = .01) .01) were significantly associated. The following variables were not significantly associated with length of visit: age (t = -1.44, p = .16), income (t = 106, p = .30), education (t = .17, p = .87), marital status (t = .81, p = .42), and patient question asking: prompted (t = .65, p = .52). In particular, the more patients asked self-initiated questions and companions asked any questions (self-initiated versus prompted was not differentiated for companion question asking, as discussed in the Methods section) during visits -- such as "What about the HER2 receptor?", the less they reported being fully committed to intend to adhere to the treatment plans.

## **CHAPTER SIX: DISCUSSION**

Breast cancer is a national health problem, especially for women, claiming approximately 40,000 lives every year (ACS, 2010). Because at least early-stage breast cancer (stages 0-2) is highly and successfully treatable with surgery (i.e., successful at preventing recurrence and mortality) (ACS, 2010), it can be argued that breast cancer takes a heavier toll on womens' psychosocial health compared to their physical health (Hewitt et al., 2004). Immediately following diagnosis, one of the first medical specialists that women visit is a surgeon. During these visits, which last approximately 30 minutes, women are typically educated about their breast cancer and involved in the development of a treatment plan.

This dissertation examined treatment-decision-making conversations between surgeons and women who were newly diagnosed with breast cancer. Specifically, this dissertation examined the association between patient-centered care (Beach & Inui, 2006; Bensing, 2000; Epstein et al., 2005; McWhinney, 1995) – which was operationalized in terms of communication behaviors that facilitated or embodied patients' 'participation' (Street & Millay, 2001) – and patients' psychosocial health outcomes. For surgeons, communication behaviors involved attempts to build partnerships with patients, such as soliciting patients' questions, encouraging patients' decision-making, supporting patients, and fostering a continued partnership beyond the current visit. For patients and their companions, communication behaviors involved asserting preferences (including those that challenged or disagreed with surgeons' proposals/perspectives), asking questions (either of their own volition or when solicited by surgeons), and expressing concerns.

Psychosocial health outcomes included: (1) changes (from pre- to post-visit) in two types

of patients' uncertainty about cancer (i.e., *ambiguity* and *unpredictability*); (2) changes (from pre- to post-visit) in five types of patients' *mental adjustment to cancer* (i.e., *fighting spirit, helplessness-hopelessness, anxious preoccupation, cognitive avoidance*, and *fatalism*); (3) *patients' satisfaction with visit communication*; (4) *patients' satisfaction with treatment plans*; and (5) *patients' intentions to adhere to treatment plans*. This dissertation also examined the relationship between the aforementioned communication behaviors and visit length.

This chapter has four broad goals. First, it reviews the communication behaviors examined and discusses their specification (i.e., coding) and distribution. Second, this chapter reviews and discusses the dissertation's findings and implications, as well as theoretical implications, that emerged from the meta-analysis and regression analyses. Third, this chapter discusses the dissertation's limitations. Finally, this chapter discusses directions for future research.

Communication Behaviors: Specification and Distribution

The data for the main dissertation study were initially coded for five specific behaviors: surgeon partnership building, surgeon supportive talk, assertive response (patients' and companions'), question asking (patients' and companions'), and expression of concern (patients' and companions'; Street & Millay, 2001; Street & Gordon, 2008). A qualitative thematic analysis (Strauss & Corbin, 1998) of each of these variables revealed that three of them consisted of coherent and robust sub-variables. For the first example, one specific aspect of surgeon partnership building was soliciting questions from patients, and thus surgeon partnership building was divided into question solicitation and all other. For the second example, patient assertive responses was divided into stating

preferences and challenging surgeon. For the third example, patient question asking was divided into self-initiated questions and prompted questions. Below is a review of the communication variables that were considered for this dissertation.

## Surgeon Partnership Building

Provider partnership building is defined as "communicative acts that encourage patients to discuss their opinions, express feelings, ask questions, and participate in decision making" (Street & Millay, 2001; p. 66). In general, these types of behaviors occurred at least once in 51 of the total 51 cases, with a range of 1-6 occurrences per visit. However, qualitative thematic analyses suggested specifications, as follows.

Question solicitation. One specification of the variable surgeon partnership building is the solicitation of patients' questions, such as: Do you have any other questions for me right now? This behavior occurred at least once in 42 of the total 51 cases, with a range of 1-5 occurrences per visit.

All other types of partnership building. Other moves representing surgeon partnership building included encouraging patients' decision-making (e.g., It's up to you. You have to decide what you want to have done; and It's a very personal decision. You decide what is comfortable for you), supporting patients (e.g., That makes a lot of sense), and fostering a continued partnership after the current visit (e.g., I'm certainly happy for you to shoot me some questions [over email], and then I can respond to them so just because we're not sitting here together doesn't mean that the discussion isn't continuing). These types of behaviors occurred at least once in 47 of the total 51 cases, with a range of 1-3 occurrences per visit.

# Surgeon Supportive Talk

Provider supportive talk is defined as "statements of reassurance, support, empathy, and other verbal displays of interpersonal sensitivity" (Street & Millay, 2001, p. 66). Similar to that in primary-care contexts (Street & Millay, 2001), surgeon supportive talk was very rare; for example, in one case, the surgeon supported a patient's perspective with: That makes a lot of sense. Because the variable surgeon supportive talk only occurred in five visits, it was eliminated from regression analyses.

The infrequency of surgeon supportive talk is supported by the findings of Roberts (1999), who found that oncologists treat examinations as service encounters, that is, "an occasion for giving and receiving information as opposed to commiserating with the patient" (p. 48). Along similar lines, Drew and Heritage (1992) argued that, in institutional settings generally (including medical contexts), individuals (such as providers) "withhold expressions of surprise, sympathy, agreement, or affiliation" (p. 24) in order to enact professionalism. Importantly, the infrequency of surgeon supportive talk in the present context, as defined by the coding schema, does not necessarily mean that the surgeon was not 'supportive' in a lay or vernacular sense. First, as noted by Drew and Heritage, withholding sympathy, affiliation, and so on may be a normative element of provider-patient interaction. Second, in the context of cancer-related, treatment-decision-making conversations, providers' provision of medical information – which was a central element of these conversations, but which was not coded as provider support – is actually a major form of social support (Raupach & Hiller, 2002).

### Patient Assertive Responses

Patient assertive responses is defined as "utterances in which the patient expresses his or her rights, beliefs, interests, and desires as in offering an opinion, stating preferences, making suggestions or recommendations, disagreeing, or interrupting" (Street & Millay, 2001, p. 63). In general, these types of behaviors occurred at least once in 36 of the total 51 cases, with a range of 1-8 occurrences per visit. However, qualitative thematic analyses suggested specifications, as follows.

Stating preferences. One specification of the variable patient assertive responses is when patients, without prompting from surgeons, express their treatment preferences. For example, one patient said: *I'm totally against expanders and my own tissue*. Another patient said: *Okay now at this point I do wanna get a second opinion*. These types of behaviors occurred at least once in 30 of the total 51 cases, with a range of 1-6 occurrences per visit.

Challenging surgeon. A second specification of the variable patient assertive responses is when patients correct, disagree with, or challenge the surgeon. For example, one patient attempted to correct the surgeon: I had a lumpectomy too. Another patient, in response to the surgeon's statement that her treatment is not 'an emergency,' added a sarcastic correction: In their minds. These types of behaviors occurred at least once in 18 of the total 51 cases, with a range of 1-5 occurrences per visit.

## Patient Question Asking

Patient question asking is defined as "utterances in interrogative form intended to seek information and clarification" (Street & Millay, 2001, p. 63). For example, one patient asked: What about the HER2 receptor? Included in this variable were also

patients' efforts to solicit information that were not, technically, interrogatives, such as: Since radiation was never discussed in the other visit, is it, really I don't understand what's involved with radiation; I don't know. In general, patient question asking occurred at least once in 49 of the total 51 cases, with a range of 1-32 occurrences per visit. However, qualitative thematic analyses suggested specifications, as follows.

Self-initiated questions. Patients' questions were self initiated when they were initiated by patients without being prompted by the surgeon. For example, one patient requested confirmation of the surgeon's point: So you're saying the nipple would be saved? These types of behaviors represented the canonical form of patient participation and occurred at least once in 49 of the total 51 cases, with a range of 1-32 occurrences per visit.

Prompted questions. Patients' questions were prompted when they were solicited, or otherwise explicitly encouraged, by the surgeon. For example, in one case, the surgeon asked, So what questions can I answer for you?, to which the patient replied: Uhm, during the course of the full uhm year you would be basically guiding me right? There is an interactional relationship, rooted in the organization of both action and sequence (Schegloff, 2007), between the variable surgeon partnership building: question solicitation and that of patient question asking. Although these behaviors were significantly, positively correlated, r = .51, indicating that in response to surgeon question solicitation, patients at times did not ask questions, and thus that these two behaviors/variables are conceptually distinct. One explanation for the lack of a much higher correlation between surgeon partnership building: question solicitation and patient question asking is that, in some instances, patients did not perceive a need for

additional information. However, a quite different explanation is that patients did perceive a need for additional information (i.e., they did have questions to ask) yet nonetheless declined or refused to ask. Patients' prompted questions occurred at least once in 24 of the total 51 cases, with a range of 1-3 occurrences per visit.

## Patient Expression of Concern

Patient expression of concern is defined as "utterances in which the patient expresses worry, anxiety, fear, anger, frustration, and other forms of negative affect or emotions" (Street & Millay, 2001, p. 63). Although patients entering visits were relatively anxious – that is, the mean pre-visit score for patients' anxious preoccupation, which is significantly associated with state anxiety (Bjorck et al., 1999; Cayrou et al., 2003; Cordova et al., 2003), was 3.14 out of 6.0 – it was very uncommon for patients to make direct expressions of concern. For an example, one patient said, crying: And yet losing the nipple bothers me. I don't know why. Patient expression of concern only occurred in 13 cases, which (as discussed in the method section, above) eliminated it from regression analyses. The infrequency of patients expressing concerns in the present context accords with an interview-based study by Byrne, Ellershaw, Holcombe, and Salmon (2002), who found that cancer patients overwhelmingly attempt to conceal their emotional distress from family, friends, and providers. One patient reported that she concealed her emotions from her provider because emotions are not a normative part of treatment conversations: "When you go for your treatment you all talk about your symptoms. . . but you don't talk about how you're feeling and how your family are coping or things like that" (p. 18). Another patient reported that concealing her emotions/concerns was a mechanism for saving her own (positive) face (Brown &

Levinson, 1987): "The doctor says 'how are you' and you say 'alright you know', but if you say 'no I'm not' and burst into tears you feel so embarrassed" (p. 18). One possible explanation for the infrequency of *patient expression of concern* relates to the infrequency of provider supportive talk (see above), and involves the social organization of conversation. Specifically, turns of talk are overwhelmingly sequenced (Schegloff, 2007), their form and function being heavily influenced by immediately preceding talk (Heritage, 1984). If providers do not enact 'support,' there may be few places in treatment-decision-making conversations where it is relevant (Schegloff, 1992) for patients to express concern.

## Companion Behaviors

Companions are a natural part of treatment-decision-making conversations and were present in 76% of the study visits (see also Street, 2003). The variable *companion* assertive response only occurred in 16 cases, and the variable *companion expression of* concern occurred in 0 cases; due to their infrequency, they were eliminated from regression analyses. The variable *companion question asking* occurred at least once in 35 cases, with a range of 1-20 occurrences per visit.

Findings from Meta-Analysis and Regression Analyses

The present dissertation involved two studies: A proof-of-concept study (i.e., the meta-analysis) and the main dissertation study. Each of these will be discussed in turn.

### Meta-Analysis

The first study was a meta-analysis that was conducted as a 'proof of concept/principle' for the main dissertation study (The meta-analysis was published as Venetis, Robinson, Turkiewicz, and Allen (2009) in the journal *Patient Education and* 

Counseling and reprinted with permission). As noted in the introduction (Chapter One), relative to the biomedical model of medicine (Engel, 1977, 1980; Mishler, 1981; Resier, 1978), the patient-centered model (Beach & Inui, 2006; Bensing, 2000; Engel, 1977; Epstein et al., 2005; McWhinney, 1995; Roter et al., 1997), suggests that patient-centered communication should be associated with patients' health outcomes. The overarching goal of the meta-analysis was to document that the findings of all previous comparable studies (i.e., ones of taped and coded communication behavior between patients and cancer-care physicians) generally supported an association between patient-centered communication behavior and cancer-patients' psychosocial health outcomes.

In the meta-analysis, patient-centered communication was an aggregate variable that included: (1) providers' displays of approval, empathy, concern, worry, reassurance, optimism, and positive affect; (2) both providers' and patients' social/informal talk; (3) providers' solicitation of patients' questions, concerns, and opinions; (4) patients' asking questions and voicing preferences and concerns; (5) and patients giving opinions.

Constrained by prior research, the meta-analysis was only able to examine one type of psychosocial health outcome, namely patient satisfaction, which was an aggregate variable that included: (1) patients' satisfaction with visits generally; (2) patients' satisfaction with specific aspects of visit communication (e.g., amount of information received and the treatment decision); (3) patients' satisfaction with physicians personally; and (4) patients' perceptions of their levels of control, involvement, and participation during visits; and (5) and patients' perceptions of physicians' levels of collaboration. The meta-analysis also coded for instrumental behavior, which was an aggregate variable that included physicians' question asking and patients' information giving.

The findings of the meta-analysis supported the general principle of the main dissertation study. Specifically, patient-centered communication was significantly, positively associated with patient satisfaction. One specific component of patient-centered communication, that being affective communication, was itself significantly, positively associated with patient satisfaction. As supported by past research (Hall et al., 1988; Roter et al., 1987), instrumental behavior was also significantly, positively associated with patient satisfaction. However, compared to instrumental behavior, patient-centered communication was more strongly associated with patient satisfaction; compared to both the aggregate variable of patient-centered communication and that of instrumental behavior, affective behavior was more strongly associated with patient satisfaction (see also Buller & Buller, 1987; Griffith et al., 2003).

Admittedly, the meta-analysis failed to find a significant association between participation behavior – as one specific component of patient-centered communication – and patient satisfaction. For at least two reasons, though, there was still a good rationale for studying participation behavior in the main dissertation study. First, participation behavior, as defined in the main dissertation study, included affective elements, such as provider support, patient expression of concern, and patient disagreement/challenge. Second, the meta-analysis only examined one type of psychosocial outcome, that being patient satisfaction. However, for reasons yet to be determined, in the context of cancer care, certain elements of participation behavior (e.g., patient question asking) appear to be *negatively* associated with patient satisfaction (Ishikawa et al., 2002a; Ong et al., 2000; Siminoff et al., 2000; Timmermans et al., 2007). Thus, it is possible that the relationship between patient-centered communication and patient satisfaction is uniquely

attenuated, which may not be the case for other psychosocial health outcomes, such as illness uncertainty and mental adjustment to cancer. Over the years, research has regularly found behaviors that foster patient participation to be significantly associated with other beneficial health outcomes, such as improved overall health (Kaplan et al., 1989), improved symptom resolution, lower anxiety (Stewart, 1995), recovery from discomfort, and improved emotional health (Stewart et al., 2000). In order to better address the association between patient participation behaviors and health outcomes, study 2 was conducted. This second study combined specific behaviors with a broader range of outcomes.

