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by

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Committee in charge:

Professor Joan R. Bloom, Chair
Professor Thomas Rundall
Professor Dacher Keltner

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Abstract

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by

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Doctor of Philosophy in Health Services and Policy Analysis

University of California, Berkeley

Professor Joan R. Bloom, Chair

Objective: This research evaluates the relationship between breast cancer survivors' perceived communication with providers and their sense of control over their health, health behaviors, and health outcomes. In addition, the study examines the sociodemographic, health, and psychosocial characteristics of survivors that are associated with perceptions of provider communication. The project also addresses: (1) what women regret about their breast cancer treatment five years later, and (2) what characteristics of disease and treatment predict post-treatment regret.
Methods: Interviews were conducted with breast cancer survivors in the San Francisco Bay Area. Participants were interviewed following diagnosis. Five years later, women were asked whether they had any regrets about their cancer treatment (N=449) and participated in a longer interview (N=311). A subset of 5-year participants was available for a 10-year interview (N=311). Cross-sectional and longitudinal linear regression methods, as well as qualitative analysis and logistic regression were used to examine the questions of interest.
Results: Patients' perceptions of their communication with providers were not consistently associated with their sense of control over their health, their health behaviors, or health outcomes. When examining individual characteristics, problems with provider communication were associated with self-esteem ($p<.05$) and emotional support ($p<.05$), rather than with sociodemographic characteristics. Quantitative analysis of regret revealed that women who were anxious about the future (OR=1.32; $p<.05$) or had problems communicating with physicians (OR=1.26; $p<.05$) during treatment were more likely to express regret 5 years later. In addition, women with new or recurrent cancers 5 years later were significantly more likely to regret some aspect of their primary treatment (OR=5.81; $p<.001$).
Conclusion: This research supports the need to address the psychosocial aspects of cancer care in the survivorship phase and the need to improve study design in physician-patient communication research. Evidence is also provided for addressing the unique emotional needs of women with recurrent cancers, who may experience an undue burden of regret.

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CHAPTER 1. INTRODUCTION

1.1 Overview

Physician-patient communication has received significant attention from the medical community in recent years. This attention has resulted from a general trend toward patient participation in healthcare and a greater emphasis on chronic illness care, which involves enlisting the patient's cooperation with the physician to successfully manage the illness (Haug & Lavin, 1981; Quill & Brody, 1996; Szasz, Knoff, & Hollender, 1958). Accordingly, there has been a shift away from the traditional, patriarchal model of the physician-patient relationship, which is characterized by an all-knowing physician administering treatment to a passive, compliant patient (Parsons, 1951; Szasz & Hollender, 1956). Instead, more egalitarian, holistic models of care have emerged that operate under the paradigm of patient-centered care (M.A. Stewart, Brown, Weston, Mcwhinney, & McWilliam, 2003).

Although many models of patient-centered care have been developed, all models are very similar and are generally defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001). This model of care, which emphasizes effective communication and patient participation in the clinical encounter, represents a change in the power dynamic of the physician-patient relationship. Whereas the physician has historically assumed power via technical knowledge and expertise, the patient is now seen as an equally influential partner in the interaction, capable of making treatment decisions that fit her values, lifestyle, and preferences (R. M. Epstein et al., 2005; Funnell & Anderson, 2003; M.A. Stewart et al., 2003). This model of care is hypothesized to empower the patient to self-manage her disease, adhere to treatment, and thus achieve improved health outcomes. Accordingly, this dissertation examines the association between the quality of physician-patient communication perceived by breast cancer survivors and their subsequent health behaviors and outcomes.

Breast cancer is increasingly described as a chronic illness (Institute of Medicine, 2006). Breast cancer is the most prevalent cancer among women in the United States, and an estimated 89% of women who are diagnosed survive 5 years or longer (Ries, 2007). Furthermore, many of these women experience chronic health problems that result from the disease and the associated treatment, such as fatigue and weight gain (Ganz & Bower, 2007; Goodwin et al., 1998; Pinto et al., 2002). In addition, breast cancer patients and survivors report problems navigating the health services system, and poor communication with providers is a principal concern (Degner et al., 1997; Institute of Medicine, 2006). The health concerns of the growing population of breast cancer survivors are understudied, and the role of the health services system in helping to manage the chronic health concerns of survivors also warrants further attention.

The patient's role in determining the course of breast cancer care came to attention in California via SB 1893, state legislation requiring that breast cancer patients be provided with full and understandable information about all alternative treatment choices (Myers, 1985). Recently, physician-patient communication has become a subject of national attention in newspaper articles on using "well-chosen words" to manage patient emotions, concerns over clinical information being lost in translation, and doctors' employing mindfulness in their practice (J. E. Brody, 2009; Chen, 2009a, 2009b). These legal and information trends reflect a larger movement toward patient participation in cancer care.

To date, studies examining the effects of physician-patient communication on health in cancer patients are largely cross-sectional and rarely consider later effects of treatment, aging, or survivorship care that may be relevant many years after treatment. A significant gap in the literature concerns the chronic component of cancer-related health concerns and the study of survivors' health habits in maintaining long-term wellbeing. This study extends beyond existing research on physician-patient communication by utilizing longitudinal data over ten years to examine whether patients' perceptions of physician communication are associated with a sense of control over one's health, the ongoing self-management of cancer-related chronic conditions, and health outcomes. The project also examines the relationship between perceived provider-patient communication and women's individual characteristics, including race, age, self-esteem, and emotional support. In addition, post-treatment regret is explored as an unintended consequence of patients' participation in care. Overall, the results of this project inform the literature on the psychosocial aspects of cancer survivorship care.

1.2 Power Dynamics in the Physician-Patient Relationship

Social psychological perspectives on power dynamics provide a unifying foundation for models of the physician-patient relationship. The biomedical view of the clinical encounter has traditionally been an underpinning of medical care and is characterized by a dominant physician who, on the basis of expert knowledge, acts on a passive patient. Recent trends in medical practice have somewhat mitigated this power asymmetry, promoting patient participation in the clinical encounter. Various models of care have been developed to describe and disseminate this view of the therapeutic relationship. However, these models of care have been criticized for being fragmented and theoretically weak, and social psychological research on power is therefore invoked in this project to address these shortcomings. What emerges is an integration of historical, emotional, and informational perspectives of medical communication with a clear definition of power and emphasis on the dyad. In addition, the power perspective lends credence to the hypothesis that good provider communication leads to a sense of control and empowerment with respect to one's illness, which drives self-management and, ultimately, better health.

1.3 Patient-Centered Communication in Cancer Care

Research on patient satisfaction shows that cancer survivors are typically dissatisfied with the support they get from their providers regarding follow-up care (Carmichael & Bates, 2004; Institute of Medicine, 2006). Physician-patient communication during and after cancer treatment is often found to be deficient (Mallinger, Griggs, & Shields, 2005; Meropol et al., 2003), and poor communication with providers is associated with adverse psychological outcomes such as poor adjustment to illness and anxiety (N. K. Arora, 2003; J. Engel et al., 2003). Models of psychosocial cancer care emphasize the role of physician-patient communication in engendering a sense of control over the cancer, and the importance of patient-centered communication in cancer care is further emphasized by number of recent conceptual developments in cancer communication research (N.K. Arora, Street, Epstein, & Butow, 2009; R.M. Epstein & Street, 2007). Researchers underline the need for longitudinal research on patient-centered communication and for evaluation of the pathways by which high quality communication is associated with better health outcomes (R.M. Epstein & Street, 2007; J. Street, R.L., G. Makoul, N. K. Arora, & R. M. Epstein, 2009). In accordance with these goals, this dissertation explores the links between communication, health outcomes, and patient characteristics that are associated with provider communication.

1.4 Data and Methods

The data for this study come from breast cancer survivors who reside in the San Francisco Bay Area. The analysis considers women who were interviewed about their sociodemographic, health, and psychosocial characteristics (1) during treatment and 5-years later, and (2) at 5-year survival and at 10-year survival. The dissertation uses cross-sectional and longitudinal linear regression methods, as well as qualitative analysis and logistic regression to examine provider communication, health characteristics, and post-treatment regret among breast cancer survivors. Standard error calculations account for potential heteroskedasticity and for clustering between observations on the same individual.

1.5 Significance

The existing research on physician-patient communication in cancer care is largely cross-sectional and predominantly considers the treatment phase. More research in the area of survivorship care (Institute of Medicine, 2006) is needed, and the call for longitudinal studies (N. K. Arora, 2003) in the area of provider communication is apparent. In addition, there is a dearth of research addressing the unintended consequences of patient agency and participation in the clinical encounter, and one important such topic is post-treatment regret among cancer survivors. Despite its importance in medical practice, regret is a relatively new area in cancer care research (T. Connolly & Reb, 2005; M. D. Schwartz, 2005), and studies have not considered regret over inactions (no mastectomy, not taking tamoxifen, etc.). Given these opportunities for additional research, this dissertation examines the association of physician-patient communication with self-management of chronic health conditions using existing data from young breast cancer survivors who have been followed over the 10 years since treatment. In addition, the incidence of post-treatment regret among 5-year survivors is explored.

Specifically, the following aims are undertaken:

Aim 1: To evaluate the relationship between survivors' perceived communication with providers and their sense of control over their health, health behaviors, and health outcomes,

Aim 2: To determine the sociodemographic, health, and psychosocial characteristics of survivors that are associated with perceptions of provider communication, and

Aim 3: To assess the content of survivors' post-treatment regrets and to ascertain what characteristics during treatment predict regret 5 years later.

1.6 Dissertation Outline

The dissertation is divided into in seven chapters. This introduction has outlined the theoretical perspective, research aims, and significance. The second chapter presents a literature review that describes the historical context and theoretical perspectives relevant to physician-patient communication, underscoring power as a unifying theme in the literature.

The patient-centered care framework and the empirical literature linking physician-patient communication to health are also discussed. This framework is then applied to the case of breast cancer survivors. The third chapter presents the conceptual framework and hypotheses linking breast cancer survivors' experiences during treatment and survivorship to their sense of control over their health, their health behaviors, and their self-reported health outcomes. Sample characteristics and measures are also introduced, and the analysis plan is presented. Chapter 4 describes the statistical and qualitative methods used to evaluate the hypotheses, and chapter 5 presents the results of the analysis with an evaluation of each hypothesis. Chapter 6 discusses the results in the context of existing research and summarizes the strengths and limitations of the project. Finally, chapter 7 offers implications for practice and areas for future research, and concluding statements close the dissertation.

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

The psychosocial aspects of cancer care, and breast cancer care specifically, have recently been the subject of increased research. The growing population of cancer survivors combined with patients' demonstrated dissatisfaction with the information they receive from providers has drawn attention to the need for better provider communication in cancer care. However, the literature on patient-centered communication is fragmented both theoretically and methodologically. This chapter summarizes the literature in the following areas:

1. Power-based theoretical models of the physician-patient relationship,
2. The research in patient-centered care and regret as a potential unintended consequence,
3. The state of communication research in breast cancer suvivorship care.

In this chapter, the literature in each area is summarized along with subjects that would benefit from additional research.

2.2 Concepts of the physician-patient relationship: History and context

Sociological and philosophical models of the physician-patient relationship exist along a continuum anchored at either end by two extremes: the ontological or biomedical model of care delivery and the ecological model. The biomedical view characterizes the body and its disease as separable entities. In contrast, the ecological view depicts the person, the disease, and the larger environment as inextricably intertwined, emphasizing the individual and personal aspects of illness (M.A. Stewart et al., 2003). Szasz and Hollender have developed three models of the physician-patient relationship along the biomedical-ecological continuum: (1) activity-passivity (relational prototype: parent-infant), (2) guidance-cooperation (parent-adolescent), and (3) mutual participation (adult-adult) (Szasz & Hollender, 1956). They emphasize that each model is applicable under a different set of circumstances. Whereas the activity-passivity model is most applicable in situations with an unconscious or anesthetized patient, the guidance-cooperation is relevant to postoperative care and drug prescribing, and the mutual participation model is applicable to chronic illness patients. In a similar vein, Emanuel and Emanuel (1992) have redefined the physician-patient relationship more recently, presenting four models of the physician-patient relationship along the biomedical-ecological continuum characterized by relative levels of patient autonomy: (1) Paternalistic (doctor as guardian), (2) Informative (doctor as technical expert), (3) Interpretive (doctor as adviser), and (4) Deliberative (doctor as teacher-friend).

The biomedical, or patriarchal, view of the patient has dominated Western medical practice since the late 1800s (M.A. Stewart et al., 2003). This perspective is akin to the activity-passivity or paternalistic/informative models outlined above. The significant scientific advances of the eighteenth and nineteenth centuries led to the concept of the doctor as "the expert engineer of the body as a machine" (Szasz et al., 1958). In this view, physicians classify and treat disease by drawing on a proprietary, scientifically complex body of knowledge. Accordingly, physicians are viewed as technically expert, knowledgeable individuals, and patients have traditionally been expected to surrender and follow "doctor's orders." Consistent with this view, Parsons (1951) conceptualizes the physician-patient interaction as a patriarchal relationship in which the physician, by virtue of his technical expertise, assumes control and makes treatment decisions for a dependent, passive patient. Parsons emphasizes that the "sick role" of the patient is institutionally defined as "helpless and therefore in need of help" (p. 440). By establishing a physician-disease relationship and defining the patient as helpless, the traditional biomedical model of healthcare delivery has engendered an asymmetry in the physician-patient relationship whereby power is disproportionately bestowed on the physician. As Maseide (1991) notes, "Medical dominance is seen as legitimate, rational and necessary."

2.3 Social power and the physician-patient relationship: A theoretical perspective

2.3.1 Definition

As a result of the "medical dominance" trend in concepts of the physician-patient relationship, the construct of power has received attention in the recent literature on doctor-patient relationships. Despite this attention, much of the literature on "power" in the physician-patient relationship has failed to provide an adequate definition of the term as it operates in the medical context, instead invoking very general or dictionary definitions of power (Canter, 2001; Goodyear-Smith & Buetow, 2001; Haug & Lavin, 1981; McGregor, 2006)or failing to define the term altogether (Heath & Nessa, 2007; Porter, 1997; Quill & Brody, 1996). The psychological literature on social power, which has developed independently of the medical literature on physicians' power, has given more attention to the definitions, related constructs, and social functions of power, and defines power as "an individual's relative capacity to modify others' states by providing (or withholding) resources" (Keltner, Gruenfeld, & Anderson, 2003). This definition highlights power as (a) a relational construct and (b) a result of control over resources, such as a base of expert knowledge (Emerson, 1962; French & Raven, 1959). Because the physician has a significant base of medical knowledge relative to the patient and ultimately controls treatment, a power asymmetry underlies the doctor-patient relationship (Goodyear-Smith & Buetow, 2001; Gwyn & Elwyn, 1999), and the onus therefore falls upon the physician to manage the dynamic of the physician-patient relationship (Quill & Brody, 1996).

2.3.2 Current trends in patient care

Recently, ideals of medical practice have moved toward the ecological view, and practitioners have consequently utilized alternative models of the physician-patient relationship (H. Brody, 1987; Emanuel & Emanuel, 1992; Salmon & Hall, 2003; Szasz & Hollender, 1956). These ecologically-based models emphasize cooperation and patient-provider egalitarianism in healthcare, acknowledging the patient's participation in the remedial process (Kaba & Sooriakumaran, 2007). For example, Emanuel and Emanuel (1992) advocate the deliberative model as the preferred relationships in their typology. Medical practice is increasingly moving in the direction of the ecological view for three fundamental reasons: (1) modern American psychiatry has emphasized the patient's role as a major determinant of treatment success, (2) medical practice increasingly focuses on chronic illnesses, which requires patient participation and adherence to treatment, and (3) there has been a societal drift toward increased access to information and a consumerist trend toward patient choice in the case of the physician-patient relationship (G. L. Engel, 1977; Haug & Lavin, 1981; Quill & Brody, 1996; Szasz et al., 1958).

The recent literature on power in the physician-patient relationship has thus emphasized the need for patient empowerment and autonomy in the medical encounter and advocates a relative increase in patients' power. For example, Goodyear-Smith and Buetow (2001) advocate patients and providers sharing power, with "each exercising different but equally important sources of power" where the patient is an expert in his or her body, lifestyle, values, and preferences. Quill and Brody (1996) similarly advocate an "enhanced autonomy" model of medical care, in which the physician communicates medical information in accessible language to the patient and considers the patient's personal experience and treatment goals in making treatment recommendations. Heath and Nessa (2007) succinctly explain the goal of increasing patients' relative power as an "increase [in] the agency of both parties…The task of the doctor and patient is to work together to achiever greater…control over disease."[1] Consistent with this view, Stewart et al. (2003), Funnell and Anderson (2003), and McGregor (2006) have emphasized the importance of patient empowerment in managing chronic illnesses. They assert that patients are empowered when their knowledge, control, resources, and experience are sufficient to make, implement, and evaluate their own treatment decisions. By focusing on patient education (i.e., a transfer of resources from provider to patient) and the patient as an individual, the patient is made to feel less like an object and more like an agent (Roter & Hall, 2006).

2.3.3 Shortcomings in existing theory

This shift has driven patient-centered care as the emerging model of chronic care delivery (Kaba & Sooriakumaran, 2007; M.A. Stewart et al., 2003). Patient-centered care has evolved largely as a clinical method for empowering patients to participate in their own care and has been linked to improved health behaviors and health outcomes. However, due to an emphasis on physician behavior and the development of a clinical method, this framework (while underscoring the importance of patient empowerment) has rarely engaged the psychological literature on social power and control. As a result, the physician-patient relationship is most often studied as a unique aspect of medicine rather than one of many manifestations of social behavior characterized by power relations.

In addition, the pathways through which patients translate their communication with providers into health behaviors and subsequent outcomes have historically been inadequately defined and have lacked theoretical foundation (Griffin et al., 2004). In an attempt to remedy these deficiencies, *Patient Education and Counseling* recently dedicated a special issue to developing theory around provider communication (Cameron, de Haes, & Visser, 2009). The resulting issue reflects rather than remedies the fragmentation of provider communication research, spanning topics from neuroscience (Finset & Mjaaland, 2009) to a regurgitation of Karl Weick's organizational perspective (G. L. Kreps, 2009). The issue also underscores the dire state of theory in the field of patient-provider communication. Hall and Mast (Hall & Schmid Mast, 2009) offer structured suggestions regarding how authors can integrate theory into their communication research, noting that existing communication research is widely criticized for being a-theoretical or *latently*

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[1] Some authors (Maseide, 1991; Heath & Nessa, 2007) express concern that a relative increase in patients' power may lead to a corresponding loss of therapeutic power on the part of the physician, given the rising trend in consumerism. In contrast, others, such as Porter (1997), invoke Foucault's perspective and note that "holistic" care expands the power of the doctor's clinical gaze beyond health concerns into all aspects of life, and egalitarian healthcare may therefore be unattainable in practice.

theoretical, whereby a unifying body of theory underlies a work without specifically informing the hypotheses.

Two of the articles in the issue explicitly invoke social psychological perspectives. Neumann and her colleagues (2009) discuss the importance of clinical empathy. The role of provider emotion, and particularly empathy, in the clinical encounter is essential to patients' communicating more about their condition. In turn, this leads to a more accurate diagnosis and a treatment plan that is sensitive to patients' individual needs, generating improved health outcomes. However, empathy is only one dimension of effective provider communication, which, in addition to emotional response, also includes fostering relationships, information exchange, decision-making, enabling self management, and managing uncertainty (de Haes & Bensing, 2009; R.M. Epstein & Street, 2007). Empathy in the context of patient-provider relationship can be subsumed by theories of social power. Power differentials mitigate judgmental accuracy whereby more powerful parties make inaccurate judgments about the attributes of less powerful individuals and are more likely to invoke stereotypes (Ebenbach & Keltner, 1998). Accordingly, a significant power differential in the patient-provider relationship compromises the physician's tendency to pay careful attention to the emotional attributes of individual patients, decreasing the demonstration of empathy in the clinical encounter.

