

**Dyadic Analyses of the Influence of Chronic Conditions on the  
Biopsychosocial Wellbeing and Health-Promoting Behaviors of  
Individuals with Advanced Cancer and Their Family Caregivers**

by

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A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
(Health Behavior and Health Education)  
in the University of Michigan  
2015

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This dissertation is dedicated to my family.

To my mom & dad, for supporting me in countless ways;  
my siblings, nieces and nephews for keeping me grounded;  
my extended family for encouraging me; and,  
my husband, for believing in me.

I thank God for each of you.

## ACKNOWLEDGEMENTS

“In everything give thanks...” I Thessalonians 5:18

First, I would like to thank God for giving me the strength to finish this dissertation. Through the ups and downs of my life, God has sustained me and I know He will continue to do so. I am thankful for His love, His grace and His many blessings.

I have received a tremendous amount of support as I have worked to complete my PhD program. I firmly believe that “there are no coincidences with God” so I am thankful for every person, opportunity and experience that has contributed to my passion to pursue this work and my growth and development as an individual and scholar. While I will make a few brief acknowledgments here, I am overwhelmingly grateful for it all.

Thank you, to my dissertation committee, for your encouragement, confidence in my abilities, and for taking an interest in my work. Thank you, Cleo Caldwell, my program advisor and committee chair, for all of the time you spent helping me to develop my ideas and the research skills necessary to turn those ideas into scholarly work. Thank you, Laurel Northouse, for being so very gracious with your time, your knowledge and resources. I am grateful for the opportunity to use your data and I appreciate the many patients and caregivers who participated in this work. Thank you, Mary Janevic, for all the coffee chats and for helping me develop my ideas and my writing. Thank you, Nancy Janz, for the many times you let me know that this work will make a contribution to the field. Thank you, Trace Kershaw, for helping me to develop my dyadic data analysis skills. I benefitted greatly from the support of each of you.

Thank you to the Fathers and Sons Research Team, including Shervin Assari, Lynda Fuerstnau, Erica Odukoya, and Alvin Thomas, for giving me a scholarly home. Thank you to Linda Chatters, Derek Griffith, and Larry and Stephanie Rowley, for your continued personal and professional encouragement and support. Thank you to Missy Plegue, CSCAR consultant, for all of your patience and assistance with my statistical analysis.

Thank you to Rackham Graduate School, the Department of Health Behavior & Health Education, the Center for the Education of Women – and the wonderful faculty and staff represented therein - for the funding and resources to pursue and complete my degree program.

To my colleagues and friends - my PhD cohort, the CRECH family, Chatters mentoring group, OAMI & SOE folks and so many others – thank you. Thank you to Casta Guillaume, Aisha Langford, Trichelle Lemons, Jacinta Florek, and Timeka Tounsel for the walk-and-talks, prayers, emails, texts, phone calls, meals, coffee dates, writing sessions and hugs.

Thank you to my Bible Baptist Church and Canton Christian Fellowship church families for your prayers, guidance and encouragement and reminding me to keep God first in all things.

It is hard to put into words what my family means to me. Thank you to the Herbert, Stanton, Griffin, Ellis, Ramirez, and Hernandez families, and all of the connected roots and branches of my large and growing family tree. You have housed, fed, prayed for, and encouraged me – and James – and continue to be a constant source of support for us. I enjoy our time together, and these days, it never feels like we have enough. You help me to remember what is important in life. I appreciate all of you so very, very much.

Finally, thank you to my husband and best friend, James. I am thankful that God blessed me with you. You inspire me and you have believed in me when I did not believe in myself. Your love and support are priceless. This journey has been so much brighter because of you.

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## **ABSTRACT**

This dissertation examined the influence of pre-existing chronic health conditions on the biopsychosocial wellbeing and health-promoting behaviors of individuals with advanced breast, colorectal, lung or prostate cancers and their family caregivers (N=484 dyads). The first study examined how the number of patient and caregiver chronic conditions influenced their engagement physical activity, diet and sleep behaviors over time. The second study explored the relationship between cancer and non-cancer related symptom distress (predictors), cancer-related threat appraisals (mediators) and individual- and family-related self-efficacy for coping with cancer (outcomes). In this analysis, dyadic comorbidity burden was considered as a moderator of these relationships in a multigroup framework. In the third study, patient and caregiver meaning-based coping were tested as mediators and moderators of the relationship between chronic health conditions and quality of life.

Building on the actor-partner interdependence model (APIM) for dyadic analysis, each study considered independent (actor) and interdependent (partner) effects. In each study, actor and partner effects were evident. Results from the first study indicated that patients' number of chronic conditions was associated with their own exercise and sleep behaviors and the sleep behaviors of caregivers. In addition, caregivers' number of chronic conditions was associated with their own exercise, diet and sleep behaviors and the exercise behaviors of patients. Results from the second study indicated that patient and caregiver symptom distress influenced their own threat appraisals and self-efficacy, and in some cases, the threat and self-efficacy of their dyadic partner. In addition, differences were seen when comparing model results from the four dyadic

comorbidity burden groups. In the third study, patient and caregiver number of chronic conditions negatively influenced their quality of life and the quality of life of their dyadic partner. Caregiver meaning-based coping was a mediator, but not a moderator, of this relationship.

Approximately 7 out of 10 dyads had a patient or caregiver with multiple chronic conditions. Overall, the findings suggest that it is important to consider how the chronic conditions of both patients and caregivers, in addition to the advanced cancer, influence their health-related outcomes. Research, practice and policy efforts should consider patient and caregiver wellbeing.

## CHAPTER I

### Introduction and Literature Review

Despite advances in screening and treatment, cancer morbidity and mortality continues to be a pressing public health issue (ACS, 2013). It is estimated that in 2015, over 1.6 million people in the United States will be diagnosed with cancer and approximately 580,000 will die from the disease, making it the second leading cause of death (ACS, 2015). The four most common cancer types in the United States are colorectal, breast, prostate, and lung (excluding nonmelanoma skin cancers). Though there are many differences in the diagnosis and treatment of these cancers, one unfortunate similarity is that a diagnosis of advanced cancer represents a particularly challenging time for individuals who are diagnosed as well as their loved ones.

#### Advanced Cancer Diagnosis

At advanced stages of disease, individuals with cancer face a significant number of physical and emotional challenges that can impact their quality of life (Rodriguez, Mayo, & Gagnon, 2013; Rummans et al., 2006) as patients<sup>1</sup> are often dealing simultaneously with side effects from treatment and symptoms from the disease itself (Given, Sherwood, & Given, 2008). Patient needs during this time are multifaceted. Fatigue (Barnes & Bruera, 2002; Stone, Hardy, Broadley, Kurowska, & A'Hern, 1999), pain (Donnelly & Walsh, 1995; Given, Given, &

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<sup>1</sup> Throughout this dissertation, I will often refer to individuals who have had cancer as patients. This is in part reflective of the clinical nature of the original study from which the data originated. I would like to acknowledge, however, that there are diverse naming preferences of individuals who have had cancer and my use of only a few of those terms should not be viewed as an indication of value or individual identity.

Kozachik, 2001), depression and anxiety (Lloyd-Williams, Shiels, Taylor, & Dennis, 2009; Mystakidou et al., 2005) are just some of the issues confronted by this population.

One of the most defining characteristics of advanced cancer is the limited life-expectancy. At this stage, treatment goals are no longer curative and long-term remission is deemed unlikely. A transition to advanced disease does not mean that end-of-life, as measured in days or weeks, is near; some patients may live for months and years after progressing to advanced disease (Haylock, 2010; Siegel, Miller, & Jemal, 2015). Regardless of the length of survival after an advanced cancer diagnosis, patients benefit greatly from assistance with pain and other symptom management; dietary and nutritional counseling; and, psychosocial and spiritual support (Gaertner, Weingartner, Wolf, & Voltz, 2013; Peppercorn et al., 2011).

Unfortunately, research on patients with advanced cancer is limited compared to early stage cancers or end-of-life care. This has implications for the quality of interventions designed to identify and meet their needs. Researchers and practitioners have called for more support for patients throughout this stage and prior to end-of life in order to best support their efforts to maximize both quantity and quality of life (Bruera & Hui, 2010; Osta et al., 2008).

### **Advanced Cancer Caregiving**

Family members are often a primary source of support for individuals with advanced cancer (Kim & Given, 2008; Kim et al., 2008). In 2012, there were an estimated 3.5 million informal caregivers of people with cancer living in the United States, many of whom were family members (Martin et al., 2012). Family caregivers have been defined as “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (FCA, 2006, p. 5). Shortages of health workers, increased medical costs, and an emphasis on providing care

outside of medical institutions have resulted in more out-patient care and an increased need for family caregivers (Talley & Crews, 2007). Assistance with symptom management and daily activities are common needs of individuals with advanced cancer that family caregivers often provide (Barnes & Bruera, 2002; Riley-Doucet, 2005). Because of the responsibilities placed upon caregivers and the psychosocial impact of this role (Stenberg, Ruland, & Miaskowski, 2010), caregivers are considered a vulnerable population (Dilworth-Anderson, Goodwin, & Williams, 2004; Pinquart & Sörensen, 2007) and caregiving is recognized as a critical issue for the field of public health (Talley & Crews, 2007).

While much can be gleaned from the extant literature on patients and caregivers across diseases, it is important to consider the unique aspects of the cancer experience. In a study comparing the experiences of caring for someone with cancer, dementia, diabetes, and frail elderly, the authors noted differences in caregiving outcomes by patient disease type (Kim & Schulz, 2008). In addition, it is also important to understand differences in patient and caregiver experiences across all stages of cancer. Patients with advanced cancer often require more hours of care than those with earlier stages of disease (ACS, 2012). This speaks to the difficulties patients face as the disease progresses as well as the increased responsibilities of caregivers at that time.

### **Statement of the Problem**

In light of all the difficulties that accompany a cancer diagnosis, what often receives less attention is that many people with cancer – and their caregivers – are already facing ongoing health challenges (Ogle, Swanson, Woods, & Azzouz, 2000). Chronic diseases have been defined as illnesses that progress slowly, are long in duration, typically have no cure, and have the potential to severely impact functional status and quality of life (IOM, 2012). In 2010, it was

estimated that approximately 53% of the population in the United States had a chronic condition such as diabetes, hypertension, and arthritis and 25% of the population had multiple chronic conditions (Ward & Schiller, 2013). In recent years, more attention has been paid to how patient comorbidities - that is, how other conditions that coexist with the advanced cancer (IOM, 2012) - influence treatment and prognosis (Ogle et al., 2000).

Previous research has noted that cancer likely affects both the severity of chronic illness and the outcomes of comorbid conditions (Ogle et al., 2000; Smith et al., 2008). There is, however, a noticeable lack of literature considering how comorbidities influence patients with advanced cancer beyond the clinical implications. In addition, despite considerable research on the burden of care faced by family caregivers, less attention has been given to how the caregivers' own health concerns (i.e. chronic conditions) influence their outcomes. Thus, there is a need for research that examines the implications of chronic disease for patients and their family caregivers outside of the clinical setting. Lastly, given the connectedness inherent in the patient-caregiver dyadic relationship, it is very useful to understand how an individual's experiences, beliefs and behaviors influence those of the other dyad member.

## **Purpose**

The purpose of this dissertation study is to explore the independent and interdependent effects of chronic conditions on health-related outcomes of patients with advanced cancer and their family caregivers. This dissertation research helps to fill a gap in literature by focusing on the influence of patient *and* caregiver health-related factors within the context of the advanced cancer caregiving experience. This dyadic approach recognizes the mutual influence of patients and caregivers and views the interrelationships between their individual level factors (i.e. chronic

conditions) and experiences as a critical component of understanding the functioning of the dyad as a whole.

Over the course of three separate studies, I explore the influence of patient and caregiver chronic conditions on their health-promoting behaviors; their symptom distress and cognitive appraisals; and, their meaning-based coping and quality of life. These outcomes were chosen for a number of specific reasons. First, literature on and interventions with patients and caregivers in the advanced cancer context often does not focus on physical health behaviors or health outcomes (Courneya & Friedenreich, 2007; Kim & Schulz, 2008). This is despite growing evidence of the importance of health-promoting behaviors for individuals with advanced disease (Albrecht & Taylor, 2012; Barrera, 2002; Lee, Cho, Miaskowski, & Dodd, 2004) and noted differences in the experiences of advanced cancer caregivers compared to early stage cancers or other diseases (Given, Given, & Kozachik, 2001). Second, because of the dynamic and reciprocal relationship between physical factors (chronic conditions, symptom distress, health behaviors) and psychological factors (appraisals, quality of life) (Cohen, Janicki-Deverts, & Miller, 2007; McEwen & Gianaros, 2010), studying these factors simultaneously provides an important exploration of the patient and caregiver experience. Third, while the stress that comes with illness and caregiving deserves considerable attention (Mystakidou et al., 2006; Pinquart & Sörensen, 2007), there has been increasing attention to the personal growth that comes with these challenging experiences (Moreno & Stanton, 2013). Improved knowledge of the positive and negative aspects of disease and illness can lead to a more balanced and nuanced approach to intervention. Finally, evidence has consistently shown that cancer has an impact on the family system, even beyond the patient-caregiver relationship (Edwards & Clarke, 2004; Ell, 1996; Rolland, 2005). As a result, patients and caregivers may be helping other family members cope



with the illness and its consequences. Additional attention to family dynamics could inform interventions that include the broader family system.

In the remainder of this chapter, I present a conceptual model that has been designed to guide this work and a review of the theories that support this research. Thereafter, a rationale for the proposed dissertation study will be provided through a review of relevant empirical literature. This will be followed by the aims for the dissertation research.

### **Conceptual Model**

The model in Figure 1.1 proposes causal linkages among factors that are hypothesized to influence health-related outcomes of individuals with advanced cancer (referred to as “patient”) and their family caregivers (referred to as “caregiver”). The numbers in the model represent the empirical studies that will be conducted (studies 1, 2 and 3). The model includes an intrapersonal domain, comprised of individual appraisal and coping processes and individual characteristics (e.g. chronic conditions, demographics) and an interpersonal domain, which represents the simultaneous experiences of the patient and caregiver and their influence on one another. There are at least two important reasons for studying these factors at the dyad level. First, it helps to draw attention to the interdependent factors that influence caregiver and patient outcomes (Glajchen, 2004; Kayser, Watson, & Andrade, 2007; Lyons, Zarit, Sayer, & Whitlatch, 2002). Second, an abundance of research has shown that social relationships and social factors significantly influence health through behavioral, psychosocial, and physiological pathways (Caldwell et al., 2004; Cohen, Underwood, Gottlieb, & Fetzer, 2000; Ellis, Caldwell, Assari, & Hill-DeLoney, 2014; House, Landis, & Umberson, 1988; Israel & Rounds, 1987; Umberson & Montez, 2010).

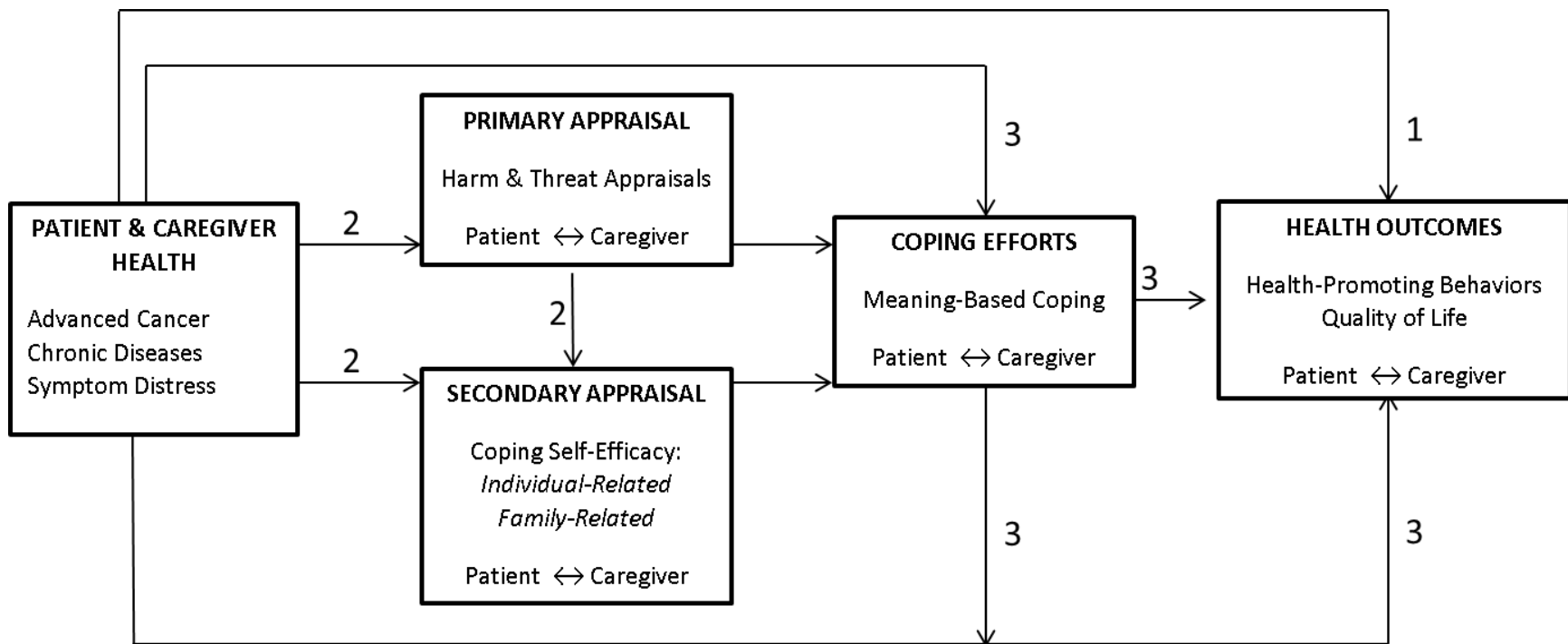


Figure 1.1. Conceptual Model of Factors Mediating and Moderating the Relationship Between Health (Advanced Cancer, Chronic Disease, and Symptom Distress) and Health Outcomes (Behaviors and Quality Of Life) among Patients with Advanced Cancer and Their Family Caregivers.

*Note:* The numbers in the figure correspond to the three dissertation studies that tested the associated model paths (studies 1-3).

## **Theoretical Framework**

The model in Figure 1.1 is informed by two key theories: the transactional model of stress and coping and interdependence theory. The transactional model of stress and coping posits that the way that individuals interpret a stressor (e.g. appraisal of illness or caregiving) and how they manage that stressor (e.g. coping behaviors) mediate their stress-related outcomes (Folkman, 1984; Folkman & Moskowitz, 2004; Wenzel, Glanz, & Lerman, 2002). Folkman (1984) argues that this theory is fundamentally relational because stress is best defined as a dynamic relationship between a person and their environment. Interdependence theory focuses on how the interactions between two people (e.g. caregivers and patients) influence their feelings, emotions, beliefs and thoughts (Van Lange & Rusbult, 2012). This theory is useful for considering the relational factors that influence stress, coping, and health-related outcomes among patients and caregivers.

A defining feature of social exchange theories such as interdependence theory – and one that is particularly useful for this study – is the emphasis on both individual and between-persons aspects of relationships (Chadwick-Jones, 1976; Cropanzano & Mitchell, 2005). Interdependence theory supports the examination of the interdependent effects that often exist within dyads; for example, how a patient influences their own health behaviors and also how a caregiver influences the behaviors of the patient. According to this theory, feelings, emotions, beliefs and thoughts are influenced by social interactions and these factors, in turn, influence behavior (Van Lange & Rusbult, 2012). A key strength of this theory is an in-depth conceptualization of interpersonal aspects of relationships (Van Lange & Rusbult, 2012).

Two main components of interdependence theory - interdependence processes and interdependence structure – provide guidance for understanding interactions between two people.

*Interdependence processes* are useful for understanding how individuals react to the situations they face and in particular, the degree to which they take the needs of self or others into account. Investigations of interdependence processes could also include how a person's beliefs and interests related to a given situation change over time after considering the needs of others. *Interdependence structure* focuses on the ways that people relate to each other within a given situation. Two types of control are typically considered when evaluating interdependence structure in the patient-caregiver context. *Actor control* refers to the influence that a person's actions have on their own outcomes, such as when a patient's actions influence their own outcomes. *Partner control* refers to the influence that a person has on their partner's outcomes, such as when a patient's actions influence their caregiver's outcomes. The conceptual model includes each type of control. For example, actor control is represented in the relationship between a patient's primary appraisal and their own coping efforts, and partner control is demonstrated through the consideration of how a patient's primary appraisal affects the coping efforts of the caregiver.

Within the patient and cancer caregiver relationship, there are a number of reasons to expect some degree of interdependence. Patients may rely on caregivers for assistance with care needs, interactions with medical professionals, and fulfilling social obligations. Conversely, caregivers' ability to fulfill these tasks will be influenced by caregivers' own responsibilities, needs and obligations. Patients and caregivers often live together, and this shared living arrangement involves a degree of mutual understanding about roles and responsibilities. Within close and familial relationships, there are shared expectations about the appropriateness of certain communication and coping behaviors. These expectations may influence patient and

caregiver interactions. Thus, the examination of interdependence within a patient and caregiver relationship warrants attention.

## **Literature Review**

**Patient and caregiver health.** This model considers three key aspects of patient and caregiver health: the patient's diagnosis of advanced cancer; patient and caregiver chronic conditions; and patient and caregiver symptom distress. These factors are hypothesized to directly or indirectly influence appraisal processes, coping efforts, and health outcomes.

**Chronic disease.** Chronic diseases are regarded as one of the most pressing public health issues for a number of reasons, including the rising prevalence of these conditions among various populations (Anderson & Horvath, 2004); associated health care costs (Lugtenberg, Burgers, Clancy, Westert, & Schneider, 2011; Wolff, Starfield, & Anderson, 2002); and, the negative consequences of these conditions on morbidity and mortality (Ward & Schiller, 2013). Chronic diseases such as diabetes, arthritis, heart diseases, and depression have the potential to severely limit the functioning and quality of life of individuals with these conditions (Clark, 2003). The presence of *multiple* chronic conditions (i.e. multimorbidity) brings a number of significant challenges to the daily lives of individuals who have them and these challenges are now gaining increased attention (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005; Janevic, Ellis, Sanders, Nelson, & Clark, 2013; Janevic, Janz, Connell, Kaciroti, & Clark, 2011; Kamerow, 2012; Clark, 2011). It is estimated that approximately one-quarter of the U.S. population is facing multiple chronic conditions (Ward & Schiller, 2013).

