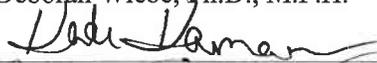


ILLNESS PERCEPTIONS OF PATIENTS WITH LATE-STAGE CANCER
AND THEIR PARTNERS

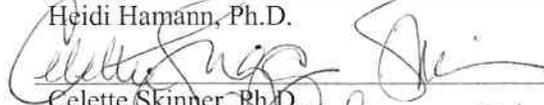
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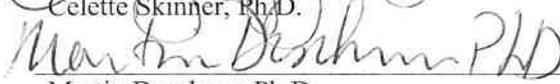
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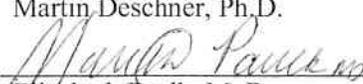
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DEDICATION

To my father, Curtis H. Patterson, who taught me the value of family, laughter, perseverance, and enjoying life. To my mother, Carolyn M. Patterson, who has stood by all of us in our darkest moments with grace and dignity. To my husband, Scott E. Croom, who has supported me in every possible way over the past five years. All three of these people have taught me time and time again that happiness truly is being married to your best friend.

ILLNESS PERCEPTIONS OF PATIENTS WITH LATE-STAGE CANCER
AND THEIR PARTNERS

by

ANDREA ROSE CROOM

DISSERTATION

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The University of Texas Southwestern Medical Center at Dallas

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

The University of Texas Southwestern Medical Center at Dallas

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by

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I would like to thank Dr. Deborah Wiebe for her mentorship and support throughout the past five years. She has pushed me to take chances, even when she was not sure that things would work out in my favor. I could not have navigated my way through emerging adulthood without her guidance. I would also like to recognize Dr. Heidi Hamann who has helped me navigate the world of psychological oncology. I would also like to thank the remaining members of my Graduate Committee, Dr. Elizabeth Paulk, Dr. Celette Skinner, and Dr. Martin Deschner for their invaluable input and support. I also appreciate the support and recognition that I have received from Dr. Betsy Kennard, Dr. Munro Cullum, and Dr. Monty Evans.

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Andrea Croom, 2012

ILLNESS PERCEPTIONS OF PATIENTS WITH LATE-STAGE CANCER
AND THEIR PARTNERS

ANDREA ROSE CROOM, Ph.D.

The University of Texas Southwestern Medical Center at Dallas, 2012

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As treatments improve and patients with late-stage cancer live longer, it is important to examine factors associated with their psychological adjustment and illness-related behaviors. The current studies used the Common-sense Model of Self-regulation (Leventhal, Brissette, & Leventhal, 2003) to understand how patients and their partners manage the demands of this understudied illness context. The Common-sense Model proposes that individuals create mental representations about their illness to make sense of and develop strategies to manage the illness. The current studies were the first to examine (a) whether patients' illness perceptions are associated with advanced illness behaviors (e.g., completing advance directives; NCI, 2005), which are crucial for receiving quality care at the end-of-life, and (b) whether perceptions of both patients and partners are associated with psychological adjustment. A dyadic perspective is important because cancer is not an individual experience, but rather affects

significant others in the patient's life.

Female patients with late-stage breast, gynecological, or lung cancer and their spouses or unmarried partners independently completed self-report measures of their illness perceptions, relationship experience, psychological adjustment, and advanced illness behaviors (N= 105 patients and 88 partners). Data were examined at both intrapersonal (individual) and interpersonal (dyadic) levels. The first study demonstrated that patients' individual perceptions of cancer were better predictors of their quality of life than clinical characteristics of cancer (e.g., stage, illness duration). Advanced illness behaviors were associated with higher quality of life and were predicted by illness perceptions (i.e., illness severity and illness coherence), as well as by clinical and personal characteristics. The second study suggested that patients' and partners' psychological adjustment reflected their individual illness perceptions, as well as aspects of their relationship (i.e., relationship quality and social constraints in discussing cancer). There was limited evidence that incongruence in patients' and partners' illness perceptions was related to poorer adjustment, potentially because illness perception congruence was high. Findings from these studies demonstrate the importance of designing interventions to improve communication between patients, partners, and health care professionals about late-stage cancer beliefs.

TABLE OF CONTENTS

CHAPTER 1. INTRODUCTION	1
CHAPTER 2. REVIEW OF THE LITERATURE FOR STUDY ONE	
Late-Stage Cancer and Psychological Adjustment.....	4
Illness Perceptions and the Common-Sense Model of Self- Regulation.....	9
CHAPTER 3. PREDICTORS OF QUALITY OF LIFE AND ADVANCED ILLNESS BEHAVIORS IN FEMALE PATIENTS WITH LATE-STAGE CANCER	
Abstract.....	18
Introduction.....	20
Method.....	25
Results.....	32
Discussion.....	35
CHAPTER 4. REVIEW OF THE LITERATURE FOR STUDY TWO	
Cancer as a Dyadic Experience.....	48
Interpersonal Perspective on Illness Perceptions.....	50
CHAPTER 5. ASSOCIATIONS BETWEEN ILLNESS PERCEPTIONS AND PSYCHOLOGICAL ADJUSTMENT IN WOMEN WITH LATE-STAGE CANCER AND THEIR PARTNERS: A DYADIC APPROACH	
Abstract.....	59

Introduction.....	61
Method.....	65
Results.....	75
Discussion.....	80
CHAPTER 6. INTEGRATED CONCLUSIONS	93
APPENDICES.....	98
REFERENCES	109

LIST OF TABLES

CHAPTER TWO

TABLE 2-1. Description of Illness Perception Variables.....	13
---	----

CHAPTER THREE – STUDY ONE

TABLE 3-1. Participant Characteristics across Treatment Sites for Total Sample.....	43
---	----

TABLE 3-2. Descriptive Information for Measure of Advanced Illness Behaviors.....	45
---	----

TABLE 3-3. Sample Means, SDs, and Pearson Correlation Coefficients Between Illness Perception Variables and Clinical Characteristics.....	46
---	----

TABLE 3-4. Pearson Correlation Coefficients Between Personal Characteristics, Clinical Characteristics, and Illness Perceptions with Outcome Variables.....	47
---	----

TABLE 3-5. Multiple Regression Analyses Testing Personal Characteristics, Clinical Characteristics, and Illness Perceptions Predicting Outcome Variables.....	48
---	----

CHAPTER FIVE – STUDY TWO

TABLE 5-1. Participant Demographic and Illness Characteristics for Current Sample	87
---	----

TABLE 5-2. Sample Means, SDs, and Pearson Correlation Coefficients Between Illness Perception Variables and Patient and Partner Outcome	
---	--

Variables	88
TABLE 5-3. Sample Means, SDs, and Pearson Correlation Coefficients Between Congruence Scores and Patient and Partner Outcome Variables.....	90

APPENDICES

TABLE A-1. Characteristics and Comparisons of the Total Sample and Specific Cancer Types.....	101
TABLE A-2. Percentage of Family and Medical Team Support Reportedly Received by Patients when Completing Advanced Illness Behaviors.....	103
TABLE A-3. Distribution of Four Different Types of Couple Illness Perception Belief Types	104
TABLE A-4. Analysis of Variance Assessing Patient Outcome Variables by Four Different Types of Couple Illness Perception Belief Types....	105
TABLE A-5. Analysis of Variance Assessing Partner Outcome Variables by Four Different Types of Couple Illness Perception Belief Types.....	107

LIST OF FIGURES

CHAPTER TWO

FIGURE 2-1. Diagram of Leventhal’s Common-Sense Model of Self-Regulation.....	11
---	----

CHAPTER FOUR

FIGURE 4-1. Diagram of Dyadic Illness Perception Model Utilized for Study 2.....	53
--	----

CHAPTER FIVE – STUDY TWO

FIGURE 5-1. Couple Illness Perception Belief Type for Illness Identity Associated with Patient Report of Depression	91
FIGURE 5-2. Couple Illness Perception Belief Type for Cyclical Timeline Associated with Partner Report of Anxiety.....	92

LIST OF APPENDICES

APPENDIX A Advanced Illness Behavior Questionnaire98

APPENDIX B Additional Analyses 101

LIST OF DEFINITIONS

Advanced Illness Behaviors – Behaviors that are recommended to be performed by someone who has been diagnosed with a life-limiting illness

Common-Sense Model of Self-Regulation – Proposes that when individuals are faced with a health threat, they develop illness perceptions in order to make sense of and develop strategies to manage the illness

Health-Related Quality of Life – The subjective impact that an illness has on multiple domains of a person's life (i.e., social, emotional, physical, functional)

Illness Centrality – A subjective report of how integral a role an illness plays in the patient's self-identity

Illness Perceptions – The cognitive representations or beliefs about an illness that individuals form when faced with a health threat

Illness Perception Congruence – The extent to which patients and partners have similar (congruent) or dissimilar (incongruent) beliefs about different aspects of the illness

Late-Stage Cancer – Cancer that is far along in its growth, and has spread to the lymph nodes or other places in the body (stage III or IV)

Psychological Adjustment – Subjective report of symptoms of anxiety and depression

Relationship Quality – The multi-dimensional subjective experience of a relationship with a partner or spouse (i.e., consensus, satisfaction, and cohesion)

Social Constraint – The subjective experience of feeling limited to express thoughts and feelings to another person

CHAPTER ONE

Introduction

Statement of the Problem

Late-stage cancer (stage III and IV) is a complex but understudied health experience. Patients who are diagnosed with a progressed illness often have limited treatment options and receive mixed messages or insufficient information about their prognosis (Zhang et al., 2009). Symptoms of distress are common in adult patients with late-stage cancer and their partners; if not treated, such symptoms can impact quality of life, social functioning, adherence to treatment, and increase overall healthcare costs (Kadan-Lottick, Vanderwerker, Block, Zhang, & Prigerson, 2005; National Comprehensive Cancer Network [NCCN], 2010). Patients with late-stage cancer are also expected to navigate a complex system of advanced illness behaviors such as completing advanced directives or choosing whether to participate in clinical trials (National Cancer Institute [NCI], 2005), which if not completed may result in serious consequences for the patient, their caregivers, the hospital, and society (Larson & Tobin, 2000; Mack, Weeks, Wright, Block, & Prigerson, 2010; Teno, Fisher, Hamel, Coppola, & Dawson, 2002; Wright et al., 2008; Zhang et al., 2009). Little is known about what factors predict the psychological adjustment of patients with late-stage cancer and their partners. As treatments improve and patients with late-stage cancer live longer, it is especially important to understand factors associated with their psychological

adjustment and advanced illness behaviors (Peppercorn et al., 2011; Rose et al., 2009).

When faced with a serious health threat, such as a diagnosis of late-stage cancer, people form cognitive illness perceptions to understand their experience (Leventhal et al., 1997). Illness perceptions have been found to predict psychological adjustment and important illness outcomes within individual patients coping with acute and chronic illnesses (Hagger & Orbell, 2003), including early-stage cancer, but only one study has examined illness perceptions in the context of late-stage cancer (Price et al., in press). In addition, illness perceptions have only recently been examined from a dyadic perspective (e.g., Figueiras & Weinman, 2003). Assuming a dyadic perspective is important because cancer is not an individual experience, but rather affects significant others in the patient's life, such as their spouse or partner (e.g., McLean & Jones, 2007).

The current program of research was designed to understand the role of illness perceptions in predicting the psychological adjustment and advanced illness behaviors of female patients diagnosed with late-stage cancer and their spouses or unmarried partners. Data were examined at both intrapersonal (individual) and interpersonal (dyadic) levels. The first study took an intrapersonal perspective, examining how illness perceptions were associated with quality of life and completion of advanced illness behaviors in female patients with late-stage cancer. The second study took a dyadic perspective, examining

how patients' and partners' personal illness perceptions were associated with their own symptoms of anxiety and depression, as well as how illness perception congruence was associated with their individual symptoms of anxiety and depression. Understanding these associations will facilitate the design of interventions to promote communication and adjustment in patients with late-stage cancer and their partners.

CHAPTER TWO

Review of the Literature for Study One

Late-Stage Cancer and Psychological Adjustment

In the United States, approximately 1,639,000 new cancer cases and 577,000 deaths from cancer are estimated to occur in 2012. Lung cancer is the leading cause of cancer death in women and has a five-year survival rate of 16%. Breast cancer is the most frequently diagnosed cancer in women and is the second leading cause of cancer death among women. Gynecologic cancers (i.e., cervical, ovarian, uterine, vaginal, and vulvar) are less common in general, but are more difficult to detect and are often diagnosed at a late stage with lower survival rates (American Cancer Society [ACS], 2012). Late-stage cancer is the term used to refer to Stage III and IV cancer diagnoses and indicates that the cancer has spread or metastasized to other areas of the body. Cancer diagnosed at a late stage has often gone undetected, shown rapid progression, or recurred, which can leave patients and family members feeling unprepared to adjust to living with a life-limiting illness and managing a complex treatment regimen. In addition, because the cancer is not localized to one specific area, late-stage cancer is often more difficult to treat with fewer treatment options and poorer response to treatment (Peppercorn et al., 2011). There is limited research that focuses on late-stage cancer patients and the research that does exist tends to emphasize end-of-life decision making (e.g., Wright et al., 2008) and prognostication (e.g., Christakis &

Lamont, 2000). However, patients with late-stage cancer are living longer, making it increasingly important to look at long-term quality of life and psychological adjustment to living with a life-limiting illness (Peppercorn et al., 2011; Rose et al., 2009).

Patients with late-stage cancer frequently receive mixed messages or insufficient information about their prognosis and face difficult treatment decisions (Zhang et al., 2009). Documented communication about prognosis between the physician and patient is relatively rare (less than 40% of terminally ill patients; Bradley et al., 2001; Mack et al., 2010), and most patients are less involved in decision making than they would like to be (Gaston & Mitchell, 2005). In general, physicians report discomfort with approaching conversations about prognosis. When they do engage in these conversations, physicians are likely to overestimate how long the patient has left to live (Christakis & Lamont, 2000; Larson & Tobin, 2000; von Gruenigen & Daly, 2005) and to use optimistic statements while they are delivering bad news (Robinson et al., 2008). Patients with late-stage cancer often cling to these hopeful statements and overestimations, making them less likely to engage in end-of-life planning behaviors (e.g., completing advance directives) and to place less emphasis on comfort and quality of life (Christakis & Lamont, 2000). Options for treatment of late-stage cancer are growing rapidly, but the effectiveness of these treatment strategies are disputed by health care professionals and are often difficult for patients to

understand (Matsuyama, Reddy, & Smith, 2006). For example, when patients hear the terms “chemotherapy” or “radiation,” they frequently associate these terms with curative treatment. In late-stage cancer, however, these treatments are often used for palliation of symptoms rather than cure (Matsuyama et al., 2006). This mutual emphasis on hope and prolonging life restricts end-of-life conversations, as well as patients’ understanding of the illness and the need to engage in advanced illness behaviors (Larson & Tobin, 2000).

In the context of late-stage cancer, failing to complete advanced illness behaviors may result in serious consequences for the patient, their caregivers, the hospital, and society. These behaviors include making decisions about future medical treatment (e.g., advance directives), getting affairs in order to make sure that things will be properly cared for in the future (e.g., finances, children), and making decisions about the dying process and remembrance (e.g., hospice, funeral arrangements; NCI, 2005). Patients with late-stage cancer also have the opportunity to choose if they would like to participate in survivorship groups (e.g., Susan G. Komen) and clinical trials, which might benefit future cancer patients. The most well-studied advanced illness behavior is developing advance directives, which allow patients to share their wishes about treatment preferences and to appoint a medical power of attorney to make decisions for them in the event that they are incapacitated. Completion of advance directives is low among the general public and in patients with cancer (Ditto & Hawkins, 2005). In a

study by Bauer-Wu and colleagues (2009), 40% of women with stage IV breast cancer did not have an advance directive and had not shared their wishes for end-of-life treatment with their family members. Failure to engage in discussions about end-of-life issues or to complete advance directives has been associated with increased use of life-sustaining treatments (e.g., CPR, ventilation), longer intensive care unit stays, lower levels of hospice care, and increased health care expenditure (Larson & Tobin, 2000; Teno et al., 2002; Zhang et al., 2009). This is concerning given that patients who received aggressive medical care in their last week of life are reported to have worse quality of life (Mack et al., 2010) and their caregivers are at higher risk for developing major depressive disorder, having poorer quality of life, and experiencing regret after the patient's death (Wright et al., 2008).

Female patients with late-stage cancer may be more prone to experiencing psychological distress than either male patients or patients diagnosed with earlier stage cancer. A diagnosis of late-stage cancer carries distressing attributes, such as fear of death, grief about current or anticipated losses, concerns about loved ones and being a burden, side effects of treatment, treatment procedures, and having to make difficult treatment decisions (Kadan-Lottick et al., 2005). Psychological distress including major depressive symptoms, anxiety, and role adjustment problems have been reported in 15-50% of adult patients with late-stage cancer (McLean & Jones, 2007; see Rabkin, McElhiney, Moran, Acree, &

Folkman, 2009, for null results). People diagnosed with cancer are more likely than the general public to experience symptoms of distress, and patients with late-stage cancer have been found to experience distress at higher levels than the general cancer population (Bowers & Boyle, 2003; Lictenthal et al., 2009; Manne, 1998; Northouse et al., 2002; Norton et al., 2004; see Kissane et al., 2004, for null results). In addition, female patients are at higher risk for experiencing psychological distress after a cancer diagnosis than are male patients (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hodges, Humphris, & Macfarlane, 2005; Manne, 1998; Northouse, Mood, Templin, Mellon, & George, 2000; Tuinstra et al., 2004), making female patients diagnosed with late-stage cancers a particularly vulnerable population. Untreated psychological distress in patients with late-stage cancer is associated with poorer quality of life, amplified pain, poorer social and physical functioning, poorer adherence to treatment, increased desire for hastened death, shorter survival time, and increased healthcare costs (Bowers & Boyle, 2003; Kadan-Lottick et al., 2005; Lloyd-Williams, Shiels, Taylor, & Dennis, 2009; NCCN, 2010; Ransom, Sacco, Weitzner, Azzarello, & McMillan, 2006).