In another article from the same issue that draws on psychological perspectives, Salmon and Young (Salmon & Young, 2009) relate attachment theory to the patient-provider relationship, drawing an analogue to the child-parent relationship. Interestingly, Salmon and Young note the asymmetry in the patient-provider relationship and the traditional dependence of the patient on the provider without explicitly discussing social power and the associated theory and research. Theories of social power provide a useful orienting framework for approaching physician-patient communication and have the potential to unify recent theoretical developments in medical communication, running a common thread between seemingly different perspectives.

In addition, both attachment and empathy theories hold the individual as the unit of analysis. On the other hand, social psychological perspectives on power, as summarized in this chapter, emphasize the dyadic nature of clinical encounter. Power and empowerment underlie much of medical communication research, and they provide a theoretical link between the dynamic of the clinical encounter, the patient's cognitive and emotional response, health behaviors, and subsequent outcomes (Aujoulat, D'Hoore, & Deccache, 2007). Therefore, the next section summarizes the research on patient-centered care, linking patient-provider communication to health outcomes, while invoking the psychological literature on power and control to augment the hypothesized pathways between patients' perceptions of provider communication and health.

2.4 The Patient-Centered Care Framework

2.4.1 Definitions and existing models

Patient-centered care represents a battery of changes – from system-wide reorganization to individual behaviors – in the way health care is delivered. Definitions of patient-centeredness abound, and various conceptual frameworks of patient-centered care have been developed (for a review, see (Mead & Bower, 2000)). The dominant clinical methods are summarized here. Building largely on Balint's concept of person-centered medicine, Stewart and her colleagues (2003) propose the most comprehensive patient-centered method, advocating a clinical encounter that "(a) explores the patient's main reason for the visit, concerns, and need for information (b) seeks an integrated understanding of the patients' world – that is, their whole person, emotional needs, and life issues, (c) finds common ground on what the problem is and mutually agrees on management, (d) enhances prevention and health promotion, and (e) enhances the continuing relationship between the patient and the doctor". Stewart and her colleagues note that "the practitioner must be able to empower the patient, share the power in the relationship, and this means renouncing control which has traditionally been in the hands of the professional. This is the moral imperative of patient-centered practice."

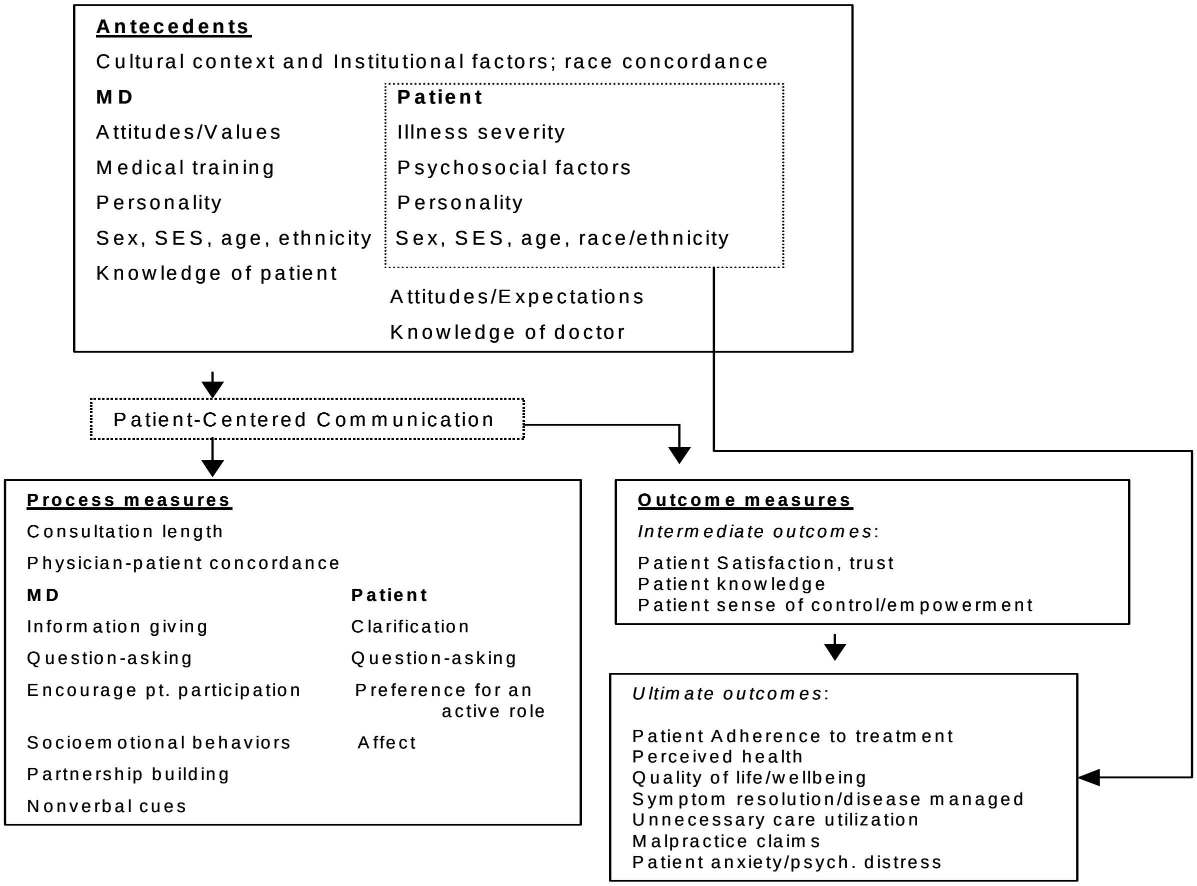
In an effort to synthesize general definitions of patient-centeredness and Stewart's conceptual model, Mead and Bower (2000) present five core elements of patient-centeredness in the physician-patient interaction: (1) The biopsychosocial perspective, which involves the patient's psychological and social characteristics (G. L. Engel, 1977), (2) the 'patient-as person', which involves understanding the patient's "biography" and illness experience, (3) sharing power and responsibility, which involves a shift to mutual participation, (4) the therapeutic alliance, which includes the patient's reactions to treatment options and agreement over goals, and (5) the 'doctor-as-person', which emphasizes recognition of the inherent subjectivity of the physician and self-awareness with respect to the physician's emotional responses. Finally, Epstein and his colleagues (2005) distinguish between 'patient-centeredness' (a moral philosophy), patient-centered care (actions in service of patient-centeredness), and patient-centered communication (PCC), which includes four core elements: (1) Eliciting and understanding the patient's perspective, (2) Understanding the patient within a 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.

Despite slightly different definitions, the perspectives have notable similarities and can be considered different iterations of the same idea. Patient-centered care is most commonly viewed as a clinical method for structuring the physician-patient interaction and is defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001). This holistic approach stands in contrast to traditional models of the doctor-patient relationship, which view the patient as a passive recipient of medical care from the all-knowing physician (Parsons, 1951). Patients are seen as having a more powerful role in the patient-provider interaction, and the physician is responsible for imparting professional guidance to empower the patient to self-manage his or her health (Quill & Brody, 1996; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). The physician's ability to communicate with patients is an integral part of patient-centered care and includes the provision of emotional support as well as clinically relevant information (Mead & Bower, 2000). As a result of patients' increased power in the clinical encounter, they derive greater satisfaction with their provider, more knowledge, and experience a greater sense of agency and control over their illness (C. Anderson & Berdahl, 2002; M.A. Stewart et al., 2003). Consequently, patients may adhere to treatment more often and experience improved health (DiMatteo, 1994; M. Stewart et al., 2000).

2.4.2 Research on Patient Centered Communication, Antecedents

Research efforts in patient-centered communication are summarized in Figure 2a. Antecedents to physician-patient communication are summarized in the first box. Generally, cultural context and institutional factors (policies, rules, and regulations) shape the role relationships between the patient and provider. However, each patient and each provider also have certain individual characteristics that are hypothesized to shape the clinical encounter. Some research indicates that physicians develop certain communication styles along the biomedical-ecological continuum that vary by gender, ethnicity and socioeconomic status (Cooper & Roter, 2002; Flocke, Miller, & Crabtree, 2002). However, other studies find no effects of physician gender, education, and ethnicity on clinical style (Cooper & Roter, 2002; Krupat, Bell, Kravitz, Thom, & Azari, 2001). Still additional research indicates that race/gender concordance between physicians and patients may facilitate patient-centered communication (Cooper et al., 2003). Overall, physician characteristics that affect the patient-provider interaction are still not well understood, and provider-focused research has focused more on physician skills training and interventions to improve physician-patient communication than on predisposing factors.

Figure 2a. Research in Patient-Centered Communication



Patient characteristics that are hypothesized to affect the physician-patient relationship have received significantly more attention than corresponding physician characteristics. This increased attention to patient characteristics is warranted because (1) patients' individual characteristics, emotional states, and sociodemographic factors comprise the perceptual filter through which provider communication is translated into behavioral change, treatment adherence, and improved health outcomes, and (2) some patient factors (Figure 2a. Dashed Box: Patient) have also been associated with patients' health and behavior independently of communication with providers. These confounding variables are considered in the proposed project, and they are therefore elaborated. They include the patient's (1) personality (R. M. Epstein et al., 2005; M. Stewart et al., 2000) including self-esteem (Barkow et al., 1975; McGregor, 2006), which may influence attitudes toward one's health as well as the ability to communicate effectively with powerful others,, (2) general level of social support (Stewart, 2000), a lack of which may decrease health (Fiske & Taylor, 1991) and increase the level of need for provider support, (3) illness severity (Cooper & Roter, 2002), which is negatively associated with future health and with patient perceptions of provider communication[2], and (4) various sociodemographic characteristics. For example, older patients, minorities, and patients of lower socioeconomic status (SES) have been shown to experience both worse health and poorer communication with providers (Cooper & Roter, 2002; Royak-Schaler et al., 2009). This is consistent with the finding that psychological perceptions of social status are positively associated with health (Adler, Epel, Castellazzo, & Ickovics, 2000). However, in a sample of low-income adults, Jensen and his colleagues (2009) found that younger, white, and functionally literate patients experienced lower satisfaction with provider communication. The authors hypothesize that these demographic groups tend to push for a higher standard of care when coping with illness. Accordingly, Harrington, Noble, and Newman (2004)note that the patient characteristics that affect communication are not well understood and warrant further research.

2.4.3 Process measures

Much of the research focused on patient or physician communication skills training and interventions has utilized process measures (Figure 1: Process Measures) as "outcome" variables, examining the effect of communication interventions on aspects of the clinical encounter, such as question-asking, emotional displays, and information giving. In addition, these measures are used in observational studies examining the association of physician-patient communication with health. This project does not explicitly address process measures and does not consider them goals in and of themselves. Rather, they are correlates of patient perceptions of their communication with physicians and, consequently, drivers of health behaviors and outcomes. Process measures are therefore discussed briefly in that context.

Generally, high quality physician-patient communication is associated with a greater incidence of physician-patient agreement (Flocke et al., 2002; Krupat et al., 2001), but does not result in longer consultations (M. Stewart et al., 1999). In addition, physician-based

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[2] This is hypothesized to occur for two reasons: (1) The sicker patient perceives worse communication with providers because his or her subsequent health is poorer and he/she attributes this to poor care, and/or (2) physicians find treating sicker patient less gratifying and thus communicate more poorly with them (review in Cooper & Roter, 2002).

communication interventions are associated with physicians' giving more clinically relevant information to the patient (Flocke et al., 2002; Griffin et al., 2004), asking more questions (Griffin et al., 2004; Mead & Bower, 2000), using more nonverbal communication (eye contact, (Mead & Bower, 2000) expressing positive affect (Griffin et al., 2004; Mead & Bower, 2000), and encouraging greater patient participation in the consultation (Hall, Roter, & Katz, 1988; Michie, Miles, & Weinman, 2003). Patient-based communication skills training has shown increases in patients' preferences for an active role in consultations (Harrington et al., 2004), more question-asking (Griffin et al., 2004; S. H. Kaplan, Greenfield, & Ware, 1989; Michie et al., 2003), greater affect expression (S. H. Kaplan et al., 1989), and more requests for clarification from the physician (Harrington et al., 2004).

These characteristics of high quality physician-patient communication are also consistent with the psychological literature on power, which indicates that people in positions of greater power are given more chances to speak than individuals with low power (Berger, Rosenholtz, & Zelditch, 1980), experience more positive affect, and express their true attitudes (C. Anderson & Berdahl, 2002). In addition, Beisecker and Biesecker (1990) as well as Ogden and her colleagues (2002) have demonstrated patients' desire for information regarding their illness, which is consistent with the psychological literature indicating that information-seeking indicates a desire for control (Fiske & Depret, 1996). Although these interaction characteristics are mentioned in much of the literature, patient-centered communication is generally defined as *flexibility* in physicians' communication style that is adaptable to the individual patient rather than a checklist of behaviors (M. Stewart, 2001; M.A. Stewart et al., 2003). Still, these interaction characteristics have been associated with improved patient behaviors and outcomes, which are summarized in the next section.

2.4.4 Patient Health Behaviors and Health Outcomes

Patient-centered care, and good doctor-patient communication more specifically, have been positively associated with patient satisfaction with care (Ditto, Moore, Hilton, & Kalish, 1995; Roter, Hall, & Katz, 1987), patients' sense of control over their illness (Baker et al., 2005; D. S. Brody, Miller, Lerman, Smith, & Caputo, 1989; Harrington et al., 2004), reduced anxiety regarding their illness (M. A. Stewart, 1995), increased adherence to medical treatment (Ciechanowski, Katon, Russo, & Walker, 2001; DiMatteo, 1994; Korsch, Gozzi, & Francis, 1968), better quality of life (Kerr, Engel, Schlesinger-Raab, Sauer, & Holzel, 2003a, 2003b; Meredith, Orlando, Humphrey, Camp, & Sherbourne, 2001), and improvement in multiple chronic care outcomes (S. H. Kaplan et al., 1989; M. A. Stewart, 1995) in diabetes (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002), depression (Meredith et al., 2001), heart failure (Baker et al., 2005), and other chronic conditions (S. H. Kaplan et al., 1989). Critical reviews of the literature (Harrington et al., 2004; Mead & Bower, 2000; M. Stewart et al., 1999; M. A. Stewart, 1995) highlight the robustness of the association of good provider communication with patient satisfaction, adherence to treatment, and health outcomes (summarized in Figure 2a: Outcomes). Meredith and colleagues (2001) also suggest that patient perceptions of communication may be more important to self-management than participatory decision-making.

The pathway from good physician-patient communication to improved health behaviors and outcomes, described in detail in the next chapter, is largely attributed to the patient empowerment and sense of control that results from a patient-centered clinical encounter. This is supported by Michie, Miles, and Weinman (2003), whose systematic review of the literature on patient-centeredness in chronic illness care indicates that physician-patient communication characterized by patient activation/empowerment, as opposed to only eliciting the patient's viewpoint, is more consistently associated with improved health outcomes. Kaplan, Greenfield, and Ware (1989) also found that, out of multiple objective indicators of physician-patient communication (including physician and patient positive and negative affect, physician and patient information sharing, direction and exchange patterns, etc.), patient control was most substantially related to better health outcomes.

These findings are also consistent with the psychological literature on power and control, which indicates that people who experience power engage in action, show persistence, and expend effort toward goals, while powerless individuals display negative emotion and passivity (C. Anderson & Berdahl, 2002; Galinsky, Gruenfeld, & Magee, 2003; Keltner et al., 2003). In addition, individuals who feel that they can control their health live longer, experience better physical wellbeing (Taylor, 2008), engage in more preventive health behaviors (such as diet and exercise) and experience better health (Seeman & Seeman, 1983).

2.4.5 Existing Methods and Measurement

Patient-centered communication has been measured in a number of different ways with a multitude of different instruments. In medical schools, physician-patient communication is often measured using standardized patients, individuals who are trained to portray the role of a patient with a specific medical condition, or via direct observation by physicians (M.A. Stewart et al., 2003). In research settings, physician-patient communication has been studied using observation, communication interventions (pre-post or case-control designs), and randomized controlled trials. In addition, many different methods and instruments exist for measuring physician-patient communication. The types of measures are summarized in Table2.1 (Inui & Carter, 1985; Mead & Bower, 2000; M. A. Stewart, 1995).

In a review of patient-provider communication instruments, Boon and Stewart (1998) identified 44 distinct measurement instruments (as of 1996) related to either medical education or research with significant content overlap. These instruments fell into three, general categories: Observational measures, physician perceptions of physician-patient communication, and patient perceptions of physician-patient communication. Each method of measurement has significant advantages and drawbacks. The proposed project is concerned with patients' perceptions of communication with their physicians, and that method will therefore receive particular attention.

Table 1.1 Patient-Centered Communication: Types of Measurement

Methods	
Educational	Observational
Interventional	RCT
Type of Measurement of MD-Patient Communication	
Observational:	Direct observation
	Videotape
	Audiotape
	Transcript
	Standardized patients
Perceptual:	
Patient	Interview
	Survey, single-encounter
	Survey, General
Provider:	Interview
	Survey, single-encounter
	Survey, General

Both observational and perceptual measures of physician-patient communication have been employed in research. Physicians' perceptions of the care they deliver are less common, and observational measures of the clinical encounter (direct, video/audiotaped, or transcribed) and patient perceptions of their care are most common. In addition, patient perceptions of a single encounter versus general perceptions of communication with providers are hypothesized to measure distinct constructs (R. M. Epstein et al., 2005). Although observational measures have the great advantages of avoiding patient-level confounding variables and of objectively measuring aspects (dialogue, behaviors, etc.) of the physician-patient dyad, both parties likely change their behavior as a result of being observed (R. M. Epstein et al., 2005).

In addition, physician behavior does not directly drive patients' health. Rather, patients must *perceive* that they have power, input, and understanding in their interactions with physicians and translate that perception into health behaviors and outcomes (M. A. Stewart, 1995). Accordingly, "expert" ratings of physicians' communication with patients correlate only moderately with patients' perceptions (R. M. Epstein et al., 2005; M. Stewart et al., 2000). Moreover, using both observational measures and patient perceptions, Stewart (2000) found that patients' perceptions, but not observational indicators, were significantly associated with health outcomes. She subsequently reported that "the best way of measuring patient centredness is an assessment made by the patients themselves" (M. Stewart, 2001). Arora (2003) has echoed this, noting that observational measures may be inadequate in capturing the patient's perspective, which is what affects the patient's behavior and outcomes. Therefore, it is likely the case that patients' overall ratings of their care over time, rather than single clinical encounters, correspond to improved health in the long term. Nonetheless, Epstein and his colleagues (2005) warn that patients may be unable to distinguish between their global attitudes, satisfaction, and specific aspects of physician-patient communication. However, Meredith and others (2001) found that patients being treated for depression were able to assess distinct aspects of their care. Overall, triangulation of communication measurement methods is ideal, but patients' perceptions are an accepted way of measuring physician-patient communication and are increasingly used in national quality benchmarks, such as the National Committee for Quality Assurance HEDIS measures(National Committee for Quality Assurance (NCQA), 2008). However, studies that measure patient perceptions of communication need to control for patient-level confounders, including psychosocial variables, and employ a longitudinal design to difference out the effect of the potential, unmeasured individual confounders. This is particularly important given the discrepancy between observational studies, which find a consistent relationship between perceived communication and health, and the findings of randomized controlled trials with communication interventions, which are mixed at best (Griffin et al., 2004).

2.4.6 The unintended consequences of patient-centered care: Patient regret of medical decisions

In the framework of patient-centered care, medical decisions are assumed to be undertaken cautiously and with considerable attention to available information (R. M. Kaplan, Ganiats, & Frosch, 2004; Sheehan, Sherman, Lam, & Boyages, 2007). However, the complexity of these decisions combined with a sense of increased relative power and responsibility can potentially lead to regret among patients who feel that one or more of their treatment decisions were suboptimal. Additionally, patients are commonly dissatisfied with the information they receive, and many fail to achieve their preferred role in medical decision-making. In some decision-making scenarios, additional options can make a given situation less attractive rather than more so, and people may prefer another individual to make a decision for them (Beattie, Baron, Hershey, & Spranca, 1994). An increased number of alternatives can also create an "intractable information problem" and raise the standards of what defines a successful outcome, overwhelming the person. As a result, a "failure to meet those standards in a domain containing multiple options encourages one to treat failures as the result of personal shortcomings rather than situational limitations, thus encouraging a causal attribution for failure that [is] 'depressogenic'" (B. Schwartz et al., 2002). Accordingly, regret has received increased attention in the medical decision-making literature (T. Connolly & Reb, 2005; Terry Connolly & Zeelenberg, 2002; Kernan & Lepore, 2009; Smith, 1996).