**Chronic disease & cancer.** There are a number of important reasons why chronic diseases should also be of concern when considering cancer-related outcomes. First, chronic diseases have been identified as a possible risk factor for a number of leading cancers, including

colorectal cancers and breast cancers (Larsson, Mantzoros, & Wolk, 2007). Second, research has shown a higher prevalence of chronic disease among individuals with cancer compared to those without cancer (Bellizzi & Rowland, 2007; Koroukian, Murray, & Madigan, 2006; Ogle et al., 2000; Smith et al., 2008). Ogle and colleagues (2000) presented two plausible reasons for the noted associations between chronic conditions and cancer prevalence. Pathologic processes that lead to the development and progression of chronic conditions, and that are similar among cancer and some chronic diseases, could contribute to these associations. Second, tobacco use, lack of physical activity, and a poor diet are examples of lifestyle related risk factors that have been identified for cancer and many chronic diseases.

Another important reason to consider chronic conditions in conjunction with cancer is because of the mutual influence that they have on one another. Previous research has found that chronic diseases can influence the progression of cancer and that cancer affects the severity and outcomes of other chronic illnesses (Ogle et al., 2000). While within the context of clinical care the complexity of treating cancer and comorbid conditions has been recognized, it has been argued that the management of chronic conditions may not be seen as a priority by patients or clinicians in the face of life-threatening conditions that severely impact life expectancy such as advanced cancer (Piette & Kerr, 2006). It is also unclear whether interventions that focus on patients and caregivers in home settings view the management of chronic conditions, in addition to the cancer, as a priority. Some evidence suggests that chronic diseases have a larger impact on physical and mental related quality of life than the cancer diagnosis itself (Denlinger & Engstrom, 2011; Smith et al., 2008), but the extent to which this influence holds where advanced disease exists is not known. Moreover, despite research that has found chronic conditions to be associated with earlier stages of cancer diagnosis (Fleming, Pursley, Newman, Pavlov, & Chen,

2005; Moritz & Satariano, 1993), in some cases, mortality from cancer has been increased among those with chronic conditions (Read et al., 2004; Yancik et al., 1998).

***Chronic disease & caregiving.*** Multimorbidity likely also influences the care provided by family caregivers of individuals with advanced cancer. It is suspected that the demands of managing chronic diseases, in addition to the cancer, increase a patient's need for assistance and caregiver burden (Ogle et al., 2000). Caring for a person with cancer and other major health problems has implications for the health of the patient (e.g. symptoms, mobility, etc.), which in turn, influences the needs of and challenges faced by the caregiver (Weiss, Leff, Chad Boulton, & Boyd, 2012). This is in line with previous research that has found a direct relationship between increased patient needs and caregiver burden and an inverse relationship between patient needs and caregiver health (Faison, Faria, & Frank, 1999; Kurtz, Kurtz, Given, & Given, 1995).

Unfortunately, there is a lack of research investigating how multiple chronic conditions influence the advanced cancer caregiving experience. Evidence-based guidelines on how to treat multimorbidity have been identified as a pressing need (Kamerow, 2012) and given that caregivers often provide the majority of care to patients, it would be critical to consider the experiences of patient-caregiver dyads as well. Smith and colleagues (2008) found that individuals with cancer who had two or more chronic conditions had significantly worse physical and mental health compared to those facing multimorbidity without cancer. Furthermore, despite the prevalence of multiple chronic conditions, many initiatives to address chronic diseases focus on one condition at a time (Wolff, Starfield, & Anderson, 2002).

Given the prevalence of chronic disease in the United States, it is also critical to consider that family caregivers may be facing one or more chronic conditions themselves. The physical and mental health of family caregivers has implications for the burden they face and the care

they provide (Lau, 2010; Northouse, Mood, Templin, Mellon, & George, 2000; Northouse, Williams, Given, & McCorkle, 2012; Northouse, 2012; Northouse, Katapodi, Schafenacker, & Weiss, 2012). Some studies have found that caregivers have worse physical and mental health than non-caregiving populations (Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). However, the demands of caregiving may make it difficult for caregivers to attend to their own health needs (Acton, 2002; Vitaliano et al., 2003). Where a chronic disease or multiple chronic diseases exist, caregivers' inattention to self-care can be particularly detrimental (Hoffman, Lee, & Mendez-Luck, 2012).

*Cancer, caregiving & symptoms.* Symptom control is a critical desire of patients with advanced cancer (Peppercorn et al., 2011) and symptoms often occur concurrently (Aktas, Walsh, & Rybicki, 2010). Walsh and Rybicki (2006) identified seven symptom clusters of individuals with advanced care: fatigue; anorexia-cachexia; neuropsychological; upper gastrointestinal; nausea and vomiting; aerodigestive; debility; and pain. They note that recognition of and intervention for symptoms are important for symptom relief and management. Unfortunately, many patients' involvement with palliative and supportive care teams, which specialize in symptom management and quality of life, occur very late in the disease course when the management of death is a concern (Peppercorn et al., 2011). Lack of management of patient symptoms may influence patients' functional and psychological wellbeing, which has implications for caregivers who often are a primary source of day-to-day support for patients in these areas. Less considered is caregivers' own experience with physical and psychological symptoms that result from their own health concerns. In addition, previous research suggests that caregivers' experience with symptoms may be related to their own physical and psychological wellbeing and the physical and psychological wellbeing of the patient (Palos et al., 2011).



**Chronic disease & symptoms.** Individuals with multiple conditions are susceptible to the consequences of each condition, separately, as well as the effects of having a number of conditions simultaneously (Vogeli et al., 2007). A number of researchers have found evidence of both additive and synergistic effects when examining the outcomes of multimorbidity. As the number of chronic conditions increase, so do individuals' functional impairments (i.e. additive effects) and among certain combinations of conditions, more disability is found than what is anticipated when adding the expected functional consequences of each condition alone (i.e. synergistic effects) (Fried, Bandeen-Roche, Kasper, & Guralnik, 1999; Fultz, Ofstedal, Herzog, & Wallace, 2003; Rijken, van Kerkhof, Dekker, & Schellevis, 2005). For patients with advanced cancer and their caregivers, this would suggest that as the number of chronic conditions they are managing increases, the prevalence and severity of symptoms to manage might increase as well. In this model, it is expected that patient and caregiver symptom distress will influence their appraisal processes, such that those who are experiencing more symptoms are expected to have more negative appraisals of the severity of the cancer/caregiving experience and their ability to cope. Though limited, studies have shown that both patient and caregiver symptoms may influence their appraisal processes (Northouse et al., 2002; Northouse et al., 2007).

**Appraisal.** Consistent with the transactional model of stress and coping and interdependence theory, the conceptual model illustrates that family caregivers and patients are expected to evaluate the significance of cancer (i.e. *primary appraisal*) and evaluate their own ability to cope with the cancer and help their family to manage the stress of the illness (i.e. *secondary appraisal*). According to Lazarus and Folkman (1984), primary and secondary appraisals interact to shape the degree of stress that a person experiences and their reactions to the stressor. Due to the demands of chronic diseases – including symptoms, management, and

possibilities for long-term consequences – they could be an additional source of stress that influences patient and caregiver cancer-related appraisal processes (Lewis, 1986; McKenry & Price, 2005).

***Primary appraisal.*** Patients and caregivers may appraise their situation in a number of ways (Kim, Baker, & Spillers, 2007). Primary appraisals can be viewed as irrelevant when they are not believed to influence wellbeing; benign-positive when they are not taxing or will have positive implications on wellbeing; or stressful when harms/losses, threats, or challenge are expected (Folkman, 1984). Stressful appraisals are the primary focus of this dissertation. Harm/loss refers to appraisals in which damage or a negative outcome has already occurred (Folkman, 1984). Examples of this include a patient's perceived loss of independence or a caregiver's perceived loss of income due to decreased work outside of the home. A threat appraisal occurs when there is the potential for a harm or loss to occur (Folkman, 1984). A patient's concern that they will lose mobility with disease progression or a caregiver's fear that they could lose valued friendships because of decreased social interactions are examples of threats. Lastly, challenges are appraisals that identify opportunities for personal growth despite the expectation or presence of difficulty (Folkman, 1984). Patients and caregivers who believe that the illness experience may strengthen their relationship with each other have made a challenge appraisal.

Stress appraisals (i.e. threat, harm/loss) have been a strong predictor of patient and caregiver outcomes (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003; Burton et al., 1997; Fitzell & Pakenham, 2010; Northouse, Kershaw, Mood, & Schafenacker, 2005) and represent a key component of the stress and coping process (Folkman, 1984; Lynch et al., 2008). In a recent study examining the adjustment of cancer caregivers after diagnosis, stress appraisals were found

to be the strongest predictor of all adjustment-related outcomes (Fitzell & Pakenham, 2010). Evidence suggests, however, that it is also important to consider the appraisals of both members of the dyad when examining health-related outcomes (Downey, Engelberg, Curtis, Lafferty, & Patrick, 2009). What also becomes evident when reviewing appraisals within the context of illness and caregiving is that harm/loss, threat, and challenge appraisals are not mutually exclusive. That is, a situation is likely to be appraised in a number of ways that may change over time (Folkman, 1984; Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008).

***Chronic disease & primary appraisal.*** Unfortunately, there is limited information about the influence of comorbidities on cognitive appraisals (Franks & Roesch, 2006). A study by Lynch and colleagues (2008) found that comorbidities were associated with patient threat appraisals, but this study did not take into account two important factors: stage of disease and appraisals of the family caregiver. Other research has found that caregiver appraisals are related to their assessments of patient illness severity as well as their illness-related demands (Pitceathly & Maguire, 2003), but the role of chronic conditions was not considered. In a meta-analysis of appraisals among people with cancer, Franks and Roesch (2006) noted that stage of disease is often not taken into account in this literature. Moreover, research has tended to emphasize the appraisals of patients, though evidence suggests that caregiver appraisals are also very influential (Lyons et al., 2002).

***Secondary appraisal.*** Within the transactional model of stress and coping, *self-efficacy* is viewed as a type of secondary appraisal (Wenzel et al., 2002). Self-efficacy can be defined as the belief an individual has in their capacity to reach a desired outcome (Bandura, 2004). Caregiver and patient self-efficacy to manage the various demands that accompany illness and caregiving can positively influence their outcomes (Gaugler et al., 2008; Mystakidou et al., 2010;

Northouse, Katapodi, Song, Zhang, & Mood, 2010). In addition, prior research has found self-efficacy to be predicative of engagement in individual behaviors such as physical activity and chronic disease management (Clark & Dodge, 1999). In this model patient and caregiver efficacy about their ability to cope is of primary concern. Patient and caregiver self-efficacy about their ability to help other members of their family cope with illness-related stressors are also considered.

In addition to making appraisals about the significance of advanced cancer for themselves, and their own ability to cope, patients and caregivers may also be concerned about their family members (Lewis, 1986). A family can be defined as individuals who develop close, personal relationships over time (Weihs & Politi, 2006) and can contain biological and nonbiological members (Settles, Steinmetz, Peterson, & Sussman, 1999). Experiences within the family context help shape the meaning that individuals give to health and illness (Downe-Wamboldt, Butler, & Coulter, 2006). Unfortunately, investigations of patient and caregiver appraisals within the context of the larger family are limited. Some research has noted that more stressful appraisals exist when patients believe that their treatment or their diagnosis has caused a significant amount of stress within their family (Bowman et al., 2003). Other researchers have highlighted the stress process as a communal one, in which individuals take into account the wellbeing of others when attempting to manage their stress (Lyons, Mickelson, Sullivan, & Coyne, 1998). The attention to both patient and caregiver self-efficacy to help themselves *and* others addresses a gap in the literature in this area

***Chronic disease & secondary appraisal.*** Patient and caregiver self-efficacy has been associated with a number of key psychological (Hendrix, Landerman, & Abernethy, 2013; Hirai et al., 2002; Kurtz, Kurtz, Given, & Given, 2005; Porter, Keefe, Garst, McBride, & Baucom,

2008) and physical health outcomes (Campbell et al., 2004; Jerant, Franks, & Kravitz, 2011; Porter et al., 2008). While self-efficacy has been noted as a predictor of engagement in individual behaviors such as physical activity and disease management (Clark & Dodge, 1999), the influence of chronic diseases on self-efficacy to cope with advanced cancer has not been a main topic of study. The presence of chronic diseases, however, might represent an additional stressor that could influence patient and caregiver self-efficacy (Parkerson Jr et al., 1989; Kriegsman, Penninx, & van Eijk, 1994). Furthermore, given the importance of family in understanding and making meaning of health issues and health behaviors (Allen, Blieszner, & Roberto, 2000; Campbell, 1986) patient and caregiver prior experiences with managing chronic diseases within a family context could influence their ability to manage cancer as well (Lewis, 1990; Patterson, 1988).

**Coping efforts.** Coping efforts have been defined as an individual's cognitive and behavioral efforts to manage stress (Folkman, Lazarus, Gruen, & DeLongis, 1986). While emotion-focused coping and problem-focused coping are often considered in the research (Folkman & Moskowitz, 2004), this study focuses on a more understudied dimension of coping efforts: meaning-based coping.

***Meaning-based coping.*** The conceptual model takes into account the meaning that both the caregivers and the patients derive from the cancer because evidence suggests that meaning-based coping affects individual and dyad-level outcomes (Kim, Schulz, & Carver, 2007; Mellon, 2002). *Meaning-based coping*, which includes positive reappraisals and reinterpretations of stressors, is thought to sustain an individual's use of problem and emotion-focused coping efforts (Chatters & Taylor, 2005; Wenzel et al., 2002). Past research has shown that the ability of caregivers and patients to find positive aspects of the illness experience and meaning for the

challenges they face can be beneficial for the wellbeing of the individual and dyad (Kim, Schulz, et al., 2007; Kramer, 1997). Thus, even where difficulties might exist, finding meaning could buffer or mediate the relationship between illness-related stress and health outcomes. In this study, challenge appraisals – or appraisals which identify opportunities for growth – will be conceptualized as a form of meaning-based coping.

Identifying positive consequences of illness and caregiving and/or appraising the situation as challenging can be very beneficial for patient and caregiver wellbeing, both individually and as a dyadic unit (Kim, Schulz, et al., 2007; Nijboer et al., 1998; Wise & Marchand, 2013). Previous research has found that the ability of family caregivers to find a positive meaning is associated with improved outcomes (Cohen, Colantonio, & Vernich, 2002; Kim, Baker, et al., 2007; Kramer, 1997). Patients who view their experience more hopefully (Northouse et al., 2005), find meaning in their illness (Mellon, Northouse, & Weiss, 2006), view it as a learning experience, or an experience that can lead to personal growth, experience better quality of life (Franks & Roesch, 2006). Given this evidence, and the emotional and psychological ties that exist within a patient-caregiver dyad, the influence of one dyad member's meaning-based coping on the quality of life outcomes of the other also warrants further investigation.

The moderating role of meaning-based coping is included in the transactional model of stress and coping. According to that model, the magnitude of meaning-based coping is thought to influence coping efforts as well as health-related outcomes. It is also possible, however, that meaning-based coping could also serve as a mediator of the relationship between chronic conditions and quality of life. Mediation is useful for understanding the mechanisms for change while moderation is useful for understanding factors that influence the magnitude of an effect

(Judd, Kenny, & McClelland, 2001). As mediators and moderators are both useful for understanding and intervening on health issues (Judd et al., 2001) and some researchers have identified gaps in the investigation of mediators and moderators of patient and caregiver outcomes (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne 2008), both of these relationships will be examined in this dissertation.

***Chronic disease & meaning-based coping.*** Higher challenge appraisals – or opportunities for personal growth despite the expectation or presence of difficulty – have been associated with higher positive affect, higher life satisfaction, and better adjustment among caregivers (Fitzell & Pakenham, 2010). Researchers have called for the inclusion of meaning and benefit-finding in programs for patients and caregivers, given its positive impact on outcomes (Kim, Baker, et al., 2007; Kim, Schulz, et al., 2007). It is unclear, however, how the stress of comorbidities might influence patient and caregiver ability to find meaning in their experiences or their quality of life, despite the noted prevalence of chronic conditions in this population (Kreitler, Peleg, & Ehrenfeld, 2007). This knowledge could be particularly useful for designing research and interventions to address this factor.

**Health-promoting behaviors.** Among patients, a healthy diet, physical activity, and adequate sleep has been associated with a number of positive health outcomes including increased energy (Porock, Kristjanson, Tinnelly, Duke, & Blight, 2000; Rock et al., 2012), decreased fatigue (Headley, Ownby, & John, 2004; Rock et al., 2012), and improvements in quality of life (Lee, Cho, Miaskowski, & Dodd, 2004; Ravasco, Monteiro-Grillo, Vidal, & Camilo, 2005). Among caregivers, evidence of poor quality diets (Samuel-Hodge et al., 2000), decreased physical activity (Burton, Newsom, Schulz, Hirsch, & German, 1997) and reports of more fatigue and less time for sleep than non-caregivers (Berger et al., 2005; McCurry, Gibbons,

Logsdon, Vitiello, & Teri, 2009) suggest that caregivers need support in these areas.

Furthermore, given the influence of disease progression, and the dynamic nature of caregiving and disease management, an understanding of behaviors at different points in the disease process is useful.

***Physical activity.*** There is strong evidence to support the idea that physical activity is a very important component of daily activities for people with a history of cancer (Courneya, 2003, 2009; Courneya & Friedenreich, 1997) and can be beneficial to their physical and emotional wellbeing (Lee et al., 2004; Lynch et al., 2008). Much of this literature, however, focuses upon individuals who do not have advanced cancer or combines results from those with early and late stages of disease (Lowe, 2011). Cancer survivors who do not have advanced cancer are at a much greater chance of succumbing to other diseases within their lifetimes (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Pinto & Trunzo, 2005). In literature that has focused more exclusively on patients with advanced cancer, evidence is not robust enough to warrant overarching recommendations for physical activity for this population (Rock et al., 2012). However, existing evidence suggests that many individuals with advanced cancer can engage in and benefit from physical activity interventions (Cheville et al., 2013; Oldervoll et al., 2011; Porock et al., 2000; Rummans et al., 2006). For family caregivers, physical activity has a number of important benefits, including weight control; psychological wellbeing; reduced risk of heart disease; and reduced risk for developing some types of cancer (NCI, 2009). However, caregiving has been found to be a barrier to physical activity and it is not clear how much physical activity caregivers receive from caregiving related-tasks (Fredman, Bertrand, Martire, Hochberg, & Harris, 2006; Wilcox, Castro, King, Housemann, & Brownson, 2000).



**Diet.** People with advanced cancer often find it difficult to manage their diet and meet nutritional recommendations (Rock et al., 2012). Malnutrition is a common concern for people with advanced cancer, resulting from side-effects of treatment, psychological factors, the cancer itself (Barrera, 2002; Ravasco et al., 2005). Weight loss after a cancer diagnosis has been related to a number of poor outcomes, including decreased patient wellbeing, less resistance to infections, and functional disability (Jagoe, Goodship, & Gibson, 2001; Ravasco, Monteiro Grillo, & Camilo, 2007). While weight loss is often believed to be an unavoidable consequence of advanced cancer, some researchers argue that it is not inevitable (Rock et al., 2012). Research focused on improving the diet of people with advanced cancer has seen improvements in appetite (Rock et al., 2012) and increases in caloric and nutritional intake (Payne, Wiffen, & Martin, 2012; Ravasco et al., 2005; Shragge, Wismer, Olson, & Baracos, 2007).

Moreover, the eating behaviors of patients can be a challenge for both patients and caregivers (Hopkinson & Corner, 2006). In a qualitative study of older patients with cancer and their family caregivers, researchers found that female caregivers were particularly distressed when patients ate in a way that caregivers deemed inadequate with regard to the amount or the type of food eaten (Locher et al., 2010). Despite the lack of studies on the diet of caregivers with advanced cancer, and how it may change over time (Kim & Given, 2008), broader research on the importance of nutrition, especially among those with chronic conditions (Bodenheimer, Lorig, Holman, & Grumbach, 2002), make it an important issue to consider (Beesley, Price, & Webb, 2011).

**Sleep.** Sleep disturbances are prevalent among people with cancer (Berger et al., 2005). Poor quality sleep or inadequate amounts of sleep among patients can lead to impairments in functioning, poorer treatment outcomes and decreased wellbeing (Vena, Parker, Cunningham,

Clark, & McMillan, 2004) and has been associated with cancer symptoms and cancer treatment (Engstrom, Strohl, Rose, Lewandowski, & Stefanek, 1999). In addition, while age has been identified as an important factor to consider when evaluating the sleep of people with cancer, comorbid conditions may play more of a role than age. There has been a call for more research in this area (Berger et al., 2005; De Santo, Lucidi, Violani, & Di Iorio, 2005). Unfortunately, patient-provider conversations often do not address sleep problems (Engstrom et al., 1999; Vena et al., 2004). This makes addressing this issue particularly challenging.

In addition, many caregivers report not getting enough rest and this seems to become more problematic as the amount of care required increases (Burton et al., 1997). Caregivers of people with cancer report sleep problems that are consistent with reports from caregivers of people with other serious conditions (Carter, 2003; Happe & Berger, 2002; McCurry et al., 2009). Depression, a common response to caregiving and a loved one's illness, may be exacerbated by chronic sleep loss (Carter, 2003).

***Chronic conditions & health behaviors.*** The development and management of chronic conditions are primarily driven by modifiable lifestyle factors such as physical activity and diet (Pignone et al., 2003; Warburton, Nicol, & Bredin, 2006). Because of this, the prevalence of chronic conditions is often clustered within families who also share environments, beliefs, and subsequently, behaviors, which influence their lifestyles and health conditions. Few studies, however, have attempted to quantify the extent of this interdependence within families. Among caregivers, the demands of caregiving have been shown to make it difficult for them to take time to recuperate from illnesses (Burton et al., 1997), suggesting that caregivers might also neglect care and treatment from chronic conditions as well. It is also possible that the influence of conditions on behavior may change over time for a number of reasons, including disease

progression, changes in treatment and management regimens, psychological adjustment/ maladjustment to disease and other stressors.

**Quality of life.** Quality of life represents an individual's experience with various dimensions of wellbeing, such as physical, emotional, social, and functional (Brucker, Yost, Cashy, Webster, & Cella, 2005). Though many definitions exist, Felce and Perry provided the following conceptualization:

Quality of life is defined as an overall general wellbeing that is comprised of *objective and subjective evaluations* of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values. (1996; p. 52)

Quality of life has been identified as an important measure among people with cancer, especially for those with advanced disease and for whom curative options are no longer available (Northouse et al., 2005). In outlining the key elements of care for patients with advanced cancer, Peppercorn and colleagues (2011) argue that at the time of an advanced cancer diagnosis, and throughout the course of the illness, the prioritization and enhancement of patient quality of life are critical. Literature on patients and caregivers following a cancer diagnosis often focus on the impact of the illness on their quality of life; less often considered is the influence of pre-existing health problems.