## Regression Analyses

The main study's results and implications are described below. However, as the main dissertation study was an exploratory analysis and data was collected from one surgeon with 51 of his newly-diagnosed breast-cancer patients, all results and implications are specific to this particular population and context. The author recognizes that findings are not necessarily generalizable to all patient populations or all breast-cancer populations and their surgeons. The author also recognizes that additional research is necessary before any physician or patient training modules can be created or implemented. Additionally, as an exploratory study (versus a deductive, hypothesis-driven study), the majority of the associations between independent and dependent variables were not statistically significant. This lack of association is important because it aids in identifying which communication-participation behaviors and which dependent variables should be the focus of future studies. For example, because communication-

participation variables were not associated with patients' satisfaction with visit communication, one may be hesitant to include this variable in future research.

The main dissertation study examined the association between communicationparticipation behaviors and five psychosocial health outcomes (i.e., illness uncertainty about cancer, mental adjustment to cancer, patients' satisfaction with surgeons' visit communication, patient satisfaction with treatment plan, and patient intention to adhere to the treatment plan), as well as visit length. In the following subsections, results are reviewed and implications are drawn. Note that, for each dependent variable, there was a primary, secondary, and tertiary analysis. In the primary analyses, the independent variables were surgeon partnership building, patient assertive responses, patient question asking, and companion question asking. The secondary analyses took under consideration the sub-variables that inductively emerged from the primary independent variables, and included the variables of surgeon partnership building: question solicitation, surgeon partnership building: other, patient assertive responses: stating preferences, patient assertive responses: challenge surgeon, and patient question asking: self-initiated. While the primary and secondary analyses focused exclusively on communication behaviors as independent variables, the tertiary analyses also considered the influence of age, education, ethnicity, income, marital status, religiosity, perceived social support, prior history with this surgeon, prior history with any surgeon.

Two Types of Illness Uncertainty

Illness uncertainty is defined as "the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues" (Mishel, 1988, p.

225). Among cancer patients, increased levels of illness uncertainty are associated with several deleterious psychosocial health outcomes, such as problems with psychological adjustment, (Christman, 1990; Germino et al., 1998; Mishel & Braden, 1987; Neville, 1998), tension, anger, depression, and fatigue (Stieglis et al., 2004), sadness and pessimism (Mishel et al., 1984), symptom distress, including pain, nausea, and insomnia (Phillips-Salimi et al., 2007), decreased quality of life (Padilla et al., 1992; Sammarco & Konecny, 2008; Wallace, 2003), decreased optimism and motivation (Mishel et al., 1984), increased anxiety, fear, depression, and hopelessness (Nelson, 1996; Wong & Bramwell, 1992), and decreased hope (Wonghongkul et al., 2000).

Change in ambiguity uncertainty. Both theoretically and empirically (Mishel, 1988; Mishel & Braden, 1987; Mishel et al., 1984; Padilla et al., 1992), a fundamental aspect of illness uncertainty is ambiguity. Illness ambiguity involves the "absence of cues or vagueness of cues" concerning the general state of the illness and the general plan of treating the illness (Mishel, 1997). In none of the regression analyses, no communication-participation variables were found to be significantly associated with a change in patients' ambiguity uncertainty. It is very possible that ambiguity uncertainty change is much more strongly associated with a different communication variable, namely surgeon information giving, which is an instrumental (vs. participation) communication behavior that was not measured. The surgeon conducted and organized treatment-decision-making conversations in a very 'stock' fashion; he began by informing and educating patients about treatments for the breast (i.e., surgery), and then proceeded to do the same for the rest of the body. For example, after introductions, the surgeon frequently started conversations as follows:

"So you basically have to come up with two plans. Plan number one is how do you treat the breast and plan number two is how you treat the rest of the body. Uhm, so you'll hear me talk about the breast and the rest."

The surgeon then would often speak in a relatively uninterrupted fashion, with both patients and their companions reserving their questions until the surgeon was complete. Only after the surgeon completed his 'stock talk' did he solicit patients' questions. It is likely that the surgeon's education/information giving talk reduced patients' ambiguity uncertainty.

Change in unpredictability uncertainty. Both theoretically and empirically (Liao, Chen, Chen, & Chen, 2008; Mishel, 1988; Mishel & Braden, 1987; Mishel et al., 1984), another fundamental aspect of illness uncertainty is a lack of predictability. Illness unpredictability involves a "lack of contingency between treatment and outcomes" (Mishel, 1997, p. 8). The primary regression analysis revealed that surgeon partnership building is significantly, negatively associated with a change in patients' unpredictability uncertainty, and thus associated with a positive psychosocial health outcome (i.e., patients become *less* uncertain). In the secondary analysis, the variable *surgeon* partnership building was divided into two discrete variables, including soliciting questions and 'other' behaviors. The secondary regression analysis revealed that only one of the two sub-dimensions of surgeon partnership building – namely, surgeon partnership building: question solicitation – was significantly, negatively associated with unpredictability uncertainty. It was noted earlier that the surgeon's initial 'stock' informational/educational talk was likely to reduce patients' *ambiguity* uncertainty. However, this 'stock' talk did not always address issues of *unpredictability*, such as

patients' personal treatment timelines. The correlation between surgeons' soliciting questions and patients' *unpredictability uncertainty* can be interpreted in at least two ways: (1) A decrease in patients' *unpredictability uncertainty* throughout visits 'causes' surgeons to solicit more questions; and (2) Surgeons' solicitations of questions 'causes' a decrease in patients' levels of *unpredictability uncertainty*, most likely through providing patients with interactional spaces to address issues of unpredictability. The first interpretation seems less likely, because surgeons would have to be able to evaluate patients' decreasing levels of uncertainty (which is a psychological state), and because, even if surgeons were able to do so, one would expect them to respond by soliciting fewer (vs. more) questions. From a communication standpoint, the secondary analysis reveals a concrete training objective. Specifically, although all aspects of surgeons' partnership building are likely important (i.e., the variable *surgeon partnership building: other*), surgeons should be trained to explicitly solicit patients' questions, with questions such as: *What questions can I answer for you?* 

## Mental Adjustment to Cancer: Coping

Mental adjustment to cancer, or coping, is defined as "cognitive and behavioral responses the patient makes to the diagnosis of cancer" (Watson et al., 1988, p. 203). Cancer patients' inability to cope is associated with a decrease in patients' quality of life, including increased depression (Söllner et al., 1999), increased cancer-related worries concerning physical, emotional, and relational problems (Grassi et al., 2004), increased sexual problems (Ferrero et al., 1994), and decreased life satisfaction (Herbert et al., 2009). The main dissertation study examined five dimensions of coping – *fighting spirit*,

helplessness-hopelessness, anxious preoccupation, cognitive avoidance, and fatalism – each of which will be discussed in turn.

Change in fighting spirit. Fighting spirit is defined as patients' "regarding cancer as a challenge and adopting a positive attitude" (Greer, 2000, p. 848). Among breastcancer patients, increases in *fighting spirit* are associated with decreases in anxiety and depression (Akechi et al., 2001; Cayrou et al., 2003; Grassi et al., 2004; Ho et al., 2003, 2004; Kang et al., 2008; Link et al., 2003; Nordin et al., 1999; Nordin & Glielius, 1998; Schnoll et al., 1995; Schnoll et al., 1998; Watson et al., 1991; Watson et al., 1994), emotional distress (Classen et al., 1996; Cordova et al., 2003; Ferrero et al., 1994), health distress (Ho et al., 2004), cancer worry (e.g., about recurrence; Lampic et al., 1994), and psychological stress (Grassi et al., 2005). Increases in fighting spirit are associated with increases in well-being (Lampic et al., 1994; Whitford et al., 2008), improved emotional functioning and adjustment (Nordin & Glielius, 1998; Schnoll et al., 1995), and quality of life (Levine & Targ, 2002; Nordin & Glielius, 1998; Schnoll et al., 1998). In the primary analysis, none of the communication variables were significantly associated with changes in patients' fighting spirit from pre- to post-visit. However, in the secondary analysis, the variable patient assertive responses was divided into two discrete variables, including stating treatment preferences and challenging surgeon. In the secondary analysis, the variable patient assertive responses: stating preference was significantly, negatively associated with *increases* in patients' *fighting-spirit*, and thus with a positive health outcome (i.e. patients emerged from visits with higher levels of *fighting spirit*). The tertiary analysis suggested that this relationship held even when factoring in other noncommunication variables. Additionally, the tertiary analysis suggested that patients' previsit levels of *perceived social support* are associated with *decreases* in patients' *fighting spirit*. However, this finding is contradictory to prior research among breast cancer patients that finds that increased social support is associated with greater *fighting spirit* (Akechi et al., 1998; Grassi et al., 1993). Future research should reexamine the relationship between *social support* and *fighting spirit*.

Given the lack of significant associations in the primary analysis, the significant finding in the secondary and tertiary analysis can be explained in the following manner. Fighting spirit is characterized as a coping style in which patients feel like they can affect the course of their cancer, and in which patients want to participate in treatment decisionmaking (Grassi et al., 1993; Greer, 1991; Link et al., 2003). The sub-variable patient assertive responses: challenging surgeon potentially represents interpersonally disaffiliative behavior that involves patients struggling to affect the course of their cancer in the face of surgeons' differing positions, and thus has the potential to be associated with a reduction in patients' *fighting spirit*. This interpretation is supported by the fact that the variable patient assertive responses: challenging surgeon was associated with a (non-significant) decrease in patients' fighting spirit. Alternatively, the sub-variable patient assertive responses: stating preferences is the very embodiment of patientcentered, treatment-decision making, and has the potential to be associated with an increase in *fighting spirit*. When these two sub-variables are combined, as they were in the primary analysis as *patient assertive responses*, it is possible that they 'negate' each other in terms of patients' fighting spirit.

The connection between *patient assertive responses: stating preferences* and *fighting spirit* and has strong face validity. Because this connection is correlational, there

are at least two interpretations: (1) An increase in patients' *fighting spirit* throughout visits (through a variety of potential mechanisms, such as receiving 'encouraging' or pleasantly unexpected treatment information, etc.) 'causes' them to assert their preferences more frequently; and (2) The assertion of preferences 'causes' increases in patients' *fighting spirit*. From a communication-intervention perspective, the second interpretation suggests that patients could be trained to assert their preferences, and surgeons could be trained to solicit such preferences (as a form of partnership building).

Change in helplessness-hopelessness. Helplessness-hopelessness is a coping style characterized by pessimistic attitudes, fear, and negative appraisals of cancer diagnoses (Glese-Davis & Spiegel, 2003; Mishel, 1988). Among breast-cancer patients, increases in helplessness-hopelessness are associated with increases in anxiety and depression (Akechi et al., 2001; Grabsch et al., 2006; Reuter et al., 2006; Schnoll et al., 1998; Watson et al., 1991), increases in psychological distress (Ferrero et al., 1994), decreases in quality of life (Cotton et al., 1999; Schnoll et al., 1998), decreases in well-being (Levine & Targ, 2002), and decreases in emotional health, social functioning, vitality, and mental health (Anagnostopoulos et al., 2006). In both the primary and secondary analysis, no communication variables were significantly associated with changes in patients' helplessness-hopelessness from pre- to post visit. It is interesting to note that, in both the primary and secondary analysis, while not significant, the variables associated with surgeon partnership building, patient assertive responses, and patient question asking were associated with increases in patients' helplessness-hopelessness over the course of visits (This was not the case for companion question asking, which was not

significantly associated with *decreases* in patients' *helplessness-hopelessness* over the course of visits).

Change in anxious preoccupation. Anxious preoccupation is characterized by persistent anxiety and a pessimistic attitude that lends to negatively evaluating medical information and physical symptoms (Greer, 1991). Among breast-cancer patients, increases in anxious preoccupation are associated with increases in anxiety and depression (Akechi et al., 2001; Grabsch et al., 2006; Reuter et al., 2006; Schnoll et al., 1998; Watson et al., 1991), increases in psychological distress (Ferrero et al., 1994), decreases in emotional health, social functioning, vitality, and mental health (Anagnostopoulos et al., 2006), and decreases in quality of life (Schnoll et al., 1998).

In both the primary and secondary analysis, no communication variables were significantly associated with changes in patients' anxious preoccupation from pre- to post-visit. However, the tertiary analysis found that, when adjusting for both communication and non-communication variables, such as patients' education, the variable patient assertive responses: states preference was significantly associated with decreases in patients' anxious preoccupation. Three potential explanations exist: (1) as the visit progresses, patients become less anxious, and as a result, feel compelled to participate and state preferences. A second, more plausible explanation is that the act of stating one's treatment preferences aids the patient in feeling more in control of her cancer, thus resulting in her becoming less anxious. The third explanation is the surgeon's response to the patients' stated preferences may enable the patient to feel less anxious, particularly if the response is autonomy-supportive (Ryan & Deci, 2000). Future research should examine surgeons' responses to patients' stated treatment preferences to

expand the understanding of how specific communication behaviors are associated with patients' reductions in anxiety.

There was at least one association that trended toward significance, which is notable given the main study's small sample size (see limitations, below). For example, both the primary analysis (p = .06) and tertiary analysis (p = .07) revealed that increases in companion question asking were associated with decreases in patients' anxious preoccupation (p = .06). This correlation can be interpreted in at least two ways: (1) The increase of patients' anxious preoccupation throughout visits 'causes' patients' companions to ask more questions; or (2) The asking of questions by patients' companions 'causes' reductions in patients' anxious preoccupation. There are at least two reasons to dismiss the first interpretation: (a) It relies on companions' tenuous ability to (at least directly) recognize and monitor changes in patients' anxious preoccupation, which is a psychological state; and (b) It runs counter to theory and research suggesting that information acquisition can serve as a mechanism for reducing anxiety (That is, as patients' levels of anxious preoccupation subside, we would expect less, not more, question asking). Alternatively, the second interpretation suggests the 'power' of communication, and the future possibility of intervening in companions' behaviors. For example, companions, rather than patients, could be trained in question asking or how to effectively participate in the treatment-decision-making visit.

Change in cognitive avoidance. Cognitive avoidance is characterized by a constant redirecting of thoughts to avoid thinking about cancer and a preference for a passive role in treatment decision-making (Shields et al., 2004; Watson et al., 1994). Despite some inconsistency, prior studies generally find that, among breast cancer

patients, increases in cognitive avoidance are associated with increases in depression (Reuter et al., 2006), increases in psychological distress (Ferrero et al., 1994), decreases in quality of life (Cotton et al., 1999), and decreases in spiritual well-being (Levine & Targ, 2002). In both the primary, secondary, and tertiary analysis, no communication variables were significantly associated with changes in patients' *cognitive avoidance* from pre- to post visit. One potential explanation for a lack of significant associations may be related with the nature of the variable *cognitive avoidance*. In hindsight, it appears problematic to ask patients about their degree of cognitively avoiding thoughts of cancer and treatment when patients are currently in surgeons' clinics, have already met with and had physical examinations with surgeons, and are preparing for treatment-decision-making conversations.

Change in fatalism. Fatalism is a maladaptive coping strategy characterized by patients' acknowledgement of the diagnosis, a 'resigned' attitude toward the illness, and a lack of desire to actively participate in information seeking or treatment decision-making (Cordova et al., 2003; Greer, 1991; Shields et al., 2004). Prior studies generally find that, among breast-cancer patients, increases in fatalism are associated with increases in negative outcomes, such as anxiety and depression (Akechi et al., 2001; Watson et al., 1991) and decreases in quality of life (Cotton et al., 1999).