Regret is a psychological construct defined as a negative cognitive and emotional state derived from comparing one's current state to what it might have been had one chosen a preferred, forgone alternative (Bell, 1982; Gilovich & Medvec, 1995; Loomes, Starmer, & Sugden, 1992; Loomes & Sugden, 1982; Marcel Zeelenberg & Pieters, 2004). Regret is characterized as (1) aversive and actively avoided, and (2) distinct from emotions such as guilt, disappointment, shame, and general negative affect (T. Connolly & Reb, 2005; van

Harreveld, Rutjens, Rotteveel, Nordgren, & van der Pligt, 2009). It results from intrapersonal harm (Berndsen, van der Pligt, Doosje, & Manstead, 2004) and thus tends to be strongly associated with a sense of responsibility or self-agency (i.e. power) for the aversive outcome as well as self-blame (Brehaut et al., 2003; Terry Connolly & Zeelenberg, 2002; Ordonez & Connolly, 2000; M. Zeelenberg, van Dijk, & Manstead, 2000).

Certain behavioral patterns are associated with regret. Experiencing regret may prompt a post-decision information search, whereby regretful individuals seek definite knowledge regarding the potential outcomes of forgone alternatives, even when the information has no actionable value (Shani & Zeelenberg, 2007). In addition, a temporal pattern of regret is apparent; people tend to regret actions in the short term, but regret inactions over the longer term (Gilovich & Medvec, 1995; Kahneman, 1995). Individual differences and the outcomes of prior, related events have also been shown to affect whether people have more regret over actions or inactions (Terry Connolly & Zeelenberg, 2002; Seta, McElroy, & Seta, 2001; Marcel Zeelenberg, van den Bos, van Dijk, & Pieters, 2002). Interestingly, people expect to regret acting against the suggestion of an influential other, such as a physician, more than they expect to regret compliance (and thus tend to act accordingly). In fact, regret is more likely to be experienced when faced with a loss following compliance rather than reactance (Crawford, McConnell, Lewis, & Sherman, 2002). Therefore, regret potentially looms large in any given patient-provider interaction.

2.5 Patient-Centered Communication: The case for breast cancer survivors

This dissertation examines the association between breast cancer survivors' perceptions of their communication with providers and their health behaviors and outcomes. The late effects of cancer treatment experienced by this population are often defined as chronic illnesses, but cancer survivors remain an understudied population in the literature on physician-patient communication. Therefore, the population characteristics and chronic health concerns of breast cancer survivors are outlined in this section.

2.5.1 Increasing population of breast cancer survivors

Breast cancer is the most prevalent non-skin cancer among women in the United States (National Cancer Institute, 2007). An estimated 12% of women will be diagnosed with breast cancer at some point during their lives (Ries, 2007). However, the death rate from breast cancer has declined over the past 15 years, and 88.6% of women who are diagnosed with breast cancer can now expect to survive 5 years or longer. This trend has resulted in more than 2 million women with a history of breast cancer living in the United States (Cimprich, Ronis, & Martinez-Ramos, 2002; Ries, 2007). In the San Francisco Bay Area of California, the 5-year relative survival rate from 1990 to 2004 was 98% percent for in situ disease and 92% for early-stage invasive cancer (Northern California Cancer Center, 2007). Moreover, breast cancer incidence rates in the Bay Area are higher than incidence rates in California in general (Cresswell, Gomez, Clarke, Keegan, & McClure, 2006).

2.5.2 Chronic health concerns of breast cancer survivors and the role of physician-patient communication

Although quality of life among breast cancer survivors is generally high (J. R. Bloom, Stewart, Chang, & Banks, 2004; Helgeson & Tomich, 2005), these women face unique challenges and chronic health concerns that result from the disease and its treatment (J. R. Bloom et al., 2004; Institute of Medicine, 2006). The health problems that breast cancer survivors face as a result of the disease and treatment are often understood as chronic illnesses (N. K. Arora, 2003; Institute of Medicine, 2006; Polinsky, 1994). These women are confronted by physical challenges, such as arm pain and lymphedema (Ganz et al., 2002), fatigue (Ganz & Bower, 2007), significant weight gain (Goodwin et al., 1998; Pinto et al., 2002), menopausal symptoms (van de Poll-Franse et al., 2006), impaired physical functioning (Satariano, Ragheb, Branch, & Swanson, 1990), and reduced cognitive functioning (Grunfeld, Dhesy-Thind, & Levine, 2005). In addition, survivors also experience increased psychosocial challenges involving social support, coping, and fear of cancer recurrence (Clough-Gorr, Ganz, & Silliman, 2007; Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Fobair et al., 2006; Helgeson & Tomich, 2005).

These health problems may lead to increased health care utilization in the long term (Mrozek & Shapiro, 2005). A failure to manage cancer-related chronic conditions, such as weight gain, may also increase the chances of developing comorbid illness and cancer recurrence (Carmichael & Bates, 2004; Pinto et al., 2002). In addition, the management of these ongoing health problems requires enduring behavioral change on the survivor’s part. For example, exercise and a healthy diet have been shown to reduce fatigue, enhance wellbeing among survivors, and aid in weight management (Brown et al., 2003; Ganz et al., 1996; Institute of Medicine, 2006). In accordance, the Institute of Medicine and policy-making bodies recommend ongoing management of these conditions as part of follow-up treatment for breast cancer (Grunfeld et al., 2005; Institute of Medicine, 2006) despite limited evidence on which to base clinical guidelines for survivorship care.

Additional problems reported by cancer survivors include navigating the health services delivery system. Ostensibly, breast cancer survivors can receive appropriate survivorship care from an oncologist or a primary care provider. However, women with breast cancer and cancer survivors report significant limitations to receiving survivorship care, and lack of good communication with physicians is a principal concern (Degner et al., 1997; Institute of Medicine, 2006; Jenkins, Fallowfield, & Saul, 2001). Although evidence depicting survivors’ healthcare experiences is scant (Institute of Medicine, 2006), existing research shows that cancer survivors, like other chronically ill patients, are not typically satisfied with the support they get from their providers regarding follow-up care (Carmichael & Bates, 2004; Institute of Medicine, 2006). Physician-patient communication during cancer treatment is often found to be suboptimal, and communication regarding survivorship care may be worse (Mallinger et al., 2005; Meropol et al., 2003). As evidenced by research on cancer patients and breast cancer survivors, women who experience poor communication with providers may experience greater depression and anxiety (J. Engel et al., 2003), decreased quality of life in the long term (J. Engel et al., 2003; Kerr et al., 2003a, 2003b), decreased satisfaction with care (Mandelblatt et al., 2003), and poor adjustment to their illness (N. K. Arora, 2003). In contrast, women who experience good communication with physicians sense greater control over their health, high satisfaction with their care (G. J. Kreps, 2003; Zachariae et al., 2003), more trust in their providers (N. K. Arora & Gustafson, 2008), and better knowledge regarding their illness (Maly, Leake, & Silliman, 2004).

Using evidence from preliminary qualitative research on physician-patient communication during breast cancer treatment, McWilliam and her colleagues (2000) at the

University of Western Ontario have developed a model of how provider communication shapes breast cancer patients' experience. Their model emphasizes the role of physician-patient communication in engendering a sense of control over the cancer, while poor communication creates negative affect. The model is also consistent with psychological research on power, which demonstrates that individuals who have power in a given context express more positive emotion, experience rewards (C. Anderson & Berdahl, 2002), perceive greater trust when expressing positive affect (Cameron Anderson & Thompson, 2004), and experience mental well-being and effective coping (Taylor, 2008). Moreover, communication training for physicians is shown to have positive effects on physicians' skills (Gysels, Richardson, & Higginson, 2004) and patients' participation in treatment (Street, Voigt, Geyer, Manning, & Swanson, 1995), making both patients' and physicians' communication skills worthwhile areas for research and intervention.

The importance of patient-centered communication in cancer care is further underscored by a recent proliferation of developments outlining current directions in cancer communication research (N.K. Arora et al., 2009; R.M. Epstein & Street, 2007). This work addresses patient-centered communication along the cancer care continuum, from screening to palliative care, and emphasizes the link between patient-centered communication and psychosocial outcomes, such as satisfaction, reduced depression, greater trust in providers, and control over health (N. K. Arora, Weaver, Clayman, Oakley-Girvan, & Potosky, 2009; Venetis, Robinson, Turkiewicz, & Allen, 2009; Vogel, Leonhart, & Helmes, 2009). However, authors highlight the need for longitudinal research on patient-centered communication. They also note the necessity for research on the pathways by which effective communication contributes to better health outcomes and promote a research agenda that emphasizes health outcomes and the identification of moderating variables (R.M. Epstein & Street, 2007; J. Street, R.L. et al., 2009). In accordance with these goals, this dissertation explores the links between communication, health outcomes, and patient-level confounding variables.

Gaining insights into (a) patient characteristics that are related to their perceptions of physician-patient communication and (b) the health-related consequences of good provider-patient communication may be especially relevant to breast cancer survivors for two reasons. First, women who develop breast cancer tend to be of a higher socioeconomic status (SES) than the general population, and higher SES individuals may weigh physician communication more heavily than lower SES individuals when determining whether to commit to a relationship with a provider (DiMatteo, Prince, & Taranta, 1979). Second, women (more than men) tend to cope with health-related stressors by seeking social support from others (Tamres, Janicki, & Helgeson, 2002). Existing research on physician-patient communication among breast cancer survivors demonstrates positive associations with patient satisfaction (Mallinger et al., 2005; Ong, Visser, Lammes, & de Haes, 2000), coping (Alder & Bitzer, 2003; McWilliam et al., 2000), self-efficacy (N. K. Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Han et al., 2005), and reduced traumatic stress during treatment (Han et al., 2005), as well as better quality of life in 5-year survivors (J. Engel et al., 2003; Ong et al., 2000). Still, no research has looked at the effects of perceived patient-provider communication on health behaviors and outcomes in breast cancer survivors over the long term.

2.6 Significance of the research

The body of research regarding physician-patient communication in cancer care is predominantly cross-sectional, focuses on the treatment phase of cancer, and concentrates on measures other than specific health behaviors and outcomes, such as patient satisfaction and psychological states. The few studies that have examined the association of physician-patient communication with health over time have measured communication at a single physician visit and observed depression and anxiety (J. Engel et al., 2003), quality of life (J. Engel et al., 2003; Kerr et al., 2003a; Ong et al., 2000), and satisfaction with care (Ong et al., 2000)over the long term. Notably, these studies have found positive effects of communication on these outcomes, although none has used panel data. Additional research that has looked at specific health measures, such as arm pain (Mandelblatt et al., 2003), used a cross-sectional design. Research that does not consider the late effects of cancer treatment, age-related changes in health and communication needs, or ongoing health behaviors and related outcomes does not appropriately address the challenges facing women who experience breast cancer as a chronic illness. In addition, research on physician-patient communication in breast cancer care necessitates a distinction between the treatment and survivorship phases of the illness and the development of corresponding hypotheses. The need for increased research in the area of survivorship (Institute of Medicine, 2006) and the need for longitudinal studies (N. K. Arora, 2003) that address provider interaction in cancer care are apparent.

In addition, little research has addressed the unintended consequences, such as regret, of patient agency and participation in the clinical encounter. Despite its importance in medical practice, regret is a relatively new area in cancer care research (T. Connolly & Reb, 2005; M. D. Schwartz, 2005). Although some research has examined factors associated with regret in breast cancer care, the study of regret among prostate cancer patients is more prevalent because the treatment choices have not been shown to improve survival and often have many side effects (Clark, Bokhour, Inui, Silliman, & Talcott, 2003; Davison & Goldenberg, 2003). In samples of prostate cancer patients, regret has been associated with poor quality of life, fear of recurrence, desiring more information from providers, and being of non-white race (Clark, Wray, & Ashton, 2001; Hu et al., 2008). In addition, regret is empirically distinct from dissatisfaction with care (Clark et al., 2001; Hu et al., 2008). The few studies that examine post-decision regret among breast cancer patients have noted a positive association with certain aspects of care, such as low participation in decision-making (Lantz et al., 2005) and dissatisfaction with information (Montgomery et al., 1999; Sheehan, Sherman, Lam et al., 2007), as well as psychosocial characteristics, such as poor body image and anxiety (Sheehan, Sherman, & Lam, 2007).

Notably, these studies have been largely cross-sectional, which may not accurately capture patterns of regret over the longer term (Lantz et al., 2005; Montgomery et al., 1999; Sheehan, Sherman, & Lam, 2007; Sheehan, Sherman, Lam et al., 2007). Also, these studies tend to relegate the measurement of regret to one aspect of treatment, usually primary surgery, prophylactic mastectomy, or reconstruction. Regret over other aspects of treatment, such as adjuvant therapies and physician choice, has not received yet attention in the cancer care literature. In addition, only regret over actions (mastectomy, breast reconstruction) has been studied; research to date has not considered regret over inaction (no mastectomy, not taking tamoxifen, etc.). Given these gaps in the literature, the project will examine the association of physician-patient communication with self-management of chronic health conditions using existing data from a cohort of young breast cancer survivors who have been followed over the 10 years since treatment.

CHAPTER 3. CONCEPTUAL FRAMEWORK AND HYPOTHESES

3.1 Introduction

The previous chapter summarized the theory and research to date on patient-centered communication, the relevance to breast cancer survivorship care, and regret as a possible unintended consequence of patient-centeredness. In this chapter, I synthesize the literature and draw on recent conceptual advances to outline the ways in which communication leads to improved health and state the resulting hypotheses. Although I cannot test all the possible pathways by which communication is hypothesized to affect health, the conceptual model links the literature to the hypotheses and places the analytical plan in a theoretical context. In this dissertation, I use longitudinal methods to examine the links between patient-provider communication and (a) patients' sense of control over their health (b) health behaviors, and (c) self-reported health outcomes. The study also examines post-treatment regret among breast cancer survivors and explores the link between patient-provider communication during treatment and regret at 5-year survival.

3.2 Pathways

In the past few years, increased attention has been paid to the pathways and causal mechanisms linking communication to health. Despite associations between provider communication and various psychosocial and health outcomes, communication has largely been a "black box" and has benefited from a recent proliferation of conceptual advances. This has led to some consensus on the functions of communication as well as the pathways by which communication is likely to lead to improved health.

3.2.1 The Functions of Communication

Building on previous models outlining the function of medical communication (Bird & Cohen-Cole, 1990; Lazare, Putnam, & Lipkin, 1995), Epstein and Street (2007) have outlined six essential functions of medical communication: fostering relationships, information exchange, making decisions, enabling self-management, responding to emotions, and managing uncertainty. Fostering relationships includes aspects of the clinical encounter such as rapport and trust. Information exchange involves data gathering and accurate diagnosis on the part of the physician as well as the provision of information to the patient regarding his or her illness and prognosis in an understandable manner. Decision-making involves the incorporation of patient values and preferences into treatment, and the process is "characterized by mutual engagement and participation" (p.27, Epstein and Street, 2007). Enabling self-management entails enhancing patient autonomy by supporting coping, encouraging patients to find information about their illness and to seek appropriate care, and improving patient empowerment and autonomy. Responding to emotions requires validating and legitimating patients' emotions surrounding their illness, showing empathy, and providing tangible help. Finally, managing uncertainty necessitates the promotion of probabilistic thinking and a positive attitude moving forward. This final component is essential to cancer survivorship care given the demonstrated gap between the end of cancer treatment and the transition to the survival phase (R.M. Epstein & Street, 2007; Institute of Medicine, 2006). The measure of physician-patient communication employed in this study reflects these fundamental aspects of communication although it does not explicitly cover all six aspects of communication.

3.2.2 Pathways to Proximal Outcomes

Proximal outcomes comprise the patients' psychological and emotional responses to the clinical encounter(s). These include satisfaction, trust, motivation, and a sense of control over one's illness (de Haes & Bensing, 2009; R.M. Epstein & Street, 2007; R. L. Street, Jr., G. Makoul, N. K. Arora, & R. M. Epstein, 2009). A patient's sense of the physician's emotional support, combined with a clear understanding of the illness and involvement in creating the treatment plan, engenders the proximal outcomes that create a cognitive and emotional state that is conducive to driving intermediate outcomes.

3.2.3 Pathways to Intermediate Outcomes

Intermediate outcomes involve the behavioral and social results of medical communication that mediate the relationship between proximal outcomes and health. These include quality medical decisions, seeking social support, commitment to the treatment plan, and proactive health behaviors/self-care (de Haes & Bensing, 2009; R.M. Epstein & Street, 2007; R. L. Street, Jr. et al., 2009). Adherence to health promoting activities is considered an essential stage between communication and health (R.M. Epstein & Street, 2007). However, a multitude of factors contributes to both health behaviors and outcomes, including patients' material resources and social environment, and medical communication represents only one facet of the ways in which social factors may affect health.

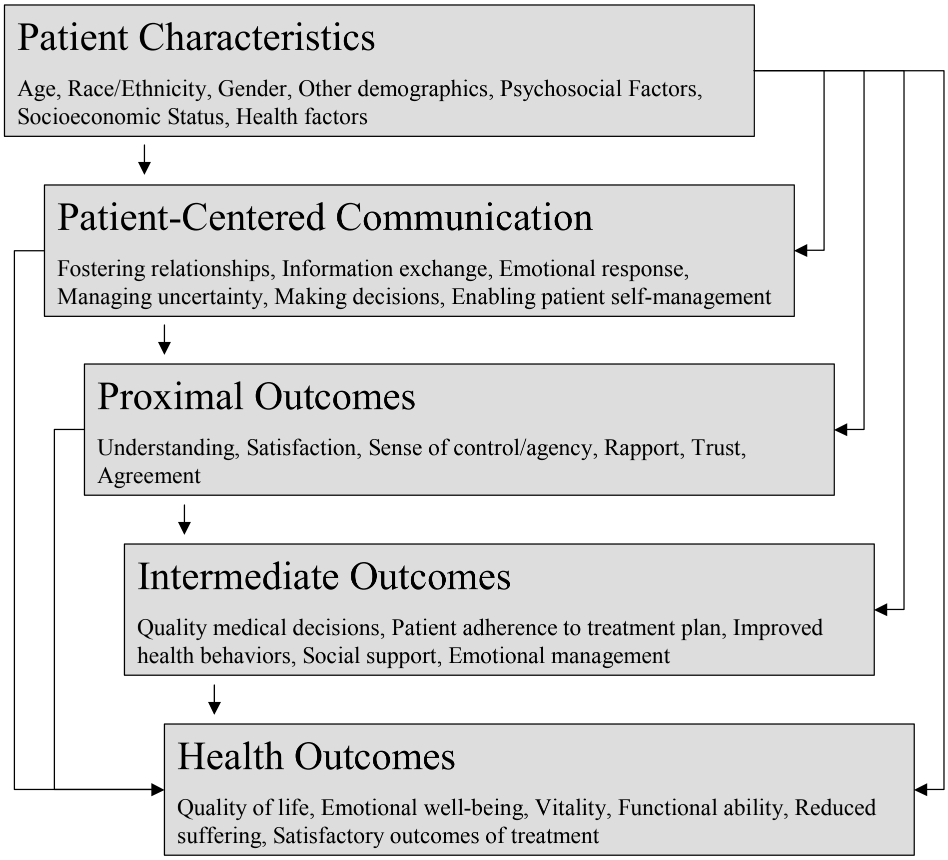
3.2.3 Pathways to Health Outcomes

Patient-centered communication leads to improved health both indirectly, via proximal and intermediate outcomes, and directly. Direct pathways by which communication might affect health outcomes include reducing physiological arousal and improving emotional well-being through therapeutic conversation (J. Street, R.L. et al., 2009) or by facilitating access to care by providing specific information on where and how to get care(R.M. Epstein & Street, 2007; Street Jr., Makoul, Arora, & Epstein, 2009). Communication can also lead to improved health outcomes indirectly through proximal and intermediate outcomes. As previously noted, if an effective medical communication improves the patient's sense of control over his or her illness and an understanding of contributing factors, the patient might then follow through with self-care and an improved lifestyle, which could lead to improved health and quality of life. This latter pathway is examined in this dissertation and provides the basis for the project's conceptual model.