**Chronic disease & quality of life.** Patient and caregiver chronic conditions may have an influence on quality of life, despite the severity of advanced disease. This association could be based on the stress associated with the disease (e.g. more complicated treatment regimens, management of multiple providers) or limitations imposed by the disease itself (Rowland & Yancik, 2006; Yancik, Ganz, Varricchio, & Conley, 2001). Research has shown that among

patients with less advanced disease and long-term survivors, chronic disease likely will have less of an influence on survival (Edwards et al., 2014); however, the impact on quality of life is important at all stages of disease. Caregiver perceptions of stress have been related to various dimensions of quality of life (Kim, Baker, et al., 2007). Where caregivers are also managing their own health concerns, in addition to caring for the patient, their quality of life may be compromised. Unfortunately, research has not examined the influence of patient and caregiver chronic diseases on their own and their dyadic partner's quality of life during advanced cancer. This work has implications for research and intervention efforts concerned with improving the wellbeing of this population.

### **Study Sample & Approach**

As outlined in my conceptual model (Figure 1.1), my dissertation work takes into account both independent and interdependent effects: the influence of patient/caregiver chronic conditions on their own health-related outcomes and those of the other member of the dyad. This dissertation will use advanced quantitative research methods to analyze data from a randomized-controlled trial that included patient-family caregiver dyads. The federally funded study “Outcomes of Triaged Family Care in Advanced Cancer” (TRIAGE) was led by Dr. Laurel Northouse, Professor Emerita of Nursing at the University of Michigan. At baseline, the sample population for this study included 484 patients with advanced cancer (breast, lung, colorectal, or prostate) and 484 family caregivers of those patients (N=484 dyads). These dyads were randomized to one of three study arms: control group, brief intervention group, or extensive intervention group. Data were collected from participants at three time points over a 6 month period.

Since the TRIAGE study focused on both patients and caregivers, and randomization occurred at the dyad level, evidence suggests that the data analysis that follows should contain the dyad as a unit of analysis (Gonzalez & Griffin, 2000; Maguire, 1999; Reis & Judd, 2000; Lyons & Sayer, 2005). Furthermore, many statistical methods make assumptions about independence that are typically violated with dyadic data (Kenny & Judd, 1986). Even when statistical tests indicate that there is a lack of independence, if theory suggests that non-independence (i.e. interdependence) is probable, statistical techniques should be chosen that reflect that evidence (Kenny, Kashy, & Cook, 2006). As many researchers have noted (Gonzalez & Griffin, 1999; Kashy & Snyder, 1995; Popp, Laursen, Kerr, Stattin, & Burk, 2008), interdependence is often of great interest to researchers who are concerned about studying dyadic data and ignoring it can bias results and overlook important data about interpersonal relationships and influence. Thus, analysis at the dyadic level can shed light on many important processes.

### **Dissertation Aims**

The aim of Chapter 2 is to examine if the number of chronic conditions or combinations of chronic conditions in patients with advanced cancer and their caregivers are associated with their health-promoting behaviors over time, specifically physical activity, diet and sleep (study 1 in Figure 1.1). Chapter 3 explores patient and caregiver multimorbidity as a moderator of the relationship between their symptom distress, primary appraisals of the cancer/caregiving experience, and their individual and family-related self-efficacy regarding the cancer or caregiving experience (study 2 in Figure 1.1). Chapter 4 presents an investigation of the mediating and moderating role of meaning-based coping on the relationship between chronic conditions and quality of life (study 3 in Figure 1.1). Lastly, in Chapter 5, I discuss the

implications of this work. These studies contribute to the literature by drawing attention to the competing health concerns faced by patients with advanced cancer and their family caregivers.

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## **CHAPTER II**

### **The Influence of Interdependence and Chronic Conditions on Health-Promoting Behaviors of Patients with Advanced Cancer and Their Caregivers**

A significant body of literature suggests that after a cancer diagnosis, many individuals engage in lifestyle behaviors that can improve their health (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Rock et al., 2012). Physical activity, a nutritious diet, and adequate sleep are associated with a number of positive health-related outcomes, including decreased functional decline and impairment (Lee, Cho, Miaskowski, & Dodd, 2004; Morey et al., 2009; Pinto, Trunzo, Reiss, & Shiu, 2002), and improvements in quality of life (Blanchard et al., 2004; Liu et al., 2013; Patterson et al., 2003). Much of this research, however, has focused on the behavioral engagement of patients with early-stage cancers or long-term survivors (Courneya & Friedenreich, 2007). At advanced stages of disease, the goal of cancer treatment is no longer curative and patient prognosis ranges from months to years, but the five-year survival is limited. Compared to individuals with early-stage disease, patients with advanced cancers may experience worse quality of life (Ravasco, Monteiro-Grillo, Vidal, & Camilo, 2004), more pain (van den Beuken-van Everdingen et al., 2007), higher symptom burden (Shi et al., 2011), and poorer physical functioning (Hebert, Zdaniuk, Schulz, & Scheier, 2009; Payne, 2007). Consequently, the challenges of advanced disease may be an impediment to patient engagement in health-promoting behaviors that could contribute to their wellbeing.

According to the transactional model of stress and coping (Lazarus & Folkman, 1984; Wenzel, Glanz, & Lerman, 2002), the way individuals interpret and cope with a stressor could influence their engagement in health behaviors. In light of all the difficulties that accompany a cancer diagnosis, what often receives less attention is that many people with cancer are already facing other ongoing health challenges (Deimling, Bowman, & Wagner, 2007; Ogle, Swanson, Woods, & Azzouz, 2000). A recent study of comorbidities among older adults with cancer revealed similarities in comorbidity prevalence for Medicare beneficiaries without cancer, breast cancer patients, and prostate cancer patients (31.8%, 32.2% and 30.5%, respectively), and higher rates for patients with colorectal cancer (40.7%) or lung cancers (52.9%; Edwards et al., 2014). These statistics alone, however, cannot speak to the impact of comorbidities on patients' daily lives. Patient comorbidities can lead to a number of difficulties, including uncertainty in symptom attribution and increased complexity of health care (Fortin et al., 2004; Vogeli et al., 2007). Within this theoretical framework, comorbidities, and symptoms or functional impairments associated with these conditions, could be additional sources of stress that impede patient health-promoting behaviors. Few studies, however, have explored the influence of patient comorbid conditions on health-promoting behaviors (Kim & Given, 2008).

The patient's health may also have a negative influence on the physical wellbeing of their family members (Northouse, 2005). Due to the complexities of disease progression, treatments to manage symptoms, and numerous associated side-effects, individuals with advanced cancers may be more likely than those at earlier stages to rely on support from caregivers (Given, Given, & Kozachik, 2001). A substantial body of literature has shown that caring for someone with cancer is quite often an emotionally and psychologically taxing experience (Bevans & Sternberg, 2012; Northouse, Williams, Given, & McCorkle, 2012). Less often investigated is the physical

health status of these caregivers during the caregiving experience (Kim & Schulz, 2008). Because chronic disease prevalence increases with age (CDC, 2003; Rowland & Yancik, 2006), cancer caregivers, who tend to be older (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013), may be managing health conditions of their own. In addition, a review of literature on the quality of life of cancer caregivers found no studies of caregiver exercise and diet behaviors (Kim & Given, 2008). Furthermore, despite the identification of cancer progression and comorbidities as key factors that may influence patient and caregiver sleep quality, researchers have argued that sleep behaviors of caregivers receive little attention from health professionals (Berger et al., 2005). Lastly, it is unclear how cancer caregiver engagement in health-promoting behaviors such as physical activity, diet and sleep might be influenced by their own chronic conditions.

Interdependence theory (Lewis et al., 2006; Van Lange & Rusbult, 2012) supports the examination of the between-persons effects that often exist within dyads, for example, how patient physical activity influences caregiver physical activity. Interdependence is especially important to consider in the advanced cancer context. The first dimension of interdependence theory, degree of interdependence, recognizes that an individual's dependence on a dyadic partner can increase or decrease over time. For example, over the course of the patient's advanced cancer diagnosis, their dependence on their caregiver may vary depending on their medical treatments and side effects (Fischer, Dolbeault, Sultan, & Brédart, 2014). The second dimension, mutuality of interdependence, recognizes that in a dyadic relationship, each individual has the ability to influence the outcomes of the other (Holmes, 2002). As illustrated in a study of patients with prostate cancer and their spousal caregivers, spousal demographic and social factors influenced patients' psychological outcomes (Kershaw et al., 2008). It is yet

unclear, however, if there is an interdependent relationship between pre-existing patient and caregiver chronic diseases and their health-promoting behaviors.

Much of the current literature examining associations between chronic disease and behavior among cancer survivors focuses primarily on decreasing survivors' risk of other chronic diseases (Brown et al., 2001; Demark-Wahnefried et al., 2005) and does not take into account how existing conditions might influence beneficial health behaviors of patients or their caregivers (Kim & Given, 2008). This is important for understanding factors which impede their engagement in health-promoting behaviors that could maintain and enhance their wellbeing. Furthermore, the extent to which caregivers' own chronic conditions influence their behaviors and those of the patient is also unknown.

One possible mechanism by which patient and caregiver conditions could influence the behavioral outcomes of the other is the stress mechanism. Research on the influence of stress on health behaviors suggests that patients and caregivers may respond to stress caused by their health conditions by engaging in behaviors such as unhealthy eating (Dallman et al., 2003; Pecoraro, Reyes, Gomez, Bhargava, & Dallman, 2004), decreasing their physical activity and increasing sedentary behavior (Stults-Kolehmainen & Sinha, 2014). Stress is also known to interfere with sleep quality and quantity (Clark et al., 2014; Juster & McEwen, 2015). As a result, more information is needed about how pre-existing chronic conditions influence the behaviors of patients with advanced disease and their caregivers. Given the increasing difficulties faced with disease progression, and possibility of associated changes in health behaviors (Aarts, Paulussen, & Schaalma, 1997; Ouellette & Wood, 1998), an examination of these factors over time could help to identify key opportunities for intervention.

## Purpose & Hypotheses

The purpose of this study is to examine the exercise, diet and sleep behaviors of patients with advanced cancer and their caregivers over a six-month period, with a particular focus on the effects of patient comorbidities and caregiver chronic conditions on engagement in health behaviors, and the interdependence of their health behaviors (see Figure 2.1). In this study, patient *comorbidities* refer to conditions other than cancer that a patient may be diagnosed with (e.g. diabetes, hypertension); caregiver chronic conditions are referred to as *conditions*. *Actor effects* refer to the influence of patient or caregiver comorbidities/conditions or behaviors on his/her own behavioral outcomes. *Partner effects* - an example of interdependence - refer to the influence of patients' or caregivers' comorbidities/conditions or behaviors on the behavioral outcomes of the other member of the patient/caregiver dyad. The specific study hypotheses are as follows:

- H1a: More frequent engagement in health-promoting behaviors (exercise, diet, sleep) among patients and caregivers at an earlier time point will be associated with more engagement in that behavior at a later time point (*actor effects*).
- H1b: More frequent engagement in health-promoting behaviors (exercise, diet, sleep) by one member of a dyad will be associated with more engagement in that behavior by the other member of the dyad at a later time point (*partner effects*).
- H2a: More *comorbidities* reported by *patients* at baseline will be associated with less engagement in *their own* health-promoting behaviors over time (*actor effects*).
- H2b: More *conditions* reported by *caregivers* at baseline will be associated with less engagement in *their own* health-promoting behaviors over time (*actor effects*).

H3a: More *comorbidities* reported by *patients* at baseline will be associated with less engagement in health-promoting behaviors of *caregivers* over time (*partner effects*).

H3b: More *conditions* reported by *caregivers* at baseline will be associated less with engagement in health-promoting behaviors of *patients* over time (*partner effects*).

## **Method**

### **Study Design**

Data for this study come from a randomized clinical trial (RCT) that tested the efficacy of brief and extensive forms of the evidence-based FOCUS program on outcomes for patients with advanced cancer and their family caregivers. Research nurses blinded to the dyads' group assignments collected data from patients and caregivers at three time points: at baseline prior to the intervention (Time 1: up to 6 months following diagnosis), following the intervention at 3 months after baseline (Time 2: up to 9 months following diagnosis), and at 6 months after baseline (Time 3: up to 1 year following diagnosis). Detailed information related to the RCT procedures, intervention content, and study outcomes have been published elsewhere (Northouse et al., 2013).

### **Participants**

At time 1 (baseline), the sample population for this study included 484 patients with advanced cancer and their family caregivers (N=484 dyads). All patients: 1) were age 21 or older; 2) had a confirmed diagnosis of advanced breast, colon, lung or prostate cancer and were within 6 months of the diagnosis, progression of their advanced cancer, or change of treatment for it; 3) were physically and mentally able to participate; 4) could speak and understand sufficient English; 5) had a life expectancy of at least 6 months (physician assessed); 6) lived within 75 miles of one of the participating medical centers; 7) provided informed consent; and,



8) had a family caregiver willing to participate. Patients were excluded from the study if they were diagnosed with multiple, primary cancer sites.

A family caregiver was defined as “the family member or significant other identified by the patient as his or her primary source of emotional or physical support during the advanced phase of cancer and confirmed by the designated individual” (Northouse et al., 2013). Family caregivers were: 1) age 18 or older; 2) mentally and physically able to participate; and, 3) able to speak and understand English. Family caregivers were excluded from the study if: 1) they had been diagnosed with cancer during the previous year and/or 2) were in active treatment for cancer.

### **Patient Sample Description**

The types of advanced cancers reported by patients were as follows: 32.4% breast cancer; 25.4% colorectal cancer; 29.1% lung cancer; and, 13.0% prostate cancer. Advanced cancers were defined as cancers at stage III or IV of disease and a limited five-year survival rate (below 50%). At baseline, the average time since the initial diagnosis was 42.5 months (SD: 55.3; range: 1-309). A majority of patients were undergoing chemotherapy treatment (68.8%). Patients also reported that they were currently receiving hormone therapy (16.5%), radiation therapy (8.3%), watchful waiting (7.6%), surgical treatment (2.9%) or another treatment not specified (5.4%). Multiple responses for treatment options were possible.

### **Instruments**

The following instruments were used to measure the selected study variables.

**Health behaviors.** Patients and caregivers reported engagement in health behaviors at three time points. Their responses to questions about their *exercise*, *diet*, and *sleep* behaviors are included in the analysis. They were asked how often in a typical week they a) exercised by

walking or doing moderate to vigorous physical activity; b) ate a balanced diet including fruits and vegetables (if allowed); and, c) got enough sleep to feel rested. Response options on the 5-point scale ranged from (0) “not at all” to (4) “5-7 times a week.”

**Comorbidities/conditions.** At baseline, patients and caregivers responded to the following question: “Do you have any other health problems (such as heart disease, arthritis, diabetes, etc.) at this time?” Respondents who answered “yes” to this question were then asked to name their health problems. The *number of comorbidities/conditions* variable was based on a count of the number of physical and mental health problems reported in response to this question. *Comorbidities* refer to the health problems reported by patients, with cancer as their index condition; *conditions* refer to the health problems reported by caregivers.

**Covariates.** The following demographic and medical characteristics were obtained from the Risk for Distress Scale – adapted from the original Omega Clinic Screening Interview (Mood & Bickes, 1989; Northouse et al., 2013; Northouse et al., 2007) – and patients’ medical records: age, sex, race (white vs. other), income, cancer type, patient treatment (chemotherapy vs. other), length of time since patient diagnosis, relationship types (spouse vs. other) and living arrangements (living together vs. other). Caregiver burden was measured using a summary score from two subscales of the Caregiver Reaction Assessment (CRA), which assesses responses to tasks and problems associated with caregiving (Given et al., 1992), and six additional items added by study researchers (16 items total). The measure has a 5-point response scale ranging from (1) “strongly disagree” to (5) “strongly agree.” Validity of the CRA has been reported (Snyder, 2005). Intervention group was also controlled for in the analysis in order to remove treatment effects.

## Data Analysis Strategy

The hypotheses (H1-H3) were examined using the actor-partner interdependence model (APIM; Kenny, Kashy, & Cook, 2006; Rayens & Svavarsdottir, 2003). This technique allows for the simultaneous analysis of actor effects, partner effects, and interdependence between members of a dyad. For H1, the actor and partner effects of patient and caregiver behaviors were examined. Significant paths were then included in subsequent models (H2&H3) testing the influence of comorbidities/conditions on behavior. To test H2a & H2b, the APIM was modified to include patient and caregiver number of comorbidities/conditions as a predictor variable (see solid lines in Figure 2.1). More specifically, the influence of patient number of comorbidities on their own behaviors over time (actor effects) and the influence of caregiver number of conditions on their own behaviors over time (actor effects) were tested. For H3a & H3b, the partner effects of patient and caregiver number of comorbidities/conditions were examined (see dotted lines in Figure 2.1). That is, the influence of patient number of comorbidities on caregivers' behaviors over time (partner effects), and the influence of caregiver number of conditions on patients' behaviors over time (partner effects) were tested. There was no significant change in the number of comorbidities/conditions reported across the three time points, so only Time 1 comorbidities/conditions were included.

Structural equation modeling (SEM) was used to estimate the model parameters using Amos Graphics version 21 (IBM, 2012). The comparative fit index (CFI), the root mean squared error of approximation (RMSEA), and the standardized root-mean-square residual (SRMR) were used to determine the adequacy of model fit. The indicators of adequate model fit for these indices (i.e. the indication that the model fits the sample data well) are a CFI above .90; and a RMSEA value of .08 or less; and SRMR value of .08 or less (Hu & Bentler, 1999; Little & Card,

2013). Because standardized solutions using path analysis software are not valid with dyadic data, the data was manually standardized (Kenny et al., 2006). Missing data was imputed using expectation maximization; maximum likelihood estimation was the estimation method. All models included covariances between predictor variables and error terms of the patient and caregiver behaviors at the same time point.

## **Results**

### **Descriptive Findings**

Background demographic information obtained from patients and caregivers at baseline is presented in Table 2.1. The average age at baseline of patients was 60.5 years (SD: 11.5; range: 26-95) and of caregivers 56.5 years (SD: 13.4; range: 18-88). A majority of patients (62%) and caregivers (56.8%) were female. Patients were predominantly White (79.3%) and the next largest racial group was African American (15.3%); Asians (1.0%), American Indian/Alaskan Natives (0.2%), Pacific Islanders (0.2%) and individuals who reported multiple races (3.9%) comprised the rest of the sample. The distribution was very similar among caregivers. Patients reported an average of 14.5 years of education (SD: 2.7; range: 7-22) and caregivers reported an average of 14.6 years (SD: 2.7; range: 7-22). Most of the patients (75.6%) and caregivers (82.9%) were married or living as married. Most caregivers were the spouse of the patient (70%) and most caregivers lived with the patient (82.6%).

The average number of comorbidities/conditions reported was 1.82 among patients (range: 0-5) and 1.48 among caregivers (range: 0-5). Most patients (77.5%) and caregivers (68.1%) reported at least one comorbidity/condition and one-third of patients (32.3%) and almost one-quarter of caregivers (23%) reported three or more comorbidities/conditions. The most commonly reported were hypertension (39.9% patients; 30.0% caregivers), heart problems

(30.4% patients; 26.4% caregivers), depression (26.2% patients; 21.9% caregivers), arthritis (18.0% patients; 16.5% caregivers), and diabetes (14.0% patients; 9.3% caregivers). There was a significant difference between patients and caregiver number of comorbidities/conditions ( $p < .001$ ).

Table 2.2 provides the frequency of patient and caregiver engagement in exercise, diet, and sleep behaviors at baseline. There were significant differences in the frequency of patient and caregiver exercise behaviors ( $p = .025$ ), diet behaviors ( $p = .006$ ), and sleep behaviors ( $p < .001$ ) at baseline. At baseline, over one-third of patients (36%) and caregivers (43.9%) reported engaging in moderate or vigorous exercise at least 3 days a week. Most patients (78.6%) and caregivers (72.2%) reported eating a balanced diet at least 3 days a week and a majority of patients (73.9%) and caregivers (61.9%) reported getting enough sleep to feel rested at least 3 days a week.

### **Effects of Behaviors over Time**

Table 2.3 provides the standardized estimates for APIM models testing exercise, diet, and sleep behaviors separately. The model fit statistics were good across all models. Two main paths were tested: the effect of an individual's behavior on their future behavior (actor effects) and the effect of an individuals' behavior on the behavior of the other member of the dyad (partner effects). Significant actor effects were found across all three behaviors (exercise, diet, sleep).

#### **Actor effects of behaviors over time (H1a).**

**Patients.** All patient actor effects were significant, supporting this hypothesis. Patient exercise at Time 1 was positively associated with their own exercise at Time 2 ( $\beta = .404$ ;  $p < .001$ ) and Time 3 ( $\beta = .168$ ;  $p < .001$ ). Patient exercise behavior at Time 2 was also associated with their own exercise behavior at Time 3 ( $\beta = .360$ ;  $p < .001$ ). Patient diet at Time 1 was positively

associated with their own diet at Time 2 ( $\beta=.392$ ;  $p<.001$ ) and Time 3 ( $\beta=.185$ ;  $p<.001$ ). Patient diet behavior at Time 2 was also associated with their own diet behavior at Time 3 ( $\beta=.446$ ;  $p<.001$ ). Patient sleep at Time 1 was positively associated with their own sleep at Time 2 ( $\beta=.362$ ;  $p<.001$ ) and Time 3 ( $\beta=.191$ ;  $p<.001$ ). Patient sleep behavior at Time 2 was also associated with their own sleep behavior at Time 3 ( $\beta=.361$ ;  $p<.001$ ).

**Caregivers.** All caregiver actor effects were significant, supporting this hypothesis. Caregiver exercise at Time 1 was positively associated with their own exercise at Time 2 ( $\beta=.457$ ;  $p<.001$ ) and Time 3 ( $\beta=.179$ ;  $p<.001$ ). Caregiver exercise behavior at Time 2 was also associated with their exercise behavior at Time 3 ( $\beta=.521$ ;  $p<.001$ ). Caregiver diet at Time 1 was positively associated with their diet at Time 2 ( $\beta=.489$ ;  $p<.001$ ) and Time 3 ( $\beta=.242$ ;  $p<.001$ ). Caregiver diet behavior at Time 2 was also associated with their diet behavior at Time 3 ( $\beta=.465$ ;  $p<.001$ ). Caregiver sleep at Time 1 was positively associated with their sleep at Time 2 ( $\beta=.352$ ;  $p<.001$ ) and Time 3 ( $\beta=.187$ ;  $p<.001$ ). Caregiver sleep behavior at Time 2 was also associated with their sleep behavior at Time 3 ( $\beta=.375$ ;  $p<.001$ ).