In summary, the existing body of literature demonstrates that late-stage cancer is a unique illness experience and therefore requires specific attention. Due to the lack of research focused on late-stage cancer patients, it is unclear whether results with early-stage cancer patients might generalize to this

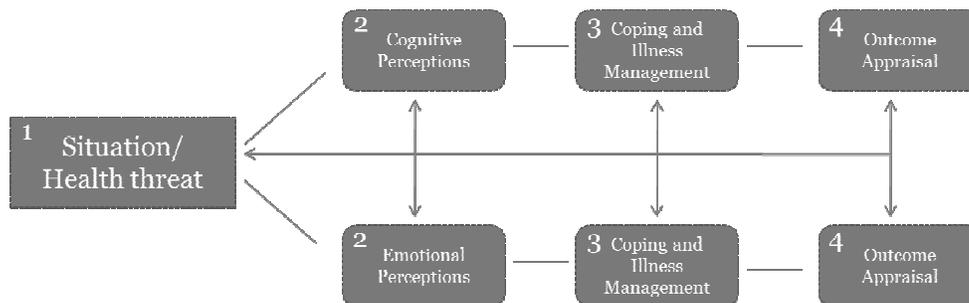
population. Patients with late-stage cancer are at risk of experiencing psychological distress during the course of cancer treatment. Psychological distress can interfere with illness management and completing advanced illness behaviors, which are essential to living with a life-limiting illness and preparing for the dying process. It is important to identify variables that are associated with psychological distress in patients with late-stage cancer, as well as patients' engagement in advanced illness behaviors, so that interventions can be designed to target these variables and improve patient adjustment to late-stage cancer.

Illness Perceptions and the Common-Sense Model of Self-Regulation

The present research drew upon the Common-sense Model of Self-regulation to understand the role of illness perceptions in predicting the psychological adjustment and advanced illness behaviors of patients with late-stage cancer. As displayed in Figure 2-1, the Common-sense Model of Self-regulation (Leventhal, Brissette, & Leventhal, 2003) proposes that when individuals are faced with a health threat, they create cognitive and emotional representations about their illness in order to make sense of and develop strategies to manage the illness. This model explains how individuals diagnosed with the same illness can have widely different beliefs about and reactions to their medical condition (Petrie & Weinman, 2006). Illness perceptions are formed through integration of the patient's personal experience with the illness (e.g., physical

symptoms), general information about the illness (i.e., lay information), and feedback from external sources such as health care providers, family, and friends (Hagger & Orbell, 2003; Leventhal et al., 2003). Illness perceptions have been found to be a significant predictor of behavioral and psychosocial outcomes above and beyond objective indicators of disease severity (Buick, 1997; Hirsch et al., 2009). For example, Rabin, Leventhal, and Goodin (2004) found that there was no significant relationship between objective disease severity (i.e., staging) and breast cancer patients' perceptions about the likely course of their disease, and that perceived timeline (not staging) predicted future distress. In other words, what was “psychologically” correct was more important in guiding behavior and emotional reactions than what was “medically” correct (Leventhal et al., 2003). In the past 30 years, the Common-sense Model has been widely studied and adapted for a variety of chronic illnesses (Hagger & Orbell, 2003; Petrie, Jago, & Devcich, 2007); however, limited research has focused specifically on illness perceptions in late-stage cancer (Price et al., in press).

Figure 2-1

Diagram of Leventhal's Common-Sense Model of Self-Regulation

Footnote: This model shows that in the face of health threats (e.g., diagnosis of cancer)¹, cognitive and emotional representations of the illness are formed².

These illness perceptions are theorized to be primary guides for illness management and coping³. The full model describes this as an ongoing process where people appraise their coping efforts and modify their illness perceptions and coping behaviors⁴. The current cross-sectional study focused on cognitive perceptions at a single point in time.

The original Common-sense Model distinguished five domains of illness perceptions: (1) *identity* – the extent of symptoms that the patient views as being part of the illness; (2) *timeline* – the anticipated course of the illness (i.e., chronic and/or cyclical); (3) *severity* – the expected negative consequences of the illness; (4) *causes* – beliefs about the cause of the illness; and (5) *control* – the extent to which the patient believes their illness can be controlled by themselves or through treatment (Petrie & Weinman, 2006). However, the model was designed to be flexible and adapted to specific illnesses and therefore it has evolved over the years (Moss-Morris et al., 2002). In late-stage cancer, there are additional domains that are likely to be important to assess. *Illness coherence* is the extent to which the patient has a clear and stable understanding of their illness. The diagnosis and treatment of cancer may also lead to the development of a *cancer self-representation*, and how central cancer is to the patient's self-identity may have important implications for psychological well-being and cancer-related behaviors (Helgeson, 2011; Park, Bharadwaj, & Blank, 2011). The most commonly used measure of illness perceptions is the Illness Perception Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002), which was designed to measure the main components of illness perceptions in Leventhal's Common-sense Model. Table 2-1 provides descriptions of the domains examined in the current program of research, as well as corresponding example items from the IPQ-R.

Table 2-1

Description of Illness Perception Variables¹

<i>Illness Perception</i>	<i>Description</i>	<i>Example Items²</i>
Illness Identity	Experience of specific symptoms as a part of cancer or its treatment	“How often do you experience fatigue as part of your cancer or its treatment?”
Chronic Timeline	Cancer does not have a foreseeable end point or is terminal	“I expect to have cancer for the rest of my life.”
Cyclical Timeline	Cancer experience fluctuates across time or is unpredictable	“My cancer is very unpredictable.”
Illness Severity	Negative consequences of having cancer	“My cancer has serious financial consequences.”
Illness Coherence	Extent to which cancer and its treatments are understandable and make sense	“The symptoms of my condition are puzzling to me.”
Personal Control	How much control patient perceives having over the cancer	“What I do can determine whether my cancer gets better or worse.”
Partner Control	How much control patient perceives their partner having over the cancer	“There is a lot which my partner can do to control my symptoms.”
Treatment Control	The ability of treatment to control cancer and/or its symptoms	“My treatment will be effective in curing my cancer.”
Centrality Beliefs	How central cancer is to their sense of self	“I think of my cancer when I think of who I am.”

¹ The current program of research did not examine the domains of causal attributions or emotional perceptions.

² Example items are obtained from the Illness Perception Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002) in all cases except for partner control and centrality beliefs. See method for information on development of these items.

How individuals perceive an illness is associated with how they adjust to the illness experience and the level of psychological distress that they experience. It has been well-documented that patients with negative illness representations report more distress and exhibit less coping flexibility when adjusting to an illness (Hagger & Orbell, 2003). In particular, patients who associate a larger number of symptoms with their illness (i.e., illness identity), who perceive more negative consequences from their illness (i.e., illness severity), or who view their illness as more unpredictable (i.e., cyclical timeline) report higher levels of anxiety and depressed mood, lower quality of life, and poorer physical health (Downe-Wamboldt, Butler, & Coulter, 2006; Rozema, Vollink, & Lechner, 2009; Scharloo et al., 2005; Thune-Boyle, Myers, & Newman, 2006). Although the majority of illness perception research has relied on cross-sectional data, Millar and colleagues (2005) found that breast cancer patients who reported higher levels of illness identity and shorter timeline beliefs at baseline were more likely to experience higher levels of distress one year after surgery. Some illness perceptions appear to be associated with more positive outcomes. For example, higher perceptions of personal and treatment control are associated with greater treatment satisfaction (Llewellyn, McGurk, & Weinman, 2007), lower levels of depression, and better quality of life (Downe-Wamboldt et al., 2006; Lowery, Jacobsen, & Ducette, 1993; Rozema et al., 2009).

Illness perceptions also have well-documented associations with

adherence to treatment (Llewellyn, Miners, Lee, Harrington, & Weinman, 2003; Lowery et al., 1993) and general coping behaviors (Orbell et al., 2008; Rozema et al., 2009); however, the current study will be the first to examine associations between illness perceptions and advanced illness behaviors. When patients' symptoms align with their perceptions of the illness, they are more likely to seek treatment and adhere to treatment recommendations. For example, in a study of patients with severe hemophilia, Llewellyn and colleagues (2003) found that patients' use of recommended treatment was significantly associated with patients identifying symptoms as part of the illness, believing that the consequences of the illness were severe, and believing that the treatment would be effective. Illness perceptions, such as high perceptions of control, are also associated with more active/problem-focused coping (Orbell et al., 2008). For example, cancer patients are more likely to alter specific behaviors (e.g., diet and exercise) if they believe that those behaviors contributed to their cancer or that they have personal control to alter those behaviors (Rabin & Pinto, 2006). However, when patients' illness perceptions do not reflect an accurate view of the illness, they are more likely to delay seeking treatment and display poorer adherence to medical recommendations (Awasthis, Mishra, & Shahi, 2006).

Timeline perceptions and prognosis are likely to be important in the late-stage cancer population because patients are likely to make decisions about advanced illness behaviors based on how much time they think they have left to

live (Rose et al., 2004). Patients with late-stage cancer do not necessarily recognize their illness as terminal (Chochinov, Tataryn, Wilson, Enns, & Lander, 2000; Mack et al., 2010; Rabin et al., 2004) and generally overestimate their chance of survival (Weeks et al., 1998). Patients who believe that they have longer to live favor aggressive treatment (Weeks et al., 1998), are more likely to enter clinical trials (Robinson et al., 2008), and might be less likely to think about making funeral arrangements or completing an advance directive if they do not perceive their cancer as terminal. For example, Chen and colleagues (2003) found that late-stage cancer patients who did not enroll in hospice had less realistic timeline beliefs and were more likely to believe that their cancer could be cured.

Only one study was identified that specifically examined illness perceptions and psychological adjustment in late-stage cancer patients. Price and colleagues (in press) conducted a cross-sectional study of 300 patients who were recently referred for hospice using the brief IPQ and measures of psychological adjustment and depression. Sixty percent of their sample was diagnosed with metastatic cancer, with most of their participants restricted in physical activity but capable of self-care (i.e., ECOG performance status of 1 or 2). Approximately 36% of their sample met criteria for a depressive syndrome. This study demonstrated that specific illness perceptions, particularly perceptions of illness severity and personal control, were associated with helplessness/hopelessness, depression, and coping behaviors; while other illness perceptions, such as causal

attributions, had few associations with adjustment to the illness. Similar to previous studies, illness perceptions were associated with psychological adjustment and depression even when statistically controlling for measures of disease status. This research demonstrates the importance and feasibility of examining associations between illness perceptions and psychological adjustment in the context of life-limiting illnesses, such as late-stage cancer. A major limitation of this study was the use of the brief IPQ, which consists of a single item for each dimension (i.e., nine items) and was not normally distributed in their sample. The current study uses a more in-depth measure of illness perceptions (Moss-Morris et al., 2002) to examine associations with psychological adjustment as well as advanced illness behaviors.

In summary, Leventhal's Common-sense Model of Self-Regulation is a well-established theory for understanding how the cognitive representations that patients form about their illness are associated with coping and adjustment. These illness perceptions are important to study because patients often adjust to and manage their illness based on these perceptions more than on clinical characteristics of their illness. Illness perceptions are not well understood in the context of late-stage cancer. The first study aimed to understand the breadth of illness perceptions maintained by patients with late-stage cancer and to determine how these perceptions are related to their quality of life and engagement in advanced illness behaviors.

CHAPTER THREE

Study One

PREDICTORS OF QUALITY OF LIFE AND ADVANCED ILLNESS BEHAVIORS IN FEMALE PATIENTS WITH LATE-STAGE CANCER

Abstract

Purpose: The 5-year survival rate for all cancers continues to increase (ACS, 2012). Because patients diagnosed with late-stage cancer are living longer, it is important to understand how to maintain their quality of life and promote advanced illness behaviors (e.g., completing advance directives). We evaluated personal, clinical, and illness perception variables that may be associated with these important outcomes. **Methods:** In a cross-sectional observational study, 105 female patients diagnosed with stage III (n=66) or IV (n=39) breast (n=44), gynecological (n=38), or lung (n=23) cancer completed self-report measures of illness perceptions, quality of life, and advanced illness behaviors. Clinical information was obtained from medical records. **Results:** Female patients diagnosed with late-stage cancer reported significantly poorer quality of life than the general population or female oncology patients based on normative data ($ps < .001$). A three-variable model including illness identity, cancer centrality, and income accounted for 61% of the variance in quality of life scores with participant experience of cancer-related symptoms (i.e., illness identity) independently accounting for 54% of the variance. There was wide variability in the number of

advanced illness behaviors that individual patients reported having completed (range = 1 to 9, $M=3.96$, $SD = 2.45$). A five-variable model accounted for 34% of the variance in behavior completion, such that higher frequency was predicted by older age, higher education level, the cancer being recurrent, and participants perceiving their cancer as more severe but also more understandable. Although illness perceptions were moderately associated with clinical characteristics of the cancer, the two sets of variables were clearly unique. **Conclusions:** Patients' perceptions of their late-stage cancer predict quality of life and engagement in advanced illness behaviors above and beyond most clinical characteristics of the cancer, and may provide important targets for intervention.

Introduction

The 5-year survival rate of patients diagnosed with late-stage cancer continues to increase (American Cancer Society [ACS], 2012), but the majority of research remains focused on cancers diagnosed at an earlier stage. Late-stage cancer is a complex health experience with patients often having limited treatment options and receiving mixed messages or insufficient information about their prognosis (Bradley et al., 2001; Mack, Weeks, Wright, Block, & Prigerson, 2010; Zhang et al., 2009). There has been a call for research with late-stage cancer patients to better understand factors associated with quality of life and the engagement in advanced illness behaviors, such as participating in clinical trials (Peppercorn et al., 2011). The present study explored personal characteristics, clinical characteristics, and illness perceptions that might be associated with quality of life and advanced illness behaviors in a cross-sectional sample of female oncology patients diagnosed with late-stage cancer.

Patients with late-stage cancer are expected to navigate a complex system of advanced illness behaviors (National Cancer Institute [NCI], 2005), which if not completed may result in serious consequences for the patient, their caregivers, the hospital, and society (Mack et al., 2010; Teno, Fisher, Hamel, Coppola, & Dawson, 2002; Wright et al., 2008; Zhang et al., 2009). To date, the most well-studied behavior is completion of advance directives, which is low among both the general public and patients diagnosed with cancer (25% to 60%; Bauer-Wu et

al., 2009; Ditto & Hawkins, 2005). This is concerning because failure to engage in discussions about end-of-life issues or to complete advance directives has been associated with increased use of life-sustaining treatments (e.g., CPR, ventilation), longer intensive care unit stays, lower levels of hospice care, and increased health care expenditure (Teno et al., 2002; Zhang et al., 2009). Similarly, fewer than 10% of adult patients diagnosed with cancer participate in clinical trials. This is unfortunate because participation in clinical trials is associated with higher survival rates for patients (Stiller, 1994), and low participation rates prolong the duration of clinical trials and delay finding results (Lara et al., 2001). Other advanced illness behaviors (e.g., participating in cancer survivorship organizations or obtaining information about hospice) have been infrequently studied, but are of potential importance to improving the care of patients living with late-stage cancer.

Health-related quality of life is another important aspect of quality cancer care for patients diagnosed with late-stage cancer (Peppercorn et al., 2011). Quality of life provides a multi-dimensional picture of disease effects on a patient's physical, mental, functional, and social well-being. Better quality of life in cancer patients has also been associated with longer survival (Epplein et al., 2011; Montazeri, 2008), particularly in patients diagnosed with late-stage cancer (Coates et al., 2000). Although adult patients with late-stage cancer endorse varying degrees of adjustment difficulties (Kissane et al., 2004; McLean & Jones, 2007; Rabkin,

McElhiney, Moran, Acree, & Folkman, 2009), it has been well-established that female patients are at higher risk for experiencing psychological distress after a cancer diagnosis (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hodges, Humphris, & Macfarlane, 2005; Manne, 1998). Identification of factors that predict health-related quality of life in female patients diagnosed with late-stage cancer may prove useful for future interventions.

Personal characteristics have been shown to be associated with patient distress and behavior, while patients' clinical characteristics have yielded inconsistent results (Mclean & Jones, 2007). For example, patients who are younger when diagnosed with cancer report poorer quality of life (Parker, Baile, De Moor, & Cohen, 2003), more depressive symptoms (Kissane et al., 2004), poorer psychological adjustment trajectories across time (Rose et al., 2009), and lower likelihood of completing advance directives (Bauer-Wu et al., 2009). Racial and ethnic minority patients are also less likely than Caucasian patients to complete advance directives or enroll in hospice services (Croom, 2010). In addition, patients with more years of education report better quality of life (Parker et al., 2003). Some studies have demonstrated that clinical characteristics such as more advanced cancer stage and longer time since diagnosis are predictors of psychological distress (e.g., Norton et al., 2004), but other studies have found no differences in adjustment based on characteristics such as cancer stage or cancer type (Helgeson, 2011; Kissane et al., 2004; Rabkin et al., 2009).