3.3 Conceptual Model

The review of the theoretical and empirical literature presented in the last chapter and the pathways outlined above are synthesized in the conceptual model shown in Figure 3a. As illustrated, patient characteristics confound the relationship between medical communication and subsequent outcomes. Communication engenders improved outcomes both through proximal and intermediate outcomes, as well as through direct mechanisms. This dissertation examines these hypothesized pathways while controlling for potential patient-level confounders. In addition, I explore the association between patient characteristics and communication to identify groups of patients who may disproportionately experience poor communication with providers. Finally, I explore the incidence of regret among patients, who may face the unintended consequences of poor communication with providers in a culture that increasingly holds patients partially responsible for their own medical decisions.

Figure 3a. Conceptual Model



Adapted from Epstein & Street, Jr., 2007 and Street, Jr., et al, 2009

3.4 Hypotheses

In this dissertation, I examine physician-patient communication among long-term breast cancer survivors. Although I do not have measures of all of the variables in the conceptual model, I explore the pathways most relevant to the theoretical perspective of power outlined in the second chapter. Specifically, I explore the associations between physician-patient communication and (a) patients' sense of control over their health, (b) their health behaviors, and (c) health-related quality of life and body mass index. These associations are expected given propositions of power theory, which imply that better perceptions of provider communication lead to an enhanced sense of control over illness and better health behaviors and outcomes. In addition, empirical associations between communication and patients' perceptions of their illness, health behaviors and outcomes support the hypotheses. In addition, I examine the association between patient characteristics and communication, as well as regret among breast cancer survivors. Toward that end, I conduct cross-sectional and longitudinal analyses using data from the treatment period and 5-year survival and data from 5- and 10-year survival to discern the relationships among the variables of interest. The hypotheses related to this conceptual model and analytic approach are presented in this section.

After controlling for sociodemographic, health-related factors, and psychosocial characteristics, I hypothesize that women who report better physician-patient communication during treatment will report (1) greater sense of control over their health, (2) better health behaviors –more physical activity and a better diet, and, consequently, and (3) better health outcomes – less fatigue, better physical health, and better weight management at 5-year survival (Baker et al., 2005; D. S. Brody et al., 1989; Harrington et al., 2004; M. Stewart et al., 1999; M. A. Stewart, 1995). Because treatment represents a time during which women are in frequent contact with the healthcare system and are transitioning to survivor status, they may be especially receptive to information related to maintaining their long-term health during that time (Institute of Medicine, 2006).

Accordingly, I further hypothesize that women who report worse communication at baseline than at 5 years will have poorer sense of control/health behaviors/outcomes compared to both women who report good communication at the first two time points and women who report better communication at baseline than at 5 years; women who have poor communication at both time points will report the poorest sense of control/health behaviors/outcomes. This ranking is hypothesized due to the aforementioned salience of the cancer treatment phase; perceived communication at treatment may be more salient than 5-year perceptions of communication with respect to survivors' health.

Hypotheses: Patient-Provider Communication and Health among Survivors

H1a: *Women who report better provider communication during treatment will report (1) greater sense of control over their health, (2) better health behaviors and, consequently, (3) better health at 5-year survival.*

H1b: *Women who report better provider communication at 5 years than at treatment will have poorer outcomes at 5 years compared to both women who report good communication overall and women who report better communication at treatment than at 5 years; women who have poor communication at both time points will report the poorest outcomes.*

H1c: *At 5 and 10 years post-treatment, women with better provider communication will have (1) greater sense of control over health, (2) better health behaviors, and (3) better health outcomes.*

The final hypothesis concerns only the survivorship phase. I hypothesize that, at 5 and 10 years post-treatment, perceived quality of communication will have a positive association with (1) sense of control over health, (2) physical activity and a better diet, and (3) lower fatigue, physical health, and weight management after controlling for psychosocial, health-related factors, and sociodemographic characteristics. Because survivors experience long-term health concerns associated with their disease and treatment, I expect that their experience will resemble that of chronic illness patients, for whom communication has been linked to long-term self-management of their condition and health outcomes (Baker et al., 2005; D. S. Brody et al., 1989; Harrington et al., 2004; Institute of Medicine, 2006; M. Stewart et al., 1999).

Drawing on findings from studies identifying populations that disproportionately experience poor communication with providers, I explore the patient-level characteristics that are associated with provider communication problems. Given the evidence racial disparities in care and the low recognition of psychological comorbidities in clinical encounters, as well as the information disparity between physicians and patients with low health literacy, certain groups of survivors are likely prone to poor communication with providers (Cooper & Roter, 2002; Maly et al., 2004). Specifically, I hypothesize that racial/ethnic minorities, older, and less educated women as well as women with low self esteem, low social support, or a greater number of chronic conditions will report poorer provider communication.

Hypothesis: Patient Characteristics and Communication with Providers

H2: *White, younger, and more educated women as well as women with high self esteem, high social support, or fewer chronic conditions will report better provider communication at 5 and 10 year survival.*

Regret among patients is a new topic in cancer care and is particularly interesting given its relevance to increasing cancer survival and the trend toward patients' taking responsibility for medical decisions. Accordingly, regret is given a somewhat different treatment, including qualitative analysis, for which there are no hypotheses. For the quantitative analysis, I expect regret to be negatively associated with psychosocial indicators during treatment, including self-esteem and emotional support (Sheehan, Sherman, & Lam, 2007; Montgomery et al., 1999). Regret is also expected to be positively associated with worries about the future and problems with physician-patient interactions (Sheehan, Sherman, & Lam, 2007; Lantz et al., 2005).

Hypothesis: Patient-Provider Communication and Post-Treatment Regret

H3: *Regret at 5-year survival will be negatively associated with psychosocial indicators during treatment, including self-esteem, anxiety, and emotional support, as well as problems with provider communication.*

CHAPTER 4. METHODOLOGY

4.1 Overview

This dissertation emphasizes quantitative methods and hypothesis testing to evaluate the association between patient-provider communication and psychosocial/health outcomes. Because regret is a new area in cancer care research, an additional qualitative component is included in the analysis of post-treatment regret to enrich an understanding of the phenomenon and to aid model specification. This chapter outlines the methods used to conduct the quantitative analysis testing the stated hypotheses and describes the qualitative methods used to analyze post-treatment regret.

4.2 Study Setting

The project uses existing, de-identified data from the three waves of interviews with breast cancer survivors in the San Francisco Bay Area that took place during treatment (baseline), at 5-year survival, and at 10-year survival. Participants lived in one of five counties – Alameda, Contra Costa, San Francisco, Santa Clara, and San Mateo – at the time of the interviews. The Committee for the Protection of Human Subjects at UC Berkeley approved all recruitment and interview processes. Breast cancer incidence rates in the San Francisco area have historically been among the highest in the world and this area is therefore home to a large population of survivors (Cresswell et al., 2006). The project investigates survivorship care issues in women who were diagnosed at a young age and therefore underwent more extreme treatment. In addition, existing cancer survivorship research rarely stratifies results by age, and very few studies examine women who were diagnosed at a young age (J.R. Bloom, Stewart, D'Onofrio, Luce, & Banks, 2008). Moreover, young survivors experience the adverse consequences of their illness and treatment for a longer period of time and may suffer additional role limitations associated with their employment, family life, and activity level. They are therefore ideal for studying the late effects of treatment over the long term.

4.3 Description of Datasets and Sample Sizes

Women who were diagnosed with breast cancer at age 50 or younger were initially recruited through the Rapid Case Ascertainment Procedure (RCA) of the Greater Bay Area Cancer Tumor Registry ten years ago and were interviewed within the first seven months of diagnosis. All of the women in the sample were diagnosed between 1994 and 1997, prior to their 51st birthday. This was the first cancer diagnosis for all participants. Following protocol from the Greater Bay Area Cancer Tumor Registry, the research team sought permission from the physician of record to contact these women. Following physicians' assent, a letter was sent to each woman. Trained interviewers set up interview appointments with eligible participants. Data were collected via in-person interviews (between 30 minutes and 2 hours) from women with breast cancer during treatment. They were interviewed about their psychosocial, physical, and spiritual wellbeing. Questions about the women's sociodemographic status were also asked.

4.3.1 Baseline Participation

Half of the participants were interviewed within 2 months of their diagnosis, and the other half were interviewed 6-7 months following diagnosis. Seven hundred women were identified within 2 months of diagnosis. Of these, 137 were ineligible, 139 were not reached by the study deadline, 61 refused, 31 had scheduling conflicts, and 332 were interviewed. Of the 1659 women identified 6-7 months following diagnosis, 430 were ineligible, 392 could not be reached by the study deadline, 379 refused, 67 had scheduling issues, and 391 were interviewed. All regression analyses controlled for the difference in time since diagnosis.

4.3.2 Five Year Participation

Five years later, 12 % of women interviewed at baseline had died, 17% were lost to follow-up, and 9% refused to participate, resulting in a sample size of 449 for the "screening" interview, which determined eligibility for the full study. During the 5-year screening interview, women were asked about their regrets regarding treatment (Hypothesis 3). For the full interview at 5-year survival, women with new or recurrent cancers (N=64) were excluded, and an additional 74 women refused to participate, resulting in a sample size of 311 for the full baseline and 5-year interviews (Hypotheses 1a and 1b).

4.3.3 Ten Year Participation

Subsequently, the research team followed up with the women who participated at 5-years and conducted similar interviews via telephone at 10 years with 311 women who were cancer-free (Hypotheses 1c and 2). Additional recruitment of 5-year survivors who did not participate in baseline interviews occurred at the 5-year collection. Therefore, data were collected at the 5-year and 10-year points from individuals who did not participate in baseline data collection. The sample sizes and overlap in participation at the 3 waves are summarized in the chart below. Data collection for the 10-year wave began in June 2005.

Chart 4.1 Number of Survivors Who Participated at Each Time Point

Years interviewed	**1-5-10**	**1-5 screener**	**1-5 full**	**5-10**
N	191	449	311	311

Data for the project come from 311 breast cancer survivors who were interviewed at treatment and 5-year survival (Hypotheses 1a and 1b), 311 women who were interviewed at 5 years and 10-year survival (Hypotheses 1c and 2), and the 449 women interviewed at baseline who were queried regarding their post-treatment regrets 5 years later (Hypothesis 3).

4.4 Data Preparation

Data were received in multiple compressed files. All files were imported from SAS format into STATA version 10 using StatTransfer version 9. Baseline and 5-year datasets were merged according to common identifiers, and variable names were matched based on question content from the original questionnaires. Additional data manipulation was necessary to create dummy variables from categorical data and to create scales. Five-year data were appended to 10-year data using common variable names checked against the original interview content to ensure correct matching, thus creating two rows of data for each identifier (long form). An additional variable was created to distinguish 5-year data from 10-year data for each individual. Again, statistical coding was performed to create dummy variables from categorical data and to create scales.

4.5 Measurement

The measures used in this study are largely validated and commonly employed in the behavioral medicine literature. The psychometric properties of those measures that are less established are described in detail. The independent and dependent variables used in statistical analyses are described in this section.

4.5.1 Independent variables

4.5.1a Sociodemographic information Age at diagnosis, race/ethnicity (White, Black, Hispanic, Asian), marital status (married/partnered, single), education (high school or less, some college, college graduate or years of education), family income (5 and 10 years only), employment status (employed full-time or part-time, Not working), and insurance status (private, public, none) were collected during the interview. Potentially time-varying variables (marital status, family income, insurance status, and employment status) were measured at all time points.

4.5.1b Health and Treatment Related Variables Type of treatment (Chemotherapy, radiation, chemotherapy and radiation; tamoxifen, none), stage of disease at diagnosis (In-situ, local, regional/remote), and type of surgery (mastectomy-no reconstruction, mastectomy-reconstruction, breast-conserving surgery) were collected as part of the interview. A continuous variable indicating the number of chronic conditions (asthma, arthritis, diabetes, heart conditions, high blood pressure, gall bladder issues, and ulcers) is also included. Participation in support groups and workshops (the interventions associated with the study for which the data were initially collected) are included as dummy controls.

4.5.1c Perceived support from others Emotional support from others (non-physician) was measured at all time points using the Likert-type *Flamer Emotional Support Scale* (Flamer, 1977). The scale includes 11 items (range: 11-44) that assess whether the women feel that they have been able to rely on someone to provide basic emotional support over the past 3 months (e.g. “comforts me when I’m blue,” “makes me feel I am loved”). At the baseline measurement of the scale, the Cronbach’s alpha was 0.91, and principal component analysis indicated that the scale is one-dimensional (J. R. Bloom, Stewart, Johnston, Banks, & Fobair, 2001).

4.5.1d Patient’s self-esteem The Rosenberg Self-Esteem Scale (Rosenberg, 1965) measured women’s self-concepts at all 3 time points (range: 0-40). The instrument contains 10 items that are rated on a Likert-type scale, such as “I feel I am a person of worth, at least on an equal plane with others.” Together, the items assess feelings of self-worth and self-respect. The test-retest reliability is 0.85, and the scale negatively correlates with depression and shyness scales (Rosenberg, 1965; Silber & Tippett, 1965).

4.5.1e Regular Provider A dummy variable representing whether a woman has a provider that she normally sees for care is included in analyses using 5 and 10-year data with provider communication as the dependent variable.

4.5.1f Patient-provider communication Patient perceptions of patient-provider communication were measured at all time points using one of three factor-derived subscales from a problems scale developed by Schain, a researcher and breast cancer survivor (Schain, 1979). The subscale consists of four items that measure whether a patient has experienced difficulty getting information from a doctor, difficulty getting emotional support from a doctor, difficulty in understanding what doctors do or say, and uncertainty regarding doctors' medical decisions. The pairwise correlations at baseline were all significant and ranged from 0.45 to 0.60, and the items have been used in previous analyses (J. R. Bloom et al., 2004) as a count of problems ranging from 0 to 4. Communication is therefore entered in multivariable analyses as a count of the number of problems women have communicating with physicians.

For hypothesis 1b, which investigates the change in physician-patient communication, women were classified as having good communication with providers if they reported 2 or fewer problems communicating with physicians and poor communication if they reported more than 2 problems communicating with physicians. This categorical classification is important for evaluating any nonlinearity in the relationship between change in communication and 5-year outcomes.

4.5.1g Additional Independent Variables in Regret Analysis

Because regret is an aversive cognitive and emotional state and the regret analysis includes only baseline independent variables, four additional psychosocial covariates were included in the model to further account for women's emotional state during treatment. These additional covariates were not included in other analyses to avoid creating circularity in model variables. However, because regret is specific to cancer treatment (rather than a measure of health generally), the additional psychosocial model predictors were appropriate.

Mental Quality of Life: Subjective mental health-related quality of life during treatment was measured using the mental component of the SF-36, a standardized scale of self-reported health derived from the Medical Outcomes Study (range: 0-100) (J. E. Ware, Jr., M. Kosinski, & S. Keller, 1994). The widely-used measure is a composite measure of eight subscales constructed using factor weights and has been shown to have high construct validity, and reliability is generally high, exceeding 0.80 in most studies (Ware & Gandek, 1998).

Shared decision-making: Patients' participation in their surgical decisions was measured via two, multiple-choice questions. The first question elicited the patient's ideal level of participation in decisions (the doctor should make the decisions, the doctor should make the decisions but strongly consider my opinion, the doctor and I should make decisions together on an equal basis, I should make the decisions but strongly consider the doctor's opinion, and I should make the decisions). The second question assessed how the decisions regarding surgery were made using the same options phrased in the past tense. This variable was entered into the models both as two separate variables and as combined measures reflecting whether actual participation was congruent with preferences (versus more or less participation than desired).

Body Image: Women's body image was measured the second of three factor-derived subscales from a problems scale developed for breast cancer patients (Schain, 1979). The subscale includes four items that measure if women feel self-conscious (embarrassed) about their body, worry about their sexual attractiveness, feel less feminine, and find it difficult to look at themselves without clothing.

Worry about the future: Anxiety regarding the future was measured by one of three factor-derived subscales from a problems scale developed for breast cancer patients (Schain, 1979). The subscale includes three items that measure whether each woman worries about what will happen to her in the future, whether she has difficulty in planning for the future, and whether she thinks about how long she might have to live.

4.5.2 Dependent Variables

4.5.2a Health locus of control Two items administered at 5 years and 10 years measured women's health locus of control using a Likert-type scale (1-4). These items address whether women perceived a sense of control over their health and whether they felt their behaviors affect whether they get sick. These items indicate health locus of control and were derived from the *Multidimensional Health Locus of Control*, a widely used and validated instrument with high construct validity and Cronbach's alphas greater than 0.70 (Wallston, Wallston, & DeVellis, 1978). The two items were summed to create a scale where two indicates a strong sense of control over one's health and eight indicates a low degree of perceived control over one's health.

4.5.2b Health behaviors The behaviors included in the analysis were chosen because they require ongoing commitment on the part of the survivors, and non-adherence to these behaviors may contribute to cancer recurrence (Carmichael & Bates, 2004) and poorer overall health (Pinto et al., 2002). At 5 and 10 years, women's diet and nutrition were assessed using the *Food Screener*, which has been shown to effectively identify individuals with high fat diets and low fruit/vegetable intake (Block, Gillespie, Rosenbaum, & Jenson, 2000). The survey instrument measures how often women have eaten specific foods (e.g. beef, fried chicken, fruit juice, green salad) over the past four months. Composite scales for fat intake and fruit/vegetable intake were included in analysis, and are summarized in Table 4.1. The Fat Scale (15-75) consists of the sum of responses to 15 items in the questionnaire with responses ranging from 1 to 5. The Fruit/Vegetable Scale (6-30) consists of the sum of responses to 6 items in questionnaire with responses ranging from 1 to 5.

Table 4.1 Diet and Nutrition Items: Food Screener

Thinking about your eating habits of the past 4 months or so, about how often do you eat each of the following foods? Please tell me how many time a week or a month you usually ate it, using whichever time period is easiest for you:

Fat Scale: Hamburgers or cheeseburgers, Beef, Fried Chicken, Hot dogs/Franks, Cold cuts, Salad dressing/Mayo, Margarine or butter, Eggs, Bacon or sausage, cheese, Whole milk, French fries, Potato chips/corn chips/popcorn, Ice cream, Donuts/pastries/cake/cookies
Fruit/Vegetable Scale: Orange juice/Real fruit juice, Any fruit, Green salad, Potatoes, Beans, Other vegetables

Response Choices: Once per month or less, 2-3 times per month, 1-2 times per week, 3-4 times per week, 5-7 times per week, more than once per day

At 5 years and 10 years, items assessing women's physical activity asked how often women usually got at least 30 minutes of physical exercise such as walking, swimming, dancing, gardening, golf, tennis, etc., measured in days per week.[3]

4.5.2c Health outcomes The health outcomes chosen are hypothesized to result from adherence to the health behaviors (diet and exercise). Body mass index (BMI), is calculated at 5 years and 10 years as 703x(weight(lbs.)/height in inches^2) and serves as a reliable indicator of body fat (Centers for Disease Control and Prevention (CDC), 2007). Unfortunately, BMI is only available for a subset of 5-year participants (N=127), and analyses are therefore performed on this subset of data.

Health-related quality of life regarding fatigue and physical health were measured at 5 years and 10 years using specific physical health indicators from the SF-36, a general measure of self-reported health derived from the Medical Outcomes Study (J. E. Ware, M. Kosinski, & S. D. Keller, 1994). The widely used measure has been shown to have high construct validity, and reliability is generally high, exceeding 0.80 in most studies (Ware & Gandek, 1998). Analyses will be performed on three physical health subscales. The general health scale (5 items) includes items such as "my health is excellent" and "I expect my health to get worse" with responses rated on a Likert-type scale. The role limitations due to physical problems scale (4 items) queries whether women have had problems with work or regular daily activities as result of their physical health over the past 4 weeks. The energy/vitality scale (4 items) queries how women have felt over the past 4 weeks with respect to how tired they are and how much energy they have had. Summary scores were calculated following Ware et al. (1994), standardizing the raw scale score to a 0 to100 scale where 0 indicates worst possible quality of life and 100 indicates best possible functioning.