In the primary analysis, no communication variables were significantly associated with changes in patients' *fatalism* from pre- to post visit. In the secondary and tertiary analyses, the variable *patient assertive responses: challenging surgeon* was significantly associated with *decreases* in patients' *fatalism*, and thus with a beneficial health outcome. This association has at least two interpretations: (1) The reduction of patients' *fatalism* 

throughout visits 'causes' patients to challenge more frequently; or (2) An increase in patients challenging surgeons 'causes' a reduction in patients' *fatalism*. Given that reductions in patients' *fatalism* are associated with increases in their reported levels of participation (Shields et al., 2004), and given that the variable *patient assertive* responses: challenging surgeon can be conceptualized as a form of participation (i.e., because it involved patients essentially arguing with the surgeon, for example challenging or disagreeing with a point of information), either of these two interpretations are viable. As such, because patients' challenges are potentially interactionally inflammatory, more research is necessary before recommending interventions designed to increase patients' challenges.

The tertiary analysis additionally revealed that increases in *patient question* asking: prompted (vs. self-initiated) was significantly associated with decreases in patients' fatalism. This association can be explained as follows. Patients who were most likely to experience decreases in fatalism were patients who began visits with high levels of fatalism. By definition, fatalism is coping style in which individual avoid active participation (Shields et al., 2004), and the sin qua non of active participation is asking questions of one's own initiative. Thus, fatalistic patients may have been much more likely to ask questions when solicited by the surgeon. Again, from a communication-intervention perspective, perhaps surgeons should be trained to solicit patients' questions. Patients' Satisfaction with Visit Communication

Among cancer patients, increases in patients' visit satisfaction is associated with increases in their quality of life three years post diagnosis (Kerr et al., 2003), decreases in patients' emotional distress three months post diagnosis (Butow et al., 1996), decreases in

patients' psychological morbidity three months post baseline (Shilling et al., 2003), and decreases in patients' anxiety three months post baseline (Steptoe et al., 1991). In the primary, secondary, and tertiary analysis, no communication variables were significantly associated with patients' post-visit satisfaction with visit communication. Note that patients' express a satisfaction bias, and this outcome variable traditionally experiences a high ceiling effect (Roberts, Cox, Reintgen, Baile, & Gilbertini, 1994; Sitza & Wood, 1997). Along these lines, in the main dissertation study, patients reported very high satisfaction (M = 8.80; range 1-9). Because of this, data were dichotomized into 'less than fully satisfied' (M < 9.0; 41%) and 'fully satisfied' (M = 9.0; 59%). This distinction may not have produced adequate and/or meaningful variance. Alternatively, communication-participation behaviors may not be the communication behaviors that are associated with *patients' satisfaction with visit communication*. Instead, satisfaction may be associated with the clarity and thorough nature of surgeons' information giving (Lally, 2009; Siminoff et al., 2000).

Patients' Satisfaction with Treatment Plans

Although prior research on patients' satisfaction with treatment plans is scant, a related variable, that of decision regret, is associated with negative health outcomes (Brehaut et al., 2003; Davison et al., 2007), such as decreased role and social functioning and increased pain (Davison et al., 2007). In accordance with prior findings in the context of cancer care regarding patient satisfaction (Ishikawa et al., 2002; Ong et al., 2000; Siminoff et al., 2000; Timmermans et al., 2007), the primary analysis revealed that increases in *patient question asking* are significantly associated with *decreases* in *patients' satisfaction with treatment plans*. This finding was refined in the secondary

analysis, which divided the variable *patient question asking* into two sub-variables, including patient question asking: self-initiated and patient question asking: prompted. The secondary analysis found that only patient question asking: self-initiated was significantly, negatively associated with patients' satisfaction with treatment plans. This association can be interpreted in at least two ways: (1) Patients' dissatisfaction with treatment plans (as they emerge and are negotiated throughout visits) 'cause' patients to ask questions; or (2) The asking of questions 'causes' patients to be more dissatisfied. Regarding the first interpretation, future research needs to examine the role of patients' pre-visit treatment expectations and whether they are met or violated during visits (e.g., often newly diagnosed breast cancer patients arrive to the visit with a preference for a particular surgical treatment, Lally, 2009). Regarding the second interpretation, it is likely that the explanatory mechanism lies not directly in patients' questions, per se, but rather indirectly in the quality of surgeons' responses and how they interface with patients' expectations. The findings of the primary and secondary analysis need to be qualified with those of the tertiary analysis, which found that, when adjusting for both communication and non-communication variables (e.g., patient age, treatment history, and perceived social support), the variable patient question asking: self-initiated was not significantly associated (p = .08) with patients' satisfaction with treatment plans; the association did, though, trend in the same direction.

Patients' Intentions to Adhere to Treatment Plans

Similar to patients' satisfaction with visit communication, the variable patients' intentions to adhere to treatment plans suffered from a ceiling effect (M = 4.67; Range = 1-5). As such, this variable was dichotomized into 'less than fully committed' (M < 5.0;

34%) and 'fully committed' (M = 5.0; 66%). Parallel to the above findings regarding patients' satisfaction with treatment plans, the primary analysis revealed that increases in patient question asking are significantly associated with decreases in patients' intentions to adhere to treatment plans. This finding was again refined in the secondary and tertiary analysis, which found that only patient question asking: self-initiated was significantly, negatively associated with patients' intentions to adhere to treatment plans. This association can be interpreted in at least two ways: (1) Patients' lack of intention to adhere to treatment plans (as they emerge and are negotiated throughout visits) 'cause' patients to ask questions; or (2) The asking of questions 'causes' patients to be more dissatisfied. Question asking is a means of soliciting information, and if responses to the questions do not fully address patients' motivation for asking, or if the information provided is contradictory to prior knowledge, patients are motivated to continue question asking. Thus, increased question asking could be the result of unsatisfactory surgeon information provision or responses to prior questions, creating dissonance in the patient and contributing to less treatment adherence.

Summary of communication and psychosocial health outcomes. In sum, three positive and trainable communication behaviors were found to be significantly associated with changes in adaptive coping styles and reduced illness uncertainty from pre- to post visit: (1) The variable patient assertive responses: stating preferences was associated with increased fighting spirit and decreased anxious preoccupation; (2) The variable surgeon partnership building: question solicitation was associated with decreased unpredictability uncertainty; (3) The variable patient question asking: prompted (i.e., questions resulting from surgeons' solicitation of questions) was associated with

decreased *fatalism*. Although a face-threatening behavior (and therefore not necessarily a candidate for patient training), the variable *patient assertive responses: challenging surgeon* was associated with decreased *fatalism*. *Patient question asking: self-initiated* had deleterious effects on two outcomes, and increases in *patient question asking: self-initiated* was associated with *less than complete satisfaction with the treatment plan* and *less than full commitment to adhering to the treatment plan*.

## Communication and Length of Visit

The findings discussed above suggest a range of possible beneficial health outcomes resulting from patients and their companions asking questions. Despite these possible benefits, prior research suggests that *question asking* extends the length of visits, either directly or indirectly through providers' responsive provision of information (Eggly et al., 2006; Ishikawa et al., 2002; Koedoot et al., 2004; Lerman et al., 1993). In line with prior research, the primary analysis revealed that both patient question asking and companion question asking are significantly associated with longer visits. The primary analysis was supplemented by the secondary analysis, which found that surgeon partnership building: question solicitation and patient question asking: self-initiated are significantly associated with longer visits. The tertiary analysis revealed that, when adjusting for both communication and non-communication variables (e.g., patient age, income, education, and marital status), patient question asking: self-initiated and companion question asking are significantly associated with longer visits. In sum, every avenue for patient-sided questions – whether it be surgeons asking for them, or patients or companions asking them – increased visit length.

## Theoretical Implications

The previously described findings should be considered in relation to the theories addressed in the review of literature (Chapter 2). Specifically, implications for uncertainty in illness theory (Mishel, 1988) and self-determination theory (Ryan & Deci, 2000) are discussed below.

Uncertainty in Illness Theory

Uncertainty in illness theory (Mishel, 1988) defines uncertainty in the health-context as "the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues" (p. 225). Two factors of illness uncertainty that were salient in this study are ambiguity uncertainty and unpredictability uncertainty. As discussed previously, *ambiguity uncertainty* concerns that with the general state of the illness and the general plan for treating the illness (Mishel, 1997). The communication-participation behaviors examined in the main dissertation were not significantly associated with *ambiguity-uncertainty change*. *Unpredictability uncertainty* concerns a lack of clarity between treatment and outcomes. The communication variable *surgeon partnership building: question solicitation* was significantly associated with a decrease in patients' *unpredictability uncertainty*.

This dissertation has implications for uncertainty in illness theory (Mishel, 1988) in at least two ways. The first implication considers the measure used to assess patients' illness uncertainty. As discussed in the Methods chapter, several of the original 23 items of the community version of the uncertainty in illness scale were deleted due to lack of relevance. Specifically, items discussing symptoms, illness progression, treatment

success, and communication with health-care providers were omitted. Among retained items, when relevant, the term "illness" was replaced with "cancer." The community version of the uncertainty in illness measure was designed to represent a single factor; however, with this study population, the factor analysis produced two factors. The resulting two factors resembled two of the four factors of uncertainty that Mishel designated for other versions of the measure (e.g., adult version). Future research may consider pursing the concept of separate dimensions of uncertainty in illness, particularly among cancer populations.

A second implication considers the role of the structure provider in uncertainty management. Uncertainty in illness theory (Mishel, 1988) explains methods of uncertainty reduction include patients' vigilance, direct action, and information seeking. However, the theory does not take into account the mechanisms by which information seeking and information giving can occur. For example, patient question asking can be either self-initiated or prompted. The theory appears to acknowledge self-initiated questions without recognizing health-care providers' role in the action of prompted questions. Surgeons' solicitation of questions can (but may not) prompt a patient or companion question which can also prompt a surgeon response, and consequently reduce patient uncertainty. Future research should further examine the role of the structure provider in uncertainty management.

## Self-Determination Theory

Self-determination theory (Ryan & Deci, 2000) argues that humans have three basic psychological needs: autonomy, relatedness, and competence. Particularly relevant to the main dissertation study was the motivation of autonomy, which is refers to the need

for individuals to direct their own behavior. As previously described in Chapter 2, the theory explains that these psychological needs can be affected by social elements such as interaction with health-care providers. Health-care providers can either engage in autonomy-supportive behaviors (e.g., encouraging patient participation) or autonomycontrolling behaviors (e.g., discouraging patient participation). Within the context of this dissertation, surgeon partnership building is exemplary of autonomy-supportive behaviors, and patient assertive responses, patient question asking (particularly selfinitiated questions), and patient expressions of concern are exemplary of patient autonomous behaviors. Prior research reports that autonomy-supportive behavior is associated with positive patient outcomes, particularly improved health behaviors (Williams & Deci, 1996a, 1996b; Williams et al., 1996) and improved adherence (Williams et al., 1998). Likewise, in the main dissertation study, surgeon partnership building, and specifically surgeon partnership building: question solicitation, was associated with reductions in patients' unpredictability uncertainty. This finding supports the claims of self-determination theory. Additionally, some patient autonomous behaviors, including patient assertive responses: stating preferences and patient assertive response: challenging surgeon, were also associated with improved outcomes, such as increases in patients' fighting spirit and reductions in patients' anxious preoccupation and *fatalism*; These findings provide further support for the theory.

However, one patient autonomous behavior in particular, *patient question asking:* self-initiated, was not associated with improved patient outcomes, as self-determination theory would predict. Rather, increased patient question asking: self-initiated was associated with lower levels of patients' satisfaction with treatment plans, and with less

than full (vs. full) intention to adhere to treatment plans. Before these findings can be integrated into the current self-determination theory, additional research is necessary to determine the causes of pateints' question asking. One possible cause is a lack of adequate response for prior questions (i.e., a surgeon-level autonomy-controlling behavior).

#### Limitations

The main dissertation study is limited in at least six ways. First, data were drawn from a single healthcare organization (the *Cancer Institute of New Jersey*) and do not necessarily generalize to other healthcare contexts, such as private surgical practices. As a *National Cancer Institute*-designated cancer center of excellence, patients frequently attend the *Cancer Institute of New Jersey* for second opinions; this was reflected in the fact that 65% of the study patients had already consulted with a different surgeon about their breast cancer, which likely affected their pre-visit levels of uncertainty and coping, as well as their post-visit ratings of satisfaction and intention to adhere, which would have been done with reference to previous surgeons and visits.

Second, the study included, and thus represented the practice of, a single surgeon. Like other types of physicians, individual surgeons have distinctive practice styles – for example, the participating surgeon performed brief physical examinations prior to treatment-decision-making conversations, whereas other surgeons do not – and have distinctive interactional styles, which likely shape those of their patients. Furthermore, the study only included 51 patients, which greatly limited statistical power.

Third, because two of the outcome variables, *patients' satisfaction with visit*communication and patients' intention to adhere to treatment plans, suffered from ceiling

effects, they had to be dichotomized, which reduced variability and potential to identify associations with other variables.

Fourth, this study was limited to an examination of psychosocial changes occurring immediately after visits, and did not track continuing changes longitudinally (cf., Fallowfield, Hall, Maguire, & Baum, 1990; Liu et al., 2006; McCaul et al., 1999; Vahdanian, Omidavri, & Montazeri, 2010).

Fifth, the findings of this study do not generalized beyond women (vs. men) with breast cancer, and do not generalize beyond breast cancer (vs. other types of cancer).

#### **Future Research**

One trajectory for future research stems directly from the aforementioned limitations. The main dissertation study should be replicated with a larger sample of practice sites, patients, and surgeons, which should be varied by physician sex (Street et al., 2005) and sub-specialty, such as general surgery vs. surgical oncology. This replication study should also alter and expand the scope of the research in at least four ways. First, the replication study should use slightly different measures of satisfaction that produce more variance. One possible measure is the Health-Care Climate Questionnaire (Williams, Ryan, & Deci, 1996); this scale assesses patients' perceptions of the providers' autonomy-supportive behavior. Second, the replication study needs to examine the role of the communication variable: *surgeon information giving* (Gordon et al., 2006; Ong et al., 1999; Takayama & Yamazaki, 2004; Timmermans et al., 2006). Prior research suggests that gaining information can reduce patients' uncertainty (Lerman et al., 1993; Shaw et al., 2001), and that uncertainty is associated with coping (Mishel et al., 1984; Wineman, Schwetz, Goodkin, & Rudick, 1996). Third, in order to enhance

potential future interventions of communication behavior, the replication study needs to examine the role of the positioning of communication behaviors, such as before, during, or after surgeons' 'stock educational' talks. Fourth, the replication study needs to examine data with structural equation modeling techniques (vs. mere regression techniques) in order to more rigorously explore the indirect and direct effect pathways from communication behavior to outcomes.