Illness perceptions may be better predictors of health-related quality of life and advanced illness behaviors than are personal or clinical characteristics (Buick, 1997; Hirsch et al., 2009). When faced with a serious health threat, such as late-stage cancer, people form cognitive illness perceptions to make sense of and develop strategies to manage the illness (Leventhal, Brissette, & Leventhal, 2003). Illness perceptions include beliefs about the extent of symptoms, the anticipated course of the illness, the expected negative consequences of the illness, the extent to which the illness can be controlled, and whether patients have a clear and stable understanding of their illness. The diagnosis and treatment of cancer may also lead to the development of a cancer self-representation, and how central cancer is to the patient's self-identity may have important implications for psychological well-being and cancer-related behaviors (Helgeson, 2011; Park, Bharadwaj, & Blank, 2011).

Research has shown that what is “psychologically” correct is often more important in guiding behavior and emotional reactions than what is “medically” correct (Leventhal et al., 2003). For example, patients with negative illness perceptions report more distress and exhibit less coping flexibility when adjusting to an illness (Downe-Wamboldt, Butler, & Coulter, 2006; Millar, Purushotham, McLatchie, George, & Murraray, 2005; Rozema, Vollink, & Lechner, 2009; Scharloo et al., 2005; Thune-Boyle, Myers, & Newman, 2006). Patients' beliefs about their illness are also highly associated with treatment satisfaction

(Frosthalm et al., 2005), adherence to treatment (Llewellyn, Miners, Lee, Harrington, & Weinman, 2003; Lowery, Jacobsen, & Ducette, 1993), general coping behaviors (Orbell et al., 2008; Rabin & Pinto, 2006; Rozema et al., 2009), and end-of-life decision making (Chen, Haley, Robinson, & Schonwetter, 2003; Rose et al., 2004; Weeks et al., 1998). The relationships among illness perceptions, psychological adjustment, and illness behaviors have been widely studied in a variety of cancer types (Awasthis, Mishra, & Shahi, 2006; Buick, 1997; Downe-Wamboldt et al., 2006; Hirsch et al., 2009; Llewellyn, McGurk, & Weinman, 2007; Scharloo et al., 2005), but have not been specifically studied in the late-stage cancer population.

The present study examined factors associated with quality of life and advanced illness behaviors in a cross-sectional sample of female oncology patients diagnosed with late-stage breast, gynecological, and lung cancers. The aims were to determine: (1) the overall level of quality of life and the frequency of advanced illness behaviors completed by this understudied population, and (2) which personal characteristics, clinical characteristics, and illness perception variables were associated with quality of life and behavior completion. We hypothesized that female patients diagnosed with late-stage cancer would infrequently complete advanced illness behaviors and would experience poorer quality of life when compared to normative samples of the general population and female oncology patients (Brucker, Yost, Cashy, Webster, & Cella, 2005). In

addition, we predicted that patients' illness perceptions would be more highly associated with quality of life and advanced illness behaviors than would clinical characteristics of the cancer. These findings have important implications for health care professionals treating women diagnosed with late-stage cancer, because they highlight the importance of communicating with patients about their perceptions of their cancer diagnosis.

Method

Sample

Data were collected as part of a larger cross-sectional study examining illness perceptions of female patients diagnosed with late-stage cancer and their partners. Eligibility criteria included female patients diagnosed with stage III or IV breast, gynecologic, or lung cancer for at least one month, living in the same residence as a spouse or unmarried partner for at least one year ($M=28.81$ years, $SD=15.99$), and able to read/write English. Participants were not recruited closer to diagnosis because many patients experience heightened initial distress that dissipates in the proceeding weeks (National Comprehensive Cancer Network [NCCN], 2010) and accurate staging often requires additional time. Additional exclusion criteria included the presence of a pre-existing co-morbid medical or psychiatric condition that prohibited completion of the questionnaires (e.g., mental retardation). Participants were recruited during routine outpatient oncology appointments through two sites of an NCI-designated cancer center that

included a university-based practice (73%) and a safety-net practice (27%). The safety-net practice is a teaching hospital with care provided by oncology fellows under the direct supervision of a medical oncologist, while the care at the university-based practice is provided directly to the patients by the same group of medical oncologists. As shown in Table 3-1, compared to the university-based practice, participants recruited from the safety-net practice were younger, had lower education and income levels, and were a more diverse racial/ethnic group ($p < .02$). Clinical characteristics of participants' cancer did not differ based on recruitment site ($p < .20$).

Eligible patients were identified for recruitment through medical record review at participating clinics. Patients were approached at the time of their routine outpatient oncology appointment after a member of the research team was introduced by clinic staff. Interested participants were enrolled and provided with a packet of questionnaires to complete at their convenience. Patients were eligible to participate in this leg of the study even if their partners declined participation. Most participants (89%) chose to complete the packets at home and return them by mail ($M = 17.63$ days, $SD = 24.33$, range = 0 to 141 days). Of the qualifying patients approached ($n=144$), 96% agreed to participate ($n=138$), of which 76% returned a completed packet ($n=105$). Reasons for refusal or failure to complete the packet primarily involved lack of interest in being studied ($n=10$), illness progression or death ($n=6$), and loss to follow-up ($n=21$). Eligible patients

who did versus did not return a completed packet were more likely being treated for stage IV rather than stage III cancer ($\chi^2=8.87, p=.01$) in the safety-net practice ($\chi^2=5.50, p=.03$), but did not differ on cancer type or illness duration ($ps > .20$).

Participants for the present study included 105 female patients diagnosed with stage III (n=66) or IV (n=39) breast (n=44), gynecological (n=38), or lung (n=23) cancer. Table 3-1 describes the demographics and clinical characteristics of the sample. Exploration of means and differences across minority racial group did not reveal clear patterns and therefore these groups were condensed into a non-Caucasian category for the remainder of the analyses. Eighty-two percent of the participants classified under gynecological cancer (n=31) were specifically diagnosed with ovarian cancer, while the remaining participants were diagnosed with either late-stage cervical, uterine, or vulvar cancer. Compared to the other two cancer types, participants diagnosed with lung cancer were older ($F=3.41, p=.04$), were less likely to be experiencing a recurrence of their cancer ($\chi^2=10.73, p=.01$), and had a lower performance status ($F=39.61, p<.00$). Although participants with gynecological cancer were more likely diagnosed with stage III versus stage IV ($\chi^2=28.78, p<.00$), most (63%) were diagnosed with stage IIIc, indicating highly progressive disease.

Procedures and Measures

The study was approved by the University of Texas Southwestern Medical Center's Institutional Review Board and the Protocol Review and Monitoring

Committee (PRMC) at Simmons Cancer Center. Participants provided written informed consent before completing the following measures.

Illness Perceptions. Patients completed the Illness Perceptions Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002) to assess seven different aspects of their beliefs about their cancer. Illness identity (i.e., symptom experience) included fifteen symptoms rated on a scale from 1 (*never occurs*) to 4 (*occurs all of the time*). The remaining items were completed using a Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*). We assessed patients’ beliefs about the onset and course of the cancer (i.e., chronic timeline and cyclical/unpredictable timeline), about potential negative consequences of the cancer (i.e., illness severity), about whether the illness and treatment are understandable and consistent (i.e., illness coherence), and about how amenable the cancer is to various types of control (i.e., patient control and treatment control). Three additional items associated with late-stage cancer were incorporated into the IPQ-R subscales. Two items developed by Buick (1997), “my cancer is terminal” and “the symptoms of my cancer will become worse over time” were included in the chronic timeline subscale, while the third item, “I see myself as a cancer survivor” was included in the treatment control subscale. Internal consistency was greater than $\alpha = .75$ for all subscales.

Cancer Self Representation. A measure of illness centrality was included to assess perceptions of how cancer affects ones sense of self; such perceptions

may be relevant to the cancer experience (Helgeson, 2011; Park et al., 2011) but are not measured by the IPQ-R. We modified items that were developed by Wiebe and colleagues (2002) for patients with diabetes, by replacing the term diabetes with cancer. These items have been reliably used with cancer populations in previous research (Helgeson, 2011; Park et al., 2011). The illness centrality measure included four items to assess the extent to which the cancer diagnosis is central to the patient's sense of self (e.g., "I think of my cancer when I think of who I am"). These items were measured using a Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*) and internal consistency was sufficient at $\alpha = .78$.

Quality of Life. Participants completed the Functional Assessment of Cancer Therapy General scale (FACT-G) to assess how cancer and its treatment are associated with quality of life (Cella et al., 1993; Webster, Odom, Peterman, Lent, & Cella, 1999). This well-validated 27-item instrument assesses four quality of life domains: 1) physical well-being, 2) social/family well-being, 3) emotional well-being, and 4) functional well-being. Items are measured using a Likert scale from 1 (*not at all*) to 5 (*very much*) with higher scores indicating better quality of life. Individual subscale scores were highly correlated with each other ($r_s = .40$ to $.67$) and with the summed total quality of life score ($r_s = .68$ to $.89$), therefore we utilized the total score ($\alpha = .93$).

Advanced Illness Behaviors. An instrument was created for this study to assess whether patients engaged in particular advanced illness behaviors.

Domains for this scale were chosen from the National Cancer Institute's booklet on coping with advanced cancer (NCI, 2005) and items were developed to reflect: 1) participation in cancer specific activities (e.g., survivorship organizations), 2) preparation for medical decision making (e.g., completing an advance directive), and 3) end-of-life planning (e.g., obtaining information about hospice). Table 3-2 displays the number of participants that completed each of nine behaviors. An advanced illness behavior score was computed by counting the total number of behaviors that each participant endorsed (range = 0 to 9; $\alpha = .76$).

Demographic and Illness Information. Participants completed a demographic questionnaire that measured basic information about their personal characteristics (e.g., age, income) and their cancer (e.g., duration, presence of metastases). With participant consent, medical records were accessed through each institution's electronic records to obtain information about diagnosis, staging, treatment, prognosis, and overall functioning at the time of the clinic visit. The Eastern Cooperative Oncology Group (ECOG) performance status is well-validated (Roila et al., 1991) and represents the oncologists' rating of the patient's functional status on a scale from 0 (*fully active*) to 4 (*completely disabled*). Serum albumin levels were included as an objective measure of liver functioning/nutritional status, because lower levels have been shown to predict

worsening disease and mortality (Corti, Guralnik, Salive, & Sorkin, 1994; Phillips, Shaper, & Whincup, 1989).

Statistical Approach

Initial analyses were conducted to examine whether samples could be combined across treatment site and cancer type. First, there were no significant differences across cancer type for any of the outcome variables ($p > .20$). Second, although patients treated at the safety-net practice had lower quality of life ($t(99) = 3.143, p = .002$) than patients being treated at the university-based practice, this difference was no longer significant when controlling for income. Thus, analyses were conducted using the full sample.

Aim 1 was addressed by obtaining descriptive statistics to assess the level of quality of life as well as the frequency of advanced illness behaviors. One sample t-tests were used to compare participants' quality of life scores to the mean scores of normative samples for both the general population and the female oncology population (Brucker et al., 2005). Multiple regression analyses were conducted to assess Aim 2 and determine which personal characteristics, clinical characteristics, and illness perceptions accounted for the most variance in quality of life and advanced illness behaviors. Because there was no definitive theoretical justification for ordering the entry of the predictor variables, all variables were entered simultaneously using a forward entry stepwise regression procedure. To reduce the number of predictor variables used in the regression

analyses, we initially examined bivariate correlations between the predictor variables and the outcome variables (i.e., quality of life and frequency of advanced illness behaviors) as well as associations between illness perceptions and clinical characteristics. Only variables that showed significant associations with either the outcome variables or with each other were included as predictors in the regression model. In all cases, the residuals were normally distributed and the collinearity tolerance was greater than 0.70, supporting the assumptions underlying regression.

Results

Descriptive Information about Quality of Life and Advanced Illness Behaviors

The average quality of life score of 73.97 ($SD=17.43$) was significantly lower than the normative average for both the general population (80.1; $t(100) = -3.53, p=.001$) and the female oncology population (82.1; $t(100) = -4.69, p < .00$). Although there was a broad range of scores (14 to 106), more than 21% of participants scored below the 10th percentile for female oncology patients (Brucker et al., 2005). As shown in Table 2, there was wide variability in the number of advanced illness behaviors completed (range = 1 to 9, $M=3.96, SD = 2.45$). The majority of participants had informally discussed their cancer and/or their future with important people in their life, but fewer had taken more formal steps to make their wishes known (e.g., completing an advance directive). The least frequently performed behaviors were obtaining information about hospice

programs and participating in cancer survivorship organizations. The outcome variables were associated with each other, such that better quality of life was associated with a higher frequency of behavior completion ($r = .200$).

Associations between Illness Perceptions and Clinical Characteristics

As can be seen in Table 3-3, participants' beliefs about the illness mapped onto the clinical characteristics of their cancer as obtained from medical record review. For example, participants diagnosed with stage IV cancer were more likely to perceive their illness as chronic, with less personal control and treatment control than participants with stage III cancer. In addition, participants who reported the presence of metastases also reported more cancer-related symptoms, beliefs that their cancer was more chronic and unpredictable, with greater negative consequences, and less personal and treatment control. Illness duration and cancer being recurrent were also associated with timeline beliefs. Although significant, these associations were quite modest indicating that illness perceptions are different than clinical characteristics and may offer unique predictive ability when assessing quality of life and behavior completion.

Associations between Predictor Variables and Outcome Variables

Table 3-4 displays the associations of personal characteristics, clinical characteristics, and illness perceptions with each outcome variable. All four of the personal characteristics examined had significant associations with quality of life or behavior completion. In particular, participants who were older or had a

higher income level reported better quality of life and a higher frequency of behavior completion. Non-Caucasian participants and participants with lower education levels completed fewer advanced illness behaviors. Clinical characteristics were generally not related to either outcome variable, although participants experiencing a cancer recurrence reported a higher frequency of behavior completion. For the most part, the illness perception variables were significantly associated with quality of life and behavior completion. Poorer quality of life was associated with participants experiencing more cancer related symptoms (i.e., illness identity), perceiving a cyclical or unpredictable timeline for their illness, believing that their illness was severe with major consequences in their life, viewing their cancer as less understandable (i.e., illness coherence), and reporting that cancer was central to their self-image. A higher frequency of behavior completion was associated with participants believing that their cancer was chronic or life-limiting, more understandable, and had major consequences.

Regression Analyses Predicting Quality of Life and Advanced Illness Behaviors

Table 3-5 displays the results of the multiple regression analyses. To examine unique predictive effects, the final analyses were entered in a stepwise model that included predictor variables that were either associated with the outcomes (i.e., quality of life or advanced illness behaviors) or that were associated with each other. Specific predictors included: 1) personal characteristics (i.e., age, ethnicity, education level, income), 2) clinical

characteristics (i.e., illness duration, cancer stage, presence of metastases, cancer recurrence), and 3) illness perceptions (i.e., illness identity, chronic timeline, cyclical timeline, illness severity, illness coherence, and cancer centrality).

A three-variable model that included illness identity, higher cancer centrality beliefs, and higher income accounted for 62% of the variance in quality of life scores, $F(3, 83) = 45.58, p < .001$. Experiencing more cancer related symptoms (i.e., illness identity) independently accounted for 54% of the variance in quality of life scores. A five-variable model accounted for 34% of the variance in advanced illness behaviors, $F(5, 79) = 9.521, p < .001$. Participants who reported completing a higher frequency of advanced illness behaviors were older, with higher levels of education, were more likely to be experiencing a cancer recurrence, and perceived their cancer as more severe but also more understandable. Each of these variables independently accounted for less than 7% of the total variance in advanced illness behaviors.

Discussion

The current study was one of the first to examine the significance of illness perceptions, personal characteristics, and clinical characteristics in predicting health-related quality of life and advanced illness behaviors in a diverse group of female patients diagnosed with late-stage cancer. In general, participants' personal characteristics as well as their cognitive perceptions of the cancer were associated with quality of life and behavior completion while clinical

characteristics of the cancer were not. Although illness perceptions appeared to be moderately associated with clinical characteristics of the cancer, the two sets of variables were clearly unique, implying that patients' understanding of their illness is not purely based on diagnostic information. This finding confirms the notion that what is "psychologically" correct is often more important in guiding patients' behavior and emotional reactions than what is "medically" correct (Leventhal et al., 2003).

Quality of life was lower in our sample of late-stage cancer patients than in the general population or a normative sample of female oncology patients (Brucker et al., 2005) and our findings indicate symptom experiences (i.e., illness identity) largely account for this. A significant portion of the variance in quality of life was accounted for by patients' perceptions of cancer-related symptoms and beliefs about how central cancer is to their self-identity. Perception of cancer-related symptoms is likely to stand in as an indicator of how severe patients perceive their cancer to be at the present moment, as well as how much their cancer interferes with their ability to function. Illness identity has been found to be an important predictor of adjustment and quality of life in studies of other cancer populations (Downe-Wamboldt et al., 2006; Thune-Boyle et al., 2006). The addition of a measure of cancer self-representation (i.e., cancer centrality) was a unique contribution, because this concept is relatively new (Wiebe et al., 2002) and has only recently been studied in the cancer population (Helgeson,

2011; Park et al., 2011). In our sample, females with late-stage cancer who believed that cancer was central to their self-identity reported poorer quality of life, which suggests that it is unhealthy for patients to define themselves in terms of their illness or that one cannot help but define one's self by cancer when it pervades all aspects of one's life. Previous research has suggested that perceptions of control are an important predictor of psychological adjustment and quality of life in patients diagnosed with cancer (Downe-Wamboldt et al., 2006; Rozema et al., 2009); however personal and treatment control were not associated with quality of life in the current sample. This might be a reflection of the fact that the IPQ-R assesses primary control (i.e., perceptions of control over the course of cancer); whereas, in the context of a seemingly uncontrollable situation, measuring secondary control (i.e., perceptions of control over internal reactions to the event) may be more appropriate (Rothbaum, Weisz, & Snyder, 1982; Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993).