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[3] Using this variable as a continuous outcome in linear regressions was compared to results from ordinal logistic regressions. Results were very similar, and the results presented are therefore those of the linear regression.

4.5.2d Post-Treatment Regret

Five years following their diagnosis, women were asked the open-ended question, "Looking back, is there anything about your treatment that you would do differently?" This question emphasizes the identification of a preferred, forgone alternative. In addition, the question identifies the survivor as the responsible party with the phrase "that *you* would do differently," thus reflecting the theoretical definition of regret. The question does not contain the word "regret" to preclude further engendering the emotion. Responses to this question were analyzed qualitatively for content using an open coding approach and were also transformed into a dichotomous variable (1=regret, 0=no regret) for use as the dependent variable in multivariable models.

4.6 Analytical Plan

Data analyses were performed using STATA version 10 statistical software. Descriptive statistics and bivariate associations were computed for all variables used in the analyses, and the sample characteristics are presented prior to the associated hypothesis tests. Correlation matrices were calculated for the continuous outcome variables to discern the association between perceived control over health, health behaviors, and health outcomes. Linear regression analyses were used to analyze baseline and 5-year data, and a post-estimation correction of the standard error estimates accounts for potential heteroskedasticity (Huber, 1967; White, 1982). Hierarchical linear regression techniques were employed to analyze the true panel data at 5-year and 10-year survival. Fixed effects models were then compared to random effects models, and the final models were computed with standard errors clustered by individual. This approach accounts for the correlations between multiple observations on the same individual. The quantitative analysis on the regret variable, which is dichotomous, employs logistic regression. As previously mentioned, the question measuring post-treatment regret is also analyzed qualitatively. The qualitative methods are described prior to the quantitative approach to Hypothesis 3, given that the purpose of the qualitative analysis is to inform the quantitative approach.

Hypothesis 1a is tested using linear regressions to determine the association of patient-provider communication during treatment with 5-year outcome variables, controlling for baseline sociodemographic and health characteristics, treatment, self-esteem, and perceived social support. The models with the SF-36 subscales as the dependent variables control for the corresponding SF-36 scale score at baseline. Hypothesis 1b is tested by regressing the *change* in physician-patient communication from treatment to 5-years post-treatment on 5-year outcomes, controlling for changes in stable and time-varying sociodemographic and health-related characteristics, self-esteem, and perceived social support. Patient-provider communication is represented by dummy variables reflecting possible combinations of baseline and 5-year communication quality: good-good, good-poor, poor-good, and poor-poor; good-good serves as the reference category. The models are summarized in Table 4.2.

Table 4.2 Multivariable Regression Models: Hypotheses 1a and 1b

Model 1a: $E(Y|X,S,C) = \beta_0 + \beta_1 X_{BL} + \beta_2 S_{BL} + \beta_3 C_{BL} + (\beta_4 Y_{BL} +)\varepsilon$

Model 1b: $E(Y|X,S,C) = \beta_1 X_{BL} + \beta_2 S_{BL} + \beta_3[\Delta X] + \beta_4[\Delta S] + \beta_5[\Delta C] + (\beta_6 Y_{BL} +)\varepsilon$

$\mathbf{X_{BL}}$=vector of baseline sociodemographic and health-related characteristics,
$\mathbf{S_{BL}}$=vector of baseline psychosocial characteristics,
$\mathbf{C_{BL}}$=baseline perceived communication with physicians, entered as a 4-item scale,
$\mathbf{Y_{BL}}$=baseline SF-36 subscale score in models where the dependent variable is SF-36 score at 5 years

$\mathbf{\Delta X}$=vector of the changes from baseline to 5-years in sociodemographic and health characteristics,
$\mathbf{\Delta S}$= vector of the changes from baseline to 5-years in psychosocial characteristics,
$\mathbf{\Delta C}$=change in communication from baseline to 5-years in perceived communication with physicians, entered as a vector of dummy variables reflecting possible combinations of baseline and 5-year communication quality.

Notes: ε~iid; Y=5-year outcomes of interest: (1) Lack of Control over Health, (2) Fat Scale Score, Fruit Scale Score, and Physical Activity, and (3) BMI, SF-36 Subscale Scores

Using panel data at 5 and 10 years (time is indexed by j), hypothesis 1c is tested using linear regressions with a random or fixed effect for each woman (indexed by i). The random or fixed effect accounts for clustering between observations, in this case multiple observations taken from the same individual at two time points. These analyses determine the association of provider communication with health locus of control, health behaviors, and health outcomes in survivors while controlling for sociodemographic and health-related characteristics, self-esteem, and emotional support.

Studies demonstrating a strong association between communication and outcomes (proximal or distal) are observational and cross sectional and are therefore susceptible to unmeasured confounding by patient-level characteristics (personality, psychosocial variables, etc.). Therefore, for each dependent variable, I ran the cross-sectional model at 5 years and 10 years, respectively, to compare findings with existing research. Then, I run the longitudinal models, first without controls and then with controls, to try to discern the effect of the individual woman on the association between provider communication and the outcomes of interest. In addition, the random effects model is compared to the fixed effects (i.e., within woman) model.

In comparing the fixed effect model to the random effect model, I want to know whether significant correlation exists between the unobserved person-specific random effects and the regressors. If there is no such correlation, then the random effects model may be more powerful. If there is such a correlation, the random effects model is inconsistently estimated and the fixed effects model is the model of choice. To compare the fixed and random effects models, a Hausman test is thus employed (Hausman, 1978). Under the null hypothesis, both estimators are consistent, but the random effects estimator is more efficient. The Hausman test statistic ($\sim X^2$; length of b degrees of freedom) is computed as:

$$H=(b_{RE}-b_{FE})'(Var(b_{FE})-Var(b_{RE}))^{-1}(b_{RE-}\ b_{FE})$$

The results of the Hausman test are used to determine the preferred model, which is then run with clustered standard errors to account for within-person correlation. The models are summarized in Table 4.3.

Table 4.3 Multivariable Regression Model: Hypothesis 1c

Model 1ci: $E(Y_{i1}|X,S,C)= \beta_0+ \beta_1X_i+ \beta_2X_{i1}+ \beta_3S_{i1}+ \beta_4C_{i1} +\varepsilon_{i1}$
Model 1cii: $E(Y_{i2}|X,S,C)= \beta_0+ \beta_1X_i+ \beta_2X_{i2}+ \beta_3S_{i2}+ \beta_4C_{i2} +\varepsilon_{i2}$
Model 1ciii: $E(Y_{ij}|X,S,C)= \beta_0+\zeta_i+ \beta_1X_i+ \beta_2X_{ij}+ \beta_3S_{ij}+ \beta_4C_{ij} +\varepsilon_{ij}$

$\mathbf{X_i}$=vector of stable individual characteristics, included in random effects models only
$\mathbf{X_{ij}}$=vector of time-varying sociodemographic characteristics
$\mathbf{S_{ij}}$=vector of psychosocial characteristics
$\mathbf{C_{ij}}$= perceived communication with physicians

Notes: ε~iid for Model 1ci and 1cii; ζ_i represents either random or fixed effect; Random effect $\zeta_i \sim N(0, \Psi)$, where Ψ is the between-woman variance, and $\varepsilon_{ij} \sim N(0,\theta)$, where θ is the within-woman variance; Y=5-year and 10-year outcomes of interest: (1) Lack of Control over Health, (2) Fat Scale Score, Fruit Scale Score, and Physical Activity, and (3) BMI, SF-36 Subscale Scores

To test hypothesis 2, cross-sectional linear models are used with the 5-year data and 10-year data separately to determine the association of sociodemographic (e.g., race/ethnicity, age, income, education), health, psychosocial (self esteem and social support), and treatment characteristics with physician-patient communication (Table 4.4). A post-estimation correction of the standard error estimates accounts for potential heteroskedasticity. This identifies subgroups of survivors that experience systematically poorer communication with providers and worse chronic health problems.

Table 4.4 Multivariable Regression Models: Hypothesis 2

Model 2: $E(C|X,S,R)=\beta_0+ \beta_1X+ \beta_2S + \beta_3R +\varepsilon$

X=vector of sociodemographic and health characteristics
S=vector of psychosocial characteristics
R=whether the woman has a physician that she normally sees

Notes: ε~iid; Y=Outcome of interest: C=Number of problems communicating with physicians

Qualitative analysis associated with hypothesis 3 was used to examine the content of the open-ended question regarding regret (Maxwell, 2005). Responses to the question were analyzed via open coding of the data to identify substantive categories of what women regret about their treatment. I reviewed the data and developed a preliminary coding dictionary for response content in a manner similar to Clark, et al (Clark et al., 2003). Affirmative responses were coded for one or more regretted aspects of treatment, and a supplementary code was thus developed to code the number of factors each woman regretted. Because the question elicited a yes/no response, the coders needed to make minimal qualitative distinctions between affirmative and negative responses. Impossible counterfactuals of the type "if X treatment option had been available at the time I was diagnosed, I would have chosen it" were coded as "no regret."

Given the phrasing of the open-ended question, I was also concerned with whether the respondents expressed regret as defined theoretically. Although I was prepared for non-regret responses, such as dissatisfaction, in which women did not assume responsibility for the things they wished had been different (e.g., my doctor did X, which adversely affected me), women tended to phrase their responses beginning with "*I wish I had* chosen a different doctor…" or "*I would have* gotten a second opinion…," recognizing their role as a decision-maker and responsible party. Conversely, women who expressed no regret phrased their responses as, "I made the right decisions" and "I don't think so. I think they [providers] could have done some things differently…," revealing that the women perceived the question as an inquiry into their evaluation of decisions they made. The few responses that expressed dissatisfaction without self-blame were coded as "no regret."

In addition, responses were coded for whether women regretted an action, an inaction, or both (ambiguous/ listed something she would do instead of what she did choose) following Gilovich and Medvec (1995). The responses of women who expressed no regret were not coded for content because the interview protocol did not call for a prompt to elaborate on negative responses. As a result, the vast majority of the negative answers were a simple "no"; any elaboration was unprompted. Following the preliminary development of categories, a second coder reviewed 15% of the data and coded the content to establish interrater reliability and raise any identifiable issues. Differences were discussed and resolved, and the final coding dictionary was developed. I performed the final analysis, which informed the variables used in the quantitative analysis.

To test hypothesis 3, multivariable logistic regression was used to assess the association between baseline characteristics and regret five years later (Table 4.5). Regret is a dichotomous variable, and independent variables include sociodemographic, health, treatment, and psychosocial characteristics. The qualitative analysis of regret informed the model specification. Results are presented as odds ratios with corresponding 95% confidence intervals. Results of all analyses are presented in Chapter 5.

Table 4.5 Multivariable Regression Model: Hypothesis 3

Model 3: $\text{Logit}\{\Pr(Y=1|X,S,C)\}= \beta_1 X_{BL}+ \beta_2 S_{BL}+ \beta_3 C_{BL}$

$\mathbf{X_{BL}}$=vector of baseline sociodemographic and health-related characteristics,
$\mathbf{S_{BL}}$=vector of baseline psychosocial characteristics, mental quality of life, physical quality of life
$\mathbf{C_{BL}}$=baseline perceived communication with physicians, entered as a 4-item scale, and baseline participation in treatment decisions

Notes: ε~iid; Y=5-year outcome of interest: Post-treatment Regret

CHAPTER 5. RESULTS

5.1 Overview

Results from the analyses outlined in the previous chapter are summarized in this chapter. Although there is significant overlap between the samples used to test the hypotheses, hypotheses 1a and 1b involve a distinct sample from 1c and 2. In addition, hypothesis 3 uses a different sample from the other hypotheses. Therefore, descriptive statistics are presented prior to the multivariable analyses for each distinct dataset.

5.2 Provider Communication among Survivors at Baseline and 5-year Survival

5.2.1 Descriptive and Bivariate Statistics at Baseline and 5-year Survival

The demographic, health, treatment, and psychosocial characteristics of women who participated at baseline and 5-years are presented in Table 5.1. On average, women were 44 years old at the time of their diagnosis. Almost 74% of the sample was white, and Asians were the next largest racial/ethnic group (13%). Hispanics and black women each comprised about 6% of participants, with women of other racial backgrounds consisting of less than 2%. Women were well educated, with 57% having obtained a college degree or higher. At baseline, 80% of women were married or partnered, and this fell to about 72% at 5-year survival ($p<0.01$). Employment among survivors fell slightly, and the vast majority of women had private insurance coverage at baseline and at 5-year survival; consequently, this variable was dropped from multivariable analysis. As the women aged, the average number of chronic conditions increased from just under 1 to 1.2.

At baseline, 19% were diagnosed with in situ disease, 48% with local disease, and 33% with regional or remote cancer. Approximately 38% underwent only chemotherapy, 18% had radiation, and 12% had both. In addition, about 41% of women took tamoxifen during the years following treatment. Forty-seven percent of women had breast-conserving surgery. The remainder chose mastectomy; 28.8% chose reconstruction and 24.6% chose no reconstruction.

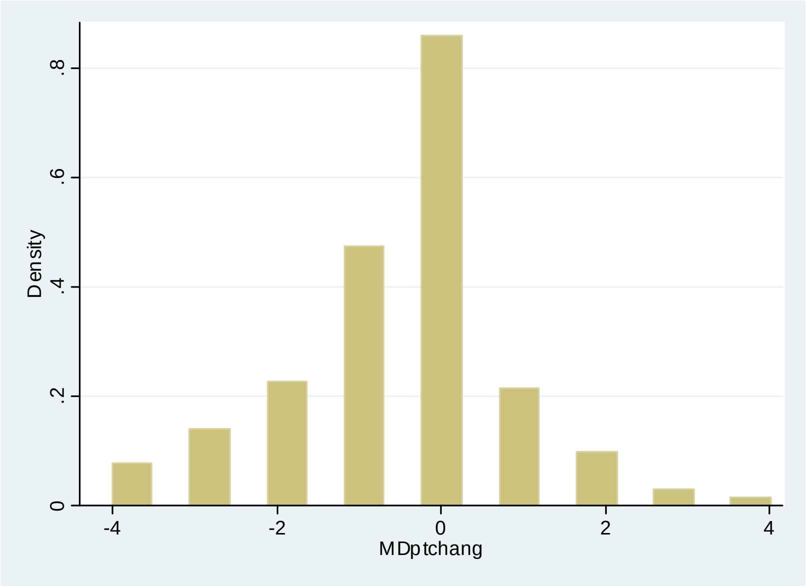
Table 5.1 Descriptive Characteristics of Survivors at Baseline and 5 years

	Baseline		5 years		
Demographic Characteristics	% or Mean	(SD)	% or Mean	(SD)	Sig. Diff.
Age at diagnosis	44.00	(4.89)			
White	75.08%				
Black	5.83%				
Hispanic	6.15%				
Asian	12.94%				
Less than college	1.94%				
Some college	41.10%				
College degree	56.96%				
Married	80.26%		71.84%		**
Employed	81.55%		81.23%		**
Private insurance	96.77%		98.05%		**
Public insurance	1.94%		1.94%		
Self pay	1.29%		0.97%		
# Chronic conditions	0.79	(0.92)	1.17	(1.11)	**
Stage at Diagnosis					
In situ	19.16%				
Local	48.05%				
Regional/Remote	32.79%				
Adjuvant therapies					
None	31.39%				
Chemotherapy	37.86%				
Radiation	18.45%				
Chemo+Radiation	12.30%				
No tamoxifen	59.22%				
Tamoxifen	40.78%				
Type of surgery					
Breast-conserving surgery	46.60%				
Mastectomy-reconstruction	28.80%				
Mastectomy-no reconstruction	24.60%				
Psychosocial characteristics					
Self-esteem (0-40)	34.12	(4.44)	34.67	(4.80)	*
Emotional support (11-44)	41.02	(4.35)	39.60	(5.28)	**
Problems communicating with MDs (0-4)	1.24	(1.39)	0.72	(1.16)	**

* p<0.05, **p<0.01

At baseline, women exhibited a mean self-esteem scale score of 34.1 and a mean emotional support score of 41.0. Self-esteem increased slightly in the survivorship phase, and perceived emotional support decreased slightly. In addition, survivors had more than one problem communicating with physicians on average, and this decreased a small amount to less than one problem on average at 5-year survival. Although most women experienced the same level of provider support at both time periods, some women's communication with providers changed. Specifically, 37.9% of women experienced good communication at both time periods, and only 2.6% of women suffered poor communication at both time periods. Sixteen percent of women experienced an improvement in communication with providers from baseline to 5-year survival, and 43% reported a decrement in communication. The variation in the number of problems experienced in communicating with physicians is shown in Figure 5a.

Figure 5a. Change in Problems Communicating with Providers: Baseline to 5 Years



The descriptive characteristics for women's beliefs about their control over their health, their health behaviors, and health outcomes are summarized in Table 5.2. Women reported that they felt a moderate amount of control over their health, averaging 3.6 on a scale from 2 to 8 where 8 reflects a lack of control over one's health. Survivors reported consuming a medium amount of both fats and fruits/vegetables, and they got 30 minutes or more of exercise almost 4 days out of the week. They reported high health-related quality of life, averaging 62.5 on the vitality scale, 82.4 on the physical role scale, and 76.4 on the general health scale. Women on average were slightly overweight, with a body mass index 26.6.

Table 5.2 Dependent Variables at 5-year Survival

Variable	Mean	(SD)
Lack of control over health (2-8)	3.63	(1.41)
Fat Scale (15-75)	30.20	(6.49)
Fruit Scale (6-30)	19.89	(3.98)
Exercise (days/week)	3.70	(2.50)
SF-36 Vitality (0-100)	62.51	(21.07)
SF-36 Physical Role (0-100)	82.44	(32.19)
SF-36 General Health (0-100)	76.38	(20.22)
BMI	26.60	(5.88)

Because the pathway from provider communication to health outcomes is hypothesized to occur via control and subsequent health behaviors, the correlations between the dependent variables are presented in Table 5.3. Contrary to expectation, the pairwise correlations are largely inconsistent. A perceived lack of control over one's health is significantly associated with fruit/vegetable and fat consumption, but not with exercise, and is associated with two of the four health outcomes – physical role functioning and general health. Fat consumption is associated with BMI, as expected, but not with the health-related quality of life measures. Fruit/vegetable consumption is associated with vitality, but not other outcomes, and exercise is significantly correlated with all outcomes with the exception of physical role functioning.

Table 5.3 Pairwise Correlations among 5-year Dependent Variables

	Lack of Control over health	Fat Scale	Fruit Scale	Exercise	SF-36 Vitality	SF-36 Physical Role	SF-36 General Health	BMI
Lack of Control over health	1							
Fat Scale	0.11*	1						
Fruit Scale	-0.12*	-0.08	1					
Exercise	-0.07	-0.20**	0.16**	1				
SF-36 Vitality	-0.08	-0.06	0.15**	0.21**	1			
SF-36 Physical Role	-0.15**	-0.09	-0.05	0.08	0.44**	1		
SF-36 General Health	-0.25**	-0.19	0.07	0.24**	0.47**	0.43**	1	
BMI	-0.09	0.41**	0	-0.37**	-0.11	-0.05	-0.15*	1

* p<0.05, **p<0.01

5.2.2 Multivariable Regressions at Baseline and 5-year Survival (Hypothesis 1a)

The results of the multivariable regression of baseline characteristics on 5-year health-related control, health behavior, and health outcomes are summarized in Table 5.4. Although the results of all independent variables in the models are presented, the relationship of interest is between problems communicating with providers and the health outcomes. That is, the question is whether women who report better physician-patient communication during treatment report (1) greater sense of control over their health, (2) better health behaviors – more physical activity and a better diet, and, consequently, and (3) better health outcomes – less fatigue, better physical health, and better weight management at 5-year survival.