If similar results are found in the replication study as were found in the main dissertation study, then research should progress in at least two directions. First, future research needs to examine the relationship between provider-patient communication and women's psychosocial health over the course of the breast-cancer experience, for example from diagnosis to surgery to chemotherapy to survivorship. Second, future research needs to intervene in surgeons' and patients' communication behavior, and to test the efficacy of such an intervention with respect to improving patients' psychosocial health outcomes. Training providers would require a two-step process: (1) first, (as noted above) additional research is needed to determine how and when patient question asking creates deleterious effects. Perhaps it is the types of questions patients are forced to ask or perhaps it is the need to seek clarification. Following those results, providers can be trained on what additional information to provide patients prior to the patient-questionasking portion of the visit (Cegala, 1997). This could potentially reduce excessive patient questions. The challenge will be to encourage patients to participate and ask questions (as surgeon question facilitation has significantly positive effects, particularly reduced unpredictability uncertainty) while attempting to prevent excessive questions (which lead to decreases in patient satisfaction with the treatment plan and less than full commitment

to adhering the treatment plan). To improve the patients' experience, patients can be trained (e.g., Cegala, Marinelli, & Post, 2000) to state their treatment preferences to their providers.

Table 1

Communication Variables, their Relationship to Satisfaction-Like Health Outcomes, and their Relative Strength-of-Relationship

Communication Variable	Relationship to Satisfaction	Relative Strength of Relationship		
1. Patient-Centered	r = .14*	$a_1$		
Communication				
1a. Affective Behavior	r = .16*	$b_1, c_1$		
1b. Participation Behavior	Ns	$c_2$		
1b1. Physician	Ns			
Facilitation				
1b2. Patient	Ns			
Participation				
2. Instrumental Behavior	r = .076*	$a_2, b_2$		

Note: Similarly lettered relationships are significantly different from one another, with lower superscripted numbers indicating a stronger relationship; All significance levels are p < .05

Table 2

Breast cancer patient socio-demographic characteristics

Age $(n = 51)$ $M = 53.88, SD = 11.35$		
Education	<i>N</i> 51	%
High School or less	14	2
Two-year college degree	8	16
B.A. degree	19	37
Post-graduate degree	10	20
Less than B.A.	22	43
B.A. or more	29	57
Household Income	46	
\$30,000 or less	9	20
\$30-60,000	4	9
\$60-75,000	8	17
\$75-\$100,000	1	2
\$100-125,000	9	20
\$125-150,000	7	15
\$150-200,000	3	6
\$200,000 +	5	11
\$0-\$75,000	21	46
\$76,000-\$200,000+	25	54

Ethnicity	51	
White	41	80
African-American	4	8
Asian	4	8
Hispanic	2	4
White	41	80
Non-white	10	20
Marital Status	51	
Single and never married	4	8
Single & divorced/widowed	15	29
Married	32	63
Single	19	37
Married	32	63
Prior history with this surgeon	51	
Had prior history	9	18
No prior history	42	82
Prior history with any surgeon	51	
Had prior history	33	65
No prior history	18	35

# Companion Presence

No companions	12	24
At least one companion	39	76
1 companion	26	49
2 companions	11	22
3 companions	2	4

Table 3 (page 1 of 4)

Bivariate Zero Order Correlation Matrix of Communication Variables with all Variables

-								
	1.	2.	3.	4.	5.	6.	7.	8.
DOC_PB	28*	10	02	07	.09	08	.27	20
PB: QS	12	08	21	16	.10	07	.20	.01
PB:Other	28*	04	.30*	.15	02	03	.15	36**
PAR_AR	03	.06	.21	.19	.11	14	.04	.01
PAR: Pref	10	.01	.24	.16	.12	01	.09	17
PAR: Chal	.12	.13	08	.15	10	25	.07	.16
PAT_Q	25	.52***	.15	.01	.10	02	.08	.05
PQ: S-I	24	.52***	.16	.01	.11	02	.07	.05
PQ: PR	20	.07	07	.01	02	12	.10	.10
COM_ Q	13	.45**	.14	10	.22	.13	.19	07
Length	38**	.50*	.30*	.01	.26	01	.22	.01

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: DOC\_PB is surgeon partnership building, PB: QS is surgeon partnership building: question solicitation; PB: Other is surgeon partnership building: other; PAR\_AR is patient assertive responses; PAR: Pref is patient assertive responses: stating preferences; PAR: Chal is patient assertive responses: challenging surgeon; PAT\_Q is patient question asking; PQ: S-I is patient question asking: self-initiated; PQ:PR is patient question asking: prompted; COM\_Q is companion question asking; length is length of visit;

X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 3 (page 2 of 4)

Bivariate Zero Order Correlation Matrix of Communication Variables with all Variables

	9.	10.	11.	12.	13.	14.	15.	16.
DOC_PB	01	•	.83***	.36*	10	.09	19	03
PB: QS	.05	.83***		22	20	08	16	.04
PB:Other	09	.36**	22	•	.16	.29*	06	12
PAR_AR	38**	10	20	.16	•	.82**	.67***	.37**
PAR: Pref	31*	.09	08	.29*	.82***	•	.17	.19
PAR: Chal	28	19	16	06	.66***	.17	•	.41**
PAT_Q	15	03	.04	12	.37**	.19	.41**	•
PQ: S-I	15	06	01	10	.39**	.20	.42**	.99***
PQ: PR	.01	.35**	.51***	25	11	06	05	.24
COM_ Q	.16	.16	.25	15	27	30*	12	.45***
Length	06	.17	.20	04	.02	.17	.17	.71**

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: DOC\_PB is surgeon partnership building, PB: QS is surgeon partnership building: question solicitation; PB: Other is surgeon partnership building: other; PAR\_AR is patient assertive responses; PAR: Pref is patient assertive responses: stating preferences; PAR: Chal is patient assertive response: challenging surgeon; PAT\_Q is patient question asking; PQ: S-I is patient question asking: self-initiated; PQ:PR is patient question asking: prompted; COM\_Q is companion question asking; length is length of visit

X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 3 (page 3 of 4)
Bivariate Zero Order Correlation Matrix of Communication Variables with all Variables

	17.	18.	19.	20.	21.	22.	23.	24.	25.	
DOC_PB	06	.35*	.16	.17	06	.31*	06	05	.03	
PB: QS	01	.51***	.25	.20	01	.31*	.01	.06	.03	
PB:Other	10	25	15	04	08	.01	12	19	.01	
PAR_AR	.39**	11	27	.14	.04	01	28*	13	.27	
PAR: Pref	.20	06	30*	.02	10	04	42**	14	.25	
PAR: Chal	.42**	05	12	.17	.06	.08	.01	12	.18	
PAT_Q	.99***	.24	.45***	.71***	12	.06	22	12	.30*	
PQ: S-I	•	.15	.43***	.71***	11	.05	23	10	.31*	
PQ: PR	.15	•	.18	.21	10	.10	.11	12	03	
COM_ Q	.43***	.18	•	.67***	10	.06	.07	.07	.28*	
Length	.71**	.21	.67**		09	02	03	18	.20	

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: DOC\_PB is surgeon partnership building, PB: QS is surgeon partnership building: question solicitation; PB: Other is surgeon partnership building: other; PAR\_AR is patient assertive responses; PAR: Pref is patient assertive responses: stating preferences; PAR: Chal is patient assertive response: challenging surgeon; PAT\_Q is patient question asking; PQ: S-I is patient question asking: self-initiated; PQ:PR is patient question asking: prompted; COM\_Q is companion question asking; length is length of visit

X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 3 (page 4 of 4)

Bivariate Zero Order Correlation Matrix of Communication Variables with all Variables

	26.	27.	28.	29.	30.
DOC_PB	.10	.12	02	.19	.04
PB: QS	.20	.13	.02	.17	.03
PB:Other	15	01	06	.05	.02
PAR_AR	01	.06	31*	18	14
PAR: Pref	14	15	23	11	18
PAR: Chal	.22	.34*	28*	17	03
PAT_Q	.10	.11	25	34*	41**
PQ: S-I	.10	.08	25	34*	41**
PQ: PR	.09	.36*	.09	13	04
COM_ Q	.03	.11	.04	07	12
Length	.06	.17	.07	17	27

\*< .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: DOC\_PB is surgeon partnership building, PB: QS is surgeon partnership building: question solicitation; PB: Other is surgeon partnership building: other; PAR\_AR is patient assertive responses; PAR: Pref is patient assertive responses: stating preferences; PAR: Chal is patient assertive response: challenging surgeon; PAT\_Q is patient question asking; PQ: S-I is patient question asking: self-initiated; PQ:PR is patient question asking: prompted; COM\_Q is companion question asking; length is length of visit

X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 4 (page 1 of 4)

Bivariate Zero Order Correlation Matrix of Dependent Variables with all Variables

	1.	2.	3.	4.	5.	6.	7.	8.
AmbUnc	09	19	06	10	09	25	01	.21
UnpUnc	08	.01	07	02	14	05	.16	.18
FSpirit	.05	16	.01	05	.01	.20	.04	03
НН	.09	16	26	27*	.09	.15	13	03
AnxPre	09	.24	.07	.14	02	11	.10	09
Avoid	04	.17	01	18	08	30*	.01	.06
Fatal	.03	.10	.16	03	03	.03	.19	.07
Sat	.04	09	.03	11	07	.10	.03	.05
RxSat	.34*	08	14	.17	17	.11	.22	04
Adhere	.18	20	08	.07	03	09	.01	.09

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: AmbUnc is ambiguity uncertainty change; UnpUnc is unpredictability uncertainty change; FSpirit is fighting spirit change; HH is helplessness-hopelessness change; AnxPre is anxious preoccupation change; Avoid is cognitive avoidance change; Fatal is fatalism change; Sat is patients' satisfaction with surgeons' visit communication; RxSat is patient satisfaction with the treatment plan; Adhere is patient intention to adhere to the treatment plan X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessnesshopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 4 (page 2 of 4)

Bivariate Zero Order Correlation Matrix of Dependent Variables with all Variables

	9.	10.	11.	12.	13.	14.	15.	16.
AmbUnc	23	01	01	08	.04	10	.06	12
UnpUnc	.06	.31*	.31*	.01	01	04	.08	.06
FSpirit	.40**	06	.01	12	28*	42**	.01	22
НН	13	05	.06	19	13	14	12	12
AnxPre	.06	.03	.03	.01	.27	.25	.18	.30*
Avoid	18	.10	.20	15	01	14	.22	.10
Fatal	.02	.12	.13	01	.06	15	.34*	.11
Sat	.12	02	.02	06	31*	23	28*	25
RxSat	.32*	.19	.17	.05	18	11	17	34*
Adhere	.08	.04	.03	.02	14	18	03	41**

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: AmbUnc is ambiguity uncertainty change; UnpUnc is unpredictability uncertainty change; FSpirit is fighting spirit change; HH is helplessness-hopelessness change; AnxPre is anxious preoccupation change; Avoid is cognitive avoidance change; Fatal is fatalism change; Sat is patients' satisfaction with surgeons' visit communication; RxSat is patient satisfaction with the treatment plan; Adhere is patient intention to adhere to the treatment plan X AXIS: (1) age: (2) education: (3) income: (4) ethnicity: (5) marital status: (6) religiosity: (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessnesshopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 4 (page 3 of 4) Bivariate Zero Order Correlation Matrix of Dependent Variables with all Variables

	17.	18.	19.	20.	21.	22.	23.	24.
	17.	10.	19.	20.	21.	22.	23.	24.
AmbUnc	11	10	10	09	•	.07	20	.36**
UnpUnc	.05	.10	.06	02	.07	•	.02	11
FSpirit	23	.11	.07	03	20	.02	•	.02
НН	10	12	.07	18	.36**	11	.02	•
AnxPre	.31*	03	.28	.20	.19	.28*	17	13
Avoid	.10	.09	.03	.06	.04	.10	08	03
Fatal	.08	.36*	.11	.17	.07	.02	.24	01
Sat	25	.09	.04	.07	.18	09	.23	01
RxSat	34*	13	07	17	.03	.19	.12	10
Adhere	42**	04	12	27	.20	.07	.11	05

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: AmbUnc is ambiguity uncertainty change; UnpUnc is unpredictability uncertainty change; FSpirit is fighting spirit change; HH is helplessness-hopelessness change; AnxPre is anxious preoccupation change; Avoid is cognitive avoidance change; Fatal is fatalism change; Sat is patients' satisfaction with surgeons' visit communication; RxSat is patient satisfaction with the treatment plan; Adhere is patient intention to adhere to the treatment plan X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessnesshopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 4 (page 4 of 4)

Bivariate Zero Order Correlation Matrix of Dependent Variables with all Variables

	25.	26.	27.	28.	29.	30.
AmbUnc	.19	.04	.07	.18	.03	.20
UnpUnc	.28	.10	.02	09	.19	.07
FSpirit	16	08	.24	.23	.12	.11
НН	13	03	01	01	11	05
AnxPre	•	.13	.03	07	.17	.21
Avoid	.13	•	.06	.03	.15	.31*
Fatal	.03	.06	•	.15	12	.02
Sat	08	.03	.15	•	.38**	.25
RxSat	.17	.15	12	.38**	•	.60***
Adhere	.21	.31*	.02	.25	.60***	•

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

NOTE: Y AXIS: AmbUnc is ambiguity uncertainty change; UnpUnc is unpredictability uncertainty change; FSpirit is fighting spirit change; HH is helplessness-hopelessness change; AnxPre is anxious preoccupation change; Avoid is cognitive avoidance change; Fatal is fatalism change; Sat is patients' satisfaction with surgeons' visit communication; RxSat is patient satisfaction with the treatment plan; Adhere is patient intention to adhere to the treatment plan X AXIS: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 5 (page 1 of 4)

Bivariate Zero Order Correlation Matrix for Demographics with All Variables

	1.	2.	3.	4.	5.	6.	7.	8.
Age	•	08	35*	.17	19	.19	.02	.24
Education	08		.39**	03	.07	.03	.01	06
Income	35*	.39**	•	.21	.20	17	.21	43**
Ethnicity	.17	03	.21	•	18	19	.03	06
Marital	19	.07	.20	18	•	.23	04	06
Religiosity	.19	.03	12	19	.23	•	10	07
DocHistory	.02	.01	.21	.03	04	10	•	34*
RXHist	.24	06	43**	06	06	07	34*	•
Support	.14	05	.08	.19	.10	.11	.08	13

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

X-Axis: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious – preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 5 (page 2 of 4)

Bivariate Zero Order Correlation Matrix for Demographics with All Variables

9.	10.	11.	12.	13.	14.	15.	16.
.14	28*	12	28*	03	10	.12	25
05	10	08	04	.06	.01	.13	.52***
.08	02	21	.30*	.21	.24	08	.15
.19	07	16	.15	.19	.16	.15	.01
.10	.09	.10	02	.11	.12	10	.10
.11	08	07	03	14	01	25	02
.08	.27	.20	.15	.04	.09	.07	.08
13	20	.01	36**	.01	17	.16	.05
•	01	.05	10	38**	31*	28*	15
	.14 05 .08 .19 .10 .11 .08 13	.1428*0510 .0802 .1907 .10 .09 .1108 .08 .271320	.1428*12 051008 .080221 .190716 .10 .09 .10 .110807 .08 .27 .20 1320 .01	.14      28*      12      28*        05      10      08      04         .08      02      21       .30*         .19      07      16       .15         .10       .09       .10      02         .11      08      07      03         .08       .27       .20       .15        13      20       .01      36**	.14      28*      12      28*      03        05      10      08      04       .06         .08      02      21       .30*       .21         .19      07      16       .15       .19         .10       .09       .10      02       .11         .11      08      07      03      14         .08       .27       .20       .15       .04        13      20       .01      36**       .01	.14      28*      12      28*      03      10        05      10      08      04       .06       .01         .08      02      21       .30*       .21       .24         .19      07      16       .15       .19       .16         .10       .09       .10      02       .11       .12         .11      08      07      03      14      01         .08       .27       .20       .15       .04       .09        13      20       .01      36**       .01      17	.14      28*      12      28*      03      10       .12        05      10      08      04       .06       .01       .13         .08      02      21       .30*       .21       .24      08         .19      07      16       .15       .19       .16       .15         .10       .09       .10      02       .11       .12      10         .11      08      07      03      14      01      25         .08       .27       .20       .15       .04       .09       .07        13      20       .01      36**       .01      17       .16