There was wide variability in both the types and total number of advanced illness behaviors that individual participants completed and completion of advanced illness behaviors was a more complex and multiply determined variable than was quality of life. Similar with other studies (e.g., Bauer-Wu et al., 2009), we found that patients who were older were more likely to have completed advanced illness behaviors. Behaviors such as completing advance directives or legal wills and making funeral arrangements often become more salient as people

age, while younger patients are less likely to have considered these behaviors. A higher level of education was the best individual predictor variable, accounting for 7% of the variance, which suggests the need for targeted interventions aimed at patients with lower levels of education. Patients diagnosed with a recurrence of their cancer were more likely to complete advanced illness behaviors. Examining the correlations between recurrence and illness perceptions, it appears that patients diagnosed with a recurrence may be more likely to recognize their illness as chronic or life-limiting. These patients might also receive less optimistic messages about prognosis from their medical team or family. In regard to the illness perception variables, patients were more likely to engage in advanced illness behaviors if they had a stable understanding of their illness (i.e., illness coherence) and recognized their cancer as a severe condition with the potential for negative consequences. This finding is consistent with previous research on illness perceptions that shows patients are more likely to engage in illness behaviors when their beliefs about the illness coincide with the clinical reality of the illness (Hagger & Orbell, 2003).

The two outcome variables in this study were related, such that better quality of life was associated with patients completing a higher frequency of advanced illness behaviors. Patients who are experiencing a greater number of cancer-related symptoms experience lower quality of life, but these are not the same patients who are engaging in a greater frequency of advanced illness

behaviors. Patients may have difficulty rallying the cognitive, emotional, or social resources necessary to complete advanced illness behaviors when they are experiencing the cancer as pervasive in multiple areas of their life. This suggests the importance of identifying ways to engage patients in completing advanced illness behaviors earlier in the illness process before symptoms become too severe or become the focus of the patient's life.

The findings from this research have implications for medical oncologists and other health care professionals who treat female patients diagnosed with late-stage cancer. We suggest that health care professionals should aim to understand their patients' perception of the cancer, particularly their beliefs about how severe it is, the extent of the symptoms they experience, and how central the cancer diagnosis is to their self-image. It should not be assumed that patients' beliefs about the illness coincide with the clinical information presented by their health care professionals, and so patients may not recognize the importance of completing advanced illness behaviors. Gaining a better understanding of their patients' beliefs will allow health care professionals to individually tailor their explanations about the realistic implications of a late-stage cancer diagnosis. Our research further demonstrated that patients are more open to informal conversations about their cancer and their future, so initially they may be more likely to engage in a conversation about their preferences and plans than to complete a formal document (e.g., advance directive). This demonstrates the

importance of designing interventions to help patients translate their conversations into documented preferences, so that they can receive care consistent with their treatment goals (Peppercorn et al., 2011; Teno et al., 2002). Promisingly, awareness that one is terminally ill and engaging in conversations with physicians about preferences for end-of-life care has been found to be associated with patients endorsing better quality of life and lower distress at the end of life (Mack et al., 2010). A randomized controlled-trial intervention with patients recovering from myocardial infarction resulted in patients being discharged from the hospital faster, and experiencing lower levels of anxiety simply by increasing patients' awareness of their illness beliefs (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009).

There are several limitations to the current study. First, the data are cross-sectional and therefore we cannot distinguish causal direction or rule out the influence of additional variables that were not assessed. Future research should consider how the associations found in the current study change across time and at different stages of cancer progression. Second, we relied on patients' self-report and the possibility exists that patients who are experiencing greater levels of distress are more likely to report negative perceptions of their illness. Third, as to not burden our sample, we limited the number of variables assessed; however, future work should investigate additional variables that have been found to be associated with quality of life and illness behaviors in other illness populations

(e.g., benefit finding or perceptions of secondary control). Finally, the current study focused on English speaking, female patients, who were diagnosed with specific types of cancer, and involved in long-term relationships. In addition, participants in our study should be considered as higher functioning patients with late-stage cancer, because they were not hospitalized and were not yet receiving hospice care. Future work should consider extending this research to a variety of cancer types, non-English speaking patients, male patients, and those patients who are potentially in their last few months of life.

The current study detailed the variables associated with quality of life and advanced illness behaviors in the rarely studied population of females diagnosed with late-stage cancer. Based on the results, three findings seem relatively clear. First, how patients perceive their cancer does not completely align with diagnostic and clinical information. Second, how patients perceive their cancer is a better predictor of their quality of life and illness behavior than clinical characteristics of their cancer. Third, predicting and improving engagement in advanced illness behaviors is a complex process, but an important one given that these behaviors are completed by a small proportion of patients and failure to complete these behaviors has been associated with numerous negative outcomes, including lower quality of life in the present study. Interventions designed to target patients' beliefs about a late-stage cancer diagnosis have significant potential for improving quality of life and increasing completion of advanced illness behaviors.

Table 3-1

Participant Characteristics across Treatment Sites for Total Sample (N=105)

<i>Characteristic</i>	<i>Total Sample</i>	<i>University- Based Practice¹</i>	<i>Safety-Net Practice²</i>	<i>Comparison Statistic</i>
	<i>N (%)</i>	<i>N (%)</i>	<i>N (%)</i>	
Race/Ethnicity				
Non-Hispanic White	68 (65%)	58 (75%)	10 (36%)	$\chi^2 = 5.68^*$
Black	13 (12%)	5 (6%)	8 (29%)	
Asian	5 (5%)	5 (6%)	0 (0%)	
Hispanic	9 (9%)	4 (5%)	5 (18%)	
Multi-Racial	7 (7%)	3 (4%)	4 (14%)	
Education Level				
\leq High school education	38 (36%)	21 (27%)	17 (61%)	$t = 3.83^{**}$
$>$ High school education	64 (61%)	54 (70%)	10 (36%)	
Income, n=94				
$<$ \$25,000	28 (27%)	10 (13%)	18 (64%)	$t = 8.00^{**}$
\geq \$25,000	66 (63%)	60 (78%)	6 (21%)	
Age (in years)				
Mean (<i>SD</i>)	58.29 (11.05)	60.07 (11.32)	53.54 (8.85)	$t = 2.75^{**}$
Range	24 to 83	26 to 83	24 to 64	
Cancer Type				
Breast	44 (42%)	28 (36%)	16 (57%)	$\chi^2 = 3.74$
Gynecological	38 (36%)	30 (39%)	8 (29%)	
Lung	23 (22%)	19 (25%)	4 (14%)	
Illness Duration (in months)				
Mean (<i>SD</i>)	16.05 (25.62)	18.36 (29.18)	9.68 (8.62)	$t = 1.55$
Range	1 to 158	1 to 158	1 to 35	
Cancer Stage				
IIIA	21 (20%)	17 (22%)	4 (14%)	$\chi^2 = 1.66$
IIIB	11 (10%)	7 (9%)	4 (14%)	
IIIC	34 (33%)	26 (34%)	8 (29%)	
IV	39 (37%)	27 (35%)	12 (43%)	
Metastases Present	71 (68%)	52 (68%)	19 (68%)	$\chi^2 = 0.14$
Cancer is Recurrent	45 (43%)	34 (44%)	11 (39%)	$\chi^2 = 0.20$
ECOG Performance Status				
Mean (<i>SD</i>)	0.34 (0.68)	0.31 (0.59)	0.43 (0.88)	$t = -0.78$
Range	0 to 3	0 to 3	0 to 3	

Serum Albumin Levels				
Mean (<i>SD</i>)	4.07 (0.40)	4.10 (0.34)	3.99 (0.52)	$t = 1.30$
Range	2.2 to 4.7	2.8 to 4.7	2.2 to 4.7	

$*p < .05$, $**p < .01$

¹ University-based practice (N=77)

² Safety-net practice (N=28)

Table 3-2

Descriptive Information for Measure of Advanced Illness Behaviors

<i>Advanced Illness Behavior</i>	<i>No. of Participants</i>	<i>%</i>
Participated in cancer survivorship organizations	28	27
Completed a document to make medical wishes known	49	47
Appointed a medical power of attorney	46	44
Considered or enrolled in a clinical trial	46	44
Made wishes known about funeral arrangements	56	53
Wrote a legal will for finances and property	47	45
Talked with people in their life about their cancer and/or their future	77	73
Put affairs in order	50	48
Obtained information about hospice programs	8	8

Table 3-3

Sample Means, SDs, and Pearson Correlation Coefficients Between Illness Perception Variables and Clinical Characteristics

<i>Variables</i>	<i>Mean (SD)</i>	<i>Illness Duration</i>	<i>Cancer Stage¹</i>	<i>Metastases¹</i>	<i>Recurrence¹</i>	<i>ECOG²</i>	<i>Albumin³</i>
<i>Illness Perceptions</i>							
Illness Identity	2.08 (0.47)	-.060	.032	.267**	.028	.120	-.128
Chronic Timeline	2.99 (1.10)	.333**	.348**	.390**	.336**	.142	.169
Cyclical Timeline	2.54 (0.81)	-.001	.018	.333**	.260**	.011	.046
Illness Severity	3.81 (0.75)	.016	.055	.251*	-.112	.109	-.058
Illness Coherence	3.79 (0.77)	-.004	-.073	-.156	-.137	.150	-.063
Personal Control	3.62 (0.70)	-.048	-.362**	-.200*	-.093	-.067	.035
Treatment Control	3.94 (0.66)	-.123	-.342**	-.421**	-.169	-.247*	.048
Centrality Beliefs	2.75 (0.94)	.019	.140	.046	-.049	.072	-.134

* $p < .05$, ** $p < .01$

¹ Biserial correlations were used for all dichotomous variables. For cancer stage, lower numbers represented Stage III and higher numbers represented Stage IV. For metastases and recurrence, lower numbers represented not present and higher numbers represented that the cancer was metastatic or recurrent.

² Higher ECOG scores represent poorer functional ability as assessed by the medical oncologist.

³ Lower Serum Albumin levels represent poorer liver functioning/nutritional status.

Table 3-4

Pearson Correlation Coefficients Between Personal Characteristics, Clinical Characteristics, and Illness Perceptions with Outcome Variables

<i>Variables</i>	<i>Quality of Life</i>	<i>Advanced Illness Behaviors</i>
<i>Personal Characteristics</i>		
Age	.276**	.215*
Ethnicity	-.132	-.199*
Education Level	.138	.270**
Income	.263*	.242*
<i>Clinical Characteristics</i>		
Illness Duration	.151	.096
Cancer Stage	-.035	.047
Metastases Present	-.165	.130
Cancer is Recurrent	-.029	.206*
ECOG Performance Status	-.149	.099
Serum Albumin Levels	.153	-.119
<i>Illness Perceptions</i>		
Illness Identity	-.745**	-.070
Chronic Timeline	-.114	.302**
Cyclical Timeline	-.372**	.006
Illness Severity	-.484**	.243*
Illness Coherence	.323**	.257*
Personal Control	.170	.148
Treatment Control	.193	-.060
Centrality Beliefs	-.507**	-.040

* $p < .05$, ** $p < .01$

Table 3-5

Multiple Regression Analyses Testing Personal Characteristics, Clinical Characteristics, and Illness Perceptions Predicting Outcome Variables

<i>Outcome Variables</i>	<i>B</i>	<i>SE B</i>	<i>β</i>	<i>ΔR²</i>
<i>Quality of Life</i>				
Income	1.210	(.567)	.145*	.02
Illness Identity	-23.121	(2.886)	-.604**	.54
Centrality Beliefs	-4.861	(1.390)	-.264**	.06
<i>Advanced Illness Behaviors</i>				
Age	.058	(.020)	.264**	.06
Education Level	.364	(.109)	.301**	.07
Cancer is Recurrent	1.077	(.501)	.219*	.04
Illness Severity	1.063	(.355)	.332**	.05
Illness Coherence	.949	(.292)	.301**	.05

* $p < .05$, ** $p < .01$

CHAPTER FOUR

Review of the Literature for Study Two

Cancer as a Dyadic Experience

The majority of research about illness perceptions focuses on individual beliefs that patients have about their illness (Berg & Upchurch, 2007), but cancer is not an individual experience (Manne, 1998). Caregivers and partners of patients with late-stage cancer are also at increased risk for experiencing psychological distress. Late-stage cancer interferes with the daily lives of patients and their families and carries increased caregiving and economic burdens (Cameron, Franche, Cheung, & Stewart, 2002; Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Feldman & Broussard, 2006). Partners have to balance their normal daily activities, additional caregiving responsibilities, and efforts to help the patient adjust to the illness, while managing their own emotional reactions to and fears about the cancer. Partners report greater distress than patients during the first year of treatment (Northouse et al., 2000), possibly as a result of observing the patient's suffering but feeling inadequate or helpless to aid them (Germino, Fife, & Funk, 1995; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Kayser, Sormanti, & Strainchamps, 1999). Even though family members report high levels of satisfaction with the caregiving experience, they also report more depressive symptoms and psychosocial stress than the general public (Cameron et al., 2002; Fleming et al., 2006; Northouse et al., 2000;

Northouse et al., 2002). As caregiving needs escalate with illness progression, psychological distress in caregivers becomes more prevalent (Emanuel et al., 2000; McLean & Jones, 2007). Untreated psychological distress in caregivers and partners of late-stage cancer patients is associated with poorer patient care, increased health problems for caregivers, and more severe grief reactions after patient death (Emanuel et al., 2000; Kelly et al., 1999).

Late-stage cancer also challenges well-established roles in the relationship, and patients' and partners' adjustment to the cancer experience is likely to be influenced by the quality of the relationship. When patients and their partners perceive greater levels of emotional support, mutual exchange of information and responsibilities, and a more cohesive relationship, they report better psychological adjustment (Kayser et al., 1999; Manne, Alfieri, Taylor, & Dougherty, 1999), greater perceptions of control (Awasthis et al., 2006), and better health outcomes (Lewis et al., 2006). Research studies with heart disease patients have also found that higher levels of marital quality predicted severity of health outcomes and survival (Coyne et al., 2001; Rohrbaugh et al., 2004) and that these effects persisted for up to eight years (Rohrbaugh, Shoham, & Coyne, 2006). In contrast, poor marital relationships are associated with higher rates of depression and anxiety in cancer populations (Baider, Koch, Esacson, & Kaplan De Nour, 1998; Feldman & Broussard, 2006; Hinnen, Hagedoorn, Sanderman, &

Ranchor, 2007; Kissane et al., 1994; Manne, Pape, Taylor, & Dougherty, 1999; Nijboer, Triemstra, Tepelaar, Sanderman, & van den Bos, 1999).

Social constraints in expressing thoughts and feelings related to cancer may undermine the psychological adjustment of both patients and partners. Even in high quality relationships, patients and partners may avoid open and truthful communication about cancer (Kilpatrick, Kristjanson, Tataryn, & Fraser, 1998). Such constraints may be particularly prevalent in late-stage cancers, as illnesses that have a poorer prognosis or are more threatening are associated with greater inhibition and constraint (Badr & Carmack-Taylor, 2006; Herzer, Zakowski, Flanigan, & Johnson, 2006). Social constraint in conversations about cancer can make it more difficult to process and gain control over negative emotions, resulting in greater psychological distress and more avoidant coping (Lepore & Revenson, 2007). Compared to male patients, female patients report a greater number of problems related to communication about cancer (Kornblith, 2006) and therefore may be at greater risk for experiencing increased psychological distress as a result of social constraints.

Interpersonal Perspective on Illness Perceptions

Although cancer is clearly more than one patient's "individual" experience, research on the central role of illness perceptions in guiding how patients manage serious illnesses has rarely extended beyond the patient's

personal perceptions. This individual approach may limit our understanding of how illness perceptions function. When faced with a health threat, people often turn to their spouses or partners to determine what health care they should seek and to elicit support for illness and health behaviors (Leventhal et al., 2003).

Partners are likely to form their own beliefs about the illness, which may or may not coincide with the beliefs held by the patient. There exists a small but growing literature on illness perception congruence between adult patients with chronic conditions and their partners (Benyamini, Gozlan, & Kokia, 2009; Figueriras & Weinman, 2003; Heijmans, de Ridder, & Bensing, 1999; Sterba et al., 2008).