Asians and less-educated individuals reported feeling less control over their health ($\beta=0.70(0.26)$; $p<0.01$). In addition, lower self-esteem was associated with feeling a lack of control over health ($\beta=-0.05(0.02)$; $p<0.10$). Provider communication was not associated with feeling a lack of control over one's health. Black women reported getting less exercise and consuming slightly fewer fruits and vegetables than white women. In addition, Asian women consumed fewer fatty foods and fruits/vegetables than white women. Radiation treatment and lower self-esteem were also associated with less fruit and vegetable consumption. Women with higher self-esteem also reported getting more exercise. Having problems communication with providers was not associated with any health behaviors.

Racial disparities were also present in the SF-36 quality of life measures. Relative to white women, black women reported lower vitality and general health, Hispanic women reported lower vitality, and Asian women reported somewhat lower general health. Higher education and more chronic conditions were associated with a lower quality of life. Local disease was associated with poorer physical role functioning relative to women who were diagnosed with in situ disease, and women who had chemotherapy reported marginally lower vitality and physical role functioning. Higher self-esteem was associated with somewhat better vitality and general health. More problems communicating with physicians was consistently and positively associated with poorer quality of life across all three measures, with effect sizes ranging from –2.4 to –5 ($p<0.05$ to $p<0.01$).

Overall, hypothesis 1a is partially supported, given the association between problems communicating with providers and the quality of life measures. However, the hypothesized pathway from communication to quality of life (psychological sense of control-behavior-outcome) is not supported. Rather, physician-patient communication and quality of life appear to be related via some other mechanism.

Table 5.4 Multivariable Regressions: Baseline Characteristics on Perceived Control over Health, Health Behaviors, and Health Outcomes (N=311)

	Dependent Variable															
	Lack of Control		Fruit Scale		Fat Scale		Exercise		SF-36: Vitality		SF-36: Physical Role		SF-36: General Health		BMI (phase 1 only)	
Demographic Characteristics	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE
Age at diagnosis	0.00	(0.02)	0.02	(0.05)	-0.08	(0.07)	0.02	(0.03)	0.10	(0.20)	0.56	(0.40)	0.49	(0.23)*	0.15	(0.12)
Black	0.00	(0.40)	-2.01	(1.09)†	2.11	(2.09)	-1.83	(0.65)**	-8.58	(4.50)†	-4.71	(9.12)	-6.71	(3.70)†	5.06	(2.74)†
Hispanic	0.04	(0.47)	-0.28	(1.06)	0.05	(1.79)	-0.46	(0.63)	-10.21	(4.76)*	-8.11	(9.40)	1.23	(4.73)	-2.30	(2.28)
Asian	0.70	(0.26)**	-1.56	(0.64)*	-3.87	(1.30)**	-0.33	(0.50)	1.73	(3.75)	-4.49	(5.68)	-6.79	(3.34)*	-1.05	(1.78)
Some college	-0.62	(0.43)	-0.88	(1.72)	-4.98	(3.69)	-0.99	(0.90)	-13.28	(7.97)†	-24.40	(6.43)**	9.67	(10.16)	-2.55	(3.08)
College degree	-0.94	(0.45)*	-0.02	(1.75)	-5.81	(3.71)	-0.90	(0.93)	-11.67	(7.87)	-18.30	(6.32)**	9.51	(10.14)	-2.48	(2.99)
Married	0.12	(0.12)	0.97	(0.63)	0.72	(0.96)	-0.21	(0.39)	-0.35	(2.94)	-2.87	(4.52)	1.49	(2.64)	1.38	(1.11)
Employed	-0.14	(0.23)	0.53	(0.60)	-0.77	(0.99)	0.41	(0.40)	3.66	(3.06)	0.51	(4.96)	3.68	(2.90)	-1.91	(1.78)
# Chronic conditions	0.01	(0.09)	-0.18	(0.26)	0.56	(0.42)	-0.08	(0.17)	-4.50	(1.41)**	-4.74	(2.15)*	-6.23	(1.45)**	0.21	(0.52)
Stage at Diagnosis																
Local	0.27	(0.26)	0.50	(0.66)	-0.08	(1.11)	0.19	(0.45)	1.88	(3.58)	-10.35	(4.56)*	-4.36	(3.26)	0.45	(1.57)
Regional/Remote	0.05	(0.33)	0.64	(0.86)	-2.46	(1.47)†	0.11	(0.55)	5.74	(4.71)	-2.34	(6.14)	2.46	(4.55)	-0.40	(2.07)
Adjuvant therapies																
None																
Chemotherapy	0.28	(0.25)	0.03	(0.73)	1.40	(1.21)	0.11	(0.45)	-6.48	(3.77)†	-9.99	(5.66)†	-5.67	(3.82)	0.27	(1.45)
Radiation	0.32	(0.25)	-1.81	(0.71)*	1.60	(1.27)	0.20	(0.52)	-2.49	(3.69)	1.28	(5.95)	-0.41	(3.60)	-1.43	(2.01)
Chemo+Radiation	0.61	(0.35)†	-1.57	(0.98)	-0.67	(1.44)	0.45	(0.58)	-3.19	(4.51)	-1.89	(6.71)	0.09	(4.09)	1.85	(2.62)
No tamoxifen																
Tamoxifen	0.09	(0.20)	0.42	(0.51)	-0.66	(0.84)	-0.46	(0.33)	-2.74	(2.60)	-2.44	(3.98)	-2.04	(2.44)	-0.58	(1.38)
Type of surgery																
Breast-conserving surgery																
Mastectomy-reconstruction	0.29	(0.22)	-1.05	(0.68)	0.91	(1.06)	0.43	(0.46)	3.00	(3.35)	-8.90	(5.96)	1.58	(3.21)	-3.02	(1.63)†
Mastectomy-no reconstruction	0.24	(0.23)	-0.30	(0.62)	1.66	(1.03)	0.17	(0.44)	3.22	(3.44)	-4.29	(5.37)	0.77	(3.29)	-0.11	(1.85)
Psychosocial characteristics																
Self-esteem	-0.05	(0.02)†	0.14	(0.06)*	-0.02	(0.09)	0.07	(0.03)**	1.19	(0.30)**	0.23	(0.47)	1.16	(0.28)**	0.07	(0.13)
Emotional support	-0.03	(0.03)	-0.03	(0.06)	0.03	(0.11)	0.00	(0.44)	0.10	(0.10)	0.58	(0.48)	-0.15	(0.26)	-0.02	(0.16)
Problems communicating with MDs	0.00	(0.06)	0.13	(0.16)	0.18	(0.26)	-0.06	(0.12)	-2.37	(0.98)*	-5.00	(1.47)**	-2.45	(0.89)**	-0.68	(0.45)
R-squared	0.12		0.13		0.15		0.07		0.20		0.16		0.27		0.20	

† p<0.10, *p<0.05, **p<0.01

All regressions control for participation phase; Reference categories: White, Less than college, Single, Unemployed, In situ stage at diagnosis, No chemo or radiation, No tamoxifen, breast-conserving surgery

5.2.3 Multivariable Regressions of 5-year Change from Baseline Characteristics and 5-year Survival (Hypothesis 1b)

The results of the multivariable regression of 5-year health-related control, health behaviors, and health outcomes on the change in characteristics from the baseline to 5-year measurement are summarized in Table 5.5. The question of interest is whether women who report worse communication at baseline than at 5 years have a poorer sense of control/health behaviors/outcomes compared to both women who report good communication at the first two time points and women who report better communication at baseline than at 5 years. In addition, I am interested in whether women who have poor communication at both time points report the poorest sense of control/health behaviors/outcomes.

Controlling for relevant baseline characteristics and changes from baseline to 5 years in those variables, the change in physician-patient communication was not associated with women's sense of control over their health. In addition, the change in physician-patient communication was not associated with health behaviors with the exception of women who reported improved communication at 5 years reporting slightly less fat consumption than women who experienced good communication with providers across the board. Women who reported improvement or decrement in their communication with providers did not differ in quality of life from women who reported good communication at both time points. However, women who reported universally poor communication with providers had significantly lower physical role functioning (β=-24.3(10.1); $p<0.05$) and general health (β=-12.6(5.6); $p<0.05$) than women who had universally good communication. In addition, among those women for whom BMI data were available (N=127), women who had poor communication with providers at baseline but not at 5 years had a slightly lower BMI.

Overall, hypothesis 1b is not supported. Although survivors who experienced poor communication with providers at both time periods reported poorer quality of life than those who experienced good communication at both time periods, the hypothesized pathway was unsupported once again. Provider communication was largely unrelated to the outcomes of interest. Although women who experienced poor communication at both time periods reported poorer physical role functioning and quality of life, this group comprised a relatively small number of women. The relationship between provider communication and the outcomes of interest is further explored in the next set of analyses.

Table 5.5 Multivariable Regressions: Change in Characteristics from Baseline to 5 years on Perceived Control over Health, Health Behaviors, and Health Outcomes (N=311)

	Dependent Variable															
	Lack of Control		Fruit Scale		Fat Scale		Exercise		SF-36: Vitality		SF-36: Physical Role		SF-36: General Health		BMI (phase 1 only)	
Quality of patient-provider communication (Baseline, 5 years)	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE	B	Rob. SE
Good-poor	0.07	(0.18)	-0.35	(0.53)	0.45	(0.85)	-0.33	(0.35)	0.04	(2.51)	-1.85	(4.01)	0.91	(2.04)	-2.01	(1.39)
Poor-good	0.28	(0.24)	-0.49	(0.70)	-2.31	(1.11)*	0.35	(0.45)	0.72	(3.27)	2.87	(4.76)	-2.07	(2.60)	-3.46	(1.58)*
Poor-poor	0.50	(0.57)	0.20	(1.53)	-0.95	(2.07)	1.46	(1.01)	-3.25	(6.61)	-24.34	(10.08)*	-12.58	(5.64)*	-0.84	(2.24)
R-squared		0.17		0.15		0.19		0.10		0.36		0.29		0.53		0.26

† p<0.10, *p<0.05, **p<0.01

Reference category: Good-good, i.e., good communication at both time points; Regressions also control for all time invariant covariates from previous regressions (age at diganosis, race, education, stage at diagnosis, treatment, surgery), the change in time-varying covariates (marital status, employment, chronic conditions, self-esteem, emotional support), and the baseline value of the 5-year dependent variable in regressions where the dependent variable is an SF-36 5-year measure.

5.3 Provider Communication among Survivors at 5 and 10-year Survival

5.3.1 Descriptive Statistics at 5 and 10-year survival

The characteristics of survivors who participated at 5 and 10-year survival are similar to those of women who participated at baseline and 5-years (Table 5.6). Women were 44.6 years old at diagnosis, and most were white (74.6%). The majority had attended some college or more at 5 years, and this increased at 10-year survival. The percentage of women who reported being employed decreased slightly from 5 to 10 years, and the vast majority of women made over 30,000 dollars per year at both time points. At their diagnosis, just over half of women had local disease, and almost 35% of women were diagnosed with regional or remote disease. The largest percentage of women underwent some combination of chemotherapy and radiation, and about 39% of women took tamoxifen for some period following their diagnosis. Forty-seven percent of women had breast-conserving surgery, and 29% had mastectomy with some type of reconstruction. Self-esteem stayed relatively constant from 5 to 10 years, as did emotional support. Women also reported slightly fewer problems communicating with physicians on average at 10 years (NS), having already reported less than one problem at 5 years.

Table 5.6 Descriptive Characteristics of Survivors at 5 and 10 years (N=311)

	5 years		10 years		
Demographic Characteristics	% or Mean	(SD)	% or Mean	(SD)	Sig. Diff.
Age at diagnosis	44.62	(4.70)			
White	74.60%				
Black	5.79%				
Hispanic	8.68%				
Asian	10.93%				
Less than college	33.44%		11.3%		**
Some college	37.62%		55.3%		
College degree	28.94%		33.4%		
Married	80.71%		78.80%		
Employed	81.03%		73.30%		*
Income $30K or less	5.37%		7.49%		
Income over $30K	94.63%		92.51%		
# Chronic conditions	1.59	(1.39)	1.55	(1.26)	
Stage at Diagnosis					
In situ	13.87%				
Local	51.61%				
Regional/Remote	34.52%				
Adjuvant therapies					
None	20.25%				
Chemotherapy	26.05%				
Radiation	20.90%				
Chemo+Radiation	32.80%				
No tamoxifen	61.41%				
Tamoxifen	38.59%				
Type of surgery					
Breast-conserving surgery	47.27%				
Mastectomy-reconstruction	28.94%				
Mastectomy-no reconstruction	23.79%				
Psychosocial characteristics					
Self-esteem	35.10	(4.64)	34.70	(4.45)	
Emotional support	39.92	(4.50)	39.78	(4.85)	
Has a usual doctor/provider	92.23%		91.32%		
Problems communicating with MDs	0.68	(1.14)	0.58	(0.95)	

* $p<0.05$, ** $p<0.01$

Table 5.7 Descriptive Characteristics of Survivors at 5 and 10 years

Dependent Variables	5 years Mean (SD)	10 years Mean (SD)	Sig. Diff.
Lack of control over health (2-8)	3.52 (1.35)	3.82 (1.24)	**
Fat Scale (15-75)	29.88 (6.19)	30.08 (6.67)	
Fruit Scale (6-30)	19.84 (4.03)	18.59 (3.55)	**
Exercise (days/week)	3.81 (2.46)	4.13 (2.36)	
SF-36 Vitality (0-100)	62.65 (21.41)	63.46 (19.94)	
SF-36 Physical Role (0-100)	82.07 (33.33)	80.79 (34.82)	
SF-36 General Health (0-100)	77.88 (19.67)	72.57 (19.87)	**
BMI	26.48 (5.58)	26.18 (4.97)	

* $p<0.05$, **$p<0.01$

Survivors at 10 years reported slightly less control over their health than they did at 5 years (Table 5.7). In addition, they consumed marginally more fruit at 10 years. Although vitality changed little, women's reports of their general health decreased slightly. Health-related quality of life remained high overall. Survivors remained slightly overweight.

Correlations among the dependent variables at 5-year and 10-year survival are presented in Table 5.8. Lack of control over health was negatively associated with fruit consumption at both measurements (but not with other health behaviors) and was negatively associated with the quality of life measures. Fat consumption was associated with BMI at 5 years, but not with other outcome variables. Fruit consumption was positively associated with exercise at both measurements and two of the quality of life measures – vitality and general health – at 5 years, but only general health at 10 years. Exercise was consistently associated with the health outcomes in both time periods in the directions expected.

Table 5.8 Pairwise Correlations among 5-year and 10-year Dependent Variables

5 years	Lack of Control over health	Fat Scale	Fruit Scale	Exercise	SF-36 Vitality	SF-36 Physical Role	SF-36 General Health	BMI
Lack of Control over health	1							
Fat Scale	0.07	1						
Fruit Scale	-0.18**	-0.02	1					
Exercise	-0.11	-0.08	0.20**	1				
SF-36 Vitality	-0.12*	-0.05	0.19**	0.26**	1			
SF-36 Physical Role	-0.14*	-0.09	0.05	0.15**	0.47**	1		
SF-36 General Health	-0.24**	-0.10	0.16**	0.27**	0.50**	0.49**	1	
BMI	-0.03	0.13*	-0.09	-0.12*	-0.18**	-0.21**	-0.22**	1
10 years								
Lack of Control over health	1							
Fat Scale	0.01	1						
Fruit Scale	-0.18**	0.06	1					
Exercise	-0.12*	0	0.21**	1				
SF-36 Vitality	-0.29**	-0.08	0.07	0.29**	1			
SF-36 Physical Role	-0.24**	-0.02	0.05	0.12*	0.53**	1		
SF-36 General Health	-0.41**	-0.05	0.13*	0.22**	0.65**	0.50**	1	
BMI	0.06	0.05	-0.03	-0.29**	-0.21**	-0.10	-0.20**	1

* $p<0.05$, **$p<0.01$

5.3.2 Multivariable Regressions at 5 and 10-year survival: True Panel (Hypothesis 1c)

The results of the analysis of the panel data appear in Table 5.9. The question of interest is whether, 5 and 10 years post-treatment, perceived quality of communication is positively associated with (1) sense of control over health, (2) physical activity and a better diet, and (3) lower fatigue, physical health, and weight management after controlling for psychosocial, health-related factors, and sociodemographic characteristics. For each dependent variable, seven models were run. The first two models represent the regressions for the two cross sections (5 years and 10 years, respectively). Fixed effects and random effects models with no control variables were then evaluated to examine the bivariate effect of provider communication on the outcomes of interest. Then, the fixed effects model and the random effects model were run with relevant covariates and compared using a Hausman test. The Hausman test determined consistency of the random effects model for two dependent variables – fat consumption and fruit/vegetable consumption. Finally, the preferred model (per the Hausman test result) is presented with standard errors that are clustered by individual to properly account for the within-woman correlation.

Table 5.9 Coefficients and Standard Errors for Independent Variable: Problems Communicating with Providers (N=311, 622 observations)

	Model 1 B(Rob. SE)	Model 2 B(Rob. SE)	Model 3 B(Rob. SE)	Model 4 B(Rob. SE)	Model 5 B(SE)	Model 6 B(SE)	Preferred
Dependent Variable	Cross section 5 years	Cross section 10 years	Random effects no controls	Fixed Effects no controls	Random Effects	Fixed Effects	Clustered SE
Lack of Control over Health	-0.03(0.07)	-0.08(0.07)	0.09(0.05)†	0.08(0.07)	-0.02(0.05)	0.06(0.07)	0.06(0.08) (FE)
Fruit/Veg. Consumption	0.46(0.19)*	0.26(0.21)	0.12(0.13)	0.04(0.17)	0.23(0.14)†	0.11(0.17)	0.23(0.14) (RE)
Fat Consumption	0.45(0.34)	-0.08(0.45)	0.13(0.24)	-0.34(0.31)	0.04(0.25)	-0.35(0.32)	0.04(0.28) (RE)
Exercise	0.43(0.12)**	-0.02(0.14)	0.07(0.09)	0.02(0.13)	0.15(0.09)	0.05(0.13)	0.05(0.14) (FE)
Physical Role Functioning	-4.35(1.78)*	-9.52(2.45)**	-6.73(1.27)**	-1.51(1.82)	-5.33(1.32)**	-0.93(1.88)	-0.93(1.83) (FE)
Vitality	-1.04(1.19)	-2.22(1.21)†	-2.06(0.71)**	0.26(0.88)	-1.15(0.71)	0.29(0.89)	0.29(0.77) (FE)
General Health	-2.29(1.02)*	-3.82(1.24)**	-3.37(0.68)**	-1.18(0.85)	-2.43(0.65)**	-0.98(0.87)	-0.98(0.97) (FE)
BMI	0.17(0.28)	-0.43(0.31)	0.23(0.12)†	0.28(0.13)*	0.21(0.12)†	0.25(0.13)†	0.25(0.19) (FE)

† p<0.10, *p<0.05, **p<0.01

Models 1, 2, 5-7 control for covariates: 5 year dummy, age at diganosis, race, education, income, stage at diagnosis, treatment, surgery, marital status, employment, chronic conditions, self-esteem, emotional support; Models 3-7 contain a 5-year dummy; FE=fixed effects, RE=random effects

Overall, hypothesis 1c is not supported. Provider communication was not associated with women's sense of control over their health. Consistent with results from previous studies, provider communication was sporadically associated with health behaviors and outcomes in the baseline-to-5-year analysis. However, the longitudinal models show a different picture. Provider communication was associated with two of the quality of life outcomes in the random effects models, but the effects in these models were deemed inconsistent. That is, there is significant, unmeasured confounding by individuals' characteristics that warrants the fixed effects approach. The preferred models with clustered standard errors show no association between provider communication and (a) women's sense of control over their health, (b) health behaviors, and (c) health outcomes. Rather, the significant effects in the baseline-to-5-year analyses and the analyses from hypotheses 1a and 1b appear to be driven by unmeasured confounding. Although the results of this analysis indicate no association between provider communication and the outcomes of interest, the inference from these findings is mitigated by the lack of variation in the variables using the fixed effects approach. That is, the fixed effects models limit the analysis to *within*-woman changes, thereby failing to consider between-woman variation. The implications for future research and the limitations of this analytic approach are discussed in the next chapter.