#### **Partner effects of behaviors over time (H1b).**

**Patient  $\rightarrow$  caregiver.** Patient exercise at Time 1 was positively associated with caregiver exercise at Time 2 ( $\beta=.141$ ;  $p<.001$ ), but not Time 3; and, patient exercise at Time 2 was marginally associated with caregiver exercise at Time 3. Patient diet behaviors (Time 1 -Time 2) were not associated with caregiver diet behaviors at later time points (Time 2 – Time 3). Patient sleep at Time 1 was not associated with caregiver sleep at Time 2 or Time 3; however, patient sleep at Time 2 was associated with caregiver sleep at Time 3 ( $\beta=.101$ ;  $p=.014$ ).

**Caregiver  $\rightarrow$  patient.** Caregiver exercise at Time 1 was not associated with patient exercise at Time 2 or Time 3; however, caregiver exercise behavior at Time 2 was positively

associated with patient exercise at Time 3 ( $\beta=.092$ ;  $p=.046$ ). Caregivers' diet and sleep behaviors (Time 1 -Time 2) were not associated with patients' diet and sleep behaviors at later time points (Time 2 – Time 3). Thus, the hypothesis was partially supported.

### **Effects of Comorbidities/Conditions on Behaviors Over Time**

Table 2.4 provides the standardized estimates for models testing the effect of patient and caregiver number of comorbidities/conditions on their exercise, diet and sleep behaviors. The model fit statistics were good across all models. Though not included in Table 2.4, all significant actor and partner effects of behaviors at one time point on future behaviors (as reported in Table 2.2), were included in these models in order to account for these effects in the subsequent analyses.

#### **Actor effects of comorbidities/conditions on own behaviors over time (H2a & H2b).**

*Patients.* Among patients, a higher number of comorbidities was associated with less patient engagement in exercise behaviors at Time 1 ( $\beta= -.117$ ,  $p=.014$ ) but more engagement in exercise behaviors at Time 3 ( $\beta=.108$ ,  $p=.006$ ). In addition, a higher number of comorbidities was associated with less quality sleep among patient at Time 1( $\beta=-.089$ ,  $p=.044$ ).

*Caregivers.* Among caregivers, a higher number of conditions was associated with less caregiver engagement in exercise behaviors at Time 1 ( $\beta= -.133$ ,  $p=.007$ ). A higher number of caregiver chronic conditions was also associated with a better diet ( $\beta=.082$ ,  $p=.039$ ) and better sleep ( $\beta=.080$ ,  $p=.047$ ) among caregivers at Time 3. Thus, the hypothesis was partially supported.

#### **Partner effects of comorbidities/conditions on others' behaviors over time (H3a & H3b).**

**Patient → caregiver.** Patient comorbidities influenced caregiver sleep: a higher patient number of comorbidities were associated with less quality caregiver sleep at Time 1 ( $\beta=-.101$ ,  $p=.017$ ).

**Caregiver → patient.** Caregiver conditions influenced patient exercise: a higher number of caregiver conditions were related to less exercise by patients at Time 3 ( $\beta=-.089$ ,  $p=.047$ ). Thus, the hypothesis was partially supported.

**Influence of covariates on behaviors.** The influence of a number of covariates was evident across models with and without patient comorbidities and caregiver conditions. Specifically, patient cancer type was associated with more patient sleep (Time 1) and increased months since patient diagnosis was associated with increased caregiver exercise (Time 2). Increased patient age was associated with more patient sleep (Time 1 & 2) and better caregiver exercise and diet (Time 1). Increased caregiver age was also associated with better caregiver diet (Time 1). Being a female patient was associated with decreased patient exercise (Time 1), but better patient diet (Time 3); being a female caregiver was associated with better patient exercise (Time 2) and worse patient sleep (Time 1). Being a white patient was associated with better patient exercise and diet (Time 1); being a white caregiver was associated with worse patient exercise (Time 1). Patient and caregiver living together was associated with better caregiver exercise (Time 2). Increased caregiver burden was associated with worse patient exercise (Time 1), diet (Time 1 & 2) and sleep (Time 3). Increased caregiver burden was associated with worse caregiver behaviors across all time points.

The influence of a number of covariates differed in models with and without comorbidities/conditions. Prior to adding comorbidities/conditions, patient cancer type, (Time 1) decreased patient age (Time 1), and patient and caregiver not living together (Time 3) were



associated with worse patient diet and increased income was associated with better caregiver sleep (Time 3). After adding comorbidities/conditions, patient and caregiver living together was associated with worse patient exercise (Time 3), a spousal relationship was associated with better patient diet (Time 3), and increased patient age was associated with better caregiver sleep (Time 2).

### **Summary of results**

As expected, higher patient and caregiver engagement in exercise, diet, and sleep behaviors were positively associated with more of their own engagement in those behaviors at later time points (H1a & H1b). Partner effects were also observed. More exercise among patients (Time 1) was associated with more exercise among caregivers (Time 2); more exercise among caregivers (Time 2) was associated with more exercise among patients (Time 3); and, better sleep among patients (Time 2) was associated with better sleep among caregivers (Time 3). When examining the influence of comorbidities/conditions, most often, patient and caregiver number of comorbidities/conditions had a negative influence on their behaviors (H2a – H3b). More patient comorbidities were associated with less patient exercise (Time 1); worse patient sleep (Time 1); and, less caregiver sleep (Time 2). More caregiver conditions were associated with less caregiver exercise (Time 1) and less patient exercise (Time 3).

There were, however, several unexpected findings. More patient comorbidities were associated with more patient exercise (Time 3). The diet of one dyad member did not influence the diet of the other across all time points and comorbidities/conditions did not influence patient diet. In addition, more caregiver conditions were associated with a better caregiver diet and sleep (Time 3).

## Discussion

Advanced cancer has been identified as the third phase in the trajectory of cancer survivorship (Rock et al., 2012). There is a need for more research on the experiences of patients and caregivers at this disease phase given the specific challenges that accompany advanced disease (Hopkinson, Brown, Okamoto, & Addington-Hall, 2012; Lee et al., 2004). The purpose of this study was to examine the relationship between patient comorbidities, caregiver chronic conditions and patient/caregiver diet, physical activity and sleep behaviors over time among a sample of patients with advanced cancers (breast, colorectal, lung and prostate) and their primary family caregiver. While multimorbidity is known to influence quality of life (Fortin et al., 2004; Smith et al., 2008), no available studies have examined the impact of multimorbidity on the physical activity, diet and sleep of this population.

Despite the challenges of advanced cancer and caregiving, a significant number of patients and caregivers reported engaging in exercise, eating a balanced diet and getting restful sleep. At baseline, over two-thirds of patients and caregivers reported eating a balanced diet or getting adequate sleep at least 3 days a week; over one-third reported engaging in moderate or vigorous exercise at least 3 days a week. Much of the previous research evaluating the health behaviors of patients with cancer has focused on those with earlier stage disease, did not analyze data by stage of disease, and did not involve family caregivers (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Demark-Wahnefried et al., 2005; Patterson et al., 2003). Data in the present study appear similar to other studies of cancer survivors of early stage disease or all-stages combined. In those studies 30% to 58% met recommended exercise guidelines or engaged in routine exercise (Bellizzi et al., 2005; Demark-Wahnefried et al., 2005); almost half (45%) ate at least five servings of fruits and vegetables per day, and most (69%) followed a low fat diet (Demark-

Wahnefried et al., 2005). Similarly, 30-80% of patients reported sleep problems (Clark, Cunningham, McMillan, Vena, & Parker, 2004).

Among patients, some research has shown a positive association between more advanced tumor stage and engaging in behaviors such as diet and exercise (Park & Gaffey, 2007). Kim and Given (2008) note that a family member's diagnosis of advanced cancer may motivate caregivers to increase engagement in health promoting behaviors, and this may be especially true in the period initially following diagnosis. In this study, previous behavior was a strong predictor of future behavior (i.e. actor effects) across all three health-promoting behaviors studied. This may suggest the importance of intervening early with patients and caregivers in order to increase health-promoting behaviors and support the maintenance of these behaviors. The adjustment to chronic and advanced disease is a dynamic and non-linear process (Clark, 2003; Stanton, Revenson, & Tennen, 2007) that requires ongoing assessment because patient and caregiver needs will vary overtime. Schulman-Green and colleagues (2011; 2012) identified the transitional period from curable to non-curable cancers as a key phase for understanding and supporting patient self-management of their illness, which includes participation in health-promoting behaviors. Future research could work to understand the effect of transitions on patient and caregiver health behaviors.

There was also evidence of interdependence in patient and caregiver health behaviors, where the behaviors of one dyad member influenced the behaviors of the other. Health behaviors are established over time (Aarts et al., 1997; Ouellette & Wood, 1998), and are highly influenced by familial and environmental factors (Gordon-Larsen, 2006; Lewis et al., 2006; Muzet, 2007; Umberson, Crosnoe, & Reczek, 2010). As expected, patient exercise at baseline had a positive influence on caregiver exercise approximately 9 months after diagnosis (Time 2); caregiver

exercise had a positive influence on patient exercise at Time 2; and, patient sleep at Time 2 had a positive influence on caregiver sleep a year after diagnosis (Time 3). Unexpectedly, no associations between patient and caregiver diet were found. Research indicates that patients face significant challenges related to appetite and diet as their cancer progresses (Brown et al., 2001); as a result, it is possible that these results are highly influenced by cancer progression.

A number of study findings suggest that multimorbidity negatively influences engagement in health-promoting behaviors. The presence of multiple chronic conditions is associated with a number of challenges, including problems with care coordination, conflicting advice, symptom attribution, and increased likelihood of adverse outcomes such as hospitalizations (PFS, 2002; Wolff, Starfield, & Anderson, 2002), but the influence of multiple chronic conditions on health behaviors is less understood. It was hypothesized that more patient comorbidities and more caregiver chronic conditions, as additional stressors, would be associated with less engagement in health-promoting behaviors. In most cases, the results aligned with the hypotheses, and more comorbidities/conditions were associated with less engagement in health-promoting behaviors. In addition to influencing behavior through a stress-related mechanism, comorbidities may have direct effects on health behaviors as well. For example, symptoms such as pain may negatively affect sleep (Theobald, 2004) and functional limitations caused by comorbidities/conditions could decrease a patient or caregiver's ability to engage in physical activity (Huang et al., 1998; Schutzer & Graves, 2004).

In other cases, however, the reverse was true: more chronic conditions were associated with more engagement in health promoting behaviors. A possible explanation for a positive association between comorbidities and positive behaviors is that individuals with more health problems may be exposed to more intervention opportunities due to increased time spent with

health care professionals in order to manage their multiple conditions. For example, patients with advanced cancer who have fatigue due to the cancer and its treatments, but also have exercise needs related to managing chronic conditions such as diabetes, may be more likely to receive advice about remaining active (Rock et al., 2012). It could be that for certain segments of patients and caregivers, more chronic conditions may provide more opportunities for positive health interventions. The management recommendations for many chronic conditions include engagement in healthy exercise, diet and sleep behaviors (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Thus, this finding could be associated with patient and caregiver use of behaviors to manage their health conditions and counter the detrimental effects of illness.

Future research could also examine the inter-relationships between different types of behavior engagement in the context of patient/caregiver relationship. Research on multiple health behavior change suggests that individual health attitudes and beliefs are interrelated and that considering multiple behaviors simultaneously in intervention and research contexts is a more accurate reflection of individual experiences (Noar, Chabot, & Zimmerman, 2008). While this body of research often considers relationships between, for example, diet and exercise within an individual, future research could examine relationships between diet and exercise within and across dyad members. Similarly, considering the management of multiple chronic conditions in intervention programs, instead of one condition at a time, could allow for a focus on the information, skills and behaviors that would increase management of various chronic conditions (Lorig et al., 1999). While intervention studies that focus on multiple health behavior change continue to emerge, the application and adaption of these interventions for patients and caregivers remains an area of need (Boult & Wieland, 2010). However, there is much potential for capitalizing on the synergistic effects of multiple behavior change within a supportive

patient/caregiver context. Given that the frequency of comorbidities increase with age, and that minorities and people of low SES often have more difficulties managing disease and engaging in health promoting behaviors (Ogle et al., 2000) due to both individual and contextual factors, these populations may be key targets for intervention.

Though limited, the emerging research on health behaviors among patients with advanced cancer support the idea that patient engagement in health-promoting behaviors, even at advanced stages, can be beneficial. Existing evidence suggests that many individuals with advanced cancer can engage in and benefit from a variety of interventions. Physical activity interventions may help to decrease fatigue and improve quality of life (Oldervoll et al., 2006; Rummans et al., 2006), whereas diet interventions may seek to combat malnutrition and weight loss (Barrera, 2002; Ravasco, Monteiro-Grillo, Vidal, & Camilo, 2005; Rock et al., 2012), and sleep interventions may aim to improve quality of life and daytime functioning (Lee et al., 2004). Previous research has demonstrated that the encouragement to engage in health-promoting behaviors by health professionals leads to positive changes in individuals, but physicians may be less likely to make behavioral recommendations for cancer survivors (Albrecht & Taylor, 2012; Denlinger & Engstrom, 2011; Rock et al., 2012). In addition, among patients with advanced cancer, lack of clear guidelines for diet and physical activity could be a barrier to physician interventions and recommendations. The study findings suggest that a number of patients are already engaging in health-promoting behaviors. Support from health professionals could be important for behavior maintenance over time and also help to improve our knowledge base and contribute to the development of guidelines for this population. Furthermore, involving a caregiver in these interventions could positively contribute to patient and caregiver outcomes (Northouse, 2005).

Future studies may also examine these findings in a large, multiethnic population of cancer patients and caregivers. Differences in factors such as familial and cultural orientations toward illness and caregiving (Baider, 2012; Dilworth-Anderson, Williams, & Gibson, 2002), varying quality and availability of health care and the disparities in the accessibility and availability of resources (Cohen, Scribner, & Farley, 2000; Jackson & Knight, 2006; Sanders, Solberg, & Gauger, 2013), could influence the associations of chronic conditions on health-promoting behaviors observed in this study. In addition, future studies should consider the differential impact of specific comorbid conditions on engagement in health behaviors among patients and caregivers. For example, diabetes may have a stronger influence on diet than arthritis, which may have a greater influence on exercise behaviors. Understanding the barriers associated with certain conditions and these behaviors could help health professionals target intervention efforts to support these behaviors in populations most in need in a timely fashion. It is also possible that the effect of the type of comorbidities/conditions may affect the three health behaviors differently.

Interdependence theory has often been used to investigate individual dispositions in specific, time-limited interactions; however, its use in broader, more long-term situations – such as a cancer illness and caregiving experience – could help elucidate the mechanisms and implications of interdependent effects (i.e. partner effects) and interdependent patterns (Holmes, 2002; Rusbult & Van Lange, 2003; Van Lange & Rusbult, 2012). For example, hypotheses and findings from the current study fall along the dimensions of *degree* and *mutuality of interdependence*. Further exploration of patient and caregiver health behaviors could examine theoretical dimensions such as *correspondence of outcomes*. This dimension involves considering expectations about dyad members goals, such as desired behavioral engagement.

Another applicable dimension is *degree of uncertainty*, which could consider how lack of information about patient and caregiver future health status or ability to engage in health-promoting behaviors influences their outcomes.

### **Limitations**

There are a number of limitations that should be noted. First, the measures of physical activity and diet asked patients and caregivers to report their engagement in behaviors in the previous week prior to data collection. Other more frequent and detailed measures of these activities could provide more accurate assessments of behavior engagement. The choice of method(s), however, should be such that it does not become overly burdensome to dyad members, especially those facing advanced cancer. Newer technologies, such as wearable fitness trackers that record physical activity and sleep behaviors, could be a good option. Second, the item used to assess sleep behaviors (i.e. “got enough sleep to feel rested”) could also be viewed as an outcome of more specific sleep hygiene behaviors, such maintaining a regular sleep schedule and decreasing caffeine intake (Irish, Kline, Gunn, Buysse, & Hall, 2014). Assessment of specific sleep hygiene behaviors would be helpful for identifying, monitoring and supporting sleep-related behaviors that influence patients’ and caregivers’ ability to get restful sleep. There was also no assessment of health-promoting behaviors prior to the advanced cancer diagnosis. This information could provide better insights into how the advanced cancer diagnosis and comorbidities may combine to influence behavior. In addition, the measure of patient and caregiver conditions was based upon their responses to an open-ended question; it is possible that providing a checklist of conditions of patients and caregivers to choose from and/or using medical records could provide more accurate assessment of chronic disease diagnoses. Another limitation of this study is lack of information regarding patient and caregiver experiences with



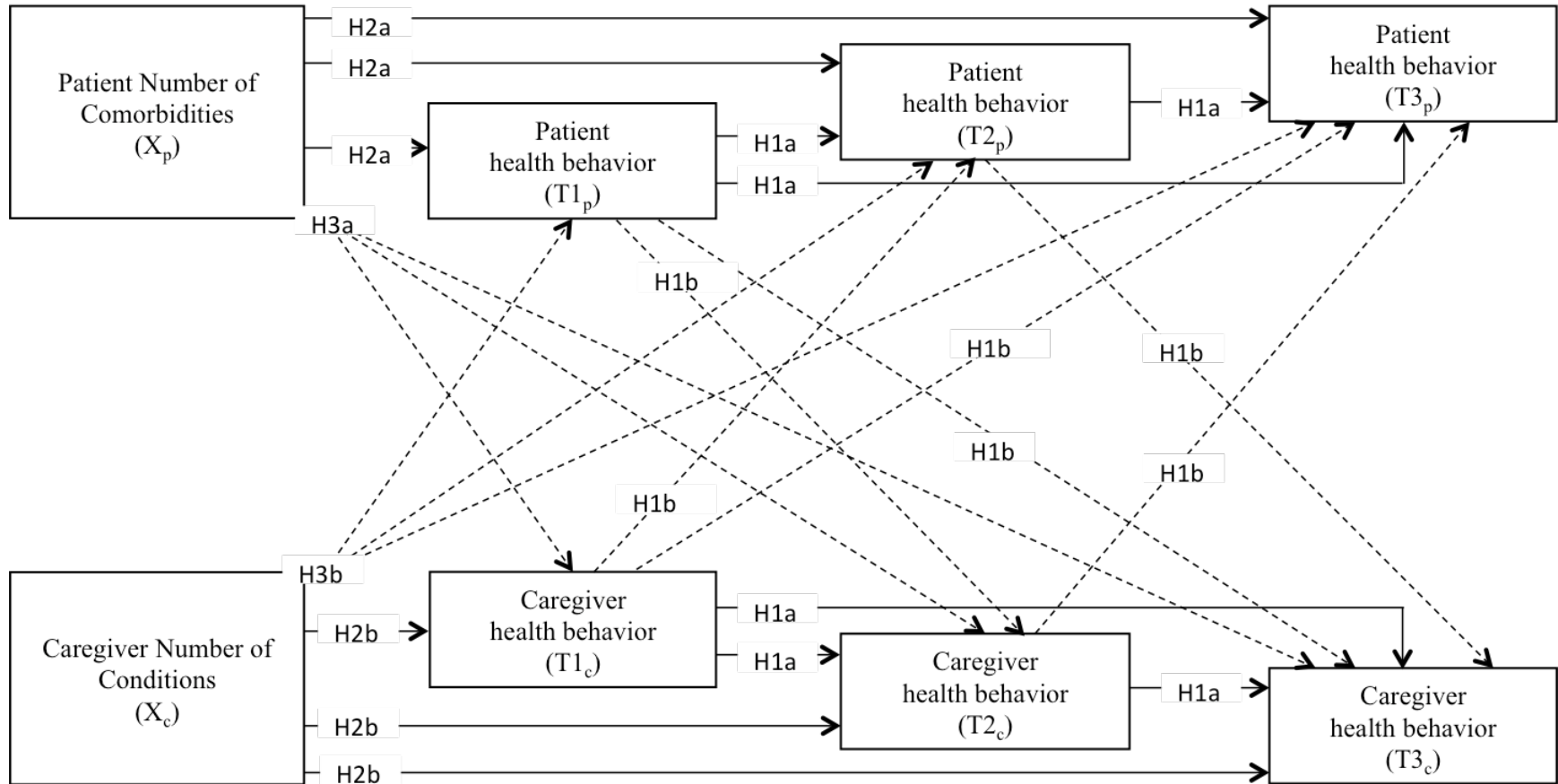
chronic disease management or chronic disease severity. Those who are managing chronic conditions adequately and/or have fewer complications from their conditions may be more likely to engage in health promoting behaviors. Lastly, a more representative racial and ethnic sample would allow for a broader understanding of the relationship of comorbidities/conditions and health-promoting behaviors in more diverse patient-caregiver contexts.

## **Conclusion**

Engagement in health-promoting behaviors among patients with advanced cancer and their family caregivers may be challenging due to symptoms and consequences of advanced disease and the existence of other patient and caregiver health conditions. However, physical activity, a balanced diet, and adequate sleep have been associated with patient and caregiver wellbeing, and thus, intervention efforts to support these behaviors are warranted. While patient and caregiver multimorbidity may present challenges to behavior engagement, it may provide opportunities as well, due to increased contact with providers to manage the conditions and the reciprocal social support for behaviors between patients and caregivers. Health care providers should encourage behaviors based on the individual health status and capabilities of patients. In addition, caregiver assessments could help to identify caregivers who may need additional support managing their own chronic conditions in addition to caring for the patients. Assistance with coordinating care and multiple provider recommendations are just a few of the challenges involved with individuals managing multimorbidity; these challenges are enhanced when both patients and caregivers are managing chronic conditions. The health behaviors and quality of life of patients and caregivers are closely linked. Interventions recognizing and supporting both self and family-management of disease could improve outcomes for both members of the dyad.

Lastly, the value that patients and caregivers place on health-promoting behaviors, especially as patients near end of life, should not be assumed. While a number of studies point towards the benefits of these behaviors with advanced disease, and some research indicates that patients and caregivers in this stage of disease have expressed interest in interventions targeting health-promoting behaviors, it is important to take individual preferences and priorities into account. For those patients and caregivers for whom behavioral interventions are appropriate and desired, it will be important to tailor those interventions and identify resources that meet the dyad's specific needs. The current research suggests, however, that patient and caregiver participation in these behaviors at this stage should not be ignored.

**Figure 2.1. Model Testing the Influence of Patient and Caregiver Number of Comorbidities/Conditions on Health Behaviors**



*Note:* Health behaviors refer to exercise, diet, or sleep behaviors. T1, T2, and T3 refer to Time 1, Time 2, and Time 3, respectively. Subscript *p* refers to patients and subscript *c* refers to caregivers. The hypotheses relevant to each path in the diagram have been noted (i.e. H1a refers to Hypotheses 1a). Independent effects (i.e. actor effects) are represented by solid lines. Interdependent effects (i.e. partner effects) are represented by dashed lines.