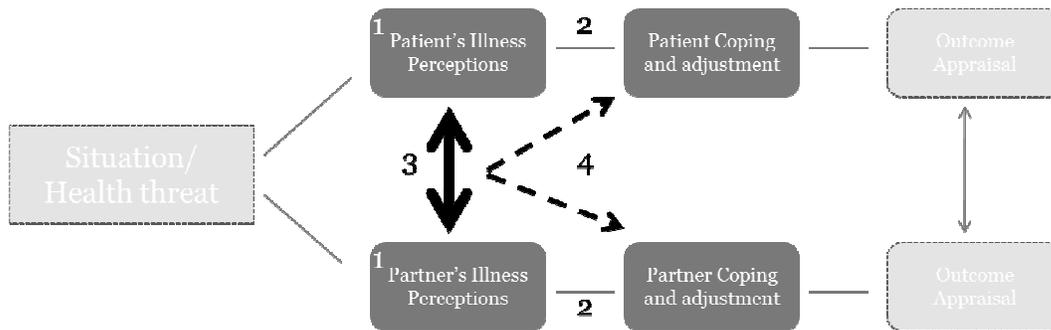
Understanding patient-partner congruence in illness perceptions is particularly important in the late-stage cancer population because partners and spouses will frequently become the primary caregivers and surrogate decision makers as the end-of-life approaches (Kaldjian, Curtis, Shinkunas, & Cannon, 2009). Family members experience varying levels of discordance about goals of treatment and treatment decisions, with as many as 75% of families reporting at least moderate disagreements (Fried, Bradley, & Towle, 2003; Siminoff, Rose, Zhang, & Zyzanski, 2006; Tang, Liu, Lai, Lui, & Chen, 2005; Yun et al., 2006; Zhang & Siminoff, 2003). In general, partners are more likely to perceive a chronic course for cancer (Hagedoorn et al., 2008) and tend to express a greater preference for pursuing life sustaining treatment than the patients (Ditto et al., 2001; Fried et al., 2003; Tang et al., 2005). A qualitative study by Salander and

Spetz (2002) found that couples dealing with the diagnosis of a brain tumor would often think about the prognosis and their information needs differently, which resulted in reports of decreased communication and “drifting apart.” Incongruent beliefs within the partner relationship could cause excessive stress for both the patient and their partner (Siminoff et al., 2006) and could ultimately result in patients receiving more aggressive treatments at the end-of-life than they would have preferred (Larson & Tobin, 2000).

Dyadic models account for both the intrapersonal (individual level) and interpersonal (couple level) context (Lewis et al., 2006), and are important for studying illness perceptions in the cancer context. Making sense of a cancer diagnosis is likely to be influenced by patients’ and partners’ individual perceptions, as well as by the convergence of their perceptions (Germino et al., 1995). As displayed in Figure 4-1, a dyadic perspective first focuses on how patients’ and partners’ individually form perceptions of the illness (#1 in Figure) that influence their own adjustment (#2). This perspective further examines the extent to which patients and partners have similar (congruent) or dissimilar (incongruent) beliefs about different aspects of the illness (#3), and the additional affect that these congruent (shared positive or shared negative) or incongruent beliefs may have on each person’s adjustment (#4).

Figure 4-1

Diagram of Dyadic Illness Perception Model Utilized for Study 2



The dyadic or interpersonal nature of illness perceptions in patients and partners has been examined in multiple ways. Initial studies focused on understanding what partners knew about the patient's cancer experience by asking partners to report their perceptions of the patient's beliefs about the cancer. In general, this research revealed low correspondence between patient and spousal perceptions of the patient's experience, with spouse perceptions of the patient's illness experiences often being more negative than patients' own perceptions (e.g., Chaitchik, Kreitler, Rapoport, & Algor, 1992). Partners perceived that patients experience more illness-related symptoms, more emotional distress, and lower levels of control over the illness than patients themselves reported (Clipp & George, 1992). Although informative, this approach ignores the role of partners' personal beliefs about the cancer.

A second approach to examining dyadic aspects of illness perceptions has measured congruence between patients' and partners' own perceptions as opposed to both partners' reports of the patient's perceptions. These studies examined psychological adjustment, functioning, and coping when patients and partners are on a "different page" about the illness (i.e., incongruent beliefs) by examining the mean difference scores between patients and partners illness perceptions as measured by the IPQ-R (Moss-Morris et al., 2002). For example, Heijmans and colleagues (1999) compared the illness perceptions of patients with Addison's Disease (an endocrine disorder) and Chronic Fatigue Syndrome to their spouses. Congruence scores were highly correlated with patient reports of quality of life, quality of the relationship, and vitality for both patient groups, but effects were stronger for patients diagnosed with Addison's Disease. This approach focuses on the mere presence of incongruence, while ignoring that shared beliefs may also have important associations with patients' and partners' psychological adjustment.

A related approach to examining dyadic perspectives on illness perceptions has been to measure not only the presence of congruence in partners' individual perceptions, but also the type of congruence that is present (e.g., shared positive or shared negative beliefs). One approach that has been used to study the type of congruent beliefs is to construct discrete groups based on whether the patient and partner are both high, both low, or incongruent on individual subscales

of the IPQ-R (Figueiras & Weinman, 2003; Sterba et al., 2008). Couples' illness perception belief types are likely to result in certain patterns of results. For example, when both patients and partners share negative illness perceptions (e.g., both partners have low perceptions of control), this congruence may actually undermine adjustment. Likewise, sharing positive perceptions of the illness may promote psychological adjustment of patients and their partners.

The form of a couple's incongruent perceptions may also be important to consider. For example, partners may perceive the illness to be less serious than patients' themselves perceive. This form of incongruence may minimize the patient's illness experience and have very different ramifications for patient and partner adjustment than if partners perceived the illness to be more serious than patients perceived.

Overall, the form of the congruent or incongruent beliefs has more important associations with patients' psychological adjustment than the absolute difference between patients' and partners' scores on illness perception subscales. Studying illness perception congruence in female patients with rheumatoid arthritis and their spouses, Sterba and colleagues (2008) found that congruence was generally high between patients and their husbands, and that incongruent beliefs were only modestly associated with patients' psychological adjustment four months later. They found that more importantly patients fared better when they shared positive beliefs about the illness with their spouse rather than sharing

negative beliefs. Figueiras and Weinman (2003) compared the illness perceptions of male myocardial infarction patients and their spouses immediately following the event and at 6- and 12-month follow-ups. They found that one third of the couples had dissimilar illness perceptions and that patients from couples with incongruent beliefs reported worse sexual functioning and lower levels of social activity. However, it was patients who shared negative illness perceptions with their partner (e.g., low control) who reported the worst outcomes overall, with more physical disability across time, lower levels of recreational and social activity, low vitality, and higher levels of health distress. When assessed, minimization by partners was associated with greater patient distress and poorer functioning than maximization (Benyamini et al., 2009; Heijmans et al., 1999; Sterba et al., 2008), suggesting that it is also important to consider the form of incongruent beliefs.

Traditionally, a greater emphasis has been placed on understanding the patient's rather than the partner's psychological adjustment. Benyamini and colleagues (2009) were the only study to examine associations of illness perception congruence with both patients' and partners' adjustment to infertility treatments. Illness perception congruence was differentially related to patients' and partners' psychological adjustment, such that males' psychological adjustment was primarily related to their personal beliefs about the illness and females' adjustment was a reflection of both their own perceptions and how

congruent their beliefs were with their partners' beliefs. Associations between illness perceptions and psychological adjustment were dependent on the specific illness perception in question, but generally more negative illness perceptions were associated with poorer adjustment in each partner (e.g., similar to previous studies, both patients and partners reported greater psychological distress when they shared perceptions of negative consequences).

When taking a dyadic approach to illness perceptions, it is important to consider the role that relationship quality plays in how couples adjust to the illness experience. Relationship quality is likely to have direct effects on each person's individual adjustment, as well as indirect effects through social constraints and illness perception congruence. Couples who are satisfied with their relationships should perceive fewer social constraints in talking about cancer, which may result in a more consistent set of beliefs about the illness. Likewise, poor relationship quality or greater levels of social constraints may create a context for incongruent perceptions to emerge. It is clear that incongruent illness perceptions are not merely a reflection of poor marital quality (i.e., people reporting satisfaction with their marriage still held discrepant illness perceptions; Figueiras & Weinman, 2003; Heijmans et al., 1999; Sterba et al, 2008). However, there is some evidence that long standing positive marital relationships serve as a buffer against negative reactivity to cancer (Northouse & Swain, 1987). Given these findings, relationship quality and/or social constraints

may moderate the associations between incongruent illness perceptions and patients' and partners' psychological adjustment. For example, if couples have a good relationship and/or are open and honest when communicating about cancer, then incongruent beliefs may be less relevant. Likewise, in the context of a negative or constrained relationship, the impact of incongruent beliefs may be more detrimental.

In summary, existing research on utilizing a dyadic approach to illness perceptions is limited, but suggests important associations with both patient and partner adjustment. This research demonstrates that when attempting to understand how patients and their partners adjust to a complex illness experience, such as late-stage cancer, it is important to consider both intrapersonal (individual level) and interpersonal (dyadic level) associations. Merely looking at incongruent beliefs might not be sufficient as research suggests that shared negative and positive perceptions are more predictive of psychological adjustment (Figueiras & Weinman, 2003; Sterba et al., 2008). Study 2 expands on the existing literature by studying associations between illness perception congruence and both patient and partner psychological adjustment in the understudied context of late-stage cancer, as well as by considering the potential role of relationship variables (i.e., relationship quality and social constraint) as independent predictors and/or moderators.

CHAPTER FIVE Study Two

ASSOCIATIONS BETWEEN ILLNESS PERCEPTIONS AND PSYCHOLOGICAL ADJUSTMENT IN WOMEN WITH LATE-STAGE CANCER AND THEIR PARTNERS: A DYADIC APPROACH

Abstract

Purpose: To examine individual and dyadic perspectives on associations between illness perceptions and psychological adjustment in women with late-stage cancer and their partners. **Methods:** In a cross-sectional observational study, 88 female oncology patients diagnosed with stage III or IV breast, gynecological, and lung cancers and their partners individually completed self-report measures of illness perceptions, relationship quality, social constraints, and psychological adjustment. **Results:** Patients' and partners' personal illness perceptions were associated with their own psychological adjustment. In both patients and partners, perceived frequency of cancer symptoms (i.e., illness identity) was associated with higher anxiety and depression, perceived coherence was associated with lower anxiety, and perceived control was associated with lower depression. Lower relationship quality and greater constraints in communicating about cancer were associated with poorer adjustment for both patients and partners. Congruence in illness perceptions was largely unrelated to either person's psychological adjustment. When congruence mattered, shared negative perceptions were associated with

poor adjustment and shared positive perceptions were associated with better adjustment. Associations between illness perception congruence and patients' and partners' psychological adjustment were not moderated by either relationship quality or social constraint. **Conclusions:** Patients' and partners' psychological adjustment to the understudied context of late-stage cancer appears related to their individual perceptions of the illness and the relationship rather than to the couple having congruent or incongruent illness beliefs.

Introduction

Late-stage cancer (stage III and IV) interferes with the daily lives of patients and their families and carries increased caregiving and economic burdens (Cameron, Franche, Cheung, & Stewart, 2002; Emanuel, Fairclough, Slutsman, & Emanuel, 2000). Partners have to balance their normal daily activities, additional caregiving responsibilities, their own emotional reactions to and fears about the cancer, and help the patient adjust to the illness. Symptoms of distress are common in both adult patients with late-stage cancer (National Comprehensive Cancer Network [NCCN], 2010) and their spouses or unmarried partners (Cameron et al., 2002; McLean & Jones, 2007). Although cancer clearly impacts both patients and their partners, research on the role of illness perceptions in guiding how patients adjust to serious illnesses has rarely extended beyond the patient's personal perceptions.

Understanding congruency in illness perceptions is particularly important in the late-stage cancer population, because partners and spouses will frequently become the primary caregivers and surrogate decision makers as the end-of-life approaches (Kaldjian, Curtis, Shinkunas, & Cannon, 2009). Incongruent beliefs within the partner relationship could cause excessive stress for both the patient and their partner (Siminoff et al., 2006) and could ultimately result in patients receiving more aggressive treatments at the end-of-life than they would have preferred (Larson & Tobin, 2000). Illness perceptions include beliefs about the

extent of symptoms, the anticipated course of the illness, the expected negative consequences of the illness, the extent to which the illness can be controlled, and whether patients have a clear and stable understanding of their illness (Leventhal, Brissette, & Leventhal, 2003; Petrie, Jago, & Devcich, 2007). Although illness perceptions have been well-studied within individual patients coping with acute and chronic illnesses, including cancer (Hagger & Orbell, 2003), limited research has explored illness perceptions in a dyadic context (Berg & Upchurch, 2007). The current study utilized a dyadic model to account for both the intrapersonal (individual level) and interpersonal (couple level) context (Lewis et al., 2006), as adjusting to a cancer diagnosis is likely to be influenced by patients' and partners' individual perceptions as well as the convergence of their perceptions (Germino, Fife, & Funk, 1995).

The growing literature on illness perception congruence between adult patients with chronic conditions and their partners has revealed several important associations with patients' psychological adjustment (Benyamini, Gozlan, & Kokia, 2009; Heijmans, de Ridder, & Besing, 1999; Figueriras & Weinman, 2003; Sterba et al., 2008). Overall, the form of the congruent or incongruent beliefs has more important associations with patients' psychological adjustment than the absolute difference between patients' and partners' scores on illness perception subscales. One approach to examining the form of illness perception congruence is to construct discrete groups based on whether the patient and

partner are both high, both low, or incongruent on individual subscales of the Illness Perception Questionnaire – Revised (IPQ-R; Figueiras & Weinman, 2003; Sterba et al., 2008). Patients fared better when they shared positive beliefs about the illness with their partner (e.g., more control), while patients who shared negative beliefs with their partner (e.g., greater severity) reported the worst adjustment overall (Figueiras & Weinman, 2003; Sterba et al., 2008).

In regard to incongruent beliefs, patients reported poorer adjustment when their partners perceived the illness to be less serious than patients' themselves perceived (i.e., minimization) rather than if partners perceived the illness to be more serious than patients perceived (i.e., maximization; Benyamini et al., 2009; Heijmans et al., 1999; Sterba et al., 2008). Traditionally, a greater emphasis has been placed on understanding the patient's rather than the partner's psychological adjustment (see Benyamini et al., 2009 for partner results); however, the current study explored associations with both patients' and partners' psychological adjustment.

When taking a dyadic approach to illness perceptions, it is important to consider the role that aspects of the relationship (i.e., relationship quality and social constraints) play in how couples adjust to the illness experience. Patients and their partners report better psychological adjustment when they perceive their relationships as supportive (Kayser et al., 1999; Manne, Alfieri, Taylor, & Dougherty, 1999), while poor relationship quality is associated with higher rates

of depression and anxiety in cancer populations (Baider, Koch, Esacson, & Kaplan De Nour, 1998; Kissane et al., 1994; Manne, Pape, Taylor, & Dougherty, 1999; Nijboer, Triemstra, Tepelaar, Sanderman, & van den Bos, 1999). Social constraints in expressing thoughts and feelings related to cancer may also undermine the psychological adjustment of both patients and partners. Such constraints may be particularly prevalent in late-stage cancer, as illnesses that have a poorer prognosis or are more threatening are associated with greater inhibition and constraint (Badr & Carmack-Taylor, 2006; Herzer, Zakowski, Flanigan, & Johnson, 2006). Beliefs about the relationship are likely to have direct effects on each person's individual adjustment as well as indirect effects through illness perception congruence. While it is clear that incongruent illness perceptions are not merely a reflection of poor marital quality (i.e., people reporting satisfaction with their marriage still held discrepant illness perceptions; Figueiras & Weinman, 2003; Heijmans et al., 1999; Sterba et al, 2008), nothing is known about whether relationship quality and/or social constraints may moderate the associations between illness perception congruence and patients' and partners' psychological adjustment. For example, if couples have a good relationship and/or are open and honest when communicating about cancer, then incongruent beliefs may be less relevant. Likewise, in the context of a negative or constrained relationship, the impact of incongruent beliefs may be more detrimental.

The present study explored individual perspectives to understand how

illness perceptions were associated with patient and partner psychological adjustment in a cross-sectional sample of female oncology patients diagnosed with late-stage breast, gynecological, and lung cancers and their partners or spouses. The study aims were to: (1) examine how patient and partner psychological adjustment were associated with their own individual beliefs about the illness, as well as with their relationship experiences (i.e., relationship quality and social constraints), (2) to determine whether patients' and partners' psychological adjustment were associated with the couple being on a "different page" about the illness (i.e., incongruent beliefs) and/or having shared positive or shared negative illness beliefs, and (3) to determine if associations between illness perception congruence and psychological adjustment were moderated by relationship experiences.

Method

Sample

Participants were recruited during routine outpatient oncology appointments through two sites of an NCI-designated cancer center that included a university-based practice (76%) and a safety-net practice (24%). Eligibility criteria included (a) female patients, (b) diagnosed with stage III or IV breast, gynecologic, or lung cancer, (c) for at least one month, (d) living in the same residence as a spouse or unmarried partner for at least one year, and (e) able to read/write English. Participants were not recruited closer to diagnosis, because

many patients experience heightened distress initially after diagnosis that dissipates in the proceeding weeks (NCCN, 2010). Additional exclusion criteria included the presence of a pre-existing co-morbid medical or psychiatric condition that may have prohibited completion of the questionnaires.