5.3.3 Multivariable Regressions at 5 and 10-year Survival: Medical Communication (Hypothesis 2)

The results of the analysis with provider communication (i.e., number of problems communication with physicians) as the dependent variable appear in Table 5.10. These models were run cross-sectionally to address the potential effects of race and age at diagnosis. The question of interest is whether racial/ethnic minorities, older, and less educated women as well as women with low self esteem, low social support, or a greater number of chronic conditions report poorer provider communication. The hypothesis is partially supported. Higher income was associated with fewer problems communicating with providers at 5-year survival, and having more chronic conditions was associated with more problems communicating with providers, which is consistent with previous findings. Being diagnosed with local disease 10 years earlier was associated with more problems communicating relative to women who were diagnosed with in situ disease. Higher self-esteem ($\beta=-0.04(0.02)/-0.03(0.01)$; $p<0.05$) and emotional support ($\beta=-0.04(0.02)/-0.05(0.01)$; $p<0.05$) were consistently associated with fewer problems with provider communication. No race, education, or age-related disparities were found.

Table 5.10 Cross-sectional Regressions on Problems Communicating with Providers (N=311)

	5 years	10 years
	B (Rob. SE)	B (Rob. SE)
Demographic Characteristics		
Age at diagnosis	-0.02 (0.02)	0.01 (0.01)
Black	-0.22 (0.30)	-0.08 (0.19)
Hispanic	0.18 (0.25)	0.21 (0.23)
Asian	0.03 (0.18)	0.10 (0.19)
Some college	-0.15 (0.15)	-0.06 (0.22)
College degree	0.24 (0.18)	-0.04 (0.23)
Married	0.33 (0.17)†	-0.05 (0.16)
Employed	0.15 (0.17)	-0.03 (0.13)
Income over $30K	-1.04 (0.39)**	-0.14 (0.23)
# Chronic conditions	0.05 (0.05)	0.11 (0.04)**
Stage at Diagnosis		
Local	0.26 (0.23)	0.37 (0.19)*
Regional/Remote	0.17 (0.27)	0.39 (0.24)
Adjuvant therapies		
Chemotherapy	-0.30 (0.23)	-0.28 (0.22)
Radiation	-0.03 (0.29)	-0.29 (0.25)
Chemo+Radiation	-0.26 (0.28)	-0.25 (0.27)
Tamoxifen	-0.10 (0.12)	-0.12 (0.12)
Type of surgery		
Mastectomy-reconstruction	-0.04 (0.24)	0.00 (0.22)
Mastectomy-no reconstruction	0.19 (0.24)	-0.32 (0.19)†
Psychosocial characteristics		
Self-esteem	-0.04 (0.02)*	-0.03 (0.01)*
Emotional support	-0.04 (0.02)*	-0.05 (0.01)**
Has a usual doctor/provider	-0.44 (0.32)	-0.01 (0.20)
R squared	0.18	0.15

† p<0.10, *p<0.05, **p<0.01

Reference Categories: White, Less than college, Single, Not working, Income $30K or less, In situ, No chemo or radiation, no tamoxifen, breast-conserving surgery, no usual provider

5.4 Baseline Characteristics and Post-Treatment Regret at 5-year Survival

5.4.1 Descriptive Statistics at Baseline and 5-year Screening Interview: Regret Analysis

At the time of treatment, participants were 44 years old on average, and were predominantly white (Table 5.11). The largest minority group in the sample was comprised of Asians (14.5%) followed by Hispanics (7.3%), and Blacks (5.8%). Eighty-two percent of women were married or partnered. Participants were well-educated, averaging 15.3 years of school, and the majority was employed either full-time (59.2%) or part-time (20.5%). Women had less than one chronic condition on average (0.8).

Approximately half of the women were diagnosed with local disease, 17.9% had ductal carcinoma in situ, and 32.4% had regional or remote cancer. Over half had a mastectomy with (29.8%) or without reconstruction (23.2%), while 47.0% chose breast-conserving surgery. The largest proportion of women had chemotherapy only (38.1%), and 17.1% had radiation only; 13.8% had both. Following primary treatment, 40.1% took tamoxifen for some period of time, and half of those women were still taking it at the time of the 5-year interview. Fourteen percent of women had a new or recurrent cancer five years after their primary breast cancer diagnosis.

Table 5.11 Demographic and health characteristics of women during treatment (N=449)

	% or Mean	(SD)
Age	44.0	(4.8)
Education (years)	15.3	(2.6)
Married	81.7%	
Chronic conditions	0.8	(0.96)
New or recurrent cancer	14.3%	
Race/Ethnicity:		
White	72.4%	
Black	5.8%	
Hispanic	7.3%	
Asian	14.5%	
Employment status:		
Works full time	59.2%	
Works part time	20.5%	
Not working	20.3%	
Stage at Diagnosis:		
In situ	17.9%	
Local	49.7%	
Remote or regional	32.4%	
Adjuvant therapy:		
No chemo or radiation	31.0%	
Chemotherapy	38.1%	
Radiation	17.1%	
Chemo and Radiation	13.8%	
Tamoxifen	40.1%	
Surgery:		
Mastectomy with reconstruction	29.8%	
Mastectomy no reconstruction	23.2%	
Breast-conserving surgery	47.0%	

While they were undergoing treatment, women exhibited a mean self-esteem scale score of 34.2 and a mean emotional support score of 40.9 (Table 5.12). They reported a mean mental quality of life score of 46.9 and a physical score of 45.9, and they expressed some worry about the future and body image concerns, averaging about two problems on each scale. In addition, they had more than one problem communicating with physicians on average. More than two thirds of women reported that they participated in treatment decision-making at the level they desired; 16.1% participated more than they would have liked, and 17.1% part participated less than they preferred.

Table 5.12 Psychosocial characteristics of women during treatment

	% or Mean	(SD)
Self-esteem (0-40)	34.2	(4.4)
Emotional support (11-44)	40.9	(4.3)
Worry about the future (0-3)	1.9	(1.0)
Negative body image (0-4)	1.7	(1.5)
Problems communicating with physicians (0-4)	1.2	(1.4)
Physical quality of life (0-100)	45.9	(9.4)
Mental quality of life (0-100)	46.9	(10.9)
Participated in surgical decision less than desired	17.1%	
Participated in surgical decision more than desired	16.1%	
Participated in surgical decision as much as desired	66.8%	

5.4.2 Qualitative Analysis of 5-year Post-treatment Regret

Five years after treatment, almost 43% of women expressed regret over some aspect of their treatment. Five percent of women regretted more than one aspect of treatment, with two aspects of treatment being the maximum number of regrets discussed (Table 5.13).

Table 5.13 Prevalence and content of regrets among young breast cancer survivors (N=449)

Regret:	
Yes	42.5%
No	57.5%
Of those women who regret some aspect of treatment (N=191)**:**	
Primary Surgery	24.1%
Chemotherapy/Radiation	21.5%
Reconstruction	17.8%
Problems with providers	13.1%
Pro-activity in care	10.5%
Tamoxifen/Hormone therapy	10.5%
Health habits/Self care	6.3%
Social Support	3.1%
Biopsy	1.6%
Hospital choice	1.6%
Clinical trial participation	0.5%
Women who regret 2 aspects of treatment	4.5%
Type of Regret	
Action	30.4%
Inaction	59.2%
Ambiguous/Instead	10.5%

Action versus inaction. Preliminary interrater reliability for the action/inaction/ ambiguous code was .81. Consistent with previous research on long-term regrets, the majority (59.2%) of participants who expressed regret did so over inactions (“I wish I had…”, “I would have…”) as opposed to actions (30.4%) (“I wish I hadn’t…”, “I wouldn’t have…”).

Regret of treatment. The regrets of the women in the sample sorted into eleven categories, and the percentage of the sample that regretted each aspect of treatment is summarized in Table 5.13. Interrater reliability for regret content was .96. The most common regret was associated with primary surgery. Typical responses included, “I would have had the other breast removed. My doctor talked me out of it at the time, and I gained weight with the chemo” and “I would have had a prophylactic mastectomy. I am unbalanced, and I do not miss my breast.” Some women who experienced a recurrence wondered whether a mastectomy would have prevented such an event. Other women said, “I would explore not having surgery” and

> “I don’t know if I would’ve had the mastectomy. Psychologically, it’s difficult. I’m still grieving the loss of my breast. I was in such a panic at the time. I worried that it would grow more. I think I may have done the lumpectomy.”

Women also regretted their adjuvant therapies. They regretted having chemotherapy because it caused premature menopause and side effects (e.g., “Yes, I would not have done the chemo. It made me worse and weakened my immune system. It caused thyroid infections. I can’t get rid of the achy bones” and “My cousin had the same thing. I would not have had radiation so I could radiate if I had a recurrence. I was not informed.”). In general, women felt ill-informed about the side effects and consequences of their treatment choices. Some of the women who expressed regret over having chemotherapy did not know beforehand that having children might not be possible in the future. Women also regretted not having chemotherapy and/or radiation (e.g., “The only thing I would’ve questioned: Was there any indicator the breast cancer was going to metastasize? I wonder if chemo would have prevented the metastasis.” and “I would insist on radiation. The oncologist told me I didn’t need it, but from my resources, I think it would be better.”). Less commonly, women voiced regret over taking or not taking tamoxifen. Some women regretted the side effects of taking it (“fatigue and body odor”), while others, particularly those with recurrent cancers, said they would have taken it or stayed on it longer.

Reconstruction was another very common regret, and women said, for example, “I would not have reconstruction because I have no feeling in [my breast] and sometimes I have pain in it,” and “I would have had the reconstruction earlier.” Regrets over flap reconstruction were particularly common due to the aesthetic result and the difficult recovery:

> “I possibly would not have gone with the TRAM flap. The stomach was what knocked me down for 7 or 8 months. The plastic surgeon should have given me more information on recovery and other issues regarding taking muscle and not just skin.”

Women also regretted significant problems communicating with physicians and said, “I would not have had the doctor I did. He had no bedside manner. He was awful.” and “I would have gotten a second opinion.” Women often mentioned physicians by name (e.g., “I would have picked a doctor who had more time. Dr. X did not see signs that I was having a bad reaction to chemo. My dose was too high. My neurologist knew what it was right away. If Dr. X took more time, he would have intervened sooner. The visits were too short.”). Although I did not code responses systematically, women who expressed no regret often spontaneously mentioned their positive physician-patient relationships as a contributing factor.

Many women wished they had been more pro-active in their care with respect to seeking information ("I would have pursued my suspicions sooner and been more assertive.") and having a better understanding of the long-term effects and side effects of their treatment options ("I wish I had been informed about the risks of lymph node dissection."). Less commonly, women regretted their health habits and self-care. For example, they wished they had taken more leave from work, improved their eating habits, and gotten more exercise. A small percentage of women regretted their choice not to solicit support from family and friends and were ambivalent about their decision not to join a support group. A small number of women also regretted their biopsy type (usually in cases of misdiagnosis) and their choice of a certain hospital for treatment or surgery. Only one woman wished she had considered participating in clinical trials.

5.4.3 Multivariable Logistic Regression of 5-year Regret on Baseline Characteristics (Hypothesis 3)

Bivariate Analysis

Bivariate analysis of regret at 5-year survival with characteristics during treatment is presented in Table 5.14. White women were slightly more likely to express regret than non-white women, and Asian women were less likely to regret. In addition, women with a new or recurrent cancer were significantly more likely to regret some aspect of their primary treatment than cancer-free women. Psychosocial characteristics during treatment that were associated with regret five years later included poor body image, worry about the future, problems communicating with physicians, and poorer physical quality of life. Pairwise correlations between psychosocial variables were moderate and did not exceed +/-.40. Therefore, multicollinearity was not expected to be an issue.

Table 5.14 Bivariate analysis of regret among breast cancer survivors

	Mean or %		
Demographic and health characteristics:	**Regret**	**No Regret**	
Age	43.9	44.1	
Education (years)	15.5	15.2	
Single	50.0%	50.0%	
Married or partnered	40.9%	59.10%	
Number of chronic conditions	0.9	0.7	
Cancer free	37.9%	62.1%	
New or recurrent cancer at 5 year survival	70.3%	29.70%	**
Race/Ethnicity:			**
White	46.6%	53.4%	
Black	50.0%	50.0%	
Hispanic	33.3%	66.7%	
Asian	23.1%	76.9%	
Employment status during treatment:			
Not working	46.2%	53.8%	
Works part time	42.4%	57.6%	
Works full time	41.1%	58.9%	
Stage at Diagnosis:			
In situ	41.2%	58.8%	
Local	42.8%	57.2%	
Remote or regional	42.8%	57.2%	
Adjuvant therapy:			
No chemo or radiation	48.9%	51.1%	
Chemotherapy	41.5%	58.5%	
Radiation	35.1%	64.9%	
Chemo and Radiation	40.3%	59.7%	
No tamoxifen	40.9%	59.1%	
Tamoxifen	45.0%	55.0%	
Surgery:			
Breast-conserving surgery	39.2%	60.8%	
Mastectomy with reconstruction	50.0%	50.0%	
Mastectomy no reconstruction	38.5%	61.5%	
Psychosocial characteristics during treatment:			
Self-esteem	34.1	34.2	
Emotional support	40.7	41.1	
Negative self image	1.9	1.6	*
Worry about the future	2.1	1.8	**
Problems communicating with physicians	1.4	1.0	**
Participated less than desired in surgery decision	46.5%	53.5%	
Participated as much as desired in surgery decision	41.4%	58.6%	
Participated more than desired in surgery decision	37.3%	62.7%	
Physical quality of life	44.6	46.9	**
Mental quality of life	46.1	47.6	†

† $p<0.1$ *$p<0.05$ **$p<0.01$

Multivariable Logistic Regression

A logistic regression with regret as the dependent variable (Table 5.15) revealed that Asian women, relative to white women, were significantly less likely to express regret 5 years after treatment (OR=.25; p<.001). In addition, Hispanic women were marginally less likely to have post-treatment regret (OR=.41; p=.07). Women with better physical quality of life were also somewhat less likely to regret (OR=.98; p=.06). With respect to psychosocial indicators, women who worried about the future (OR=1.32; p=.03) or had problems communicating with physicians during treatment (OR=1.26; p=.02) were more likely to regret some aspect of their treatment 5 years later. Finally, the odds that a woman with recurrent or new cancer expressed regret were almost 6 times those of a cancer-free woman (p<.001). No association was observed between regret and participation in decision-making, mental quality of life, self-esteem, emotional support, or body image. Regret was also not associated with types of treatment and surgery. The results presented shed light on the importance of cancer patients' psychosocial characteristics in achieving long-term, health-related wellbeing. However, the hypothesized pathways through which provider communication achieves health outcomes were largely unsupported. The implications of this project are discussed in the next chapter.

Table 5.15 Multivariable logistic regression of regret among breast cancer survivors (N=449)

Demographic and health characteristics:	**OR [95% CI]**
Age	0.97 [0.93, 1.02]
Education (years)	1.05 [0.95, 1.15]
Single	1.00
Married or partnered	0.75 [0.41, 1.36]
Number of chronic conditions	1.12 [0.87, 1.43]
Cancer free	1.00
New or recurrent cancer at 5 year survival	5.81 [2.86, 11.83] **
Race/Ethnicity:	
White	1.00
Black	1.16 [0.44, 3.04]
Hispanic	0.41 [0.15, 1.08] †
Asian	0.25 [0.12, 0.54] **
Employment status during treatment:	
Not working	1.00
Works part time	0.69 [0.34, 1.40]
Works full time	0.91 [0.51, 1.63]
Stage at Diagnosis:	
In situ	1.00
Local	0.85 [0.42, 1.69]
Remote or regional	0.73 [0.30, 1.79]
Adjuvant therapy:	
No chemo or radiation	1.00
Chemotherapy	0.93 [0.47, 1.85]
Radiation	0.72 [0.33, 1.60]
Chemo and Radiation	1.04 [0.43, 2.52]
No tamoxifen	1.00
Tamoxifen	1.27 [0.76, 2.13]
Surgery:	
Breast-conserving surgery	1.00
Mastectomy with reconstruction	1.58 [0.83, 3.04]
Mastectomy no reconstruction	0.86 [0.44, 1.69]
Psychosocial characteristics during treatment:	
Self-esteem	1.03 [0.97, 1.10]
Emotional support	0.98 [0.92, 1.04]
Negative self image	1.03 [0.86, 1.24]
Worry about the future	1.32 [1.02, 1.70] *
Problems communicating with physicians	1.26 [1.04, 1.51] *
Participated less than desired in surgery decision	1.00
Participated as much as desired in surgery decision	0.84 [0.46, 1.53]
Participated more than desired in surgery decision	0.66 [0.30, 1.46]
Physical quality of life	0.98 [0.95, 1.00] †
Mental quality of life	1.02 [0.99, 1.04]
LR Chi-sq.(28)=77.73; p<.0001	

† p<0.1 *p<0.05 **p<0.01

CHAPTER 6. DISCUSSION

6.1 Overview

This chapter discusses the results of the analysis in the context of existing literature on provider communication in cancer care. A discussion of each hypothesis is followed by a description of study limitations and a summary of findings. This chapter informs the implications for practice and future directions for research on the psychosocial aspects of cancer survivorship care.

6.2 Discussion

The overarching theme of this dissertation is to elucidate the role of provider communication in determining health and to evaluate the state of the conceptual literature and measurement of medical communication. Toward that end, hypotheses were tested surrounding the role of provider communication in determining health, individual characteristics that determine the quality of communication, and the experience of post-treatment regret among breast cancer survivors. These hypotheses are listed in Table 6.1.

Table 6.1 Hypotheses: Patient-Provider Communication and Health among Survivors

H1a: *Women who report better physician-patient communication during treatment will report (1) greater sense of control over their health, (2) better health behaviors – more physical activity and a better diet, and, consequently, and (3) better health outcomes – less fatigue, better physical health, and better weight management at 5-year survival.*

H1b: *Women who report worse communication at baseline than at 5 years will have poorer sense of control/health behaviors/outcomes compared to both women who report good communication at the first two time points and women who report better communication at baseline than at 5 years; women who have poor communication at both time points will report the poorest sense of control/health behaviors/outcomes.*

H1c: *At 5 and 10 years post-treatment, perceived quality of communication will have a positive association with (1) sense of control over health, (2) physical activity and a better diet, and (3) lower fatigue, physical health, and weight management after controlling for psychosocial, health-related factors, and sociodemographic characteristics.*

H2: *Racial/ethnic minorities, older, and less educated women as well as women with low self esteem, low social support, or a greater number of chronic conditions will report poorer provider communication.*

H3: *Regret will be negatively associated with psychosocial indicators during treatment, including self-esteem, anxiety, and emotional support, as well as problems with physician-patient interactions.*

I tested these hypotheses using data from breast cancer survivors during their treatment, at 5-year survival, and at 10-year survival. The results of baseline-to-5-year and longitudinal regression models provided limited support for the first two hypotheses and some support for the third. In addition, survivors by and large experienced good communication with providers, reporting few problems, and had high health-related quality of life.

6.2.1 Discussion of Hypothesis 1

Little support was provided for the hypothesis that physician-patient communication leads to improved health by engendering an increased sense of control over one's health, which, in turn, drives improved health behaviors. Rather, survivors' problems communicating with providers were associated only with the quality of life measures in the baseline-to-5-year models and were not associated with outcomes in the longitudinal models. However, the results of the longitudinal models should be interpreted cautiously, given that fixed effects models with a relatively small sample size lead to power problems. Because the fixed effects models limit the modeled variation to within the individual, there is less variation than is ideal given the sample size. However, the random effects models, which do not have the same problem of limited variation, showed some negative association (and a much larger effect size than the fixed effects approach) with two of the quality of life measures (physical role functioning and general health), but not with other outcomes.

Taken together, the results of the analyses related to hypotheses 1a through 1c do not provide support for the idea that provider communication empowers patients to modify health behaviors to improve their outcomes. This finding is consistent with existing research. Cross sectional findings among chronic illness and cancer patients consistently demonstrate a positive association between perceived provider communication and quality of life (J. Engel et al., 2003; Kerr et al., 2003b; Ong et al., 2000; M. A. Stewart, 1995). I replicated this finding with my cross-sectional analysis. Despite the strength of this association in the observational literature, a number of authors have noted the lackluster results of randomized controlled trials using communication interventions. Specifically, in a systematic review of communication interventions, Griffin found that fewer than half of trials demonstrated improved outcomes (Griffin et al., 2004; Street Jr. et al., 2009). Furthermore, Franks and his colleagues (2005) used multilevel analysis (patients clustered by physician) to determine whether patients experienced better outcomes as a result of their communication with physicians. Although they related perceived communication to improved health status, they found no effect at the physician level. The authors conclude that their results "reflect unmeasured patient confounding," a known shortcoming of measuring patient perceptions of communication (R. M. Epstein et al., 2005).