<sup>\*&</sup>lt;.05, \*\* <.01, \*\*\* <.001, two-tailed

X-Axis: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 5 (page 3 of 4)
Bivariate Zero Order Correlation Matrix for Demographics with All Variables

	17.	18.	19.	20.	21.	22.	23.	24.
Age	24	20	13	38**	09	08	.05	.09
Education	.52**	* .07	.45***	.50**	19	.01	16	16
Income	.16	07	.14	.30*	06	07	.01	26
Ethnicity	.01	.01	10	.01	09	02	05	27
Marital	.11	02	.22	.26	09	14	.01	.09
Religiosity	02	01	.13	01	25	05	.20	.15
DocHistory	.07	.10	.19	.22	01	.16	.04	13
RXHist	.05	.10	07	.01	.21	.18	03	03
Support	15	.01	.16	06	23	.06	.40**	13

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

X-Axis: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious—preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 5 (page 4 of 4)

Bivariate Zero Order Correlation Matrix for Demographics with All Variables

-						
	25.	26.	27.	28.	29.	30.
Age	09	04	.03	.04	.34*	.19
Education	.24	.17	.10	09	08	20
Income	.07	01	.16	.03	14	08
Ethnicity	.14	18	03	11	.17	.07
Marital	02	08	03	07	17	03
Religiosity	11	30*	.03	.10	.11	09
DocHistory	.10	.01	.19	.03	.22	.01
RXHist	09	.06	.07	.05	04	.09
Support	.06	18	.02	.12	.32*	.08

<sup>\*&</sup>lt; .05, \*\* < .01, \*\*\* < .001, two-tailed

X-Axis: (1) age; (2) education; (3) income; (4) ethnicity; (5) marital status; (6) religiosity; (7) history with current surgeon; (8) history with any surgeon; (9) perceived social support; (10) surgeon partnership building; (11) surgeon partnership building: question solicitation; (12) surgeon partnership building: other; (13) patient assertive responses; (14) patient assertive responses: stating preferences; (15) patient assertive responses: challenging surgeon; (16) patient question asking; (17) patient question asking: self-initiated; (18) patient question asking: prompted; (19) companion question asking; (20) length of visit (21) ambiguity-uncertainty change; (22) unpredictability-uncertainty change; (23) fighting-spirit change; (24) helplessness-hopelessness change; (25) anxious –preoccupation change; (26) cognitive-avoidance change; (27) fatalism change; (28) patients' satisfaction with surgeons' visit communication; (29) patient satisfaction with the treatment plan; (30) patient intention to adhere to the treatment plan

Table 6

Item Loadings for retained Ambiguity Uncertainty

Item	Item Pre-visit Item Loadings		Post-visit Item Loadings
Ambi			
1.	I have a lot of questions without answers. (R)	.72	.67
2.	My treatment is too complex to figure out. (R)	.66	.77
3.	Because of the unpredictability of my cancer,	.67	.66
	I cannot plan for the future. (R)		
4.	It is not clear what is going to happen to me. (R	.) .75	.80
5.	I have not been given a specific diagnosis (R)	.80	.57
6.	The seriousness of my cancer has been determine	ned64	.43
7.	The explanations I've been given about my can	cer .75	.62
	seem hazy to me. (R)		
8.	The results of my tests are inconsistent. (R)	.80	.66

Table 7

Item Loadings for retained Unpredictability Uncertainty

tem Pre-visit Item Loadings		Post-visit Item Loadings		
Unpredictability Uncertainty (pre-visit $N =$ ; $M = 3.50$ , $SD = .88$ , range 1-6) (post-visit $N =$ ; $M = 3.20$ , $SD = .93$ , range 1-6)				
1. I can predict how long my cancer will last.	.86	.88		
2. I can generally predict the course of my cancer.	.86	.88		

Table 8

Item Loadings for retained Fighting Spirit

Item	Pre-visit Item Loadings	Post-visit Item Loadings		
Fighting Spirit (pre-visit $N =$ ; $M = 5.36$ , $SD = .85$ , range 1-6) (post-visit $N =$ ; $M = 5.62$ , $SD = .61$ , range 1-6)				
1. I am determined to beat this cancer.	.84	.82		
2. I am very optimistic.	.84	.82		

Table 9

Item Loadings for retained Helplessness-Hopelessness

Item	Pre-visit Item Loadings	Post-visit Item Loadings
Helplessness-Hopelessness (pre-visit $N =$ ; $M = 1.44$ (post-visit $N =$ ; $M = 1.2$		
1. I feel like giving up.	.63	.90
2. I feel completely at a loss about what to do	74	.81
3. I feel there is nothing I can do to help myse	elf77	.85
4. I feel like it's the end of the world.	.87	.73
5. I can't cope.	.84	.90

Table 10

Item Loadings for retained Anxious Preoccupation

Item I		Pre-visit Item Loadings	Post-visit Item Loadings		
Anxio	Anxious Preoccupation (pre-visit $N =$ ; $M = 3.14$ , $SD = 1.27$ , range 1-6) (post-visit $N =$ ; $M = 2.98$ , $SD = 1,29$ , range 1-6)				
1.	I am upset about having cancer.	.75	.81		
2.	I feel devastated about having cancer.	.85	.84		
3.	I suffer great anxiety about the cancer.	.64	.88		
4.	I am a little frightened.	.83	.84		
5.	I feel very angry about what has happened	.79	.79		
	to me.				
6.	I am apprehensive.	.77	.82		

Table 11

Item Loadings for retained Cognitive Avoidance

Item Pre-visit Item Loading		Post-visit Item Loadings				
Cognitive Avoidance (pre-visit $N = : M = 3.3, SD = 1.40$ , range 1-6) (post-visit $N = : M = 3.16, SD = 1.60$ , range 1-6)						
1. I make a positive effort not to think about	.80	.82				
my illness.						
2. Not thinking about me helps me cope.	.85	.93				
3. I deliberately push all thoughts of cancer	.76	.94				
out of my mind.						
4. I distract myself when thoughts about my	.89	.90				
illness come into my head.						

Table 12

Item Loadings for retained Fatalism

Item	Pre-visit Item Loadings	Post-visit Item Loadings
Fatalism (pre-visit $N = : M = 4.31$ , $SD = 1.30$ , rang (post-visit $N = : M = 4.22$ , $SD = 1.26$ , range	·	
1. I've had a good life; what's left is bonus.	.72	.65
2. I've put myself in the hands of God.	.80	.80
3. I count my blessings.	.71	.78

Table 13

Item Loadings for retained Patients' Satisfaction with Surgeons' Visit Communication

Item	Item Loadings
Patient Satisfaction ( $N =$ ; $M = 8.80$ , $SD = .45$ , range 1-9)	
1. How courteous and respectful was the doctor?	.70
2. How well did the doctor understand your problem?	.75
3. How well did the doctor explain to you what he or she	.87
was doing and why?	
4. Did the doctor use words that were easy for you to understand?	.72
5. How well did the doctor listen to your concerns and questions?	.75
6. Did the doctor spend enough time with you?	.83
7. How much confidence do you have in the doctor's ability	.75
or competence?	
8. Overall, how satisfied are you with the service that you received	.77
from the doctor?	

Table 14

Item Loadings for retained Patient Satisfaction with the Treatment Plan

Item		Item Loadings
Patien	t Satisfaction with Treatment Plan ( $N = 300$ ; $M = 4.24$ , $SD = 0.67$ , range	1-5)
1.	The treatment plan is sound.	.72
2.	I understand the treatment plan.	.74
3.	It would be useful to consult with another doctor about the	.74
	treatment plan. (R)	
4.	I am comfortable with the treatment plan.	.63
5.	The treatment plan is the right one for my situation.	.93
6.	I am satisfied with the treatment plan.	.92
(D) :		

Table 15

Item Loadings for retained Patient Intention to Adhere to the Treatment Plan

Item	Item Loadings
Intention to Adhere ( $N =$ ; $M = 4.67$ , $SD = .59$ , range 1-5)	
1. I am committed to following the treatment plan.	.91
2. I intend to follow the treatment plan.	.95
3. How likely are you to follow the treatment plan?	.91

Table 16

Item Loadings for retained Perceived Social Support

Item	Item Loadings		
Social Support ( $N = 3.8$ , $SD = 3.8$ , range 1-4)			
1. Whenever I am sad, there are people who cheer me up.	.72		
2. There is always someone there for me when I need comforting.	.83		
3. I know some people upon whom I can always rely.	.61		
4. When I am worried, there is someone who helps me.	.78		
5. There are people who offer me help when I need it.	.88		
6. When everything becomes too much for me to handle, others are	.88		
there to help me.			

Table 17
Summary of Linear Regression for Ambiguity-Uncertainty Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	06	.30			.88
Surgeon Partnership Building			05	34	.73
Patient Assertive Responses			.09	.51	.61
Patient Question Asking			24	79	.44
Companion Question Asking			.09	.01	1.0

Table 18
Summary of Linear Regression for Ambiguity-Uncertainty Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	07	.38			.86
Surgeon Partnership Building: Question Solicitation			02	12	.90
Surgeon Partnership Building: Other			08	49	.63
Patient Assertive Responses: Stating Preferences			02	09	.93
Patient Assertive Responses: Challenging Surgeon			.16	.97	.34
Patient Question Asking: Self-Initiated			18	-1.12	.27

Table 19
Summary of Linear Regression for Ambiguity-Uncertainty Change, Tertiary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.01	1.23			.31
Religiosity			14	95	.35
History with Surgeon			. 19	1.34	.19
Perceived Social Support			08	57	.57

Table 20
Summary of Linear Regression for Unpredictability-Uncertainty Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.03	1.32			.28
Surgeon Partnership Building			.31	2.22	.03
Patient Assertive Responses			03	40	.69
Patient Question Asking			.10	.65	.52
Companion Question Asking			05	35	.73

Table 21
Summary of Linear Regression for Unpredictability-Uncertainty Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.03	1.35			.26
Surgeon Partnership Building: Question Solicitation			.36	2.48	.02
Surgeon Partnership Building: Other			.13	.83	.41
Patient Assertive Responses: Stating Preferences			07	48	.63
Patient Assertive Responses: Challenging Surgeon			.15	.98	.33
Patient Question Asking: Self-Initiated			.02	.10	.92

Table 22
Summary of Linear Regression for Unpredictability-Uncertainty Change, Tertiary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.08	5.32			.03
Surgeon Partnership Building: Question Solicitation			.31	2.31	.03

Table 23
Summary of Linear Regression for Fighting-Spirit Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.03	1.38			.26
Surgeon Partnership Building			10	68	.50
Patient Assertive Responses			17	97	.34
Patient Question Asking			22	-1.10	.28
Companion Question Asking			.14	.76	.45

Table 24
Summary of Linear Regression for Fighting-Spirit Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.13	2.46			.05
Surgeon Partnership Building: Question Solicitation			.01	.01	.99
Surgeon Partnership Building: Other			02	11	.91
Patient Assertive Responses: Stating Preferences			40	-2.72	.01
Patient Assertive Responses: Challenging Surgeon			.17	1.12	.27
Patient Question Asking: Self-Initiated			22	-1.46	.15

Table 25
Summary of Linear Regression for Fighting-Spirit Change, Tertiary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.23	4.59			.01
Religiosity			.15	1.19	.24
Perceived Social Support			.29	2.10	.04
Patient Assertive Responses: Stating Preferences			29	-2.09	.04
Patient Question Asking: Self-Initiated			13	-1.00	.33

Table 26
Summary of Linear Regression for Helplessness-Hopelessness Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	04	.49			.74
Surgeon Partnership Building			08	55	.58
Patient Assertive Responses			04	42	.67
Patient Question Asking			17	71	.48
Companion Question Asking			.15	.68	.50

Table 27
Summary of Linear Regression for Helplessness-Hopelessness Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	04	.58			.71
Surgeon Partnership Building: Question Solicitation			01	03	.98
Surgeon Partnership Building: Other			19	-1.18	.24
Patient Assertive Responses: Stating Preferences			06	35	.73
Patient Assertive Responses: Challenging Surgeon			10	59	.56
Patient Question Asking: Self-Initiated			07	42	.68

Table 28
Summary of Linear Regression for Helplessness-Hopelessness Change, Tertiary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.07	2.63			.08
Income			22	-1.47	.15
Ethnicity			21	-1.41	.17

Table 29
Summary of Linear Regression for Anxious-Preoccupation Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.10	2.38			.06
Surgeon Partnership Building			.01	01	.99
Patient Assertive Responses			.38	1.83	.07
Patient Question Asking			02	.12	.90
Companion Question Asking			.38	1.90	.06

Table 30
Summary of Linear Regression for Anxious-Preoccupation Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.04	1.36			.26
Surgeon Partnership Building: Question Solicitation			.05	.37	.72
Surgeon Partnership Building: Other			.01	.01	.99
Patient Assertive Responses: Stating Preferences			.19	1.28	.21
Patient Assertive Responses: Challenging Surgeon			.06	.37	.72
Patient Question Asking: Self-Initiated			.24	1.53	.13

Table 31
Summary of Linear Regression for Anxious-Preoccupation Change, Tertiary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.13	2.86			.03
Education			.06	.36	.72
Patient Assertive Responses: Stating Preferences			.32	2.15	.04
Patient Question Asking: Self-Initiated			.07	.43	.68
Companion Question Asking			.31	1.85	.07

Table 32
Summary of Linear Regression for Cognitive-Avoidance Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	05	.46			.76
Surgeon Partnership Building			.12	.80	.43
Patient Assertive Responses			09	82	.42
Patient Question Asking			.19	1.14	.26
Companion Question Asking			10	68	.50

Table 33
Summary of Linear Regression for Cognitive-Avoidance Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.04	1.40			.24
Surgeon Partnership Building: Question Solicitation			.22	1.52	.14
Surgeon Partnership Building: Other			04	25	.81
Patient Assertive Responses: Stating Preferences			16	-1.06	.30
Patient Assertive Responses: Challenging Surgeon			.28	1.77	.08
Patient Question Asking: Self-Initiated			.01	.07	.94

Table 34
Summary of Linear Regression for Cognitive-Avoidance Change, Tertiary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.10	2.85			.05
Religiosity			23	-1.64	.11
Surgeon Partnership Building: Question Solicitation			.22	1.57	.12
Patient Assertive Responses: Challenging Surgeon			.21	1.44	.16