Eligible patients were identified for recruitment through medical record review at each of the participating clinics. Patients were approached at the time of their routine outpatient oncology appointment after a member of the research team was introduced by clinic staff. Interested patients were enrolled and provided with a packet of questionnaires to complete at their convenience. Of the qualifying patients approached (n=144), 96% agreed to participate (n=138), of which 76% returned a completed packet (n=105). Reasons for refusal or failure to complete the packet primarily involved lack of interest in being studied, worsening illness progression or death, and loss to follow-up. Eligible patients who did versus did not return a completed packet were more likely being treated for stage IV cancer ($\chi^2=8.87, p=.01$) in the safety-net practice ($\chi^2=5.50, p=.03$), but did not differ on cancer type or illness duration ($ps > .20$).

Partners were approached at the same time as the patient if they were present at the clinic visit (57%), otherwise patients were asked to provide permission for their partner to be contacted by telephone about study participation. Partners were either provided with a packet at the time of the appointment or were mailed a packet of questionnaires to complete at home and

were provided with a return envelope. Seven percent of patients refused to allow their partner to be contacted about participation in the study, with the primary reason being that their partner was too busy to participate. Of the partners approached (n=126), 88% agreed to participate (n=111), of which 82% returned a completed packet (n=91). Reasons for refusal or failure to complete the packet primarily involved lack of interest in being studied, not being comfortable with answering questions pertaining to emotions about cancer, or not being proficient with reading/writing in English. No significant differences were found between patients whose partner did versus did not return a completed packet on either personal characteristics (e.g., relationship length; $ps > .09$) or cancer characteristics (e.g., illness duration; $ps > .10$).

Participants for the present study consisted of the 88 patient-partner dyads who both returned completed packets. Table 5-1 describes the demographics and clinical characteristics of the current sample. Of the patients classified under gynecological cancer, 89% were diagnosed with ovarian cancer, while the remaining were diagnosed with either cervical, uterine, or vulvar cancer. Patients diagnosed with lung cancer were significantly older ($F=3.36, p=.04$), were less likely to be experiencing a recurrence of their cancer ($\chi^2=11.39, p<.01$), and had a lower performance status ($F=32.73, p<.00$). Gynecological cancer patients were more likely to be diagnosed with stage III versus stage IV cancer ($\chi^2=23.01, p<.01$); however, the majority (61%) of these participants were diagnosed with

stage IIIc gynecological cancer, which still indicates highly progressive disease.

Procedures and Measures

The study was approved by the University of Texas Southwestern Medical Center's Institutional Review Board and the Protocol Review and Monitoring Committee (PRMC) at Simmons Cancer Center. Participating patients and partners provided written informed consent and in situations where partners were recruited via the telephone, verbal assent was obtained prior to the packet being mailed. The majority of participants (more than 90%) chose to complete the packets at home and return them in the mail (patient $M = 17.63$ days, $SD = 24.33$; partner $M = 17.60$ days, $SD = 20.77$). There was an average of six days ($SD = 16.23$) between when patients and partners completed their packets. Patients and partners were explicitly instructed to complete their packet of questionnaires in separate locations without discussing their responses. Only measures used in the present analyses are described below.

Illness Perceptions. Patients and partners completed the Illness Perceptions Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002), to assess various beliefs about the patient's cancer. This scale is the most commonly used measure of illness perceptions and has been utilized in the current literature on illness perception congruence (Benyamini et al., 2009; Heijmans et al., 1999; Figueriras & Weinman, 2003; Sterba et al., 2008). The partner's version of the IPQ-R was adapted to be written from their perspective. For example, if we asked

the patient about the extent to which she agreed or disagreed with the following statement, “I expect to have cancer for the rest of my life,” we asked the partner to report the extent to which he agreed with a similar statement, “I expect that my partner will have cancer for the rest of her life.” Eight subscales were included in the current study. We assessed illness identity by having participants rate fifteen symptoms (e.g., sleep difficulty) on a scale from 1 (*never occurs*) to 4 (*occurs all of the time*). The remaining items were measured using a Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*). We assessed participants’ beliefs about the onset and course of the cancer (i.e., chronic timeline and cyclical/unpredictable timeline), potential negative consequences of the cancer (i.e., illness severity), whether the illness and treatment are understandable and consistent (i.e., illness coherence), and how amenable the cancer is to various types of control (i.e., patient control and treatment control). As data were being collected in the context of a dyadic relationship, a subscale was added to assess beliefs about the partner’s control over the cancer and/or its symptoms with items duplicated from the patient control subscale. Three additional items associated with late-stage cancer were incorporated into the IPQ-R subscales. Two items developed by Buick (1997), “my cancer is terminal” and “the symptoms of my cancer will become worse over time” were included in the chronic timeline subscale, while the third item, “I see myself as a cancer survivor” was included in the treatment control subscale. Internal consistency was greater than $\alpha = .73$ for

patient and partner report of all subscales.

Relationship Quality. Patients and their partners completed the Revised Dyadic Adjustment Scale (RDAS) to assess the perceived quality of their relationship (Busby, Christensen, Crane, & Larson, 1995). The RDAS is a 14-item measure that assesses three dimensions of relationship quality without exclusively focusing on the context of marriage, which makes it appropriate for unmarried partners. These dimensions include: 1) consensus or agreement about areas of life (e.g., handling finances or sexual relations), 2) satisfaction with the relationship, and 3) cohesion or feeling connected. The RDAS has been described as an improvement over the original DAS (Spanier, 1976), which has been extensively used in the behavioral sciences literature. The present study used the RDAS total score where higher scores indicate better overall relationship quality ($\alpha = .86$ patients, and $\alpha = .88$ partners).

Social Constraints. Three items from the Cancer Rehabilitation Evaluation System (CARES; Schag, Ganz, & Heinrich, 1991) were used to measure social constraints in talking about cancer with a spouse (Lepore & Helgeson, 1998). Participants indicated how often they experience communication difficulties with their partner (e.g., “My partner and I had difficulty talking about cancer and what might happen”) using a Likert scale from 0 (*never*) to 3 (*often*). An average score was calculated with higher numbers indicating greater perceived constraint in

communicating about cancer. Internal consistency was adequate for both patients ($\alpha = .85$) and partners ($\alpha = .89$).

Psychological Adjustment. Patients and partners completed the Hospital Anxiety and Depression Scale (HADS; Mooney et al., 1991; Zigmond & Snaith, 1983). The HADS is a 14-item scale that assesses depression and anxiety in medical settings by removing symptoms that are generally over-endorsed by medical patients (e.g., fatigue and appetite changes). A recent systematic review of assessment instruments reported that the HADS is the most extensively validated measure of distress in cancer patients and that it has adequate internal consistency and is sensitive to change in cancer patients (Vodermaier, Linden, & Siu, 2009). Partners were administered the HADS as a measure of their own psychological adjustment so that their scores would be comparable with the scores obtained from patients. Higher scores reflect endorsement of a greater number of symptoms of anxiety and depression. Internal consistency was acceptable for both the anxiety subscales ($\alpha = .80$ patients, and $\alpha = .76$ partners) and depression subscales ($\alpha = .75$ patients, and $\alpha = .73$ partners).

Demographic and Illness Information. Participants completed demographic questionnaires that measured basic information about their personal characteristics (e.g., age, income). With patient consent, medical records were accessed through each institution's electronic records to obtain information about diagnosis, staging, treatment, prognosis, and overall functioning at the time of the

clinic visit. The Eastern Cooperative Oncology Group (ECOG) performance status is well-validated (Roila et al., 1991) and represents the oncologists' rating of the patient's functional status on a scale from 0 (*fully active*) to 4 (*completely disabled*). Serum albumin levels were included as an objective measure of liver functioning/nutritional status, because lower levels have been shown to predict worsening disease and mortality (Corti, Guralnik, Salive, & Sorkin, 1994; Phillips, Shaper, & Whincup, 1989).

Statistical Approach

Initial analyses conducted to justify the use of the full sample confirmed that there were no differences across cancer type for any of the outcome variables ($ps > .20$). Correlations were conducted to identify potential personal characteristics and clinical characteristics to be covaried in subsequent analyses. Higher income, older patient age, and longer relationship length were associated with better patient psychological adjustment, while lower ECOG performance status was associated with better partner psychological adjustment. Because patient age and relationship length were highly correlated ($r = .77$) and only relationship length continued to be associated with adjustment when both variables were examined as simultaneous predictors, age was not included as a covariate in subsequent analyses.

Aim 1 was addressed by conducting correlations and multiple regression analyses to determine which illness perception and relationship variables

individually and uniquely were associated with patients' and partners' reports of anxiety and depression. Analyses were conducted separately for patients and partners. Because there was no definitive theoretical justification for ordering the entry of the predictor variables, all variables were entered simultaneously using a forward entry stepwise regression procedure. In all cases, the residuals were normally distributed and the collinearity tolerance was greater than 0.65, supporting the assumptions underlying regression.

To explore dyadic perspectives on illness perception associations with adjustment, Aim 2 was analyzed in two ways. First, we examined whether patient and partner congruence in illness perceptions was associated with adjustment. Congruence scores were computed following procedures described by Sterba and colleagues (2008). Raw difference scores for each dyad were created by subtracting partners' scores for each of the eight illness perception dimensions from patients' scores. Absolute values of these raw differences scores were then transformed into congruence scores by subtracting them from six (one plus the maximum possible difference for partners). Congruence scores for the illness identity variable were transformed to be on a six-point scale to allow for comparison with the other illness perception beliefs. Congruence scores ranged from one (*least congruent*) to six (*most congruent*). Partial correlations of illness perception congruence with patient and partner reports of relationship variables and psychological adjustment were then computed. When congruent perceptions

were found to be correlated with patient or partner adjustment, the final regression model predicting adjustment from individual illness perceptions in Aim 1 was rerun to determine whether congruence predicted adjustment beyond these individual perceptions. For Aim 3, hierarchical regression analyses were conducted to examine whether the relationship quality or social constraint variables moderated associations between illness perception congruence and psychological adjustment (Aiken & West, 1991).

A second approach to analyzing Aim 2 defined couples by not only the absolute amount of congruence, but also by the type of congruence or incongruence that was displayed (e.g., congruent perceptions that are positive may have different associations with adjustment than congruent perceptions that are negative). Couples were coded into one of four groups based on a split using the patient's median score for each illness perception variable (1 = both partners with high beliefs, 2 = patients with high and partners with low beliefs, 3 = patients with low and partners with high beliefs, and 4 = both partners with low beliefs). One-way ANOVAs were then conducted to assess whether patients' and partners' psychological adjustment varied by group for each of the illness perception beliefs; Least Significant Difference analyses with Bonferroni corrections were used to assess which groups were significantly different from one another ($p < .05$).

Results

Descriptive Information about Patients' and Partners' Psychological Adjustment

Both patients' and partners' average anxiety scores were above the recommended clinical cut-off of 7 reported in the literature (Zigmond & Snaith, 1983). In fact, 72% of patients and 84% of partners reported significant levels of anxiety (patient $M = 9.47$, $SD = 2.88$; partner $M = 10.26$, $SD = 2.75$), indicating a highly distressed sample. In contrast, depressive symptoms were reported less frequently with 32% of patients and 18% of partners reporting scores above the cut-off (patient $M = 6.34$, $SD = 2.46$; partner $M = 5.67$, $SD = 2.46$). Patients' and partners' reports of anxiety were not correlated with each other ($r = .181$), but their depression scores were modestly correlated ($r = .301$). When compared to each other, patients reported significantly higher levels of depression ($t(86) = 2.184$, $p = .032$), while partners reported significantly higher levels of anxiety ($t(87) = -2.067$, $p = .042$).

Associations between Illness Perception and Relationship Variables and Adjustment in Patients and Partners

Table 5-2 presents descriptive information and correlations between the illness perception and relationship variables and patients' and partners' psychological adjustment. Patients' reports of anxiety and depression were both higher when they endorsed more cancer-related symptoms and perceived the cancer as more severe and less amenable to treatment. Interestingly, perceptions

that the cancer was unpredictable and less coherent were associated with higher anxiety, while perceptions of low personal control were associated with depression. Partners' adjustment was predicted from a smaller set of illness perception variables, but followed a similar pattern. Partners' anxiety and depression were both associated with symptom experiences, anxiety was associated with perceiving the cancer and treatments as being difficult to understand, and depression was associated with lower perceptions of patient and treatment control. It is also notable that better relationship quality and lower constraints in communicating about cancer were associated with better adjustment for both patients and partners. General relationship quality and cancer-specific social constraints were modestly correlated with each other ($r = -.306$ for patient and $r = -.369$ for partner), such that better relationship quality was associated with lower levels of constraint in communicating about cancer.

To identify the set of illness perception and relationship variables that uniquely predicted psychological adjustment in patients and in partners, forward entry stepwise regressions were conducted predicting anxiety and depression for patient and partner. In each of the four regression analyses, covariates, illness perceptions, and relationship variables were entered. A four-variable model accounted for 38% of the variance in patients' anxiety scores, $F(4, 76) = 13.407, p < .001$. Patients reported higher levels of anxiety when they perceived their cancer as having a greater number of symptoms (i.e., illness identity; $\beta = 0.345$,

$p < .000$), had a poorer understanding of their illness (i.e., illness coherence; $\beta = -.227, p = .016$), felt more constrained in communicating with their partner about their cancer ($\beta = 0.202, p = .044$), and had been in a relationship with their partner for a shorter period of time ($\beta = -.226, p = .016$). A three-variable model accounted for 43% of the variance in patients' depression scores, $F(3, 77) = 21.055, p < .001$. Patients reported higher levels of depression when they perceived their cancer as having a greater number of symptoms ($\beta = 0.394, p < .000$), felt more constrained in communicating with their partner about their cancer ($\beta = 0.280, p = .003$), and perceived lower overall relationship quality ($\beta = -0.232, p = .013$).

A two-variable model explained 22% of the variance in partners' anxiety scores. Partners reported higher anxiety when they perceived the patient's cancer as having a greater number of symptoms ($\beta = 0.390, p < .000$) and when they perceived a poorer understanding of the patient's illness ($\beta = -.294, p = .005$), $F(2, 75) = 11.727, p < .001$. A three-variable model accounted for 31% of the variance in partners' depression scores, $F(3, 74) = 12.753, p < .001$. Partners reported higher levels of depression when they perceived the patient's cancer as having a greater number of symptoms ($\beta = 0.314, p = .002$), felt more constrained in communicating with the patient about her cancer ($\beta = 0.237, p = .017$), and perceived the treatment as being less able to control the patient's cancer and/or its symptoms ($\beta = -0.305, p = .002$).

Associations between Illness Perception Congruence and Patient and Partner Psychological Adjustment

Patient illness perception scores were significantly and positively correlated with each corresponding partner illness perception score (r s ranging from 0.26 for illness coherence to 0.69 for chronic timeline). Table 5-3 presents descriptive information on the illness perception congruence scores, as well as correlations with patient and partner adjustment. On average, patients and partners were highly congruent in their perceptions of the cancer. As shown in Table 5-3, couple illness perception congruence had no significant associations with patients' psychological adjustment or partners' reports of depression, but had several interesting associations with partners' reports of anxiety. Lower levels of congruence on the cyclical timeline ($r = -.246$) and illness coherence ($r = -.261$) variables were associated with higher levels of partner anxiety. Multiple regression analyses for partner anxiety were rerun to include the cyclical timeline and illness coherence congruence scores into the stepwise model; however, the amount of variance explained did not significantly increase.

Table 5-3 also presents associations between the illness perception congruence scores and relationship variables (i.e., relationship quality and social constraint). Illness perception congruence was unrelated to patients' reports of relationship quality or social constraint and minimally related to partners' report of the relationship variables. Partners reported better relationship quality when

couples were less congruent about their beliefs that the partner has control over the cancer ($r = -.249$) and more congruent about their beliefs that the treatment has control over the cancer ($r = .230$). In addition, partners reported higher levels of social constraint when couples were less congruent about the frequency of symptoms ($r = -.244$) and their understanding of the illness (i.e., illness coherence; $r = -.243$). Associations between illness perception congruence and patients' and partners' psychological adjustment were not moderated by either relationship quality or social constraint.

Finally, one-way ANOVAs were used to assess whether patients' and partners' psychological adjustment varied by group for each of the illness perception beliefs (1 = both partners with high beliefs, 2 = patients with high and partners with low beliefs, 3 = patients with low and partners with high beliefs, and 4 = both partners with low beliefs). Figure 5-1 and Figure 5-2 display the significant relationships that were identified during these analyses. There was an additive effect, such that patients reported lower levels of depression when from couples where both partners reported a lower frequency of symptoms (i.e., illness identity) and higher levels of depression when from couples where both partners reported a higher frequency of symptoms, $F(3, 74) = 7.989, p < .001$. Similarly, partners reported lower levels of anxiety ($F(3, 79) = 3.510, p = .019$) and depression ($F(3, 79) = 2.900, p = .041$) when couples both reported lower beliefs that the cancer had a cyclical or unpredictable timeline.

Discussion

The current study is among the first to examine the role of illness perceptions in patients' adjustment to late-stage cancer (see also Price et al., in press), and is the only study that has examined illness perceptions from a dyadic perspective to predict both patient and partner adjustment to this understudied illness. Previous studies have examined illness perception congruence in other chronic conditions (Benyamini et al., 2009; Heijmans et al., 1999; Figueriras & Weinman, 2003; Sterba et al., 2008); however, most of these studies did not examine partner outcome variables and treated relationship quality as a covariate rather than treating it as an important independent predictor. Overall, we found that patients' and partners' psychological adjustment scores were associated with their individual beliefs about the cancer, but were generally unrelated to them having congruent or incongruent beliefs about the cancer experience. Illness perception congruence had few associations with patient or partner reports of relationship quality, confirming that being on a "different page" about the illness is not necessarily a reflection of being dissatisfied with the relationship (Figueriras & Weinman, 2003; Heijmans et al., 1999; Sterba et al., 2008). Finally, patients' and partners' beliefs about the quality of their relationship and their perceived constraint to communicate with their partner about cancer were found to be important predictors of patients' and partners' psychological adjustment, but did not moderate associations between illness perception congruence and adjustment.