Similarly, the analysis presented here supports the idea that unmeasured patient characteristics may drive the association between communication and health that is so common in observational and cross-sectional research. In this project, the baseline-to-5-year association between communication and quality of life disappeared in fixed effects models, and provider communication within individuals did not vary hugely over time. Therefore, there is the potential for patient attributes, such as personality and psychological factors, to confound any observed association. These confounding factors have received increased attention in recent conceptual literature (J. Engel et al., 2003; R.M. Epstein & Street, 2007) throwing into relief the role of patients' personality characteristics, coping styles, and psychological morbidities in determining their perceived quality of provider communication. The analyses presented controlled for some of these characteristics, including self-esteem and emotional support, but were not exhaustive.

The findings presented here also deviate from the existing literature in notable ways. Some previous research has found a positive association between provider communication and health-related control or self-efficacy (Collie et al., 2005; Han et al., 2005; Zachariae et al., 2003), which was not replicated in this analysis. In addition, provider communication was not associated with proactive health behaviors, despite findings in the literature that suggest a link between provider communication and health behaviors, namely ongoing adherence to treatment. This discrepancy may exist because the control measures and health behaviors in this research are broader than those used in other studies. Specifically, control over health, diet, and exercise are general constructs that are not particular to alleviating any one identifiable condition. This suggests that provider communication may lead to improved proximal outcomes that are *disease-specific*, rather than improving behaviors and cognitions that are generally health-maintaining.

Overall, the results of this analysis signal a deliberate end to cross-sectional research in provider communication. Given the growing evidence for patient-level confounding and the abundance of potential moderating factors, evidence from randomized controlled trials should be treated as a springboard for careful and skeptical longitudinal and experimental research moving forward. Every patient desires satisfactory and fulfilling relationships with providers in times of ill health and uncertainty, researchers included. However, many factors affect health outcomes, and the possibility exists that patient perceptions of provider communication may simply be a reflection of patients' psychosocial attributes rather than an fundamental mechanism for improving health. As quality evaluation and physician payment are increasingly based in part on patients' evaluations of their care, better methods are essential for evaluating provider communication given that observational methods of provider communication correlate poorly with health outcomes.

6.2.2 Discussion of Hypothesis 2

In the analysis investigating the association between individual characteristics and perceived communication with providers, self-esteem and emotional support were consistently associated with fewer problems communicating with providers. In addition, there was some evidence that sicker survivors (i.e., those with more chronic conditions) and lower income women experienced poorer communication with providers. These results are consistent with existing research finding that lower income individuals experience poorer communication (DeVoe, Wallace, & Fryer, 2009) and that individuals with poorer health perceive worse communication with providers. This occurs because the sicker patient attributes poor health to poor care and/or because physicians find treating sicker patient less rewarding (Cooper & Roter, 2002), and lower income individuals may be less proactive in their health care (Jensen et al., 2009). Overall, the results of this analysis provide additional support for addressing the psychosocial aspects of cancer care. Perceived communication with providers was most associated with broad, psychosocial characteristics, further supporting the possibility that perceived communication with providers is a reflection of patients' psychosocial attributes rather than a credible assessment of physicians' communication skills.

Despite the evidence against communication's link with health and a lack of demonstrated sociodemographic disparities in communication, these analyses support the assessment and treatment of psychological morbidities in breast cancer care. This study adds to the growing body of literature showing an association between general psychosocial characteristics and aspects of cancer care, such as traumatic stress, anxiety, and adjustment to illness, that are associated with long-term wellbeing (Girgis et al., 2009; Han et al., 2005; Jensen et al., 2009; Venetis et al., 2009; Vogel et al., 2009). Patients' perceptions of their communication with providers appear to vary systematically with factors that are external to the clinical encounter. Therefore, patients' general psychological states may trickle into their specific perceptions of their care and their management of their conditions, mitigating the effectiveness of treatment. Addressing these psychosocial concerns in the context of cancer treatment and survivorship care should thus increase as a priority in the health care system.

6.2.3 Discussion of Hypothesis 3

Forty-three percent of the sample expressed regret of some kind. This is generally higher than the prevalence of regret reported in previous studies, which range from 6% to 23% (Clark et al., 2003; Clark et al., 2001; Crawford et al., 2002; Davison & Goldenberg, 2003; Hu et al., 2008; Montgomery et al., 1999; Sheehan, Sherman, & Lam, 2007; Sheehan, Sherman, Lam et al., 2007), with 47.1% reported in one study on prophylactic mastectomy (Sheehan, Sherman, & Lam, 2007). In this study, regret was measured using an open-ended question regarding treatment in general. In contrast, previous research has measured regret of a specific type, such as regret due to contralateral prophylactic mastectomy (Montgomery et al., 1999), regret following breast reconstruction (Sheehan, Sherman, Lam et al., 2007), and ambivalence regarding type of treatment for prostate cancer (Clark et al., 2003; Hu et al., 2008). Therefore, the measure in the current study likely captures a broader range of post-treatment regrets.

Qualitative analysis revealed that women make precise and detailed attributions regarding their post-treatment regret. Many regrets were expressed over treatment, surgery, and reconstruction. However, an overarching theme in the responses was dissatisfaction with preliminary information regarding treatment alternatives and adverse side effects. This is unsettling in light of California legislation mandating that such information be given to patients, usually in the form of a pamphlet. Accordingly, research on a single type of treatment regret may fail to capture the range of treatment characteristics that can trigger regret. In this sample, regrets over inaction were most common. Women regretted not having mastectomies, failing to get second opinions, and neglecting to participate in their care. This finding is consistent with the temporal pattern of regret found in previous research (Gilovich & Medvec, 1995). However, the action/inaction distinction and the relative prevalence of regrets over inactions are novel findings in cancer care. Rather, research has focused on decisions made, such as having a prophylactic mastectomy and choosing breast reconstruction. This suggests a significant gap in the cancer literature on regret that warrants attention in future research, namely attention to regret over the failure to take action. This also underscores the significance of the results presented to the literature on post-treatment regret. Future research on post-treatment regret may focus as much on opportunities forgone as mistakes made.

Connolly and Reb (T. Connolly & Reb, 2005) have outlined additional research priorities for cancer-related regret. They underscore the importance of understanding the role of anticipated regret in decision-making and the function of other aspects of the decision-making process, such as information gathering, in predicting regret. They also offer suggestions for regret reduction. For example, regret reduction could occur by identifying less damaging comparisons for patients experiencing regret and by developing clear decision justifications at the time a choice is being made. On the whole, additional research with implications for practice is needed to address the psychosocial concerns of cancer survivors.

From the results of the logistic regression, possible ethnic and cultural differences in regret are apparent. In previous work, minority groups have been grouped together as "non-white" (Hu et al., 2008; Lantz et al., 2005) or the work has been done outside the United States (Sheehan, Sherman, & Lam, 2007; Sheehan, Sherman, Lam et al., 2007). As a result, there is little information on possible cultural patterns in post-treatment regret. One possible explanation for these findings may be captured in unmeasured aspects of decision making, such as including family in medical decisions. In this case, women of certain ethnic backgrounds might be reluctant to counter the wishes of family. Also, there may be certain cultural norms against expressing regret. For example, dwelling on the past might be socially unacceptable or complaining after surviving a severe illness could indicate ingratitude. Still, additional research is necessary to better qualify cultural contributors to regret.

Patients' level of participation in decision making was not associated with regret in the sample. Although previous work by Lantz and her colleagues (Lantz et al., 2005) found an association between participation in decision-making and regret in breast cancer care, that study was more narrowly focused and did not include other relevant psychosocial covariates. Despite the fact that the decision-making roles of physicians and patients were not associated with patients' subsequent regret in the current study, problems with physician-patient communication during treatment did have persistent effects over the survival period with respect to regret. This is expected given the findings of existing research on physician-patient communication. Generally, better physician-patient communication is associated with physician-patient agreement on treatment (Flocke et al., 2002; Krupat et al., 2001), physicians' giving more information to the patient (Flocke et al., 2002), and expressing positive emotion (Griffin et al., 2004; Mead & Bower, 2000). Accordingly, problems communicating with physicians could impede positive experiences during treatment, leading to regret later in life.

Worrying about the future during treatment was also positively associated with regret five years later. This is consistent with previous work that has shown an association between anxiety and regret (moderated by coping style) among breast cancer patients (Sheehan, Sherman, Lam et al., 2007). Anxiety during cancer treatment is expected. However, the psychosocial needs of breast cancer patients may require additional consideration by healthcare providers, particularly given the long term emotional consequences for women who experience an undue burden of anxiety while making medical decisions.

Finally, regret is much more prevalent among women with recurrent disease than cancer-free women. Although screening for psychological morbidity in cancer care has received increased attention in recent years (Institute of Medicine, 2008), addressing the unique needs of women with recurrence has been the subject of less research. People with recurrent cancer, despite their considerable coping skills and resilience (Bull et al., 1999), report poorer health, more hopelessness, and more social difficulties than individuals with newly diagnosed disease (Cella, Mahon, & Donovan, 1990; Northouse et al., 2002; Okamura et al., 2000). The research presented here also suggests that these women may disproportionately identify faults and experience subsequent self-blame when reflecting on their primary treatment. Accordingly, programs and interventions designed for people with recurrent cancers may be needed to address the mental health needs of this vulnerable population (Northouse et al., 2002).

Contrary to previous work on regret in cancer care (Sheehan, Sherman, & Lam, 2007), no association was observed between post-treatment regret and psychosocial characteristics, such as body image and mental health during treatment. This may be due to the fact that regret was measured five years after treatment, rather than simultaneously. Regret is likely to be a mutable cognitive-emotional construct (Gilovich & Medvec, 1995; Marcel Zeelenberg et al., 2002), and psychological factors that are associated with regret in the short-term may not have persistent relationships with regret over the longer term. Further research is needed to better understand the temporal patterns of regret in cancer survivors and the associations with psychosocial factors (J. R. Bloom, 2008).

6.3 Limitations

This work should be interpreted with attention to certain shortcomings. The participants were aged 50 or less at diagnosis and were recruited from a specific region of the United States. Therefore, findings may not be generalizable to older women or women from other geographic areas. In addition, women were asked about their health and post-treatment regret five years following treatment, creating potential bias due to loss to follow up and death. Nonetheless, using variables measured during treatment to predict later outcomes represents an improvement over cross-sectional research. Additionally, there is no information on the characteristics of women who refused to participate.

A significant limitation of the project has to do with the measurement of the constructs studied. Given that just four communication items were collected, the measure used may fail to capture the scope of the patient experience. Moreover, the communication items reflect the cumulative perceptions of the women's experiences with providers and do not distinguish between a positive experience with one provider and a negative experience with another. Future research should specifically address how multiple encounters with different providers affect patients' health over time.

Additionally, there are no explicit measures of patients' power in the proposed study. Rather, power is inferred from the literature on its corollaries, which include positive affect, acquiring health-related information, and the perception of respect. While this is consistent with previous research on physician-patient communication, this is a significant conceptual limitation of the proposed study and of the current body of research. As previously noted, the hypothesized pathway from patient-provider communication to health outcomes would benefit from additional theoretical development with respect to patients' emotions, cognitions, and perceptions of power and control.

The measure of control considered in the proposed study is particularly weak. Of an 18-item scale, only two items were administered, limiting the validity of the measure. In addition, locus of control is treated in the psychological literature as a relatively stable, global belief of the individual. In contrast, self-efficacy, or the belief, is considered to be more flexible and highly susceptible to experiential influence (such as communication with providers). Therefore, health-related self-efficacy would be a more appropriate dependent variable in the proposed project. However, health locus of control has previously been used as a dependent variable in multiple patient-provider communication studies as a measure of patients' perceived control over their illness, and significant associations have been found (Harrington et al., 2004).

As previously noted, the sample size and the fixed effects approach do not allow for distinction between a null result and low power with respect to inference from the lack of association between communication and the outcomes of interest. Given the sample size of the project, low power in the longitudinal models is highly likely. Also, despite some advantages of panel data in making more robust inferences, only correlation, not causation, can be found in the proposed work. In addition, the use of subjective measures leaves open the possibility of patient-level confounding. Because of this and the omission of physician characteristics, the models proposed are susceptible to omitted variables bias. For example, survivors' general information-seeking propensity as a coping mechanism was not measured. Miller's (1995) work has shown that some people cope with health-related stressors by seeking information ("motivators") while others ("blunters") cope via avoidance. Motivators may experience better communication and better health (Miller, 1995; Ong et al., 2000), and the omitted variable may therefore bias the communication coefficient upward.

Potential omitted variables also include personality characteristics that may contribute to a propensity to regret. Further research taking into account individual differences is necessary to better understand the psychological underpinnings of post-treatment regret in cancer survivors. However, regret in the sample was not correlated with self-esteem, a relatively stable construct, nor was it associated with body image complaints. This suggests that post-treatment regret may be relatively situation-specific. In addition, women did not use the open-ended regret question to vent about the problems with their treatment. Rather, they made concrete, specific statements regarding what they would change about their treatment.

A final limitation of the research involves the measure of regret. Because the question does not contain the word "regret," there remains the possibility that the respondents expressed an emotion other than regret, such as dissatisfaction, that does not include self-blame. However, given the phrasing of the responses ("I would have…, I wish I had…"), this is unlikely. The open-ended question is effective in identifying the scope of post-treatment regret and the action vs. inaction distinction. However, it does not directly target the intensity of regret. A Likert-type item or scale would better measure intensity. Still, published scales that purport to measure regret also have significant shortcomings (Brehaut et al., 2003; Clark et al., 2001). Continuous scales may not make a discernable distinction between individuals who have regret and those who do not (Clark et al., 2001). In addition, some of the items do not capture the responsibility and self-blame associated with regret and have been omitted from the scale in empirical studies (Diefenbach & Mohamed, 2007). The measures are also contingent on a specified treatment related decision and therefore neglect both the scope of post-treatment regrets and regrets over inaction. A more appropriate measure of regret may combine an open-ended question with supplementary Likert-type items.

6.4 Strengths of the Study

Notwithstanding these limitations, the conceptual contribution of the proposed study involves interfacing the psychological literature on power and control with the patient-centered care conceptual framework in order to better define the pathways from physician-patient communication to health. In addition, the findings of this study identify some of the psychosocial characteristics of breast cancer survivors that are associated with physician-patient communication. The results also suggest that survivors' perceptions of provider interactions are associated with health in ways that are largely confounded in the literature. Evidence is provided for (a) better study design in communication research in cancer care and (b) interventions aimed at improving survivorship care, such as communication skills training and psychosocial counseling for survivors. In a literature review of physician-patient communication in cancer care, Arora (2003) highlights the impact of provider communication on cancer patients' health. He also underscores the benefit of framing cancer as a chronic illness and has stressed the role of medical communication in his own experiences as a survivor (N.K. Arora, 2009). In addition, recent reports published by the Institute of Medicine (Institute of Medicine, 2006, 2008) emphasize medical communication as an important area for quality improvement in cancer care. Overall, evidence is mounting for the importance of physician-patient communication in quality cancer care, but continued research in this area is needed to better understand what the role provider communication plays in improving health and wellbeing.

CHAPTER 7. CONCLUSION

7.1 Overview

In general, the results of this research inform the psychosocial aspects of cancer care. This chapter summarizes the implications for practice and future research that stem from the results of the study. Concluding statements are also presented.

7.2 Implications for Practice

Overall, the results of the analysis do not support the idea that good communication with providers engenders a sense of control over health, which then leads to improved health behaviors and outcomes. Rather, the results indicate significant unmeasured confounding by patients' psychosocial characteristics in existing research that examines patients' perceptions of care. Specifically, perceived communication with physicians was most strongly associated with self-esteem and emotional support, not with sociodemographic characteristics. These findings suggest that survivors' psychosocial characteristics spill over into their perceptions of their care. Therefore, addressing the psychosocial aspects of cancer care in tandem with treatment and survivorship care could improve perceptions of care and contribute to long-term wellbeing. Given the likelihood of power problems, these results should be treated as preliminary.

This study also found that post-treatment regret is a relatively common sentiment among breast cancer survivors. It identified the variety of treatment characteristics that breast cancer survivors regret, from primary surgery and adjuvant therapies to problems with providers and the desire to have been more proactive in their care. In addition, women regretted inactions more than actions. This finding underscores a gap in the current literature on post-treatment regret, which has focused on regrets over actions. Quantitative analysis revealed that women who were anxious about the future and had trouble communicating with physicians during treatment were more likely to express regret 5 years later. Women with new or recurrent cancers were significantly more likely to regret some aspect of their primary treatment.

On the whole, this work informs the growing literature addressing the psychosocial aspects of cancer care, including assessments of women's emotional state and the use of patient navigators during treatment and into survivorship. This study also provides evidence for addressing the unique emotional needs of women with recurrent cancers, who likely experience an undue burden of regret. Understanding the causes and consequences of regret in cancer care can contribute significantly to interventions designed to ensure significant quality of life over the long term.

The implications for practice that stem from this work echo a recent Institute of Medicine report (Institute of Medicine, 2008) that calls for improvements in addressing the psychosocial aspects of cancer care. Essential areas for improvement include medical education, reimbursement for clinical services, family involvement/education, and the coordination of biomedical care with psychosocial counseling. By targeting improvements in psychosocial care to these areas, providers can depend on their training to identify and address psychosocial concerns, patients and their families can be watchful and proactive with respect to patients' emotional health, and patients can expect well-coordinated cancer care "for the whole patient" that is supported by payers via reimbursement mechanisms for mental health services. This dissertation adds to the literature base that substantiates this imperative.

7.3 Areas for Future Research

This dissertation, although providing some suggestions for practice, largely indicates that improved research methods are needed to strengthen the evidence base for medical communication. The results highlight the significant shortcomings in existing medical communication research. Specifically, the observed associations between perceived provider communication and quality of life were eliminated when examining the effects over time. Existing literature has suggested that unmeasured patient confounding represents a problem, but stops short of indicating that confounding can explain any association between communication and health. Although this research should be considered preliminary in light of its limitations, it nonetheless suggests that experimental methods and more longitudinal studies are essential to evaluating if and how provider communication translates to better health and *what*, in fact, is measured when considering patients' perceptions of their care.

The study of regret in cancer-related decisions is a burgeoning area of research, and significant issues remain to better identify the role of regret in medical decision-making and how post-decision justification may mitigate regret over time. In addition, more attention to anticipated regret and psychological morbidity in the literature on shared decision-making could help patients to make more informed decisions and experience less post-treatment regret.

This work also represents a call for theoretically informed approaches to addressing the psychosocial aspects of cancer care. As described in the second chapter, research in medical communication would benefit from better integration of psychological perspectives on power that hold the dyad as the unit of analysis and integrate the fragmented informational, emotional, and nonverbal aspects of care. In addition, existing research on post-treatment regret in cancer care lacks theoretically based measures that account for regret over both actions and inactions. As a result research on these psychosocial aspects of cancer, while informing medical practice, needs to better incorporate the larger literature on social behavior and emotion.

7.4 Concluding Statements

In conclusion, this dissertation provides evidence for addressing the psychosocial aspects of breast cancer care in the survivorship phase. In addition, this research suggests that patient-level confounding is a serious issue in cross-sectional research examining the association between provider communication and health, bolstering the call for more robust methods in exploring this link. Specifically, no association was found between perceptions of provider communication and sense of control over health or health behaviors; the link between provider communication and quality of life was tenuous. In addition, self-esteem and emotional support were strongly associated with survivors' perceptions of their care, and regret among survivors was a common occurrence that was associated with psychosocial characteristics during treatment. Moving forward, stronger theory and inference is needed to better understand the psychosocial aspects of cancer care and the relationships between specific aspects of care, patient characteristics, and health outcomes.

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