Table 35
Summary of Linear Regression for Fatalism Change, Primary

Variable	Adj. $R^2$	F	В	t	p
Step 1	06	.32			.86
Surgeon Partnership Building			.11	.71	.48
Patient Assertive Responses			.07	.15	.88
Patient Question Asking			.05	.35	.73
Companion Question Asking			.09	.32	.75

Table 36
Summary of Linear Regression for Fatalism Change, Secondary

Variable	Adj. $R^2$	F	В	t	p
Step 1	.10	2.10			.08
Surgeon Partnership Building: Question Solicitation			.19	1.30	.20
Surgeon Partnership Building: Other			.12	.81	.43
Patient Assertive Responses: Stating Preferences			23	-1.57	.12
Patient Assertive Responses: Challenging Surgeon			.43	2.77	.01
Patient Question Asking: Self-Initiated			05	32	.75

Table 37
Summary of Linear Regression for Fatalism Change, Tertiary

Variable	Adj. R <sup>2</sup>	F	В	t	p
Step 1	.23	8.08			.01
Patient Assertive Responses: Challenging surgeon			.37	2.87	.01
Patient Question Asking: Prompted			.39	3.03	.01

Table 38

Summary of Logistic Regression of Patients' Satisfaction with Surgeons' Visit

Communication, Primary

Variable	$R^2$	β	Wald $\chi^2$	p	Odds Ratio
Step 1	.16		6.52	.16	
Surgeon Partnership Building		10	.10	.78	.92
Patient Assertive Responses		24	1.72	.19	.79
Patient Question Asking		06	1.11	.29	.95
Companion Question Asking		.04	.25	.62	1.03

Table 39
Summary of Logistic Regression of Patients' Satisfaction with Surgeons' Visit
Communication, Secondary

Variable	$R^2$	β	Wald $\chi^2$	p	Odds Ratio
Step 1	.17		7.03	.22	
Surgeon Partnership Building: Question Solicitation		07	.05	.83	.94
Surgeon Partnership Building: Other		16	.10	.76	.85
Patient Assertive Responses: Stating Preferences		24	1.14	.29	.79
Patient Assertive Responses: Challenging Surgeon		49	1.83	.18	.62
Patient Question Asking: Self-Initiated		04	.94	.33	.96

Table 40

Summary of Logistic Regression of Patients' Satisfaction with Surgeons' Visit

Communication, Tertiary

Variable	$R^2$	β	Wald $\chi^2$	p	Odds Ratio
Step 1	.17		6.19	.08	
Patient Assertive Responses: Stating Preferences		26	1.48	.22	.77
Patient Assertive Responses: Challenging Surgeon		47	1.74	.19	.62
Patient Question Asking: Self-Initiated		04	.92	.34	.96

Table 41

Summary of Linear Regression for Patients' Satisfaction with Treatment Plans, Primary

Variable	Adj. $R^2$	F	β	t	p
Step 1	.09	2.15			.09
Surgeon Partnership Building			.18	1.33	.18
Patient Assertive Responses			02	.06	.80
Patient Question Asking			39	-2.08	.04
Companion Question Asking			.07	.46	.65

Table 42

Summary of Linear Regression for Patients' Satisfaction with Treatment Plans,

Secondary

Variable	Adj. $R^2$	F	β	t	p
Step 1	.06	1.61			.001
Surgeon Partnership Building: Question Solicitation			.20	1.40	.17
Surgeon Partnership Building: Other			.07	.46	.65
Patient Assertive Responses: Stating Preferences			06	38	.71
Patient Assertive Responses: Challenging Surgeon			.02	.12	.91
Patient Question Asking: Self-Initiated			34	-2.15	.04

Table 43

Summary of Linear Regression for Patients' Satisfaction with Treatment Plans, Tertiary

Variable	Adj. $R^2$	F	β	t	p
Step 1	.18	3.70			.01
Age			.27	1.92	.06
Treatment History			047	30	.77
Perceived Social Support			.24	1.82	.08
Patient Question Asking: Self-Initiated			24	-1.78	.08

Table 44
Summary of Logistic Regression of Patients' Intention to Adhere, Primary

Variable	$R^2$	β	Wald $\chi^2$	p	Odds Ratio
Step 1	.23		9.11	.05	
Surgeon Partnership Building		.04	.03	.89	1.05
Patient Assertive Responses		.07	.03	.87	1.03
Patient Question Asking		14	5.19	.02	.87
Companion Question Asking		.05	.36	.55	1.04

Table 45
Summary of Logistic Regression of Patients' Intention to Adhere, Secondary

Variable	$R^2$	β	Wald $\chi^2$	p	Odds Ratio
Step 1	.28		11.33	.05	
Surgeon Partnership Building: Question Solicitation		.15	.22	.64	1.67
Surgeon Partnership Building: Other		.13	.06	.82	1.14
Patient Assertive Responses: Stating Preferences		22	.90	.34	.80
Patient Assertive Responses: Challenging Surgeon		.44	1.54	.21	1.55
Patient Question Asking: Self-Initiated		14	7.91	.01	.87

Table 46
Summary of Logistic Regression of Patients' Intention to Adhere, Tertiary

Variable	$R^2$	β	Wald $\chi^2$	p	Odds Ratio
Step 1	.22		8.94	.01	
Education		.13	.03	.87	1.14
Patient Question Asking: Self-Initiated		12	5.81	.02	.88

Table 47
Summary of Linear Regression for Length of Visit, Primary

Variable	Adj. $R^2$	F	β	t	p
Step 1	.65	24.65			.001
Surgeon Partnership Building			.12	1.44	.16
Patient Assertive Responses			.10	.99	.33
Patient Question Asking			.64	4.10	.001
Companion Question Asking			.85	4.21	.001

Table 48
Summary of Linear Regression for Length of Visit, Secondary

Variable	Adj. $R^2$	F	β	t	p
Step 1	.53	12.43			.001
Surgeon Partnership Building: Question Solicitation			.21	2.03	.05
Surgeon Partnership Building: Other			.13	1.20	.24
Patient Assertive Responses: Stating Preferences			15	-1.41	.17
Patient Assertive Responses: Challenging Surgeon			10	91	.37
Patient Question Asking: Self-Initiated			.79	7.29	.001

Table 49
Summary of Linear Regression for Length of Visit, Tertiary

Variable	Adj. $R^2$	F	β	t	p
Step 1	.67	13.925			.01
Age			315	-1.44	.16
Income			.02	.17	.87
Education			.11	1.06	.30
Marital Status			.07	.81	.42
Patient Question Asking: Self-Initiated			.41	3.20	.01
Patient Question Asking: Prompted			.06	.65	.52
Companion Question Asking			.39	3.59	.01

#### Appendix A

Patient Pre-Visit Survey

# **Doctor-Patient Study**

All of your answers are confidential

Please read instructions carefully

1. What is your birth date?	Month	Day	Year
2. Approximately how long l diagnosed with breast car		•	v
Less than a week			
Less than a month (How m	nany weeks:	)	
More than a month (How r	many months:_	)	
3. What is your <u>highest</u> level answer)	of <u>complete</u>	ed education?	? (mark <u>one</u>
High school or less			
2 years of college (e.g. Ass	sociate's degree	e)	
4 years of college (e.g. B.A	A. or B.S degree	e)	
Advanced degree (e.g. M.A	A or Ph.D. degr	ee)	
4. What is your total <u>househ</u> with your legal spouse/pa		•	
\$30,000 or less	\$100	0,000 to \$125,00	00
\$30,000 to \$60,000	\$125	5,000 to \$150,00	00
\$60,000 to \$75,000	\$150	0,000 to \$200,00	00
\$75,000 to 100,000	\$200	),000 or more	

5. What is your primar	ry ethnicity? (mark <u>one</u> answer)
White	Black
Hispanic	American Indian/Alaskan Native
Other (Please list:	)
6. What is your marita	l status? (mark <u>one</u> answer)
Single and never	r married
Single and divor	ced/widowed
Legally married	or legal domestic partnership
7. Prior to your cancer services?	r diagnosis, how often did you attend religious
Never	2-3 times a month
less than once a year	nearly every week
about one or twice a	yearevery week
several times a year	several times a week
about once a month	

Strongly

applies to me

**<u>DIRECTIONS</u>**: Please understand all of the following statements in terms of having cancer. Read each statement carefully and then <u>circle</u> the appropriate number to indicate how you feel <u>right now</u>, that is, <u>at this moment</u>. There are no right or wrong answers. Do not spend too much time on any one statement. Please answer all of the questions.

On a scale of 1-6, please rate the following statements about having cancer:

#### 1. I feel like giving up.

apply to me

	1 1001 11110 8111	mg «p·				
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
2.	I am upset ab	out havin	g cancer.			
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
3.	I am detern	nined to be	eat this cand	er.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
4.	I make a po	sitive effo	rt not to thi	nk about m	y cancer.	
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
5.	I've had a g	good life; w	vhat's left is	bonus.		
	1 Does NOT	2	3	4	5	6 Very

6.	I feel that life	e is hopele	SS.			
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
7.	I feel devasta	ted about	having cand	er.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
8.	I see my canc	er as a ch	allenge.			
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
9.	Not thinking	about the	cancer help	s me cope.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
10	. I've put my	self in the	hands of Go	od.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
11	. I feel like it	's the end	of the world	l <b>.</b>		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

12. I feel very a	angry abou	ıt what has	happened to	me.	
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
13. I feel comp	letely at a	loss about v	vhat to do.		
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
14. I suffer gre	at anxiety	about the c	ancer.		
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
15. I try to figh	t the canc	er.			
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
16. I deliberate	ely push al	l thoughts o	f cancer out	of my mir	nd.
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
17. Since my ca I'm making			realize how	precious 1	life is and
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

18. I am not vo	ery hopefu	l about the f	uture.		
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
19. I am appre	ehensive.				
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
20. I can't han	ıdle it.				
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
21. I am a little	e frightene	d.			
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
22. I am very o	optimistic.				
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
23. I distract n	nyself when	n thoughts a	bout my ca	ncer come	into my
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

24. I count n	iy biessings.				
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
25. I feel the	re is nothing l	can do to	help myself	•	
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
26. I worry a	bout the cand	er returni	ng or getting	g worse.	
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
27. At the mo	oment I take o	one day at	a time.		
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
28. I can't c	ope.				
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
29. I have di	fficulty in beli	eving that	this happen	ed to me.	
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

Strongly

Disagree

Disagree

**DIRECTIONS**: The following questions are about your cancer. If you agree with a statement, then you would circle either "Strongly agree" or "Agree." If you disagree with a statement, then circle either "Strongly Disagree" or "Disagree." If you are undecided about how you feel, then circle "Undecided."

On a scale of 1-5, please rate the following statements:

#### 1. I don't know what is wrong with me.

Agree

Strongly

Agree

1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree		
2. I have a lo	2. I have a lot of questions without answers.					
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree		
3. It is unclea	ar how bad m	y pain will be.				
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree		
4. The purpo	4. The purpose of treatment is clear to me.					
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree		
5. I can predict how long my cancer will last.						
1	2	3	4	5		

Undecided

<b>6.</b>	My treatment is too	complex to figure out.

1	2	3	4	5
Strongly	Agree	Undecided	Disagree	Strongly
Agree				Disagree

## 7. Because of the unpredictability of my cancer, I cannot plan for the future.

1	2	3	4	5
Strongly	Agree	Undecided	Disagree	Strongly
Agree				Disagree

#### 8. It is not clear what is going to happen to me.

1	2	3	4	5
Strongly	Agree	Undecided	Disagree	Strongly
Agree				Disagree

### 9. I can generally predict the course of my cancer.

1	2	3	4	5
Strongly	Agree	Undecided	Disagree	Strongly
Agree				Disagree

### 10. I have not been given a specific diagnosis.

1	2	3	4	5
Strongly	Agree	Undecided	Disagree	Strongly
Agree				Disagree

#### 11. The seriousness of my cancer has been determined.

1	2	3	4	5
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

12. The explanations I've been given about my cancer seem hazy to me.				
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
13. The purp	ose of the trea	atment is clear to	me.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
14. I have been given many differing opinions about what is wrong with				
me.				
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
15. I usually l	know if I am	going to have a g	ood or bad day	y <b>.</b>
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
16. The results of my tests are inconsistent.				
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
17. The effectiveness of the treatment is undetermined.				
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree

18. I'm certain they will not find anything else wrong with me.

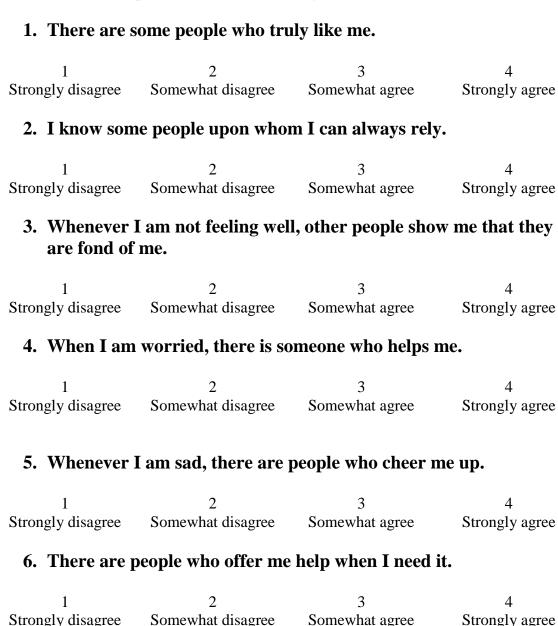
1 2 3 4 5
Strongly Agree Undecided Disagree Strongly
Agree Disagree

19. The treatment I will receive has a known probability of success.

1 2 3 4 5
Strongly Agree Undecided Disagree Strongly
Agree Disagree

**DIRECTIONS**: The following questions are about how you feel. If you agree with a statement, then you would circle either "Strongly agree" or "Agree." If you disagree with a statement, then circle either "Strongly Disagree" or "Disagree."

On a scale of 1-4, please rate the following statements:



7. There is alv	ways someone there	for me when I nee	d comforting.	
1	2	3	4	
Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	
8. When every there to hel	ything becomes too p me.	much for me to ha	ndle, others are	
1	2	3	4	
Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	
9. When I am	down, I need some	one who boosts my	spirits.	
1	2	3	4	
Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	
10. Before mal second opin	king any important nion.	decisions, I absolu	tely need a	
1	2	3	4	
Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	
11. It is impor	tant for me always t	to have someone w	ho listens to me.	
1	2	3	4	
Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	
12. I get along best without any outside help.				
1	2	3	4	
Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	

1	please rate the follow				
1. I feel tense	or "wound up."				
0 Not at all	1 From time to time, occasionally	2 A lot of the time	3 Most of the time		
2. I still enjoy the things I used to enjoy.					
0 Definitely as much	1 Not quite so much	2 Only a little	3 Hardly at all		
3. I get a sort of frightened feeling as if something awful is about to happen.					
0 Not at all	1 A little, but it doesn't worry me	2 Yes, but not too badly	3 Very definitely and quite badly		
4. I can laugh and see the funny side of things.					
0 As much as I always could	1 Not quite so much now	2 Definitely not so much now	3 Not at all		
5. Worrying thoughts go through my mind.					
0 Only occasionally	From time to time, but not too often	2 A lot of the time	3 A great deal of the time		
6. I feel cheerf	ul.				
0 Most of the time	1 Sometimes	2 Not often	3 Not at all		
7. I can sit at e	ease and feel relaxed	d.			
0 Definitely	1 Usually	2 Not often	3 Not at all		

**DIRECTIONS**: The following questions are about how you feel. Circle the

response that best represents how you feel.