Our study confirmed that symptoms of distress are common in both adult patients with late-stage cancer and their spouses or partners (NCCN, 2010; Cameron et al., 2002; McLean & Jones, 2007). The majority of participants reported symptoms of anxiety above the proposed clinical cut-offs (Zigmond & Snaith, 1983), while high levels of depressive symptoms were less common. This suggests that late-stage cancer may evoke certain symptoms of distress, but not others. Another possible explanation is that it felt more socially acceptable for participants to endorse anxiety or concern, but not to endorse symptoms of depression. Previous research has suggested that females, whether they be the cancer patients or the caregivers, are more likely to report psychological distress than males (Hagedoorn et al., 2008; Northouse et al., 2000); however, in our sample, male partners were more likely to report symptoms of anxiety while female patients were more likely to report symptoms of depression. These findings suggest that utilizing a scale like the HADS (Moorey et al., 1991; Zigmond & Snaith, 1983) that examines these symptoms as unique entities might be more beneficial than examining a composite distress score. The findings also highlight the importance of providing psychological supportive services to both patients who have been diagnosed with late-stage cancer and their partners.

Patients' and partners' levels of anxiety and depression were predicted by somewhat different constellations of individual beliefs about both the illness and the relationship. In the regression analyses, however, a pattern of a few important

variables emerged. For both patients and partners, a significant portion of the variance in psychological adjustment was accounted for by perceptions of cancer-related symptoms. Illness identity has been found to be an important predictor of adjustment and quality of life in studies of other cancer populations (Downe-Wamboldt, Butler, & Coulter, 2006; Thune-Boyle, Myers, & Newman, 2006). Perception of cancer-related symptoms (i.e., illness identity) is likely to stand in as an indicator of how severe patients and partners perceive the cancer to be at the present moment, as well as how much the cancer interferes with the patient's ability to function. The consistency and strength of these associations points to the importance of symptom management as the end of life approaches for both patients' and partners' psychological adjustment. Beliefs about the extent to which the patient or partner has a clear and stable understanding of the illness (i.e., illness coherence) were an important predictor of symptoms of anxiety. Patients and partners who feel like the cancer is a mystery to them are likely to feel tense and worried because they cannot anticipate what to expect from the cancer experience. Although the majority of the other illness perception variables were correlated with patients' and partners' symptoms of anxiety and depression, these two beliefs were prominent in the multiple regression analyses.

In the current study, patients diagnosed with late-stage cancer and their partners generally had similar perceptions of the illness. Unlike previous research (Figueiras & Weinman, 2003; Heijman et al., 1999), we found few associations

between incongruent beliefs about the cancer and patients' and partners' psychological adjustment. It is possible that, compared to other chronic illnesses, couples coping with late-stage cancer are more likely to share similar beliefs about the illness and/or that illness perception congruence is less important in the context of late-stage cancer. Patients' psychological adjustment in particular showed no evidence of associations with congruence, and although congruence on cyclical timeline and illness coherence beliefs was associated with partner anxiety, these associations did not remain when individual perceptions and relationship variables were statistically controlled. Utilizing median splits to create four distinct couple groupings allowed us to examine the impact of the congruence between patient and partner, as well as the importance of the direction of the illness perception (i.e., high or low scores on the various subscales). Our findings were consistent with research that has shown that adjustment might not depend on incongruence but rather on dyads collectively sharing negative or positive perceptions (Figueiras & Weinman, 2003; Sterba et al., 2008). Although the number of significant relationships was limited, two clear associations emerged. First, patients' psychological adjustment was related to shared beliefs about the frequency of symptoms. As mentioned earlier, illness identity is an indicator of the severity of the cancer. When patients and partners agree that the frequency of symptoms is high it is likely because the patient's cancer is clearly not going well. Likewise, partners experienced better psychological adjustment

when both they and the patient viewed the cancer as less cyclical or unpredictable (i.e., shared positive beliefs). In summary, patients' and partners' psychological adjustment is, for the most part, a function of their individual level beliefs rather than their couple level beliefs.

The addition of relationship variables (i.e., relationship quality and social constraint) was important in trying to understand psychological adjustment in the context of a dyadic relationship. It has been well-documented that poor marital relationships are associated with higher rates of anxiety and depression in cancer populations (e.g., Manne et al., 1999); however, little is known about how relationship quality is associated with illness perception congruence or social constraints. Reports of relationship quality and social constraints were only modestly associated, which indicates that patients and partners who perceive themselves as being in supportive relationships can still feel that they have difficulty communicating about cancer with their partner. Social constraint was an important predictor of patients' and partners' psychological adjustment and may be reflective of the fact that late-stage cancer is a life-threatening illness with the potential for emotion-laden conversations about death and dying (Badr & Carmack-Taylor, 2006; Herzer et al., 2006). Associations between illness perception congruence and psychological adjustment were not moderated by relationship quality or social constraints, which further indicates that being on the "same page" about the cancer is not reflective of the quality of the relationship.

The cross-sectional nature of the current study limits us from making causal interpretations about these associations. Although negative perceptions about the cancer or the relationship are likely to impact patients' and partners' psychological adjustment, it is equally plausible that participants with higher levels of depression and anxiety are more likely to evaluate the illness and their relationship negatively. Future research should consider how the associations found in the current study change across time and at different stages of cancer progression; for example, incongruent beliefs about late-stage cancer may be more important initially after diagnosis or nearer the end-of-life. In addition, it is difficult to define optimal illness perceptions for couples facing an unpredictable illness. Our data did not allow us to assess whether patients' and partners' beliefs about the illness were realistic based on medical data, rather we defined positive and negative perceptions based on what previous research has demonstrated (Hagger & Orbell, 2003; Leventhal et al., 2003). We exclusively focused on female patients and male partners to control for the established gender effect in previous research (Hagedoorn et al., 2008; Northouse et al., 2000); however, this limits the generalizability of our findings. In addition, the participants in our study should be considered as higher functioning patients with late-stage cancer, because they were not hospitalized and were not yet receiving hospice care. Future work should consider extending this research to a variety of cancer populations, non-English speaking patients, male patients, and those patients who

are potentially in their last few months of life.

Findings from this study demonstrate the importance and complexity of considering dyads when investigating beliefs about and psychological adjustment to a life-limiting illness, such as late-stage cancer. Both patients and partners demonstrated difficulty adjusting to a diagnosis of late-stage cancer, and so interventions need to be designed to target both of their needs (Carlson, Bultz, Speca, & St. Pierre, 2000). Facilitating the partner's adjustment is likely to be beneficial for both the patient and the partner as partners' perceptions of the illness and personal psychosocial adjustment are likely to influence the type and extent of support that they provide to the patient. Health care professionals are in the unique position to facilitate conversations about the cancer diagnosis, thereby decreasing social constraints. In the context of late-stage cancer, conversations may need to include dialogue about prognosis and, potentially, death and dying (Carlson et al., 2000). Interventions designed to increase communication, gain a mutual understanding of the illness, improve relationship quality, and enhance the personal meaning of the illness are likely to be successful. Early studies with such interventions have been successful in altering beliefs and improving the psychosocial adjustment of myocardial infarction patients and their partners (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009a and 2009b) and increasing marital functioning over time for late-stage cancer patients and their partners (McLean et al., 2008).

Table 5-1

Participant Demographic and Illness Characteristics for Current Sample (n=88)

<i>Characteristic</i>	Patients	Partners
Age (in years), M (<i>SD</i>)	58.2 (11.3)	59.8 (11.3)
Race/Ethnicity		
White	73 %	76 %
Black	11 %	10 %
Asian	3 %	2 %
Hispanic	7 %	7 %
Multi-Racial	6%	4 %
Education Level		
High school education or lower	36 %	30 %
More than high school education	64 %	70 %
Occupation Status		
Employed	25 %	60 %
Unemployed/Disability	43 %	9 %
Retired	32 %	30 %
Income, n=94		
< \$25,000		30 %
≥ \$25,000		66 %
Relationship Status - Married		89 %
Years Living Together, M (<i>SD</i>)	28.3 (16.1)	
Cancer Type		
Breast	40 %	
Gynecological	35 %	
Lung	25 %	
Illness Duration (in months), M (<i>SD</i>)	15.5 (25.4)	
Cancer Stage		
III	63 %	
IV	37 %	
Metastases Present	71 %	
Cancer is Recurrent	44 %	
ECOG Performance Status, M (<i>SD</i>)	0.37 (0.72)	
Serum Albumin Levels, M (<i>SD</i>)	4.1 (0.37)	

Table 5-2

Sample Means, SDs, and Pearson Correlation Coefficients Between Illness Perception Variables and Patient and Partner Outcome Variables¹

<i>Illness Perception Variables</i>	<i>Patient Report</i>			<i>Partner Report</i>		
	<i>M (SD)</i>	<i>Anxiety</i>	<i>Depression</i>	<i>M (SD)</i>	<i>Anxiety</i>	<i>Depression</i>
Illness Identity	2.09 (0.45)	.372**	.541**	2.13 (0.48)	.406**	.440**
Chronic Timeline	3.02 (1.08)	.166	.205	3.15 (1.08)	.091	.248*
Cyclical Timeline	2.57 (0.95)	.454**	.174	2.94 (0.87)	.204	.087
Illness Severity	3.85 (0.76)	.272*	.358**	3.66 (0.73)	.186	.193
Illness Coherence	3.83 (0.77)	-.391**	-.167	3.93 (0.76)	-.347**	-.133
Patient Control	3.64 (0.68)	-.105	-.284*	3.26 (0.77)	-.023	-.368**
Partner Control	2.65 (0.77)	.196	.155	3.02 (0.81)	.191	-.197
Treatment Control	3.94 (0.67)	-.262*	-.331**	3.82 (0.71)	-.207	-.438**
<i>Relationship Variables</i>						
Relationship Quality ²	51.65 (8.37)	-.165	-.315**	51.78 (8.62)	-.249*	-.435**
Social Constraint	0.82 (0.85)	.343**	.388**	0.71 (0.91)	.370**	.377**
<i>Covariates</i>						
Relationship Length		-.391**	-.183		.007	-.088

Income	-.245*	-.270*	.079	.012
ECOG Performance Status	.019	.156	.232*	.230*

* $p < .05$, ** $p < .01$

¹ This table presents correlations between patient report of illness perceptions and their own anxiety and depression scores and partner report of illness perceptions and their own anxiety and depression scores. Correlations were conducted with relationship length, income, and ECOG performance status entered as covariates.

² Higher scores indicate better relationship quality

Table 5-3

Sample Means, SDs, and Pearson Correlation Coefficients Between Congruence Scores and Patient and Partner Outcome Variables¹

<i>Illness Perception Congruence Scores</i>	<i>M(SD)</i>	<i>Patient Report</i>				<i>Partner Report</i>			
		<i>Anxiety</i>	<i>Depression</i>	<i>Relationship Quality²</i>	<i>Social Constraint</i>	<i>Anxiety</i>	<i>Depression</i>	<i>Relationship Quality²</i>	<i>Social Constraint</i>
Illness Identity	5.68 (0.29)	-.193	-.028	.054	.046	-.158	-.038	.161	-.244*
Chronic Timeline	5.30 (0.50)	-.021	-.090	.000	.080	-.053	.099	-.002	-.037
Cyclical Timeline	5.16 (0.74)	.091	-.045	.085	.164	-.246*	-.075	.191	.070
Illness Severity	5.43 (0.49)	.036	-.027	-.010	.016	-.133	.029	.209	.117
Illness Coherence	5.26 (0.57)	-.164	.038	-.039	-.094	-.261*	-.209	-.041	-.243*
Patient Control	5.28 (0.57)	.097	-.012	-.065	-.066	.174	-.218	.063	.068
Partner Control	5.28 (0.61)	.044	.062	-.200	.089	-.078	.129	-.249*	.091
Treatment Control	5.51 (0.39)	.227	.069	.064	-.053	.100	-.068	.230*	-.150

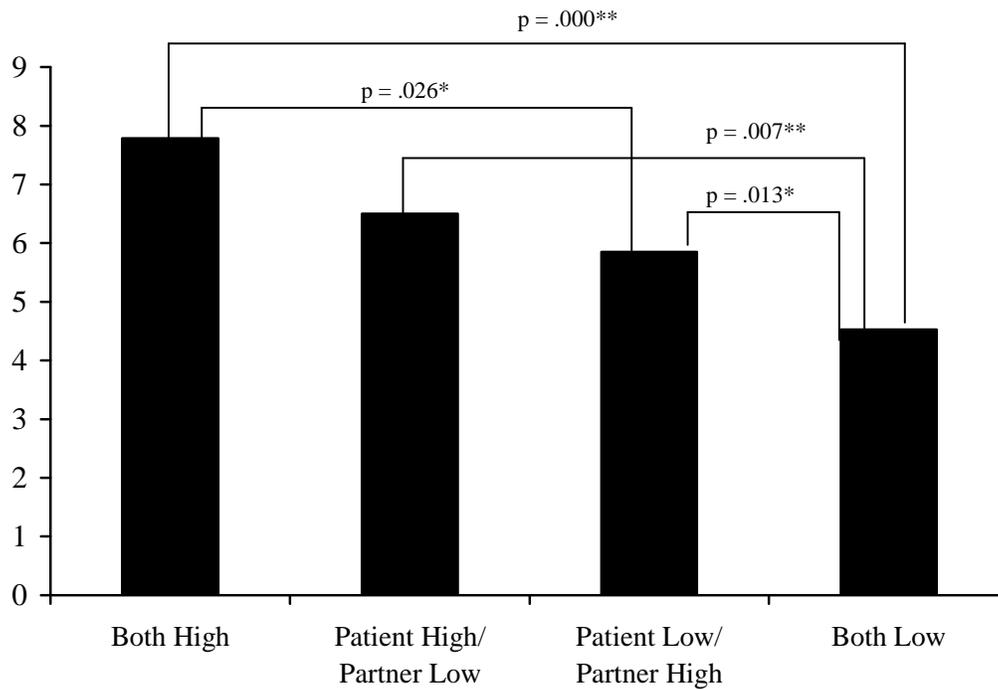
* $p < .05$, ** $p < .01$

¹ Correlations were conducted with relationship length, income, and ECOG performance status entered as covariates.

² Higher scores indicate better relationship quality

Figure 5-1

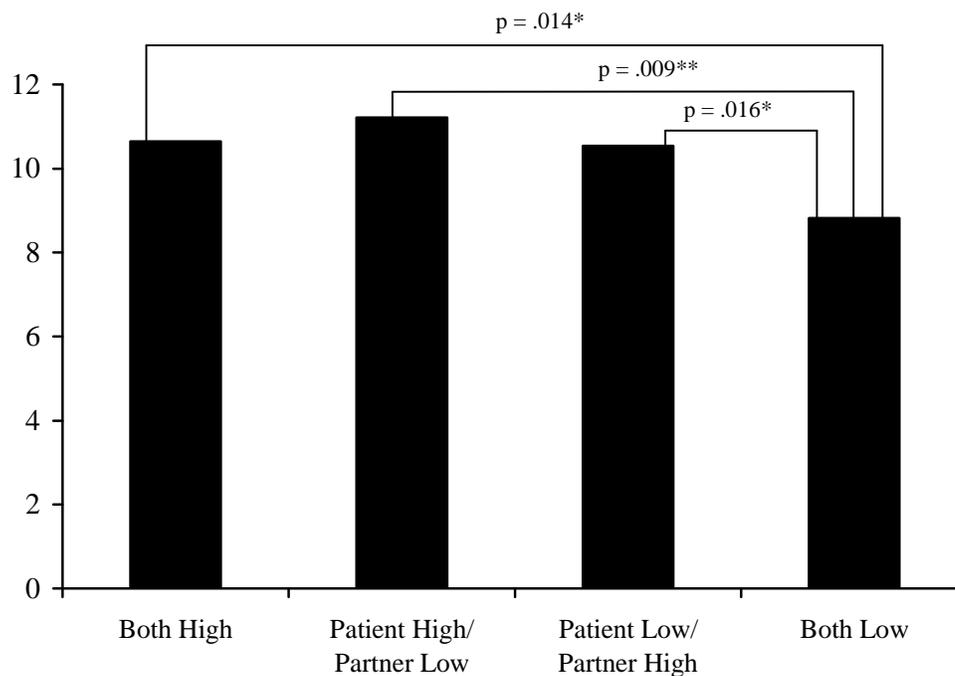
Couple Illness Perception Belief Type for Illness Identity Associated with Patient Report of Depression



Note: Figure based on analysis of variance while covarying for relationship length, income, performance status, and patient reports of relationship quality and social constraint. A similar pattern of results was found for patient report of anxiety; however, results were only marginally significant $F(3,74) = 2.561$, $p = .062$.

Figure 5-2

Couple Illness Perception Belief Type for Cyclical Timeline Associated with Partner Report of Anxiety



Note: Figure based on analysis of variance while covarying for relationship length, income, performance status, and partner reports of relationship quality and social constraint. A similar pattern of results was found for partner report of depression, $F(3,79) = 2.900, p = .041$.