Table 2.1. Patient and Caregiver Demographic Information at Baseline

	Patients (N=484)	Caregivers (N=484)	Difference Tests <sup>a</sup>
Age in years			
Mean (SD)	60.5 (11.5)	56.5 (13.4)	*
Range	26-95	18-88	
Sex (%)			
Female	62.0	56.8	NS
Male	38.0	43.1	
Race (%)			
American Indian/Alaskan Native	0.2	0	NS
Asian	1.0	1.2	
Black	15.3	15.9	
Pacific Islander	0.2	0	
White	79.3	79.6	
Multiracial	3.9	2.5	
Highest level of education in years			
Mean (SD)	14.5 (2.7)	14.6 (2.8)	NS
Marital Status (%)			
Married/Living as married	75.6	82.9	*
Divorced/Separated	13.2	8.1	
Widowed	6.0	2.3	
Never married	5.2	6.8	
Relationship to patient (%; caregiver only)			
Spouse	--	70.0	--
Daughter	--	12.0	
Son	--	3.3	
Sister/Brother	--	0.2	
Other relative	--	5.6	
Friend	--	4.3	
Unknown/Coding error	--	4.5	
Currently living with patient (caregiver only)			
% Yes	--	82.6	--

<sup>a</sup>Paired sample t-tests, McNemar's Test, or Wilcoxon Signed-Rank Test. \* $p < .05$ ; NS: not significant.

Table 2.2. Frequency of Patient and Caregiver Behaviors Per Week at Baseline

Days per week	Patients (N=484)	Caregivers (N=484)	Difference Test <sup>a</sup>
<i>Walking or moderate to vigorous exercise</i>			
	(%)	(%)	
None	28.5	19.3	*
1	15.7	15.9	
2	19.8	20.9	
3-4	21.1	28.8	
5-7	14.9	15.1	
<i>Eat a balanced diet</i>			
None	5.4	7.2	**
1	4.8	7.0	
2	11.2	13.6	
3-4	33.0	36.2	
5-7	45.6	36.0	
<i>Get enough sleep to feel rested</i>			
None	6.9	11.0	**
1	7.1	8.7	
2	12.1	18.4	
3-4	31.8	31.8	
5-7	42.2	30.2	

<sup>a</sup>Wilcoxon Signed-Rank Test. \* $p < .05$ ; \*\* $p < .01$

Table 2.3. Actor and Partner Influences on Exercise, Diet and Sleep Behavior

	Exercise	Diet	Sleep
	Model A	Model B	Model C
<b><i>Actor Effects</i></b>			
PT Behavior T1 <sub>p</sub> → PT Behavior T2 <sub>p</sub>	.404 (.041)***	.392 (.044)***	.362 (.043)***
PT Behavior T2 <sub>p</sub> → PT Behavior T3 <sub>p</sub>	.360 (.043)***	.446 (.042)***	.361 (.043)***
PT Behavior T1 <sub>p</sub> → PT Behavior T3 <sub>p</sub>	.168 (.044)***	.185 (.043)***	.191 (.043)***
<b><i>Partner Effects</i></b>			
PT Behavior T1 <sub>p</sub> → CG Behavior T2 <sub>c</sub>	.141 (.039)***		
PT Behavior T2 <sub>p</sub> → CG Behavior T3 <sub>c</sub>	.075 (.039) <sup>+</sup>	.067 (.039) <sup>+</sup>	.101 (.041)*
PT Behavior T1 <sub>p</sub> → CG Behavior T3 <sub>c</sub>			
CG Behavior T1 <sub>c</sub> → PT Behavior T2 <sub>p</sub>			
CG Behavior T2 <sub>c</sub> → PT Behavior T3 <sub>p</sub>	.092 (.046)*		
CG Behavior T1 <sub>c</sub> → PT Behavior T3 <sub>p</sub>			
<b>Model Fit</b>			
CFI	.998	.997	.995
RMSEA	.021	.028	.030
SRMR	.0129	.0123	.0167

*Note:* Estimates are standardized; standard errors are in parentheses; and, only significant parameter estimates are reported. T1, T2, and T3 refer to Time 1, Time 2, and Time 3, respectively. PT=patient; CG=caregiver. Subscript p refers to patients and subscript c refers to caregivers. Model covariates were age, sex, race, income, cancer type, patient treatment, length of time since patient diagnosis, relationship type, living arrangements, caregiver burden, and intervention group.  
<sup>+</sup>  $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$

Table 2.4. Influence of Number of Comorbidities/Conditions on Exercise, Diet, and Sleep Behaviors of Patients and Caregivers

	Exercise Model D	Diet Model E	Sleep Model F
<b>Actor Effects</b>			
<i>Patient Comorbidities (X<sub>p</sub>) → Patient Behavior</i>			
PT Comorbidities to PT Behavior T1 (T1 <sub>p</sub> )	-.117 (.048)*		-.089 (.044)*
PT Comorbidities to PT Behavior T2 (T2 <sub>p</sub> )			
PT Comorbidities to PT Behavior T3 (T3 <sub>p</sub> )	.108 (.041)**		
<i>Caregiver Conditions (X<sub>c</sub>) → Caregiver Behavior</i>			
CG Conditions to CG Behavior T1 (T1 <sub>c</sub> )	-.133(.049)**		
CG Conditions to CG Behavior T2 (T2 <sub>c</sub> )			
CG Conditions to CG Behavior T3 (T3 <sub>c</sub> )		.082 (.040)*	.080 (.041)*
<b>Partner Effects</b>			
<i>Patient Comorbidities (X<sub>p</sub>) → Caregiver Behavior</i>			
PT Comorbidities to CG Behavior T1 (T1 <sub>c</sub> )			
PT Comorbidities to CG Behavior T2 (T2 <sub>c</sub> )			-.101 (.042)*
PT Comorbidities to CG Behavior T3 (T3 <sub>c</sub> )			
<i>Caregiver Conditions (X<sub>c</sub>) → Patient Behavior</i>			
CG Conditions to PT Behavior T1 (T1 <sub>p</sub> )			
CG Conditions to PT Behavior T2 (T2 <sub>p</sub> )			
CG Conditions to PT Behavior T3 (T3 <sub>p</sub> )	-.089 (.045)*		
<b>Model Fit</b>			
CFI	.997	.996	.994
RMSEA	.023	.025	.031
SRMR	.0142	.0150	.0180

*Note:* Standard errors are in parentheses; estimates are standardized; only significant parameter estimates are reported. Though not reported here, models also include significant paths between patient and caregiver exercise behaviors (see models A-C, Table 2.3). X=comorbidity predictor variable. T1, T2, and T3 refer to Time 1, Time 2, and Time 3, respectively. PT=patient; CG=caregiver. Subscript p refers to patients and subscript c refers to caregivers. Model covariates were age, sex, race, income, cancer type, patient treatment, length of time since patient diagnosis, relationship type, living arrangements, caregiver burden, and intervention group. + $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$

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## CHAPTER III

### **Dyadic Comorbidity Burden as a Moderator of the Link Between Symptom Distress, Threat Appraisals and Self-Efficacy in Advanced Cancer and Caregiving**

A diagnosis of advanced cancer is a challenging life event for patients and families. At advanced stages of disease, the goals of treatment are no longer curative (Schofield, Carey, Love, Nehill, & Wein, 2006); 5-year survival rates are limited (Siegel, Ma, Zou, & Jemal, 2014); and, patients' cancer- and treatment-related symptoms such as pain (van den Beuken-van Everdingen et al., 2007) and fatigue (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003) are often managed with the help of family caregivers (Given, Given, & Kozachik, 2001).

Stress and coping theory (Lazarus & Folkman, 1984) suggests that patient and caregiver cognitive appraisals about the cancer experience are key contributors to their wellbeing. Specifically, these appraisals are expected to mediate the influence of advanced cancer (the stressor) on their coping efforts and their adaptation to the disease and its consequences. In this theoretical framework, *primary appraisals* are patients' and caregivers' evaluation of the significance of the advanced cancer (Wenzel, Glanz, & Lerman, 2002), such as the ways in which the cancer diagnosis threatens their lives and livelihood. *Secondary appraisals* are an assessment of their ability to manage the consequences of the illness; that is, their self-efficacy to cope with the cancer/caregiving situation (Strecher, McEvoy DeVellis, Becker, & Rosenstock, 1986). Among patients and caregivers, cognitive appraisals have been associated numerous factors, including coping strategies (Franks & Roesch, 2006); psychological functioning

(Gallagher, Parle, & Cairns, 2002); life satisfaction (Fitzell & Pakenham, 2010); and, quality of life (Northouse et al., 2002).

While evidence supports the importance of patient and caregiver appraisals in the advanced cancer context, a number of critical knowledge gaps exist in understanding the relationship between patient and caregiver physical and psychosocial health. First, a potentially important influence on their cognitive appraisals is the presence of other health-related concerns such as patient comorbidities, caregiver chronic conditions and symptoms associated with their health issues. Second, stress and coping theory highlights the individual-environmental interplay inherent in a stressful situation; however, interpersonal processes - particularly salient in the advanced cancer context - are not clearly specified. The strongly interdependent nature of the patient-caregiver relationship in this context (Lewis et al., 2006; Rusbult & Van Lange, 2003) suggests that the cognitive appraisals of one individual might influence the appraisals of the other. Third, while social support received from others has been associated with better adjustment and coping (Hebert & Schulz, 2006; Helgeson & Cohen, 1996), patients and caregivers are often expected to provide support to other family members affected by the illness (Ashing-Giwa et al., 2004; Bowman, Deimling, Smerglia, Sage, & Kahana, 2003). As such, patient and caregiver self-efficacy about their ability to help others cope could be an important interpersonal factor. The purpose of this study is to examine the influence of patient and caregiver co-occurring health problems (symptom distress, patient comorbidities, and caregiver chronic conditions) on their threat appraisals (primary appraisals) and their individual- and family-related self-efficacy to cope with cancer/caregiving (secondary appraisals).

### **Threat Appraisals & Self-Efficacy**

Despite the ordinal naming of the concepts, stress and coping theory does not propose a temporal sequence of appraisal processes; rather, primary and secondary appraisals are expected to directly influence coping efforts in an ongoing process (Lazarus & Folkman, 1987). Previous research, however, has found a relationship between the two types of appraisals (McGinty, Goldenberg, & Jacobsen, 2012; Northouse et al., 2002). For example, Northouse and colleagues (2002) found that as patient and caregiver self-efficacy (i.e. secondary appraisal) for coping with cancer/caregiving increased, their negative illness-related appraisals (i.e. primary appraisal) decreased. It is possible that the reverse relationship also exists. That is, patient and caregiver threat appraisals could influence their self-efficacy to cope with disease. Research suggests that in situations where the stressor is likely to be threatening and a source of significant strain, such as the case with advanced cancer, threat appraisals may have a significant influence on an individual's self-efficacy about their ability to cope with the illness and its consequences (Folkman, 1984; Guillet, Hermand, & Mullet, 2002; Jenkins & Pargament, 1988).

Another aspect of cancer- and caregiving-related self-efficacy that has received less attention is the self-efficacy of patients and caregivers to help other family members cope with the effects of the illness. It has long been accepted that cancer also affects the families of individuals who are diagnosed (Ashing-Giwa et al., 2004; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Segrin, Badger, Dorros, Meek, & Lopez, 2007); yet, much of the relational focus in interventions and research on adult cancers remains within the patient-caregiver dyad (Harding & Higginson, 2003; Stenberg, Ruland, & Miaskowski, 2010). As part of a family unit, patients and caregivers have concerns about how the other members of the family are handling the illness (Mellon & Northouse, 2001; Walsh, Manuel, & Avis, 2005); unfortunately, this is not often considered in patient and caregiving literature (Mellon, 1998).



Some research has noted that more stressful appraisals exist when patients believe that their treatment or their diagnosis has caused a significant amount of stress within their family (Bowman et al., 2003). Other research has highlighted communal aspects of the stress and coping process, in which individuals take into account the wellbeing of others when attempting to manage their stress (Lyons, Mickelson, Sullivan, & Coyne, 1998; Lewis et al., 2006; Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010). Overall, evidence suggests that patients and caregivers are often concerned about the effect of the cancer diagnosis on other family members (Ashing-Giwa et al., 2004; Bowman et al., 2003). Thus, in addition to considering patients' and caregivers' self-efficacy to cope as individuals with cancer or caregiving, research on patient and caregiver self-efficacy needs to be expanded to assess factors that influence their efficacy to help other family members manage cancer-related issues.

### **Co-Occurring Health Problems**

Co-occurring health issues of patients and caregivers may influence their cancer-related threat appraisals and self-efficacy. The prevalence of comorbidities among patients with cancer has been reported at or above prevalence rates of individuals without cancer (Edwards et al., 2014). In addition, given the burden of chronic diseases in the general population (Ward, Schiller, & Goodman, 2014), the chronic disease risk associated with increased age (CDC, 2003; Rowland & Yancik, 2006), and evidence that caregivers tend to be older (Edwards et al., 2002), many cancer caregivers are likely managing health conditions of their own (Kim & Schulz, 2008). In fact, individually and collectively, some patients and caregivers are managing more than one chronic health condition in addition to the advanced cancer diagnosis (Tinetti, 2012). The management of multiple chronic conditions has been associated with increased functional limitations and symptom burden (Dowling et al., 2013; Janevic, Janz, Connell, Kaciroti, & Clark,

2011; Mao et al., 2007), complications with symptom attribution (Fortin et al., 2004; Janevic, Ellis, Sanders, Nelson, & Clark, 2013; Vogeli et al., 2007) and problems managing multiple health providers (Barnett et al., 2012; Tinetti, 2012). Thus, these co-occurring health issues could be additional stressors that intensify their cancer-related threat appraisals and decrease their self-efficacy to cope with the challenges associated with cancer and caregiving.

### **Purpose & Hypotheses**

The purpose of this study is to examine the relationships between patient and caregiver chronic conditions, symptom distress, threat appraisals, and self-efficacy regarding the cancer/caregiving experience. The study hypotheses (H1-H5) are diagrammed in Figure 3.1 and are as follows:

- H1: Symptom distress reported by patients and caregivers will be positively associated with their own threat appraisals (actor effects) and the threat appraisals of the other member of the dyad (partner effects).
- H2: Threat appraisals reported by patients and caregivers will be negatively associated with their own self-efficacy (actor effects) and the self-efficacy of the other member of the dyad (partner effects) for coping with the cancer/caregiving experience.
- H3: The magnitude of the relationship between threat appraisals and self-efficacy will differ based on the dimension of self-efficacy assessed (individual-related vs. family-related).
- H4: Symptom distress will have a negative direct effect on self-efficacy and a negative indirect effect on self-efficacy through threat appraisals (mediation).

Lastly, in this study, the chronic conditions of patients and caregivers - as a unit - will be conceptualized as the comorbidity burden of the dyad and considered in a multiple group framework. Given the known challenges associated with multimorbidity (Barnett et al., 2012;

Fortin et al., 2004; Mao et al., 2007), the comorbidity burden of the dyad reflects their shared experience managing cancer and other chronic conditions. Thus, the final hypothesis:

H5: The proposed relationships between symptoms, threat appraisals and self-efficacy will differ based on the level of comorbidity burden of the dyad (moderation).

## **Method**

### **Study Design**

Data for this study come from the baseline assessment of a randomized clinical trial (RCT) for patients with advanced cancer and their family caregivers. The RCT tested the efficacy of brief and extensive forms of the evidence-based FOCUS program on patient and caregiver outcomes. Detailed information related to the RCT procedures, intervention content, and study outcomes have been published elsewhere (Northouse et al., 2013).

### **Participants**

The sample population for this study at baseline included patients with advanced cancer and their family caregivers (N=484 dyads). All patients: 1) were age 21 or older; 2) had a confirmed diagnosis of advanced breast, colon, lung or prostate cancer and were within 6 months of the diagnosis, progression of their cancer, or a change of treatment for it; 3) were physically and mentally able to participate; 4) could speak and understand sufficient English; 5) had a life expectancy of at least 6 months (as assessed by a physician); 6) lived within 75 miles of one of the participating medical centers; 7) provided informed consent; and, 8) had a family caregiver willing to participate. Patients diagnosed with multiple primary cancer sites were excluded from the study.

A family caregiver was defined as “the family member or significant other identified by the patient as his or her primary source of physical or emotional support during the advanced phase of cancer and confirmed by the designated individual” (Northouse et al., 2013). Family caregivers were: 1) age 18 or older; 2) physically and mentally able to participate; and, 3) able to speak and understand English. Family caregivers were excluded from the study if they had been diagnosed with cancer during the previous year and/or were in active treatment for cancer.

### **Patient Sample Description**

The percentages of advanced cancers reported by patients were as follows: 32.4% breast cancer; 29.1% lung cancer; 25.4% colorectal cancer; and, 13.0% prostate cancer. Advanced cancers were defined as cancers at stage III or IV of disease with a five-year survival rate below 50%. At baseline, the average time since the initial diagnosis was 42.5 months (SD: 55.3; range: 1-309). A majority of patients were undergoing chemotherapy treatment (68.8%). Patients also reported receiving hormone therapy (16.5%), radiation therapy (8.3%), watchful waiting (7.6%), surgical treatment (2.9%) or another treatment not specified (5.4%) at baseline. Multiple responses for treatment were possible.

### **Instruments**

The following instruments were used to measure the study variables. For the symptom distress, threat, and self-efficacy scales, only items which were asked of both patients and caregivers were included.

**Symptom distress.** The 16-item Symptom Scale of the Risk for Distress Scale was used to assess patient and caregiver *symptom distress* (Mood & Bickes, 1989; Northouse et al., 2007). Patients and caregivers reported on their own symptoms (e.g. pain, fatigue) and level of trouble with those symptoms. The symptoms could be related to cancer (among patients) and/or non-

cancer related health problems (among patients and caregivers) during the past week. Descriptive response options were appropriate for the symptoms and generally represented: 0) no trouble, 1) some, and 2) a lot. For example, responses for “pain symptoms” were 0) “no pain present”; 1) “some pain present, but it’s tolerable”; and, 3) “pain is severe, I’m very uncomfortable.” The z-scored total scale score was used in the analysis to standardize the items, with higher scores indicating higher symptom distress. Cronbach’s alpha coefficient of internal consistency was .741 for patients and .891 for caregivers.

**Threat appraisal.** Patient *threat appraisals* were assessed with a subscale of the 32-item Appraisal of Illness Scale and caregiver threat appraisals were assessed with a subscale of the 27-item Appraisal of Caregiving Scale (Lambert, Yoon, Ellis, & Northouse, 2015; Oberst, 1991a, 1991b). Respondents were instructed to answer the questions based upon how they felt “over the last week including today.” An example item is “This situation threatens to overwhelm me.” Both instruments have a 5-point response scale ranging from “strongly disagree” to “strongly agree.” Cronbach’s alpha coefficient of internal consistency for the 11-item threat subscale was .902 for patients and .887 for caregivers. The total subscale score was used in the analysis with higher scores indicating higher threat appraisals.

**Self-efficacy.** Patient and caregiver self-efficacy to manage the impact of the illness was measured using the 17-item CASE Scale (Lewis, 1996), modified from the original 23 item scale. Two subscales were created for use in this analysis. The 11-item *individual-related self-efficacy* subscale measured the confidence that a patient or caregiver had in their ability to manage the general impact of cancer on themselves. An example item from this subscale is “I am confident that I can put the cancer into proper perspective in my life.” The 4-item *family-related self-efficacy* subscale measured the confidence that a patient or caregiver had in their ability to

manage the impact of cancer on their family. An example item from this subscale is “I am confident that I have what it takes to help my family through the illness.” Responses to these items were on a 10-point scale ranging from 0 (not at all confident) to 10 (very confident). The total subscale scores were used in the analysis with higher scores indicating higher self-efficacy. Among patients, Cronbach’s alpha coefficient of internal consistency for individual- and family-related self-efficacy subscales was .962 and .936, respectively. Among caregivers, Cronbach’s alpha coefficient of internal consistency for the individual- and family-related self-efficacy subscales was .949 and .908, respectively.

**Dyadic comorbidity burden.** At baseline, patients and caregivers were asked: “Do you have any health problems (such as heart disease, arthritis, diabetes, etc.) at this time?” Those who answered “yes” to this question were then asked to name their health problems. Patients or caregivers who reported 0-1 health problems were designated as having a *low* number of conditions; those who reported 2 or more health problems were designated as having a *high* number of conditions. Four dyadic comorbidity burden groups were created based on these designations: 1) patient-low/ caregiver-low; 2) patient-high/caregiver-low; 3) patient-low/caregiver-high; and, 4) patient-high/caregiver-high.

**Covariates.** Age, sex, income, patient cancer type, patient treatment (chemotherapy vs. other; hormone therapy vs. other), length of time since patient diagnosis, living arrangements (living together vs. other), and the relationship between patient and caregiver (spouse vs. other) were obtained from patients’ medical records and the Risk for Distress Scale, which was adapted from the original Omega Clinic Screening Interview (Mood & Bickes, 1989; Northouse et al., 2007; Northouse et al., 2013), and were used as covariates. Caregiver burden was also controlled for in the analysis to account for variability in caregiving demands. It was measured using a

summary score from two subscales of the Caregiver Reaction Assessment (CRA), which assesses responses to tasks and problems associated with caregiving (Given et al., 1992), and six additional items added by study researchers (16 items total). The measure has a 5-point response scale ranging from (1) “strongly disagree” to (5) “strongly agree.” Validity of the CRA has been reported (Snyder, 2005).

### **Data Analysis Strategy**

Descriptive analysis was conducted using SPSS version 22 (IBM, 2013). Path analysis with structural equation modeling (SEM) was used to test the study hypotheses and estimate the model parameters separately for the full sample and for each comorbidity burden group, controlling for the covariates, using Amos Graphics version 22 (Arbuckle, 2013). The SEM was based on the Actor Partner Interdependence Model (APIM; Kenny, Kashy, & Cook, 2006; Rayens & Svavarsdottir, 2003). The APIM captures actor effects, partner effects, and the interdependence between members of a dyad. Actor effects refer to the effect that the patient or caregiver has on his or her own outcomes. Partner effects refer to the effect that one individual has on the outcome of the other. In this analysis, the dyad is treated as the unit of analysis in order to account for the interdependence of the data. The dataset was structured in dyadic format so that each dyad was represented as a single case. Standardized solutions using path analysis software are not valid with dyadic data, so the data were manually standardized (Kenny et al., 2006). Missing data were imputed using expectation maximization and maximum likelihood estimation was the estimation method. All models included covariances between predictor variables, and covariances between error terms of patient and caregiver threat appraisals, and efficacy variables.