0 Not at all	1 Sometimes	2 Very often	3 Nearly all the time		
9. I get a sort of frightened feeling like "butterflies" in the stomach.					
0 Not at all	1 Occasionally	2 Quite often	3 Very often		
10. I have lost interest in my appearance.					
0 I take just as much care as ever	I may not take quite as much care	I don't take as much care as I should	3 Definitely		
11. I feel restless as I have to be on the move.					
0 Not at all	1 Not very much	2 Quite a lot	3 Very much indeed		
12. I look forward with enjoyment to things.					
0 As much as I ever did	1 Rather less than I used to	2 Definitely less than I used to	3 Hardly at all		
13. I get sudden feelings of panic.					
0 Not at all	1 Not very often	2 Quite often	3 Very often indeed		
14. I can enjoy a good book or radio or TV program.					
0 Often	1 Sometimes	2 Not often	3 Very seldom		

8. I feel as if I am slowed down.

You have completed this survey! Thank you! Please give it to the research assistant, and you will see the doctor shortly. Appendix B

Patient Post-Visit Survey

# **Doctor-Patient Study**

All of your answers are confidential Please read instructions carefully **<u>DIRECTIONS</u>**: Please complete the following.

1. Is this the first time that you have had an appointment with this particular doctor?
Yes
No (I have had an appointment with this doctor in the past)
2. Is this the first time that you have had an appointment with this particular doctor?
Yes
No (I have had an appointment with this doctor in the past)
3. Is this the first breast surgeon you have spoken to about your treatment decision?
Yes
No (I <u>have</u> talked with a different breast surgeon about my treatment plan)
4. Please list all of the other people (such as a spouse, friend, sibling parent, relative, other) who were with you in the room with the doctor:
Person 1:
Person 2:
Person 3:
Person 4:
Person 5:

<b><u>DIRECTIONS</u></b> : Please read each statement carefully, and then <u>circle</u> the
appropriate choice below the statement to indicate how you feel about <u>how</u>
the doctor treated you today. There are no right or wrong answers.

1. How co	urteou	s and r	espect	ful was the d	octor?	•		
1 Not at all courteous	2	3	4	5 Moderately courteous	6	7	8	9 Very courteous
2. How we	ell did 1	the doc	ctor un	derstand you	ır pro	blem?		
1 Did not understand at all	2	3	4	5 Moderately understood	6	7	8	9 Understood very well
3. How we why?	ell did 1	the doc	ctor ex	plain to you v	what h	e or sh	e was d	loing and
1 Did not explain at all	2	3	4	5 Moderately explained	6	7	8	9 Explained very well
4. Did the	doctor	use w	ords th	nat were easy	for yo	ou to ur	ndersta	nd?
1 Used very <u>hard</u> words	2	3	4	5 Used moderate words	6	7	8	9 Used very <u>easy</u> words
5. How we	ell did	the doc	ctor lis	ten to your co	oncerr	s and q	questio	ns?
1 Did not listen at all	2	3	4	5 Moderately listened	6	7	8	9 Listened very well

6. Did the	doctor	spend	enoug	h time with	you?			
Spent very little time	2	3	4	5 Spent moderate about of time	6	7	8	9 Spent as much time as required
	7. How much confidence do you have in the doctor's ability or competence?							
1 No confidence	2	3	4	5 Moderate confidence	6	7	8	9 Total confidence
	8. Overall, how satisfied are you with the service that you received from the doctor?							
1 Completely dissatisfied	2	3	4	5 Moderately satisfied	6	7	8	9 Completely satisfied

**<u>DIRECTIONS</u>**: Please understand all of the following statements in terms of having cancer. Read each statement carefully and then <u>circle</u> the appropriate number to indicate how you feel <u>right now</u>, that is, <u>at this moment</u>. There are no right or wrong answers. Do not spend too much time on any one statement. Please answer all of the questions.

On a scale of 1-6, please rate the following statements about having cancer:

## 1. I feel like giving up.

1.	I feel like givi	ıng up.				
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
2.	I am upset ab	out having	g cancer.			
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
3.	I am detern	nined to b	eat this cand	er.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
4.	I make a po	sitive effo	rt not to thi	nk about my	y cancer.	
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

## 5. I've had a good life; what's left is bonus.

1	2	3	4	5	6
Does NOT					Very
apply to me					Strongly
					applies to me

0.	i ieei that iiie	e is nopeie	SS.			
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
7.	I feel devasta	ted about	having cand	er.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
8.	I see my cano	er as a ch	allenge.			
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
9.	Not thinking	about the	cancer help	s me cope.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
10	. I've put my	self in the	hands of Go	od.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
11	. I feel like it	's the end	of the world	l.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

12. I feel very a	angry abou	it what has	happened to	o me.	
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
13. I feel comp	letely at a	loss about v	what to do.		
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
14. I suffer gre	at anxiety	about the c	ancer.		
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
15. I try to figh	t the canc	er.			
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
16. I deliberate	ely push al	l thoughts o	f cancer out	of my mi	nd.
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
17. Since my ca I'm making	_		realize how	precious	life is and
Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

18. I am not ve	ery hopefu	l about the f	future.		
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
19. I am appre	hensive.				
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
20. I can't han	dle it.				
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
21. I am a little	e frightene	d.			
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
22. I am very o	ptimistic.				
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
23. I distract m head.	nyself whe	n thoughts a	bout my ca	ncer come	into my
1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

24	. I count my bl	lessings.				
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
25	. I feel there is	nothing I ca	an do to helj	myself.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
26	. I worry abou	t the cancer	returning o	r getting wo	orse.	
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
27	. At the mome	nt I take one	day at a tir	ne.		
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
28	. I can't cope.					
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me
29	. I have difficu	lty in believ	ing that this	happened t	o me.	
	1 Does NOT apply to me	2	3	4	5	6 Very Strongly applies to me

Disagree

**DIRECTIONS**: The following questions are about your cancer. If you agree with a statement, then you would circle either "Strongly agree" or "Agree." If you disagree with a statement, then circle either "Strongly Disagree" or "Disagree." If you are undecided about how you feel, then circle "Undecided."

### 1. I don't know what is wrong with me.

Agree

1	2	3	4	5
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
2. I have a lo	t of questions	without answers	•	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
3. It is unclea	ar how bad m	y pain will be.		
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
4. The purpo	se of treatme	nt is clear to me.		
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
5. I can pred	ict how long r	ny illness will las	t <b>.</b>	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
6. My treatm	ent is too con	ıplex to figure ou	t.	
1 Strongly	2 Agree	3 Undecided	4 Disagree	5 Strongly

7. Because of future.	the unpredic	tability of my illi	ness, I cannot p	olan for the
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
8. It is not cle	ear what is go	ing to happen to	me.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
9. I can gene	erally predict	the course of my	y illness.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
10. I have no	t been given a	a specific diagnos	sis.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
11. The serio	usness of my	illness has been	determined.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
12. The expla	nations I've l	been given about	my cancer see	m hazy to me.
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree
13. The purp	ose of the trea	atment is clear to	me.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree

<b>14.</b>	I have been	given many	differing	opinions	about	what is	wrong with
me.	•						

1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree	
15. I usually	know if I am	going to have a g	ood or bad day	y <b>.</b>	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree	
16. The resul	ts of my tests	are inconsistent.			
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree	
17. The effect	tiveness of the	e treatment is un	determined.		
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree	
18. I'm certa	in they will no	ot find anything o	else wrong witl	n me.	
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree	
19. The treatment I will receive has a known probability of success.					
1 Strongly Agree	2 Agree	3 Undecided	4 Disagree	5 Strongly Disagree	

**<u>DIRECTIONS</u>**: You and the doctor discussed <u>a plan for how to treat your cancer</u>. The following questions are about this <u>treatment plan</u>. Please read each statement and then circle the response that best represents how you feel about the plan.

### 1. The treatment plan is sound.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

### 2. I am committed to following the treatment plan.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

### 3. I understand the treatment plan.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

# 4. It would be useful to consult with another doctor about the treatment plan.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

## 5. I intend to follow the treatment plan.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

## 6. I am comfortable with the treatment plan.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

## 7. More information about the treatment plan would help.

1	2	3	4	5
Strongly disagree	Somewhat disagree	Neutral	Somewhat Agree	Strongly agree

## 8. The treatment plan is the right one for my situation.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

## 9. I am satisfied with the treatment plan.

1	2	3	4	5
Strongly	Somewhat	Neutral	Somewhat	Strongly
disagree	disagree		Agree	agree

## 10. How likely are you to follow the treatment plan?

1	2	3	4	5
Not likely		Moderately		Very likely
		likely		

<u>**DIRECTIONS**</u>: For the following questions, please give your <u>best guesses</u>. There are no right or wrong answers.

1.	The way n	ny doctor and	l I speak is			
	1 Very similar	2 Moderately similar	Slightly	Slightly	5 Moderately different	Very
2.	My doctor	and I have	ethr	nic backgro	unds	
	Very	2 Moderately similar	Slightly	Slightly	Moderately	Very
3.	The way n	ny doctor and	l I reason a	bout proble	ems is	
	1 Very similar	2 Moderately similar	3 Slightly similar	4 Slightly different	5 Moderately different	6 Very different
4.		of people I sp spends his/ho	-			s of people
	Very	2 Moderately similar	Slightly	Slightly	Moderately	Very
5.	My doctor	and I have	styles	s of commu	nication	
	Very	2 Moderately similar	Slightly	Slightly	Moderately	Very
6.	My doctor	and I are	in terms	of race		
	1 Very similar	2 Moderately similar	3 Slightly similar			6 Very different

7.	My docto	r and I have _	gener			
	Very	2 Moderately similar	Slightly	Slightly	Moderately	
8.	My docto	r and I are	in terms	of cultures		
	Very	2 Moderately similar	Slightly	Slightly	Moderately	Very
9.	My docto	r and I have _	spirit	ual beliefs		
	Very	2 Moderately similar	Slightly	Slightly	Moderately	Very
10	. My docto	or and I are _	in term	s of skin col	or	
	Very	2 Moderately similar	Slightly	Slightly	Moderately	Very

You have completed this survey! Please give it to the research assistant prior to leaving. Thank you!

#### Appendix C





#### CONSENT TO TAKE PART IN A RESEARCH STUDY

**TITLE OF STUDY:** Communication-Participation Behavior during the Delivery of Breast-Cancer Care

Principal Investigator: Thomas Kearney, MD

The Cancer Institute of New Jersey

195 Little Albany Street New Brunswick, NJ 08901

(732) 235-6777

This consent form is part of an informed consent process for a research study and it will give information that will help you to decide whether you wish to volunteer for this research study. It will help you to understand what the study is about and what will happen in the course of the study.

After all of your questions have been answered, if you still wish to take part in the study, you will be asked to sign this informed consent form.

The study doctor (the principal investigator) or another member of the study team (an investigator) will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand.

You are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

#### Why is this study being done?

The purpose of this study is to examine how breast cancer patients, their companions (when applicable), and their doctors make decisions about treatment options. This study is interested in how patients, companions, and doctors talk about different options and how they decide on which treatments to be pursued.

#### Why have you been asked to take part in this study?

You have been asked to participate in this study because you are a newly diagnosed breast cancer patient who will be talking about treatment options with your doctor today.

#### Who may take part in this study? And who may not?

You may participate in this study if:

- you are a newly diagnosed, early-stage female breast-cancer patient
- you speak English fluently
- you can complete a short questionnaire without assistance before and two questionnaires after the treatment discussion with your doctor.
- you are at least 18 years old
- all of your companion(s) is/are at least 18 years old
- all of your companion(s) speak English fluently
- all of your companion(s) give informed consent

You may not participate in this study if:

- you are not a newly diagnosed, early-stage female breast-cancer patient
- you do not speak English fluently
- you are younger than 18 years of age
- you need assistance with questionnaires
- any of your companions are younger than age 18
- any of your companions do not speak English fluently
- any of your companions do not give informed consent

#### How long will the study take and how many subjects will participate?

Approximately 180 women with early-stage breast cancer will participate in this study. Because breast-cancer patients tend to bring companions to their visits and because the companions will be counted as participants during the treatment discussion, the total number of participants could reach 300 or greater. If you decide to participate, you will be asked to complete a short pre-visit survey, post-visit survey immediately after the treatment discussion, and allow for the videotaping of the treatment discussion with the doctor. Each survey should take no more than 15 minutes. The video-taping of the treatment discussion will last as long as you, your companions, and the doctor are discussing treatment options and until you exit the room. This conversation usually lasts between 30 minutes and 1 hour. All video-recorded research will be done at this site.

#### What will you be asked to do if you take part in this research study?

If you decide to participate in this study, you will be asked to complete a short prediscussion survey, allow for the video-taping of the treatment discussion, and complete a short post-discussion survey today. The surveys will ask such questions as how you are feeling or how much you would like to participate in the treatment discussion.

## What are the risks and/or discomforts you might experience if you take part in this study?

Because the conversation will be videotaped, you might feel mildly nervous, embarrassed, or self conscious. Transcripts and images of your conversation may be used for teaching purposes.

#### Are there any benefits for you if you choose to take part in this research study?

You will receive \$20 for your participation. Your participation will help us have a better understanding of communication between patients, companions and their doctors when deciding what treatment to seek. Knowing more about the communication process will give us a better understanding of how decisions are made when patients are newly diagnosed with breast cancer.

#### What are your alternatives if you don't want to take part in this study?

There are no research alternatives available. Your only choice is not to take part in this study.

## How will you know if new information is learned that may affect whether you are willing to stay in this research study?

During the course of the study, you will be updated about any new information that may affect whether you are willing to go on taking part in the study. If new information is learned that may affect you after the study or your follow-up is completed, you will be contacted.

#### Will there be any cost to you to take part in this study?

There will be no cost to you or your companion(s) to participate in this study.

#### Will you be paid to take part in this study?

You will be paid \$20 to participate in this study.

#### How will information about you be kept private or confidential?

In addition to key members of the research team, the following people will be allowed to inspect parts of your medical record and your research records related to this study:

- The Institutional Review Board (a committee that reviews research studies)
- Officials of the University of Medicine and Dentistry of New Jersey
- Researchers at Rutgers approved for this study

• Office for Human Research Protections (OHRP) (regulatory agency that oversees human subject research.)

By taking part of this study, you should understand that the study collects demographic data and data on your health. This data will be recorded by the study doctor/investigator who may store and process your data with electronic data processing systems. Because the information from the tapes may be used in multiple studies, and because the completion dates of those studies cannot be predicted in advance, the tapes will be kept indefinitely.

Your personal identity, that is your name and other identifiers, will be kept confidential. You will have a code number and your actual name will not be used. Only your study doctor will be able to link the code number to your name.

Your data may be used in scientific publications. If the findings from the study are published, you will not be identified by name. Your identity will be kept confidential. The exception to this rule will be when there is a court order or when a law exists requiring the study doctor to report communicable diseases, In this case, you will be informed of the intent to disclose this information to the state agency. Such a law exists in New Jersey for diseases such as cancer, infectious diseases such as hepatitis, HIV, viruses and many others.

The study doctor/investigator will be allowed to examine the data in order to analyze the information obtained from this study, and for general health research.