CHAPTER SIX

Integrated Conclusions

This broad investigation was designed to understand how female patients diagnosed with late-stage breast, gynecological, or lung cancer and their spouses or unmarried partners thought about and adjusted to the illness experience. Using the Common-sense Model of Self-regulation (Leventhal et al., 2003), data were examined at both intrapersonal (individual) and interpersonal (dyadic) levels. The first study demonstrated that how patients perceived their cancer was a better predictor of their health-related quality of life and advanced illness-related behavior than clinical characteristics of their cancer (e.g., stage, illness duration). The second study revealed that patients' and partners' psychological adjustment were associated with their individual beliefs about the cancer and their relationship, and mostly unrelated to them having congruent or incongruent beliefs about the cancer experience. The current program of research resulted in several important theoretical contributions to the understanding of the late-stage cancer experience, as well as suggesting helpful clinical implications.

Prior to this study, only one other study had examined illness perceptions specifically in the context of late-stage cancer (Price et al., in press). Even in the context of a life-limiting illness, what was “psychologically” correct was more important in guiding behavior and emotional reactions than what was “medically” correct (Leventhal et al., 2003). By far, perceptions of the symptoms associated

with cancer and/or its treatment (i.e., illness identity) had the strongest association with all outcome variables. Illness identity is likely to stand in as an indicator of how severe patients' perceive their cancer to be at the current time, as well as how much their cancer interferes with their ability to function. Although this is not new information as previous studies have found similar results (Downe-Wamboldt et al., 2006; Rozema et al., 2009; Thune-Boyle et al., 2006), the amount of variance explained by this single variable was striking and reinforces the importance of health care professionals addressing symptoms associated with cancer and/or its treatment (e.g., fatigue, nausea). It was also clear that patients and partners benefit psychologically from viewing the cancer experience as stable and understandable (i.e., illness coherence) with a predictable timeline (i.e., cyclical timeline). Interventions designed to help couples to stay informed and educated about the prognosis of their cancer and what they should expect at different stages of treatment may help to alleviate some of this unpredictability.

Illness perceptions have only recently been examined from a dyadic perspective. Couples' illness perceptions are likely to evolve together, but are not guaranteed to be the same because patients and partners have different belief systems, assess the illness using different sources of information and personal experiences, and may have different coping goals (Berg & Upchurch, 2007). Participants in the current sample generally held similar beliefs about the cancer experience, which might partially explain why we found fewer results than

previous studies where congruence scores were lower (Benyamini et al., 2009; Heijmans et al., 1999; Figueriras & Weinman, 2003; Sterba et al., 2008). In the current sample, patients' and partners' psychological adjustment was clearly associated with their individual beliefs and only minimally associated with the congruence between their beliefs. When associations were found, it was typically not an issue of couples being on a different page about the illness (i.e., incongruent beliefs), but rather an additive effect of couples sharing the same positive or negative beliefs.

Several illness perceptions found to be important predictors of adjustment and behaviors in other illness populations (Hagger & Orbell, 2003), did not play as important of a role in the context of late-stage cancer. We hypothesized that viewing the illness as chronic or terminal would be a particularly important belief for this population; however, that did not turn out to be the case. This implies that patients' long-term beliefs about their cancer may not be as important to their adjustment as their beliefs about the current status of their cancer (i.e., illness identity). In addition, the three control variables were minimally associated with the outcome variables. This might be a reflection of the fact that the IPQ-R assess primary control (i.e., perceptions of control over the cancer); whereas, in the context of a seemingly uncontrollable situation, measuring secondary control (i.e., perceptions of control over internal reactions to the event) may be more appropriate (Rothbaum et al., 1982; Thompson et al., 1993).

These studies also added to the literature by including several domains that have been minimally studied in this disease population or in conjunction with illness perceptions. First, an instrument was created for this study to assess whether patients engaged in particular advanced illness behaviors (NCI, 2005). Based on the advanced illness behavior literature, the assumption was made that completing a greater frequency of these behaviors could be viewed as beneficial. This new scale deserves further development because assessing behavioral outcomes lends credence to the theoretical assumption that patients' beliefs about the illness impact not only their emotional adjustment but also their illness-related behaviors. Second, the addition of a measure of cancer self-representation (i.e., cancer centrality) was a unique contribution, because this concept is relatively new (Wiebe et al., 2002) and has only recently been studied in the cancer population (Helgeson, 2011; Park et al., 2011). In the current sample, when females with late-stage cancer believed that cancer was central to their self-identity, they reported poorer quality of life. This suggests that it is unhealthy for patients to define themselves in terms of their illness or that one cannot help but define one's self by cancer when it pervades all aspects of one's life. Finally, the current study assessed beliefs about the quality of the relationship as well as perceptions of cancer-specific social constraints, which were found to be important predictors of patients' and partners' psychological adjustment, but were minimally related to illness perception congruence.

Even though the current data suggest that it is not necessary to get patients and their partners on the “same page” about the illness, it is still recommended to design interventions aimed at improving communication between patients, their partners, and health care professionals about beliefs about the cancer (Broadbent et al., 2009a and 2009b; Ditto et al., 2001; Frosthalm et al., 2005; McLean et al., 2008; Northouse et al., 2007; Petrie, Cameron, Ellis, Buick, & Weinman, 2002). When health care professionals understand patients’ and partners’ perceptions of an illness they can be more mindful when explaining the realistic implications of the cancer diagnosis. Likewise, it is important for patients and health care professionals to understand partners’ perceptions of the illness as their beliefs are likely to influence their own psychological adjustment, as well as the type and extent of support that they provide to the patient. Continued research in this area, as well as interventions designed to increase the frequency of engaging in advanced illness behaviors, will help move toward the goal of improving the care and adjustment of couples living with late-stage cancer (Peppercorn et al., 2011).

APPENDIX A
Advanced Illness Behavior Questionnaire

Instructions: Many people with and without cancer engage in the following behaviors. We would like to know which of the following behaviors you have completed and additional information about your decision making process.

	Have you done the following:	Briefly describe how you decided to <u>do or not do</u> the following:	If yes, who helped you make this decision or complete this task: (check all that apply)	If yes, do you consider this decision as being:
1. Participated in cancer survivorship organizations (Susan G. Komen Foundation, SHARE, etc.)	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner
2. Completed a document to make your medical wishes known (advance directive, living will, Do Not Resuscitate order, Five Wishes document)	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner
3. Appointed a medical power of attorney (someone who can make medical decisions for you)	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner

	Have you done the following:	Briefly describe how you decided to <u>do or not do</u> the following:	If yes, who helped you make this decision or complete this task: (check all that apply)	If yes, do you consider this decision as being:
4. Considered or enrolled in a clinical trial for experimental treatment	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner
5. Made funeral arrangements or made your wishes known about burial preference (for example, cremation vs. burial)	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner
6. Wrote a legal will for your finances and other property	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner
7. Talked with special people in your life about your cancer and your future	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner

	Have you done the following:	Briefly describe how you decided to <u>do or not do</u> the following:	If yes, who helped you make this decision or complete this task: (check all that apply)	If yes, do you consider this decision as being:
8. Put your affairs in order (for example, organized finances and important documents, cleared up insurance issues)	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner
9. Obtained information about Hospice programs	<input type="checkbox"/> Yes <input type="checkbox"/> No		<input type="checkbox"/> Partner/spouse <input type="checkbox"/> Parents or Siblings <input type="checkbox"/> Your children <input type="checkbox"/> Medical Team <input type="checkbox"/> Friends <input type="checkbox"/> Other:	<input type="checkbox"/> Just your own <input type="checkbox"/> Yours, but it indirectly affects your spouse/partner <input type="checkbox"/> Shared with your spouse/partner

APPENDIX B
Additional Analyses

Table A-1

Characteristics and Comparisons of the Total Sample and Specific Cancer Types

<i>Variables</i>	<i>Total Sample M (SD)</i>	<i>Breast Cancer M (SD)</i>	<i>Gynecological Cancer M (SD)</i>	<i>Lung Cancer M (SD)</i>	<i>Statistic for Comparison</i>
<i>Personal Characteristics</i>					
Age (in years)	58.29 (11.05)	55.67 (10.19)	58.43 (11.66)	62.96 (10.48)	$F = 3.41^*$
Relationship Length (in years)	28.81 (15.99)	26.02 (14.46)	28.63 (17.54)	34.43 (15.28)	$F = 2.14$
Education Level (% > high school)	61 %	68 %	53 %	61 %	$\chi^2 = 19.16$
Occupation Status (% employed)	25 %	32 %	21 %	17 %	$\chi^2 = 18.28^*$
Approximate Income (% > \$50,000)	51 %	55 %	45 %	57 %	$\chi^2 = 10.87$
Ethnicity (% non-Hispanic Caucasian)	65 %	61 %	66 %	70 %	$\chi^2 = .50$

<i>Variables</i>	<i>Total Sample M (SD)</i>	<i>Breast Cancer M (SD)</i>	<i>Gynecological Cancer M (SD)</i>	<i>Lung Cancer M (SD)</i>	<i>Statistic for Comparison</i>
<i>Clinical Characteristics</i>					
Illness Duration (in months)	16.05 (25.62)	20.77 (30.57)	13.61 (25.12)	11.04 (11.61)	$F = 1.37$
Cancer Stage (% Stage IV)	37 %	45 %	21 %	48 %	$\chi^2 = 28.78^{**}$
Metastases Present (% yes)	68 %	75 %	63 %	61 %	$\chi^2 = 2.34$
Cancer Recurrence (% yes)	43 %	52 %	50 %	13 %	$\chi^2 = 10.73^{**}$
Health Insurance (% yes)	78 %	70 %	84 %	83 %	$\chi^2 = 2.93$
ECOG Performance Status	0.34 (0.68)	0.18 (0.46)	0.03 (0.16)	1.17 (0.83)	$F = 39.61^{**}$
Serum Albumin Levels	4.07 (0.40)	4.18 (0.29)	4.05 (0.45)	3.90 (0.42)	$F = 3.98^*$
<i>Outcome Variables</i>					
Quality of Life	73.97 (17.43)	72.54 (18.14)	75.82 (17.15)	73.83 (17.00)	$F = 0.34$
Anxiety	9.58 (2.95)	9.90 (2.99)	9.75 (2.84)	8.74 (2.99)	$F = 1.25$
Depression	6.36 (2.45)	6.39 (2.36)	6.22 (2.36)	6.52 (2.83)	$F = 0.11$
Advanced Illness Behaviors	3.96 (2.45)	3.45 (2.51)	4.31 (2.42)	4.36 (2.32)	$F = 1.58$

* $p < .05$, ** $p < .01$

Table A-2

Percentage of Family and Medical Team Support Reportedly Received by Patients when Completing Advanced Illness Behaviors

<i>Advanced Illness Behavior</i>	<i>No. of Participants</i>	<i>%</i>	<i>If Yes, Helped by Partner or Family</i>	<i>If Yes, Helped by Medical Team</i>
Participated in cancer survivorship organizations	28	27	64 %	14 %
Completed a document to make medical wishes known	49	47	78 %	12 %
Appointed a medical power of attorney	46	44	83 %	9 %
Considered or enrolled in a clinical trial	46	44	72 %	43 %
Made wishes known about funeral arrangements	56	53	80 %	0 %
Wrote a legal will for finances and property	47	45	81 %	0 %
Talked with people in their life about their cancer and/or their future	77	73	68 %	13 %
Put affairs in order	50	48	66 %	2 %
Obtained information about hospice programs	8	8	88 %	13 %

Table A-3

Distribution of Four Different Types of Couple Illness Perception Belief Types

<i>Illness Perception</i>	<i>Both High</i>	<i>Patient High/ Partner Low</i>	<i>Partner High/ Patient Low</i>	<i>Both Low</i>
Symptoms	27	12	21	24
Chronic Timeline	32	8	13	33
Cyclical Timeline	25	11	27	24
Illness Severity	30	19	14	25
Illness Coherence	14	16	15	43
Patient Control	11	25	10	41
Partner Control	36	7	24	19
Treatment Control	18	17	14	37

Table A-4

Analysis of Variance Assessing Patient Outcome Variables by Four Different Types of Couple Illness Perception Belief Types¹

<i>Illness Perception</i>	<i>Both High</i>		<i>Patient High/ Partner Low</i>		<i>Partner High/ Patient Low</i>		<i>Both Low</i>		<i>F Statistic (3, 77)</i>
	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	
Symptoms									
Anxiety	9.72 _a	.50	10.70 _a	.68	9.43 _{a,b}	.53	8.44 _b	.51	2.561 [†]
Depression	7.44 _a	.39	6.49 _{a,c}	.53	6.12 _c	.41	4.69 _b	.40	7.989**
Chronic Timeline									
Anxiety	9.87	.46	8.68	.88	9.89	.71	9.26	.45	0.695
Depression	6.58	.38	6.22	.73	7.06	.58	5.76	.37	1.446
Cyclical Timeline									
Anxiety	10.42	.50	10.16	.72	9.20	.47	8.77	.53	2.061
Depression	6.45	.44	6.57	.63	6.74	.41	5.73	.47	0.936
Illness Severity									
Anxiety	9.72 _a	.45	10.52 _a	.56	8.09 _b	.74	9.33 _a	.50	2.374 [†]
Depression	6.96	.39	6.27	.49	6.73	.64	5.55	.43	2.070
Illness Coherence									
Anxiety	8.69	.71	9.27	.69	9.79	.69	9.89	.39	0.795
Depression	5.99	.61	6.30	.59	6.08	.59	6.61	.34	0.355

<i>Illness Perception</i>	<i>Both High</i>		<i>Patient High/ Partner Low</i>		<i>Partner High/ Patient Low</i>		<i>Both Low</i>		<i>F Statistic (3, 77)</i>
Patient Control									
Anxiety	10.24	.78	9.67	.51	8.42	.84	9.58	.40	0.873
Depression	6.09	.68	6.36	.44	5.73	.73	6.57	.35	0.413
Partner Control									
Anxiety	9.91	.45	9.29	.94	9.74	.51	9.17	.57	0.405
Depression	6.21	.39	6.27	.82	6.55	.44	6.51	.49	0.140
Treatment Control									
Anxiety	9.15	.60	9.85	.65	9.10	.69	9.93	.44	0.583
Depression	6.07 _{a,b}	.49	7.09 _a	.54	5.23 _b	.57	6.73 _a	.37	2.350 [†]

[†] $p < .10$, $*p < .05$, $**p < .01$

¹ Controlling for Patient Age, Income, ECOG Performance Status, Relationship Quality, and Social Constraint

Footnote: When F-statistic was significant, mean scores with different subscripts are significantly different from one another as examined by Least Significant Difference analyses with Bonferroni correction

Table A-5

Analysis of Variance Assessing Partner Outcome Variables by Four Different Types of Couple Illness Perception Belief Types¹

<i>Illness Perception</i>	<i>Both High</i>		<i>Patient High/ Partner Low</i>		<i>Partner High/ Patient Low</i>		<i>Both Low</i>		<i>F Statistic (3, 78)</i>
	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>	
Symptoms									
Anxiety	10.61 _{a,b}	.52	9.21 _b	.71	11.32 _a	.54	9.32 _b	.53	3.114*
Depression	6.00 _a	.45	4.35 _b	.62	6.33 _a	.47	5.21 _{a,b}	.47	2.574 [†]
Chronic Timeline									
Anxiety	10.07	.47	11.06	.91	11.29	.73	9.82	.45	1.256
Depression	5.97	.40	4.50	.78	5.78	.62	5.31	.39	1.164
Cyclical Timeline									
Anxiety	10.65 _a	.51	11.21 _a	.73	10.54 _a	.49	8.82 _b	.51	3.510*
Depression	5.66 _{a,b}	.43	5.57 _{a,b}	.62	6.35 _a	.42	4.59 _b	.43	2.900*
Illness Severity									
Anxiety	10.80	.48	10.34	.59	10.07	.73	9.33	.53	1.432
Depression	6.25	.41	4.81	.50	5.71	.61	5.22	.45	1.815
Illness Coherence									
Anxiety	9.44	.78	10.30	.69	9.89	.72	10.44	.40	0.480
Depression	4.93	.66	5.59	.58	6.15	.61	5.55	.34	0.613

<i>Illness Perception</i>	<i>Both High</i>		<i>Patient High/ Partner Low</i>		<i>Partner High/ Patient Low</i>		<i>Both Low</i>		<i>F Statistic (3, 78)</i>
Patient Control									
Anxiety	11.14	.81	9.99	.54	9.99	.87	10.15	.41	0.516
Depression	5.11	.68	5.88	.45	4.86	.73	5.59	.34	0.608
Partner Control									
Anxiety	10.75	.46	8.49	.97	10.02	.52	10.05	.59	1.531
Depression	5.37	.39	5.66	.83	5.27	.44	6.32	.49	0.978
Treatment Control									
Anxiety	9.62	.63	10.32	.63	9.55	.69	10.81	.45	1.099
Depression	4.84 _a	.53	5.75 _{a, b}	.53	4.51 _a	.58	6.22 _b	.37	2.544 [†]

[†] $p < .10$, * $p < .05$, ** $p < .01$

¹ Controlling for Partner Age, Income, ECOG Performance Status, Relationship Quality, and Social Constraint

Footnote: When F-statistic was significant, mean scores with different subscripts are significantly different from one another as examined by Least Significant Difference analyses with Bonferroni correction

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