Critical ratios of differences provided by the Amos pairwise comparison test (z-scores) were used to assess differences between two specific parameters of interest: the influence of threat appraisals on individual-and family-related self-efficacy (hypothesis 3). Mediation effects were tested using the bootstrapping procedure in Amos (hypothesis 4). Moderation effects were tested through multigroup analysis (hypothesis 5). Cross-group invariance was tested in order to determine whether or not the paths (for the model as a whole) were significantly different across the four comorbidity burden groups. This involved comparing a model where all paths were constrained to be invariant across groups (constrained model) and a model without path constraints (unconstrained model). Pairwise comparison tests (z-scores) were used to assess differences between parameters that were significant across individual groups.

Three fit indices were used to determine the adequacy of model fit: the comparative fit index (CFI), the root mean squared error of approximation (RMSEA), and the standardized root-mean-square residual (SRMR). The indicators of adequate model fit for these indices (i.e. the indication that the model fits the sample data well) are a CFI value of .90 or more; a RMSEA value of .08 or less; and, a SRMR value of .08 or less (Hu & Bentler, 1999; Little & Card, 2013).

## **Results**

### **Descriptive Statistics**

**Demographic characteristics.** Patient and caregiver demographic information is presented in Table 3.1. The average age of patients was 60.5 years (SD: 11.5; range: 26-95); caregivers were 56.5 years on average (SD: 13.4; range: 18-88). Most patients (62%) and caregivers (56.8%) were female. Patients were predominantly White (79.3%) and the next largest racial group was African American (15.3%); Asians (1.0%), American Indian/Alaskan Natives (0.2%), Pacific Islanders (0.2%) and individuals who reported multiple races (3.9%) comprised



the rest of the sample. The racial distribution was very similar among caregivers. Patients reported an average of 14.5 years of education (SD: 2.7; range: 7-22) and similarly, caregivers reported an average of 14.6 years (SD: 2.7; range: 7-22). A majority of patients (75.6%) and caregivers (82.9%) were married or living as married. Spousal caregivers were most common (70%) and most caregivers lived with the patient (82.6%).

**Comorbidity burden.** Patients reported an average of 1.82 non-cancer health problems (SD: 1.44; range: 0-5) and caregivers reported an average of 1.48 health problems (SD: 1.35; range: 0-5). There was a significant difference between patient and caregiver number of conditions ( $p < .001$ ). The most commonly reported were hypertension (39.9% patients; 30.0% caregivers), heart problems (30.4% patients; 26.4% caregivers), depression (26.2% patients; 21.9% caregivers), arthritis (18.0% patients; 16.5% caregivers), and diabetes (14.0% patients; 9.3% caregivers). Among patients, 46.3% were designated as having a low comorbidity burden (0-1 conditions) and 53.7% were designated as high (2+ conditions). Among caregivers, 53.9% were designated as low (0-1 conditions) and 46.1% were designated as high (2+ conditions). The percentages of each of the dyadic comorbidity burden groups are as follows: patient-low/caregiver-low, 28.3% (n=137); patient-high/caregiver-low, 25.6% (n=124); patient-low/caregiver-high, 17.8% (n=86); and, patient-high/caregiver-high, 28.3% (n=137).

**Study variables.** Table 3.2 provides the means and standard deviations for symptom distress, threat appraisals, and self-efficacy variables for the total sample and each comorbidity burden group. Significant differences were found between patient and caregiver threat appraisals ( $p < .001$ ) and symptom distress ( $p < .001$ ) in the total sample and across all groups. Significant comorbidity burden group differences were also noted for caregiver symptom distress ( $p < .001$ ), in that caregivers with high levels of comorbidity reported more symptom distress than their low-

comorbidity counterparts. Specifically, caregivers in the patient-low/caregiver-high group reported more symptom distress than caregivers in patient-low/caregiver-low ( $p=.004$ ) and patient-high/caregiver-low ( $p<.001$ ) groups. Similarly, caregivers in the patient-high/caregiver-high group reported more symptom distress than caregivers in patient-low/caregiver-low ( $p<.001$ ) and patient-high/caregiver-low ( $p<.001$ ) groups.

### **Total Sample Analysis**

Standardized results from testing the model with the total sample are presented in Figure 3.2. The model fit was good (CFI=1.00; RMSEA <.000; SRMR=.001).

**H1. Symptoms→threat.** Patient symptom distress was positively associated with patient threat appraisals ( $\beta= .544, p<.001$ ). Caregiver symptom distress was positively associated with caregiver threat appraisals ( $\beta= .196, p<.001$ ). The second part of the hypothesis was partially supported: caregiver symptom distress was positively associated with patient threat appraisals ( $\beta= .094, p<.018$ ).

**H2. Threat → efficacy.** Patient threat appraisals were negatively associated with patient individual-related self-efficacy ( $\beta= -.467, p<.001$ ) and family-related self-efficacy ( $\beta= -.427, p<.001$ ). Caregiver threat appraisals were negatively associated with caregiver individual-related self-efficacy ( $\beta= -.576, p<.001$ ) and caregiver family-related self-efficacy ( $\beta= -.504, p<.001$ ). No partner effects were indicated. Thus, this hypothesis was partially supported.

**H3. Individual vs. family -related self-efficacy.** The strength of the relationship between threat and the two-dimensions of self-efficacy were compared. This hypothesis was partially supported. Among caregivers only, the relationship between threat appraisals and self-efficacy differed based on the dimension of self-efficacy assessed (not shown in Figure 3.2).

There was a significant difference between the influence of caregiver threat appraisals on

caregiver individual-related self-efficacy ( $\beta = -.576$ ) compared to caregiver family-related self-efficacy ( $\beta = -.504$ ); the influence of threat on individual-related self-efficacy was larger ( $z = -3.139, p = .002$ ).

**H4. Direct and indirect effects of symptoms on self-efficacy.** The direct effect of symptom distress on self-efficacy and the indirect effect of symptom distress on self-efficacy (through threat appraisals) were tested; this hypothesis was partially supported. Patient symptom distress had a negative direct effect ( $\beta = -.131, p = .028$ ) and negative indirect effect (through patient threat appraisals) on patient individual-related self-efficacy ( $\beta = -.255, p = .001$ ). Patient symptom distress also had a negative direct effect ( $\beta = -.157, p = .016$ ) and negative indirect effect (through patient threat appraisals) on patient family-related self-efficacy ( $\beta = -.232, p = .001$ ). Patient symptom distress did not have a direct or indirect effect on caregiver self-efficacy.

Caregiver symptom distress had a negative indirect effect (through caregiver threat appraisals) on caregiver individual-related self-efficacy ( $\beta = -.114, p = .003$ ). Caregiver symptom distress also had a positive direct effect ( $\beta = .075, p = .043$ ) and negative indirect effect (through caregiver threat appraisals) on caregiver family-related self-efficacy ( $\beta = -.100, p = .003$ ). In addition, caregiver symptom distress also had an indirect effect (through patient threat appraisals) on patient individual-related self-efficacy ( $\beta = -.045, p = .016$ ) and patient family-related self-efficacy ( $\beta = -.041, p = .016$ ).

### Multiple-Group Analysis

To test Hypothesis 5, cross-group invariance was assessed. Constraining the model parameters to be equal across the four comorbidity burden groups resulted in worse overall model fit ( $\chi^2 = 395.509, df = 312, p = .001$ ). Thus, the null hypothesis that the paths were the same across the comorbidity burden groups was rejected. The unconstrained model fit the data well

(CFI=.998; RMSEA=.039; SRMR=.003). Figures 3.3-3.6 present the model results for each comorbidity burden group. Below, multigroup analysis results are presented, highlighting where the model results a) aligned or differed from total group results and b) aligned or differed between comorbidity burden groups.

**H1. Symptoms→threat.** Similar to the total group analysis, patient and caregiver symptom distress was positively associated with their own threat appraisals (actor effects). The magnitude of this relationship differed across some groups. Among patients and caregivers, this effect was larger in the patient-low/caregiver-low group compared to the patient-high/caregiver-high group (patients:  $z=-2.022$ ,  $p=.043$ ; caregivers:  $z=2.354$ ,  $p=.019$ ). In addition, among caregivers, this effect was larger in the patient-high/caregiver-low ( $z=-4.358$ ,  $p<.001$ ) and patient-low/caregiver-high groups ( $z=-3.439$ ,  $p<.001$ ) compared to the patient-high/caregiver-high groups.

The partner effect of caregiver symptom distress on patient threat appraisals observed in the total group was only observed in the patient-low/caregiver-low group ( $\beta=.283$ ,  $p=.020$ ).

**H2. Threat → efficacy.** In line with total group results, patient and caregiver threat appraisals were negatively associated with their own individual- and family-related self-efficacy (actor effects). The magnitude of the actor effects was similar across all the comorbidity burden groups. For example, the influence of patient threat on patient individual-related self-efficacy was similar across all groups.

**H3. Individual- vs. family-related efficacy.** While in the total group, the influence of *patient* threat on the two dimensions of self-efficacy was similar, a significant difference was seen in the patient-high/caregiver-high group ( $z=-2.507$ ,  $p=.012$ ), with threat associated significantly more with individual self-efficacy than family self-efficacy. In addition, while a

difference between the two dimensions was among in caregivers in the total group, it was only observed in the patient-high/caregiver-low group ( $z = -2.859, p = .010$ ). In both cases, caregiver threat was associated with significantly more individual self-efficacy than family self-efficacy.

**H4. Direct and indirect effects of symptoms on efficacy.** The direct effect of symptom distress on self-efficacy observed in the total group was not observed in all comorbidity burden subgroups. The negative direct effect of patient symptom distress on patient individual-related self-efficacy was only observed in the patient-low/caregiver-high ( $\beta = -.345, p = .023$ ) and patient-high/caregiver-high groups ( $\beta = -.245, p = .026$ ); the magnitude of these effects were similar ( $p > .05$ ). The direct effect of patient symptom distress on patient family-related self-efficacy was only seen in the patient-high/caregiver-high group ( $\beta = -.329, p = .004$ ).

Among caregivers, the direct effect of caregiver symptom distress on caregiver individual-related self-efficacy (marginal in the total group analysis) was significant in the patient-high/caregiver-low group ( $\beta = .387, p = .002$ ). Lastly, the direct effect of caregiver symptom distress on caregiver family-related self-efficacy observed in the total sample was only significant in the patient-high/caregiver-low group ( $\beta = .340, p = .009$ ).

Similar to the total group, all of indirect actor effects were significant. In all of the comorbidity burden groups, patient and caregiver symptom distress had a negative indirect effect (through their own threat appraisals) on both dimensions of their self-efficacy ( $p < .05$ ). Also similar to the total group results, patient symptom distress did not have a direct or indirect effect on caregiver self-efficacy in any of the sub-groups. The negative indirect effects of caregiver symptom distress on patient individual-and family-related self-efficacy (through patient threat appraisals) was only observed in the patient-low/caregiver-low and patient-high/caregiver low groups ( $p < .05$ ).

## **Influence of Covariates**

Caregiver burden was consistently associated with higher caregiver threat appraisals and lower caregiver family-related self-efficacy. Though not consistent across all groups, patient and caregiver gender, their age, patient treatment, months since diagnosis, living arrangements and income were significantly associated with the threat and efficacy.

## **Summary of Results**

Table 3.3 provides a summary of the study findings. There were several findings that were similar across all models tested. First, more patient symptom distress was associated with higher patient threat appraisals. Similarly, more caregiver symptom distress was associated with higher caregiver threat appraisals. The magnitude of this effect, however, differed between some of the comorbidity subgroups. Second, higher patient threat appraisals were associated with decreases in both dimensions of self-efficacy among patients. This was also true for caregivers. Third, the threat appraisals of one dyad member did not influence the self-efficacy of the other in any of the models tested. Fourth, patient and caregiver symptom distress had an indirect effect on their self-efficacy (both dimensions) through their own threat appraisals.

There were also several findings that differed across groups. First, in the total sample and groups where caregiver comorbidity burden was low, more caregiver symptom distress was associated with higher patient threat appraisals. This partner effect was not observed in the other groups. Second, patient symptom distress was associated with higher caregiver threat appraisals in the total sample and patient-low/caregiver-low group. Thus, in the patient-low/caregiver low group, patient symptom distress influenced caregiver threat and caregiver symptom distress influenced patient threat. Third, where direct effects of symptom distress on patient self-efficacy were observed, results aligned with the study hypothesis and more symptom distress was

associated with lower self-efficacy. Unexpectedly, where direct effects of more caregiver symptom distress on efficacy were observed, higher symptom distress was associated with higher caregiver individual-related and family-related self-efficacy (total sample and patient-high/caregiver-low group). Fourth, the influence of threat on the two dimensions of efficacy was not consistent across groups; but where differences were observed, threat had a stronger influence on individual-related self-efficacy. Lastly, caregiver symptom distress had an indirect influence on patient individual- and family-related efficacy in the total sample and groups where caregiver comorbidity burden was low. Patient symptom distress did not have an indirect effect on caregiver self-efficacy in any of the groups.

### **Discussion**

The purpose of this study was to examine the influence of co-occurring health problems of patients with advanced cancer and their family caregivers (symptom distress, patient comorbidities, and caregiver chronic conditions) on their cancer/caregiving related threat appraisals and their individual- and family-related self-efficacy for coping with cancer/caregiving. Specifically, dyadic comorbidity burden was tested as a moderator of the relationship between patient/caregiver symptom distress (predictors), threat appraisals (mediators), and self-efficacy (outcomes). Actor and partner effects were also tested. Dyadic comorbidity burden was conceptualized as the combination of patient and caregiver individual comorbidity burden: low/low, high/low, low/high, and high/high. This is the first known study to conceptualize patient comorbidities and caregiver chronic conditions in this manner. A benefit of this approach is the ability to consider how the shared comorbidity experience of patients and caregivers – as a unit – influences hypothesized relationships.

Across all groups, more symptom distress among patients and caregivers – which included symptoms related to cancer and non-cancer health problems - was associated with their own higher threat appraisals (actor effects). This supports the hypothesis that patient and caregiver appraisal of the significance of advanced cancer for their wellbeing will be influenced by their co-occurring health concerns. As Tishelman and colleagues (1991) describe, symptom distress can be considered a physical and psychological experience. Physically, the effects of the symptoms themselves could influence how threatening patients and caregivers appraise the cancer/caregiving situation. Psychologically, the meanings the symptoms have for an individual also have importance. For example, patients' experience of symptoms could be perceived as turning points in their health status (Windell, Norman, Lal, & Malla, 2014) or reminders of their current and future dependency on others (Oechsle, Wais, Vehling, Bokemeyer, & Mehnert, 2014). Caregivers' experience of symptoms could be perceived as a consequence of providing care and a reminder of their own care needs (Northouse, Williams, Given, & McCorkle, 2012; Skalla, Smith, Li, & Gates, 2013).

Interestingly, the magnitude of the symptom-threat actor effect differed across comorbidity burden groups. The effect was the weakest in the patient-high/caregiver-high group. One possible explanation could be differences in the level of chronic disease and symptom management experience of the dyad members. For example, where at least one dyad member has a low level of comorbidity burden, he/she may also lack disease and symptom management experience. In these cases, caregivers' symptoms may have a bigger effect on their cancer-related threat appraisals because they feel underprepared for their role (patient-low/caregiver-low and patient-high/caregiver-low group) or feel worried about managing their own health where the patient depends more heavily on them to know what to do (patient-low/caregiver-high



group). Conversely, caregivers in the patient-high/caregiver-high group may benefit from the experience that both dyad members have managing symptoms and chronic conditions, and consequently, their own symptoms may be less influential on their cancer-related appraisals. This interpretation of these findings is supported by past research which has found that caregivers who feel more prepared for their role report lower levels of anxiety (Henriksson & Årestedt, 2013), and burden (Scherbring, 2002); however, more research in this area is needed.

Another important finding of this study is the presence (and absence) of partner effects when examining the influence of symptom distress on threat appraisals. More caregiver symptom distress was associated with higher patient threat appraisals in the total sample. In the multigroup analysis, however, these direct effects were significant only where patient and caregiver comorbidity burden was low (i.e. patient-low/caregiver-low group). In addition, the patient-low/caregiver-low group was the only group where both patient and caregiver partner effects of symptom distress on threat appraisals were observed. These findings could be a reflection of experience with disease management. That is, a dyad member may be more affected by the symptoms of the other where low levels of comorbidity burden exist. Another explanation for this finding could be related to the concept of salience (Taylor & Fiske, 1978). Specifically, the health symptoms of one member of the dyad may be more salient to the other, and exert greater influence on threat appraisals, where few other health problems currently or have previously existed. This interpretation is supported by the *lack* of partner effects, in the patient-high/caregiver-high group, where we might expect health issues to be more commonplace for dyad members.

In all groups, patient and caregiver threat appraisals helped to explain the relationship between their own symptom distress and self-efficacy for coping with cancer. Partner mediation

effects, however, were less consistent. These effects were seen in the total sample and groups where caregiver comorbidity burden was low. In those cases, caregivers' symptom distress indirectly affected the self-efficacy of patients to cope with the disease. This suggests that the management of patient *and* caregiver symptoms may benefit patients' self-efficacy to cope with the disease. While a number of studies have reported how various domains of self-efficacy (e.g. general, symptom management, caregiving self-efficacy) predict symptom-related outcomes, this study contributes to the literature by demonstrating that cancer and non-cancer related symptoms are an important predictors of cancer/caregiving related self-efficacy and identifies threat appraisals as an important underlying mechanism. Increasing patient and caregiver self-efficacy is a common focus in cancer interventions. These findings suggest that attention to patient and caregiver symptom distress could positively influence self-efficacy related intervention outcomes.

Surprisingly, none of the findings suggested that the threat appraisals of one dyad member influenced the efficacy of the other. It may be that patient-caregiver communication - which could explain how threat appraisals are made known between dyad members - may also need to be considered in order to observe this type of effect. Furthermore, evidence suggests that within the context of illness and caregiving, appraisals may change over time (Lazarus & Folkman, 1984; Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008). It is possible that partner effects might be seen in longitudinal assessments. Future research in this area is warranted.

A novel contribution of this study is the assessment of family-related self-efficacy (patient or caregiver confidence in their ability to help their family cope with the illness) in addition to individual-related self-efficacy (confidence in their own ability to cope). Consistently, more threatening patient and caregiver appraisals of the cancer/caregiving situation

were associated with less perceived ability to cope with illness-related challenges – and this was true for both self-efficacy dimensions. Given the seriousness and complexity of the advanced cancer/caregiving situation, it may be surprising to consider how patients and caregivers are helping others cope with the illness. Evidence shows, however, that cancer has a significant impact on the entire family system and despite their own needs, patients and caregivers provide support to others (Ashing-Giwa et al., 2004; Hagedoorn et al., 2008; Segrin et al., 2007). I found that their self-efficacy to do so was influenced by their physical health. While much of the cancer literature has focused on how social support *from* family members influence patient and caregiver outcomes (Given et al., 2001; Lin & Bauer-Wu, 2003), more research is needed on how giving social support *to* family members affects patients and caregivers. Though the consequences of giving social support may be positive and negative (Burg & Seeman, 1994; Uchino, 2006), it is important to note that providing social support may fulfill patients' and caregivers' desire to maintain valued familial roles and give meaning to their lives (Patterson, 2002).

Theory and research on self-efficacy often focuses on individual efforts (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011). Similarly, research on adults with advanced cancer and caregivers often conceptualize the “family” as represented by these two individuals. In reality, as noted by Bandura and colleagues (2011), the dyad “is but one of the multiple interdependent subsystems operating within a family system.” Factors associated with family systems – including interdependence, support, alliances, and resources – likely influence an individual's own self-efficacy in various domains (Bandura, 2000; Bandura et al., 2011). As such, we would expect that aspects of the dyad and the broader family system would influence the degree of individual- and family-related self-efficacy reported by patients and caregivers in

this study. This should be considered explicitly in future research. In addition, future studies may benefit from understanding the relationship between patient, caregiver and broader family members' individual self-efficacy and their collective family efficacy for coping with the disease, caregiving, and its consequences. Very little research has been done in this area (Bandura et al., 2011). Understanding these different types of efficacy will likely be useful to interventions focused on self- and family management of cancer and chronic conditions (Grey, Knafl, & McCorkle, 2006).

### **Limitations**

There are number of study limitations. First, patients were asked to report about their cancer and non-cancer related symptoms. It could be useful to try to determine if patients' beliefs about the cause of the symptoms (i.e. cancer related or non-cancer related) influence their appraisal and self-efficacy. One of the challenges in collecting this information, however, is that it can often be difficult for individuals to determine a cause for symptoms where multimorbidity exists. Another limitation of this study is that information about the severity of chronic conditions was not collected. Whether an individual was managing severe heart disease (alone) or well-controlled hypertension (alone) they would have been designated as "low" for the comorbidity classification. Future research should also consider the severity of patient and caregiver chronic conditions when considering the influence of their co-occurring health problems. In addition, the study cut point of two conditions for the classification of "high" in the comorbidity group was chosen in order to represent multimorbidity independent of cancer; however, the study results may have differed if individuals with 1 or more conditions were classified as "high" or if cancer was also considered in the determination of patient number of conditions. Lastly, it is important to remember that this is a cross-sectional study. Longitudinal

analysis could help to determine the causal ordering of the symptom and appraisal relationship, and highlight key points of transition and need throughout the trajectory of the advanced cancer and end-of-life experience.

## **Conclusions**

One of the novel contributions of this study is the examination of how the relationship between symptoms and cognitive appraisals vary by dyadic comorbidity burden. Conducting the analysis for the entire patient and caregiver sample without attention to these groupings would have masked important differences between dyads based on their comorbidity burden. Future research should attempt to replicate these findings and consider how patient and caregiver comorbidities – as a unit – influences their health-related outcomes and whether dyadic comorbidity burden moderates the relationships between other biopsychosocial factors.