If you do not sign this approval form, you will not be able to take part in this research study.

You can change your mind and revoke this approval at any time. If you change your mind, you must revoke your approval in a written request to Dr. Kearney. Beginning on the date that you revoke your approval, no new personal health information will be used for research. However, the study doctor/investigator may continue to use the health information that was provided before you withdrew your approval.

You have the right to look at your study data at your study doctor's office and to ask for corrections of any of your data that is wrong.

It is possible for confidentiality to be breached if someone recognizes your voice from your video image.

## What will happen if you do not wish to take part in the study or if you later decide not to stay in the study?

You may choose not to be in the study. If you do choose to take part it is voluntary. You may refuse to take part or may change your mind at any time.

If you do not want to enter the study or decide to pull out of the study, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

#### Who can you call if you have any questions?

If you have any questions about taking part in this study or if you feel you may have suffered a research related injury, you can contact one of the following investigators:

Dr. Thomas Kearney Dr. Jeffrey Robinson

The Cancer Institute of New Jersey Dept of Communication, Rutgers University

195 Little Albany Street 4 Huntington Street

New Brunswick, NJ 08901

Email: Kearney@umdnj.edu

Office: (732) 235-6777

New Brunswick, NJ 08901

Email: jrob@scils.rutgers.edu

Office: (732) 932-7500 x 8128

If you have any questions about your rights as a research subject, you can contact:

The UMDNJ IRB director Office: (732) 235-9806

Additionally, if you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at: Rutgers University, the State University of New Jersey, Institutional Review Board for the Protection of Human Subjects, Office of Research and Sponsored Programs, 3 Rutgers Plaza, New Brunswick, NJ 08901-8559

Tel: 732-932-0150 ext. 2104, Email: humansubjects@orsp.rutgers.edu

#### What are your rights if you decide to take part in this research study?

You have the right to ask questions about any part of the study at any time. You should not sign this form unless you have had a chance to ask questions and have been given answers to all of your questions.

Consent for Videotaping, Tape Recording, etc. for Educational and Research Purposes

You hereby authorize the making of videotapes, tape recordings, or photographs by Robert Wood Johnson Medical School and the Cancer Institute of New Jersey. You also authorize RWJMS and its faculty to show, play, or retain such videotapes, movies, tape recordings, or photographs, with explanatory text if desired, for the use of medical and health profession students, and/or other health personnel in the interest of medical education; knowledge; or research regarding treatment discussions and/or factors that affect each of these areas; and to publish such videotapes, tape recordings, or photographs in journals, books, or other educational media.

Your consent is given subject to the condition that:

The name of the breast cancer patients and any companions will not be identified in the videotapes, movies, tape recordings, or photographs.

The making of videotapes, movies, tape recordings, or photographs be subject to approval and supervision of the Institute, and that all videotapes, movies, tape recordings, and photographs taken shall be shown to the undersigned if he so requests at the time he signs this consent: and all prints and negatives be destroyed if he so requests.

The videotapes, movies, tape recordings, or photographs not be used for commercial or public media purposes without further consent of the family.

This authorization is expressly intended to release from liability and hold harmless the state of New Jersey, Robert Wood Johnson University Hospital, the University of Medicine and Dentistry of New Jersey Robert Wood Johnson Medical School and the Cancer Institute of New Jersey, their staff, officers, employees and agents from any and all liability which may result from the taking, printing, retaining, and using of said videotapes, tape recordings, or photographs.

This authorization and release are expressly intended to be binding upon the undersigned, his heirs, executors, administrators, successors, and assigns.

You	have	read	and	understand	the	above	and	do	hereby	agree	to	procedure	to	be
under	taken													
Subje	ct Sig	natur	e						Da	ate				
J	٠	,												

#### AGREEMENT TO PARTICIPATE

I have read this entire form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form or this study have been answered.

Subject Name:	
·	
Subject Signature:	Date:

### **Signature of Investigator/Individual Obtaining Consent:**

To the best of my ability, I have explained and discussed the full contents of the study including all of the information contained in this consent form. All questions of the research subject and those of his/her parent or legal guardian have been accurately answered.

Investigator/Person Obtaining Consent:		
Signature:	Date:	

#### Appendix D





#### CONSENT FOR THE COMPANION TO TAKE PART IN A RESEARCH STUDY

**TITLE OF STUDY:** Communication-Participation Behavior during the Delivery of Breast-Cancer Care

Principal Investigator: Thomas Kearney, MD

The Cancer Institute of New Jersey

195 Little Albany Street New Brunswick, NJ 08901

(732) 235-6777

This consent form is part of an informed consent process for a research study and it will give information that will help you to decide whether you wish to volunteer for this research study. It will help you to understand what the study is about and what will happen in the course of the study.

After all of your questions have been answered, if you still wish to take part in the study, you will be asked to sign this informed consent form.

The study doctor (the principal investigator) or another member of the study team (an investigator) will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand.

You are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

#### Why is this study being done?

The purpose of this study is to examine how breast cancer patients, their companions (when applicable), and their doctors make decisions about treatment options. This study

is interested in how patients, companions, and doctors talk about different options and how they decide on which treatments to be pursued.

#### Why have you been asked to take part in this study?

You have been asked to participate in this study because you are accompanying a newly diagnosed breast cancer patient who will be talking about treatment options with her doctor today.

#### Who may take part in this study? And who may not?

You may participate in this study if you are the companion of a newly diagnosed, early-stage breast cancer patient. You must be a native English speaker, or has learned to speak English fluently. You must also be at least 18 years old.

You may participate in this study if:

- you are the companion of a newly diagnosed, early-stage female breast-cancer patient
- you speak English fluently
- you are at least 18 years old

You may not participate in this study if:

- you do not speak English fluently
- you are younger than 18 years of age
- you do not give informed consent

#### How long will the study take and how many subjects will participate?

Approximately 300 women with early-stage breast cancer will participate in this study. Because breast-cancer patients tend to bring companions to their visits and because the companions will be counted as participants during the treatment discussion, the total number of participants could reach 900 or greater. If you decide to participate, you will be videotaped during the treatment discussion with the doctor. The video-taping of the treatment discussion will last as long as the breast cancer patient, you and any other companions, and the doctor are discussing treatment options and until you exit the room. This conversation usually lasts between 30 minutes and 1 hour. All video-taped research will be done at this site.

#### What will you be asked to do if you take part in this research study?

If you decide to participate in this study, you will be asked to allow for the video-taping of the treatment discussion.

## What are the risks and/or discomforts you might experience if you take part in this study?

Because the conversation will be videotaped, you might feel mildly nervous, embarrassed, or self conscious. Transcripts and images of your conversation may be used for teaching purposes.

#### Are there any benefits for you if you choose to take part in this research study?

You will not receive any direct benefits from participating in this research. Your participation will help us have a better understanding of communication between patients, companions and their doctors when deciding what treatment to seek. Knowing more about the communication process will give us a better understanding of how decisions are made when patients are newly diagnosed with breast cancer.

#### What are your alternatives if you don't want to take part in this study?

There are no research alternatives available. Your only choice is not to take part in this study.

## How will you know if new information is learned that may affect whether you are willing to stay in this research study?

During the course of the study, you will be updated about any new information that may affect whether you are willing to go on taking part in the study. If new information is learned that may affect you after the study or your follow-up is completed, you will be contacted.

#### Will there be any cost to you to take part in this study?

There will be no cost to you, the breast cancer patient, and any other companions to participate in this study.

#### Will you be paid to take part in this study?

You will not be paid to participate in this study.

#### How will information about you be kept private or confidential?

In addition to key members of the research team, the following people will be allowed to inspect parts of your medical record and your research records related to this study:

- The Institutional Review Board (a committee that reviews research studies)
- Officials of the University of Medicine and Dentistry of New Jersey
- Researchers at Rutgers approved for this study

• Office for Human Research Protections (OHRP) (regulatory agency that oversees human subject research.)

By taking part of this study, you should understand that the study collects demographic data and data on the patient's health but not any information about you other than your image. This data will be recorded by the study doctor/investigator who may store and process your data with electronic data processing systems. Because the information from the tapes may be used in multiple studies, and because the completion dates of those studies cannot be predicted in advance, the tapes will be kept indefinitely.

Your personal identity, that is your name, address, and other identifiers, will be kept confidential. You will have a code number and your actual name will not be used. Only your study doctor will be able to link the code number to your name or the breast cancer patient's name.

Your data may be used in scientific publications. If the findings from the study are published, you will not be identified by name. Your identity will be kept confidential. The exception to this rule will be when there is a court order or when a law exists requiring the study doctor to report communicable diseases, In this case, you will be informed of the intent to disclose this information to the state agency. Such a law exists in New Jersey for diseases such as cancer, infectious diseases such as hepatitis, HIV, viruses and many others.

The study doctor/investigator will be allowed to examine the data in order to analyze the information obtained from this study, and for general health research.

If you do not sign this approval form, you will not be able to take part in this research study.

You can change your mind and revoke this approval at any time. If you change your mind, you must revoke your approval in a written request to Dr. Kearney. Beginning on the date that you revoke your approval, no new personal health information will be used for research. However, the study doctor/investigator may continue to use the health information that was provided before you withdrew your approval.

You have the right to look at your study data at your study doctor's office and to ask for corrections of any of your data that is wrong.

It is possible for confidentiality to be breached if someone recognizes you from your video image.

## What will happen if you do not wish to take part in the study or if you later decide not to stay in the study?

You may choose not to be in the study. If you do choose to take part it is voluntary. You may refuse to take part or may change your mind at any time.

If you do not want to enter the study or decide to pull out of the study, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

#### Who can you call if you have any questions?

If you have any questions about taking part in this study or if you feel you may have suffered a research related injury, you can contact one of the following investigators:

Dr. Thomas Kearney Dr. Jeffrey Robinson

The Cancer Institute of New Jersey Dept of Communication, Rutgers University

Email: Kearney@umdnj.edu Email: jrob@scils.rutgers.edu
Office: (732) 235-6777 Office: (732) 932-7500 x 8128

If you have any questions about your rights as a research subject, you can contact:

The IRB director

Office: (732) 235-9806

#### What are your rights if you decide to take part in this research study?

You have the right to ask questions about any part of the study at any time. You should not sign this form unless you have had a chance to ask questions and have been given answers to all of your questions.

Consent for Videotaping, Tape Recording, etc. for Educational and Research Purposes

You hereby authorize the making of videotapes, tape recordings, or photographs by Robert Wood Johnson Medical School and the Cancer Institute of New Jersey. You also authorize RWJMS and its faculty to show, play, or retain such videotapes, movies, tape recordings, or photographs, with explanatory text if desired, for the use of medical and health profession students, and/or other health personnel in the interest of medical education; knowledge; or research regarding treatment discussions and/or factors that affect each of these areas; and to publish such videotapes, tape recordings, or photographs in journals, books, or other educational media.

Your consent is given subject to the condition that:

The name of the breast cancer patients and any companions will not be identified in the videotapes, movies, tape recordings, or photographs.

The making of videotapes, movies, tape recordings, or photographs be subject to approval and supervision of the Institute, and that all videotapes, movies, tape recordings,

and photographs taken shall be shown to the undersigned if he so requests at the time he signs this consent: and all prints and negatives be destroyed if he so requests.

The videotapes, movies, tape recordings, or photographs are not be used for commercial or public media purposes without further consent of the family.

This authorization is expressly intended to release from liability and hold harmless the state of New Jersey, Robert Wood Johnson University Hospital, the University of Medicine and Dentistry of New Jersey Robert Wood Johnson Medical School and the Cancer Institute of New Jersey, their staff, officers, employees and agents from any and all liability which may result from the taking, printing, retaining, and using of said videotapes, tape recordings, or photographs.

This authorization and release are expressly intended to be binding upon the undersigned, his heirs, executors, administrators, successors, and assigns.

You have read and understand the above undertaken.	and do hereby agree to procedure to be
Subject Signature	Date:
AGREEMENT TO	) PARTICIPATE
I have read this entire form, or it has been rea what has been discussed. All of my questions answered.	
Subject Name:	
Subject Signature:	Date:
Signature of Investigator/Individual Obtain	ning Consent:
To the best of my ability, I have explained an including all of the information contained in tresearch subject and those of his/her parent or answered.	his consent form. All questions of the
Investigator/Person Obtaining Consent:	

Signature: Date:

(date)

## Appendix E



(sign your name here)



Date		
	Research-Participant Payment Form	
	ommunication-Participation Behavior during Cancer Care	the Delivery of Breast-
•	r: Thomas Kearney, MD ffrey D. Robinson, Ph.D.	
I understand that I,	(print name here)	_, received \$20 for
participation in this re	esearch project.	

## Appendix F







Date	
Research Part	icipant Payment-for-Donation Form
Name of Project: Communication Cancer Care	n-Participation Behavior during the Delivery of Breast-
Primary Investigator: Thomas I Sub-Investigator: Jeffrey D. Rol	•
I understand that I,receive \$20	, was eligible to
the research project donate it to the <i>Cure</i> is a nonprofit organization problem by preventing cancer, sathrough research, education, adverged my confidentiality in this research.	(print name here) project, and that I declined this money in favor of having the Susan G. Komen for the Cure. Susan G. Komen for on dedicated to the eliminating cancer as a major health ving lives, and diminishing suffering from cancer, becacy, and service. I understand that, in order to protect in project, this donation will be made directly by the I thus I am not eligible for a tax deduction.
(sign your name h	ere) (date)

#### **Endnotes**

- Mishel (1999) conceptualizes cancer as an acute illness experience.
- Any forthcoming references of findings of a dimension of the mental adjustment to cancer scale (e.g., Fighting Spirit) could have been deduced from studies using either the MAC or the Mini-MAC.
- Unless Street and Millay (2001) is cited, examples are drawn from Street's Verbal Behavior Coding Guide; R. L. Street, personal communication, March 15, 2009.
- Similar to prior research (Street & Gordon, 2008), this study found that patients who brought companions did not differ from those who did in terms of: education ( $\chi^2$  (1, N=51) = .30, p=.58), age (F = .16, p=.69, t(49)=.59, p=.56), ethnicity ( $\chi^2=.09$ , p=.77), household income ( $\chi^2$  (1, N=46) = 1.89, p=.17), and prior history with breast surgeon ( $\chi^2$  (1, N=51) = .03, p=.87). Perhaps obviously, compared to unmarried patients, married patients were significantly more likely to bring a companion (e.g., their husband) ( $\chi^2$  (1, N=32) = 18, p=.001); however, there were no such differences between unmarried patients ( $\chi^2$  (1, N=19) = .47, p=.49). In contrast to the findings of Street and Gordon, this study found that, compared to patients who did not bring companions (20.42 minutes), those who did (29.49 minutes) experienced significantly longer visits (F(49) = 4.10, t (32.94) = -3.46, p=.001). The effect of companion presence and participation is further explained in subsequent analyses.

The logistic regression output provides two  $R^2$  values: Nagelkerke  $R^2$  and Cox and Snell  $R^2$ . Both statistics adjust for the sample size; however, the Nagelkerke  $R^2$  is reported because it adjusts the Cox and Snell value to best approximate the normal interpretable range of a linear multiple regression (Tabachnick & Fidell, 2007).

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- Note: \* denotes inclusion in meta-analysis in Study One
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