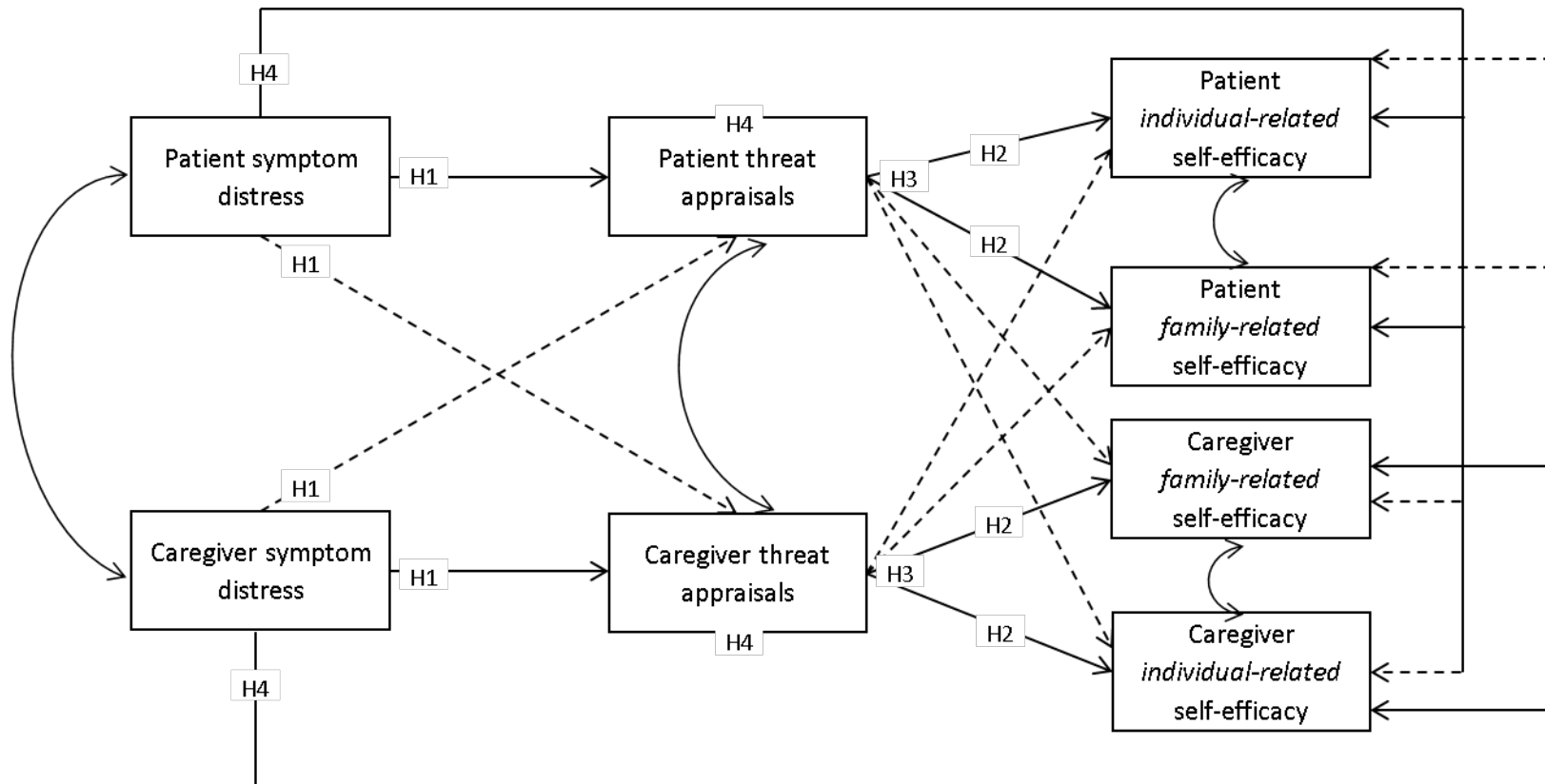
There are a number of successful interventions for improving symptom management for patients. This study also lends support to the idea that the management of caregivers' symptoms is a worthwhile intervention goal as well. While caregiver assessment tools often take caregiver health into account, the use of caregiver assessment tools in practice is not consistent. Increased usage of caregiver assessments may be helpful for identifying where the need for intervention and resources may exist.

Individual- and family-related self-efficacy were influenced by patient and caregiver symptom distress and threat appraisals. The focus on family-related self-efficacy to cope with cancer is a key contribution of this study as previous research has often focused on this concept for individuals or dyad members only (how they help each other cope). The extent to which patients and caregivers are providing social support by helping other family members cope with the illness is a worthwhile area of future research. In addition, though not always reflected in

research literature, for many families, caregiving is a shared task. Though often one individual takes on a primary caregiving role, others may share in caregiving tasks. It could be that reciprocity in social support is even more valued where these types of care teams exist. Differences in family structure (e.g. size, number of children, patient and caregiver roles) could influence family-related efficacy and is also an important area of future research.

Many patients with advanced cancer and their family caregivers also have co-occurring health conditions. In this study, almost 75% of dyads had one member who was managing two or more chronic conditions – in addition to the advanced cancer. A major finding of this study is that patient and caregiver chronic conditions and symptom distress influenced their cognitive appraisals and self-efficacy. Given the noted importance of appraisals and self-efficacy in the stress and coping process, future research and intervention should take into account how the health concerns of both members of the dyad influence their wellbeing and other health-related outcomes.

**Figure 3.1. Model Testing the Influence of Patient and Caregiver Symptom Distress on Threat Appraisals and Efficacy**



*Note:* Independent effects (i.e. actor effects) are represented by solid lines. Interdependent effects (i.e. partner effects) are represented by dashed lines. Error covariances are represented by curved double-headed arrows. The hypotheses relevant to each path in the diagram have been noted (i.e. H1a refers to Hypotheses 1a). Hypothesis 5 – testing this model on dyadic comorbidity burden groups – is not represented in the model.

Table 3.1. Patient and Caregiver Demographic Information at Baseline

	Patients (N=484)	Caregivers (N=484)	Difference Tests <sup>a</sup>
Age in years			
Mean (SD)	60.5 (11.5)	56.5 (13.4)	*
Range	26-95	18-88	
Sex (%)			
Female	62.0	56.8	NS
Male	38.0	43.1	
Race (%)			
American Indian/Alaskan Native	0.2	0	NS
Asian	1.0	1.2	
Black	15.3	15.9	
Pacific Islander	0.2	0	
White	79.3	79.6	
Multiracial	3.9	2.5	
Highest level of education in years			
Mean (SD)	14.5 (2.7)	14.6 (2.8)	NS
Marital Status (%)			
Married/Living as married	75.6	82.9	*
Divorced/Separated	13.2	8.1	
Widowed	6.0	2.3	
Never married	5.2	6.8	
Relationship to patient (%; caregiver only)			
Spouse	--	70.0	--
Daughter	--	12.0	
Son	--	3.3	
Sister/Brother	--	0.2	
Other relative	--	5.6	
Friend	--	4.3	
Unknown/Coding error	--	4.5	
Currently living with patient (caregiver only)			
% Yes	--	82.6	--

<sup>a</sup>Paired sample t-tests, McNemar's Test, or Wilcoxon Signed-Rank Test. \* $p < .05$ ; NS: not significant.



Table 3.2. Patient and Caregiver Means and Standard Deviations for Main Study Variables by Total Sample and Comorbidity Burden group

Measure	Total Sample (N=484)				PT-Low/CG-Low (n=137)				PT-High/CG-Low (n=124)				PT-Low/CG-High (n=86)				PT-High/CG-High (n=137)			
	PT		CG		PT		CG		PT		CG		PT		CG		PT		CG	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Symptom Distress <sup>a, b</sup>	10.25	4.65	6.18	6.23	9.79	4.68	<b>5.11</b>	4.01	10.58	4.78	<b>4.94</b>	4.22	10.08	4.42	<b>6.99</b>	4.24	10.51	4.63	<b>7.88</b>	9.42
Threat Appraisals <sup>c</sup>	35.90	9.13	30.98	8.53	35.46	9.89	30.64	8.34	35.67	9.53	30.24	8.69	35.82	8.51	31.60	8.49	36.60	8.36	31.59	8.62
Individual-Related SE	85.85	19.20	85.49	18.21	86.78	19.71	84.07	18.50	86.85	17.86	85.71	17.72	85.83	19.75	87.56	17.85	84.02	19.57	85.40	18.64
Family-Related SE	31.04	7.94	31.72	6.90	31.12	8.23	31.73	6.73	31.08	7.84	31.40	7.04	31.19	8.17	32.56	6.57	30.83	7.65	31.48	7.16

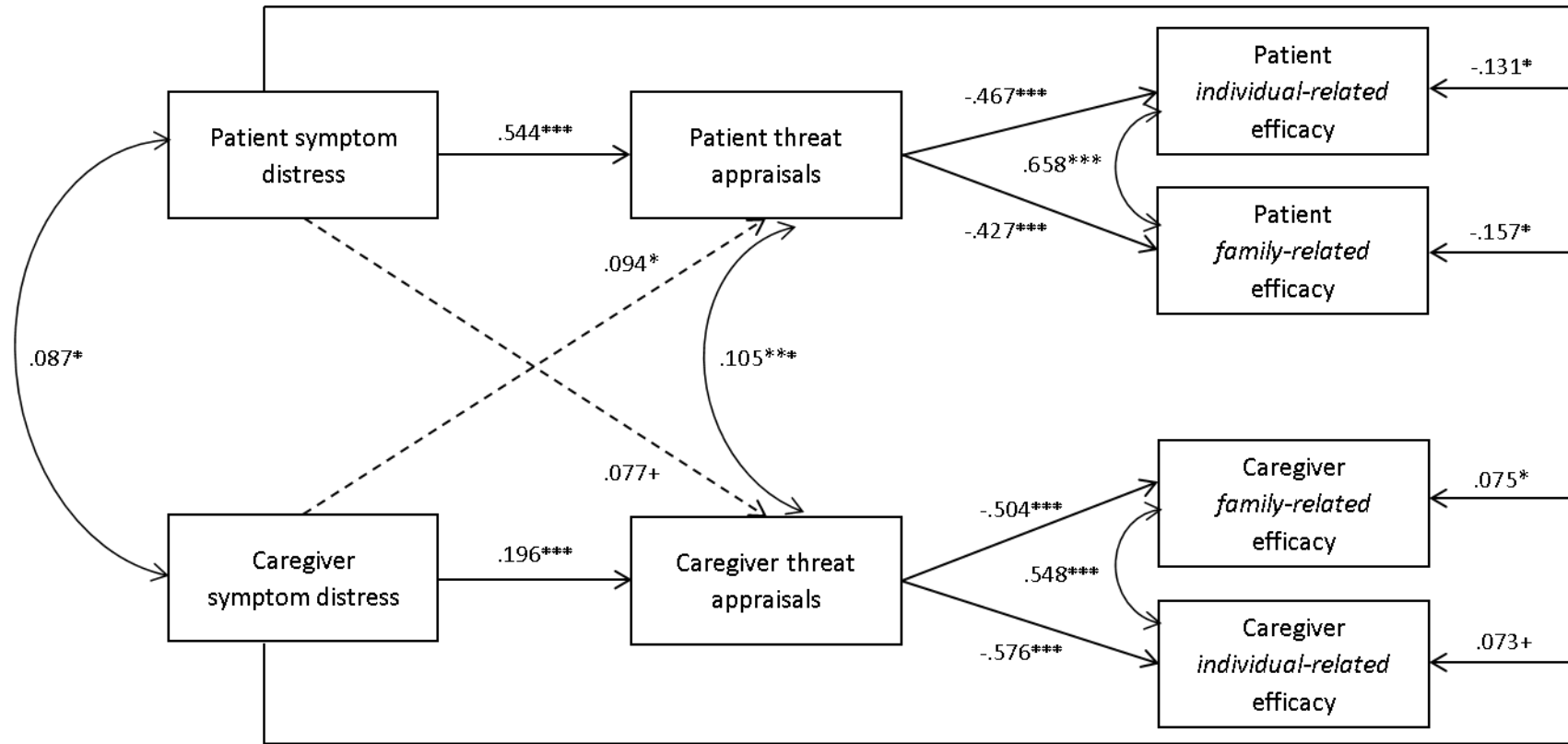
Note: PT=patient; CG=caregiver; M=mean; SD=standard deviation; SE=self-efficacy.

<sup>a</sup>Paired t-tests: There was a significant difference between patient and caregiver symptom distress ( $p < .001$ ) in the total sample and across all groups (darker shading).

<sup>b</sup>Kruskall-Wallis test: Caregiver symptom distress (boldface) differed by comorbidity burden group ( $F=7.150, p < .001$ ). Caregivers in the patient-low/caregiver-high and patient-high/caregiver-high groups had significantly higher symptom distress than caregivers in the patient-low/caregiver-low and patient-high/caregiver-low groups.

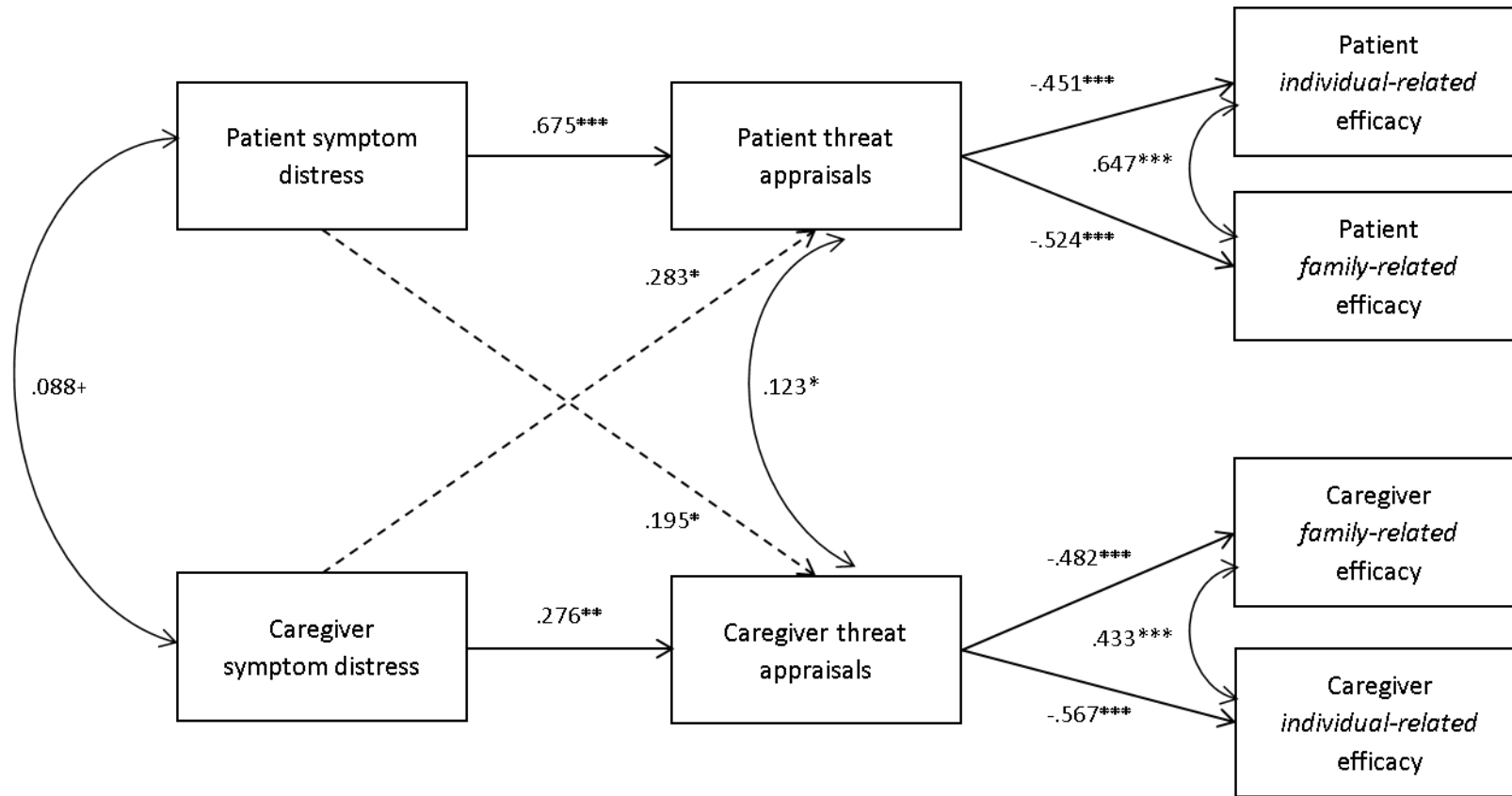
<sup>c</sup>Paired t-tests: There was a significant difference between patient and caregiver threat appraisals ( $p < .001$ ) in the total sample and across all groups (lighter shading).

Figure 3.2. Total Sample Analysis



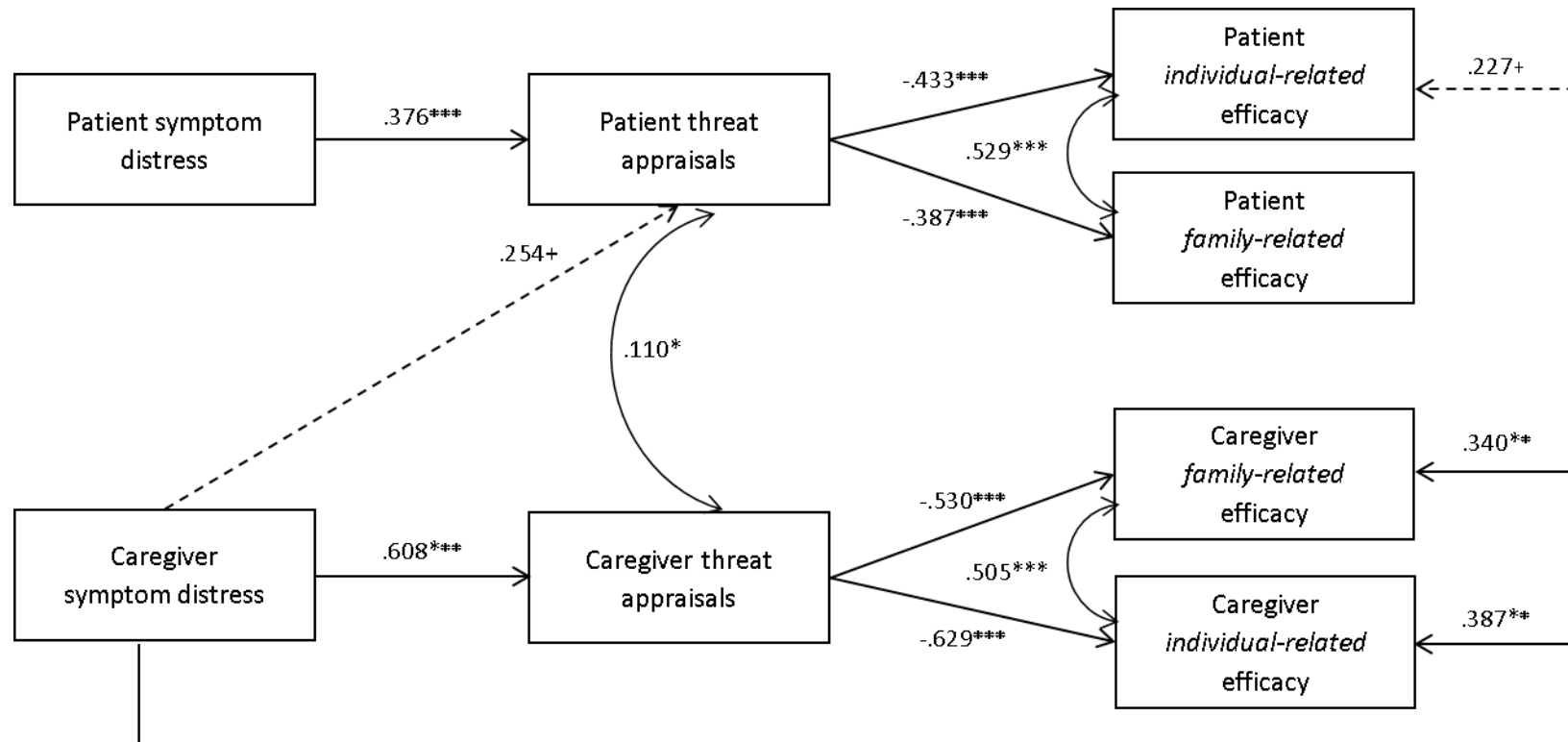
Note: Estimates are standardized; only significant parameter estimates are reported. Independent effects (i.e. actor effects) are represented by solid lines; interdependent effects (i.e. partner effects) are represented by dashed lines; error covariances are represented by curved double-headed arrows. Model covariates were age, sex, income, patient cancer type, patient treatment, length of time since patient diagnosis, patient and caregiver relationship type, living arrangements, and caregiver burden. + $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

Figure 3.3. Patient-Low/Caregiver-Low Group



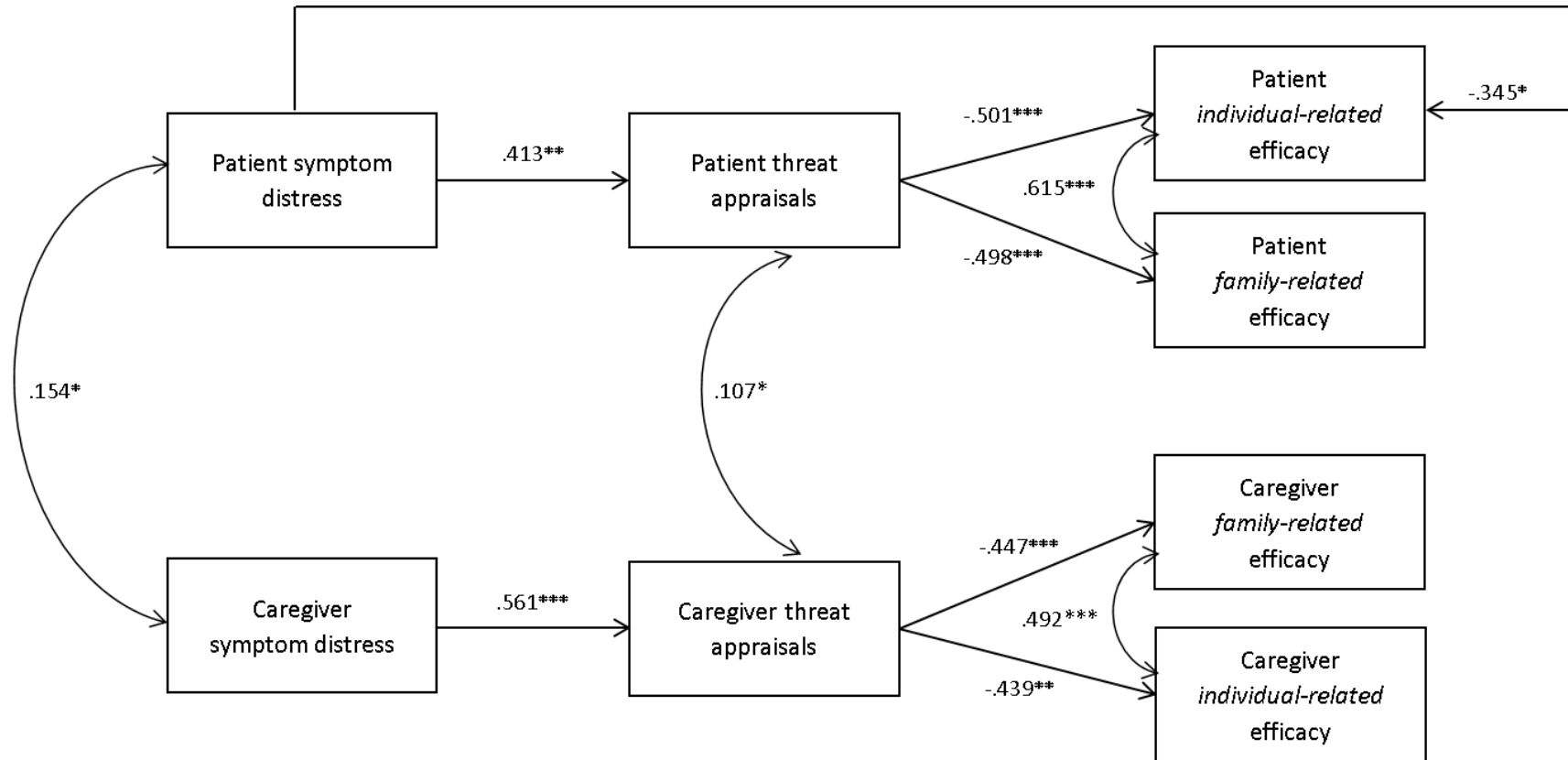
Note: Estimates are standardized; only significant parameter estimates are reported. Independent effects (i.e. actor effects) are represented by solid lines; interdependent effects (i.e. partner effects) are represented by dashed lines; error covariances are represented by curved double-headed arrows. Model covariates were age, sex, income, patient cancer type, patient treatment, length of time since patient diagnosis, patient and caregiver relationship type, living arrangements, and caregiver burden. + $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

Figure 3.4. Patient-High/Caregiver-Low Group



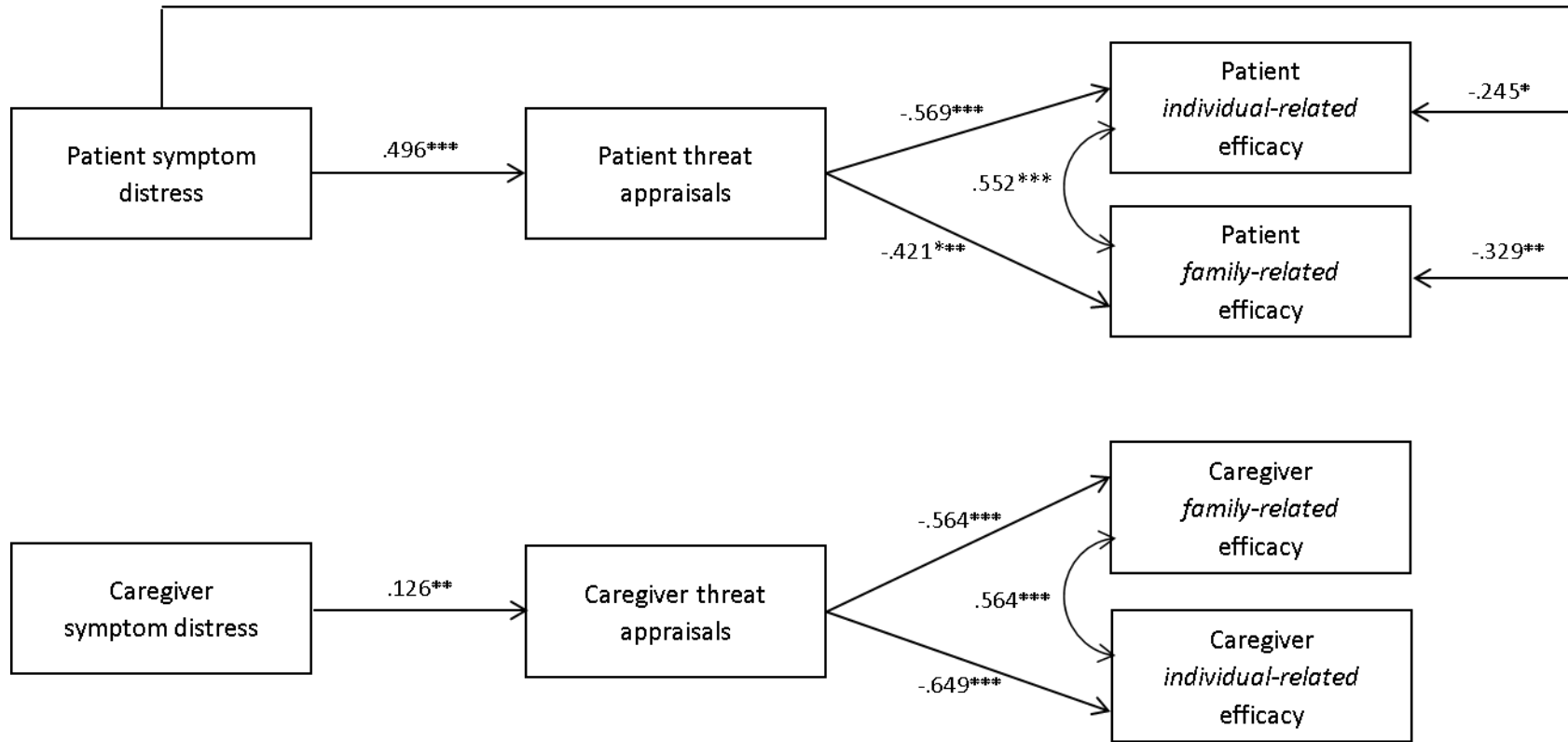
*Note:* Estimates are standardized; only significant parameter estimates are reported. Independent effects (i.e. actor effects) are represented by solid lines; interdependent effects (i.e. partner effects) are represented by dashed lines; error covariances are represented by curved double-headed arrows. Model covariates were age, sex, income, patient cancer type, patient treatment, length of time since patient diagnosis, patient and caregiver relationship type, living arrangements, and caregiver burden. + $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

Figure 3.5. Patient-Low/Caregiver-High Group



Note: Estimates are standardized; only significant parameter estimates are reported. Independent effects (i.e. actor effects) are represented by solid lines; interdependent effects (i.e. partner effects) are represented by dashed lines; error covariances are represented by curved double-headed arrows. Model covariates were age, sex, income, patient cancer type, patient treatment, length of time since patient diagnosis, patient and caregiver relationship type, living arrangements, and caregiver burden. + $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

Figure 3.6. Patient-High/Caregiver-High Group



Note: Estimates are standardized; only significant parameter estimates are reported. Independent effects (i.e. actor effects) are represented by solid lines; interdependent effects (i.e. partner effects) are represented by dashed lines; error covariances are represented by curved double-headed arrows. Model covariates were age, sex, income, patient cancer type, patient treatment, length of time since patient diagnosis, patient and caregiver relationship type, living arrangements, and caregiver burden. + $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$

Table 3.3. Summary of Results – All Models

	Total Sample	PT-Low/ CG-Low	PT-High/ CG-Low	PT-Low/ CG-High	PT-High/ CG-High
<b>Hypothesis 1</b>					
PT Symptom → PT Threat	↑	↑	↑	↑	↑
CG Symptom → CG Threat	↑	↑	↑	↑	↑
PT Symptom → CG Threat	↑ <sup>m</sup>	↑			
CG Symptom → PT Threat	↑	↑	↑ <sup>m</sup>		
<b>Hypothesis 2</b>					
PT Threat → PT Individual SE	↓	↓	↓	↓	↓
PT Threat → PT Family SE	↓	↓	↓	↓	↓
CG Threat → CG Individual SE	↓	↓	↓	↓	↓
CG Threat → CG Family SE	↓	↓	↓	↓	↓
PT Threat → CG Individual SE					
CG Threat → PT Individual SE					
PT Threat → CG Family SE					
CG Threat → PT Family SE					
<b>Hypothesis 3</b>					
PT Threat → PT Individual SE vs PT Family SE					↑
CG Threat → CG Individual SE vs CG Family SE	↑			↑	
<b>Hypothesis 4</b>					
PT Symptom → PT Individual SE	↓			↓	↓
PT Symptom → PT Family SE	↓				↓
CG Symptom → CG Individual SE	↑ <sup>m</sup>		↑		
CG Symptom → CG Family SE	↑		↑		
PT Symptom → CG Individual SE					
PT Symptom → CG Family SE					
CG Symptom → PT Individual SE			↑ <sup>m</sup>		
CG Symptom → PT Family SE					
PT Symptom → PT Threat → PT Individual SE	↓	↓	↓	↓	↓
PT Symptom → PT Threat → PT Family SE	↓	↓	↓	↓	↓
CG Symptom → CG Threat → CG Individual SE	↓	↓	↓	↓	↓
CG Symptom → CG Threat → CG Family SE	↓	↓	↓	↓	↓
PT Symptom → CG Threat → CG Individual SE					
PT Symptom → CG Threat → CG Family SE					
CG Symptom → PT Threat → PT Individual SE	↓	↓	↓		
CG Symptom → PT Threat → PT Family SE	↓	↓	↓		

Note: PT=Patient; CG=Caregiver; SE=Self-Efficacy. ↑ represents positive effects and ↓ represents negative effects ( $p<.05$ ); superscript m denotes marginal effects ( $.05<p<.10$ ).

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## CHAPTER IV

### **The Mediating and Moderating Role of Meaning-Based Coping on the Relationship Between Chronic Conditions and Quality of Life Among Patients with Advanced Cancer and Their Caregivers**

Quality of life among individuals with advanced cancer is a multidimensional representation of their wellbeing, useful for evaluating the biopsychosocial impact of illness from their own perspective (Revicki et al., 2000). Symptoms related to their treatment and disease progression (Given, Given, & Kozachik, 2001) such as pain (Martinez et al., 2014; Walsh, Donnelly, & Rybicki, 2000) and fatigue (Barnes & Bruera, 2002; Stone, Hardy, Broadley, Kurowska, & A'Hern, 1999), as well as the psychological burden of a limited life expectancy (El-Jawahri et al., 2014; Maltoni & Amadori, 2002) are just a few factors that may negatively influence their quality of life. Family members and friends are often their most important source of support. At advanced stages the disease, however, the work of these caregivers may be particularly complex and burdensome (Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2007). Caregiver quality of life is a valuable measure of the multifaceted impact of providing care on various dimensions of wellbeing, heavily influenced by a patient's physical and emotional needs (Wadhwa et al., 2013). Common tasks associated with caring for someone with advanced cancer (hereinafter also referred to as patients) include symptom management, assistance with daily activities, and emotional support (Given et al., 2001). Compared to

caregivers of patients whose treatment goals are curative, advanced cancer caregivers have reported lower quality of life (Weitzner, McMillan & Jacobsen, 1999).

Unfortunately, advanced cancer is not the only health problem that patients and caregivers face that can influence their quality of life: many patients and caregivers are also managing chronic conditions. A study of cancer caregivers found that at the time of cancer diagnosis, 36% of patients were already receiving assistance for pre-existing illnesses and 35% of the caregivers in the study were managing serious illnesses of their own (Thomas, Morris & Harman, 2002). Despite these challenges, patient's and caregiver's ability to find positive meaning in their experience could help mitigate the negative effects of the health problems on their quality of life (Park, 1997). There is a noticeable lack of literature, however, exploring this relationship. The purpose of this study is to examine the mediating and moderating role of meaning-based coping on the relationship between pre-existing health problems (patient comorbidities and caregiver chronic conditions) and quality of life among patients with advanced cancer and their caregivers.

### **Cancer & Comorbidity**

Across most cancer types, the existence of comorbid chronic conditions is common. Compared to the general population, people with cancer often report similar or higher prevalence chronic health conditions (Hewitt, Rowland, & Yancik, 2003; Koroukian, Murray, & Madigan, 2006; Ogle, Swanson, Woods, & Azzouz, 2000; Smith et al., 2008; Edwards et al., 2014). A number of biological, psychosocial, and behavioral mechanisms have been identified as contributors to the higher prevalence rates of comorbidities among people with cancer (NCI, 2014; Ogle et al., 2000). Biologically, similarities in processes that lead to the development of chronic diseases and cancers, aging, as well as cancer treatments that contribute to the

development of chronic conditions, could help explain these associations (NCI, 2014; Ogle et al., 2000; Rowland & Yancik, 2006). Psychosocially, factors such as depression and perceived social isolation could influence chronic disease risk and physiological functioning through excessive reactions to stress and the resulting negative effects on immune function (Cacioppo & Hawkley, 2003; Hawkley & Cacioppo, 2003; NCI, 2014; Reiche, Nunes, & Morimoto, 2004). Tobacco use, lack of physical activity, and a poor diet are examples of behavioral risk factors that have been identified for cancer and many chronic diseases (Ogle et al., 2000). These relationships support research that takes both cancer and comorbidity into consideration (NCI, 2014).

The presence of comorbidities among individuals with cancer or a history of cancer has been associated with their morbidity and mortality. Patient comorbidities complicate symptom attribution and increase disease burden (Dowling et al., 2013; Mao et al., 2007; Fortin et al., 2004; Vogeli et al., 2007) and contribute to poorer cancer prognosis (Extermann, 2007; Piccirillo, Tierney, Costas, Grove, & Spitznagel Jr, 2004) and higher mortality rates (Daskivich et al., 2011; Klabunde, Legler, Warren, Baldwin, & Schrag, 2007; Patnaik, Byers, DiGuseppi, Denberg, & Dabelea, 2011). Furthermore, when patients are managing multiple comorbidities, they are susceptible to the consequences of each condition, separately, as well as the effects of having a number of comorbidities simultaneously (Vogeli et al., 2007). These findings suggest that managing multiple chronic conditions, in addition to cancer, has important implications for patient health; but the extent of this influence on quality of life in the context of advanced cancer is not understood.

### **Caregiver Chronic Conditions**

The health and quality of life of the caregivers of patients with advanced cancer are also of concern. Across many disease types, studies have shown that caregivers often have worse

health outcomes than non-caregivers (Schulz & Beach, 1999). In particular, caregivers who provide more intense support, which often occurs with advanced disease, fare worse than their counterparts with less demanding responsibilities (Talley & Crews, 2007; Weitzner, McMillan, & Jacobsen, 1999). Various factors such as caregiver mental health, perceived burden, patient needs and symptom distress have been identified as key predictors of cancer caregiver quality of life at advanced stages of disease (Kim & Given, 2008; Wadhwa et al., 2013); but less is known about how cancer caregivers' own chronic conditions influence their wellbeing (Given et al., 2004; Grunfeld et al., 2004). Given the significant prevalence of chronic conditions in the general population (Ward et al., 2014), increase age as a significant risk factor for chronic conditions (Rowland & Yancik, 2006), and the fact that cancer caregivers tend to be older (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013), it is very likely that caregivers will be managing chronic conditions of their own. Furthermore, evidence suggests that caregivers providing help with activities and tasks, as is often found with advanced cancer caregivers (Thomas, Morris & Harman, 2002), are less likely than non-caregivers to engage in self-care behaviors (Burton, Newsom, Schulz, Hirsch, & German, 1997) which could exacerbate their management of chronic health conditions and consequently, their quality of life.

### **Meaning-Based Coping**

Despite these challenges, patients and caregivers often find ways to thrive. The transactional model of stress and coping identifies meaning-based coping as the positive reappraisal and reinterpretation of a stressor (Wenzel, Glanz, & Lerman, 2002). Patients with cancer who identify benefits or meaning in their illness (Mellon, Northouse, & Weiss, 2006; Lethborg, Aranda, Bloch, & Kissane, 2006) or view it as an experience that can lead to personal growth may experience better quality of life (Franks & Roesch, 2006). The ability of family



caregivers to find positive meaning in their caregiving experience is also associated with improved outcomes, such as fewer depressive symptoms, lower perceived burden and better self-rated health and quality of life (Cohen, Colantonio, & Vernich, 2002; Kim, Baker, & Spillers, 2007; Kramer, 1997). Where both patient and caregivers identify positive aspects of the illness experience and meaning for the challenges they face (i.e. stress of advanced cancer, caregiving and other health concerns), the wellbeing of the patient-caregiver dyad may be enhanced (Kim, Schulz, & Carver, 2007; Kramer, 1997). Less is known, however, regarding how one dyad member's meaning-based coping influences health-related outcomes, such as quality of life, of the other dyad member.

While patient and caregiver chronic health problems may be an additional source of stress (Checton, Magsamen-Conrad, Venetis, & Greene, 2014), stress and coping theory suggests that meaning-based coping may moderate the relationship between pre-existing chronic conditions and quality of life. For example, where a negative relationship between pre-existing chronic conditions and quality of life exists, this effect could be *attenuated* in individuals who engage in more meaning-based coping. It is also possible, however, that meaning-based coping could mediate the relationship between chronic conditions and quality of life. As a mediating variable, meaning-based coping would help explain *why* pre-existing chronic conditions influence quality of life. Mediators and moderators are both useful for understanding and intervening on health issues (Judd, Kenny, & McClelland, 2001) including patient and caregiver health outcomes (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008).

### **Patient & Caregiver Interdependence**

Interdependence theory focuses on how the interactions of two people – in this case, patient and caregiver dyads – influence both of their emotions, beliefs and actions (Van Lange &

Rusbult, 2012). There are a number of reasons why patient and caregiver chronic conditions, meaning-based coping, and quality of life might be interrelated. First, the nature of a caregiving situation includes a degree of dependence; as a result, the stressors, emotions and challenges of one individual could influence the experiences of the other. Second, individuals who assume an informal caregiving role are often family members or emotionally close significant others of the patient; as such, a degree of shared concern for the impact of illness and caregiving on their lives is expected. Thus, while research often investigates how patients influence caregiver outcomes, it is quite possible that caregivers influence patient outcomes as well.

### **Purpose & Hypotheses**

This study examines the mediating and moderating role of meaning-based coping on the relationship between pre-existing health problems (patient comorbidities and caregiver chronic conditions) and quality of life in patients with advanced cancer and their family caregivers. In accordance with interdependence theory, actor control refers to the influence that a person's actions have on their own outcomes, and partner control refers to the influence that a person has on their partner's outcomes. Figure 4.1 depicts the model used for this study. The specific hypotheses are as follows:

- H1: Patient comorbidities and caregiver conditions will be inversely associated with their own quality of life (i.e. actor effects) and the quality of life of their dyadic partner (i.e. partner effects)
- H2: Patient comorbidities and caregiver conditions will be inversely associated with their own meaning-based coping (i.e. actor effects) and the meaning-based coping (MBC) of their dyadic partner (i.e. partner effects)

- H3: Meaning-based coping will be directly associated with (a) patients' and caregivers' own quality of life (i.e. actor effects) and (b) the quality of life of the dyadic partner (i.e. partner effects)
- H4: Meaning-based coping will mediate the relationship between comorbidities/conditions and quality of life for each dyad member.
- H5: Meaning-based coping will moderate the relationship between comorbidities/conditions and quality of life for each dyad member.

## **Method**

### **Study Design**

Data used in this study come from a randomized clinical trial (RCT) that tested the efficacy of a brief and extensive form of the evidenced based FOCUS program on outcomes for patients with advanced cancer and their caregivers (Northouse et al, 2013). Detailed information related to study procedures, intervention content, and intervention outcomes have been published elsewhere (Northouse et al., 2013). For the current analysis, only baseline data were included; thus, intervention effects are not reported.

### **Participants**

At baseline, the sample population for this study includes 484 patients with advanced cancer and their family caregivers (N=484 dyads). Advanced cancers were defined as cancers at stage III or IV of disease and a limited five-year survival rate (below 50%). All patients: 1) were age 21 or older; 2) had a confirmed diagnosis of advanced breast, colon, lung or prostate cancer and were within a 6-month window of having a new advanced cancer diagnosis, progression of their advanced cancer, or a change of treatment for it; 3) were physically and mentally able to participate; 4) could speak and understand sufficient English; 5) had a life expectancy of at least

6 months (physician assessed); 6) lived within 75 miles of one of the participating medical centers; 7) provided informed consent; and, 8) had a family member willing to participate. Patients were excluded from the study if they were diagnosed with multiple primary cancer sites.

A family caregiver was defined as “the family member or significant other identified by the patient as his or her primary source of emotional or physical support during the advanced phase of cancer and confirmed by the designated individual.” Family caregivers were: 1) age 18 or older; 2) mentally and physically able to participate; and, 3) able to speak and understand English. Family caregivers were excluded from the study if: 1) they had been diagnosed with cancer during the previous year and/or 2) were in active treatment for cancer.

### **Patient Sample Description**

The types of cancers reported by patients were as follows: 32.4% breast cancer; 25.4% colorectal cancer; 29.1% lung cancer; and, 13.0% prostate cancer. At baseline, the average time since the initial diagnosis was 42.5 months (SD: 55.3; range: 1-309). Most patients were receiving some sort of treatment (89%). Of those patients, a majority of patients were undergoing chemotherapy treatment (76.4%). Patients also reported currently receiving hormone therapy (18.3%), radiation therapy (9.2%), experimental therapy (8.5%), surgical treatment (3.2%) or another treatment not specified (6%). Multiple responses for treatment options were possible.

### **Instruments**

The following instruments were used to measure the selected study variables. For the meaning-based coping and quality of life scales, only items that were comparable between patients and caregivers were included in the analysis.

**Comorbidities/conditions.** Patients and caregivers responded to the following question: “Do you have any other health problems (such as heart disease, arthritis, diabetes, etc.) at this

time?” Respondents who answered “yes” to this question were then asked to name their health problems. No restrictions were placed on the number of problems they could report. The *number of comorbidities/conditions* variable was based on a count of the number of problems reported in response to this question. *Comorbidities* refer to the health problems reported by patients, with cancer as their index condition. *Conditions* refer to the chronic health problems reported by caregivers. This variable was included as a single item observed variable in the analysis.

**Meaning-based coping.** Meaning-based coping was assessed in patients with four items from the benefit dimension of the Appraisal of Illness Scale and in caregivers with four items from the benefit dimension of the Appraisal of Caregiving Scale (Oberst, 1989, 1991a, 1991b). Content validation for the scales has been reported (Oberst, 1989; Lambert, Yoon, Ellis, & Northouse, 2015). Respondents were instructed to answer the appraisal questions based upon how they felt “over the last week including today.” The full patient scale is a 32-item measure while the full caregiver scale is a 27-item measure; however, the benefit subscale used here consisted of 4 items which appeared in patient and caregiver instruments. Both instruments used a 5-point response scale ranging from (1) “strongly disagree” to (5) “strongly agree.” Higher scores indicated more positive meaning-based coping. The internal reliability for the benefit subscale was .746 among patients and .703 among caregivers. An example item from this scale is “I’ve grown a lot since this situation began.” A latent variable with four indicators measuring patients’ meaning-based coping and another latent variable with four indicators measuring caregivers’ meaning-based coping were used in their analysis.

**Quality of life.** Patient quality of life was measured with version 4 of the *Functional Assessment of Cancer Therapy: General Scale* (FACT-G; Cella et al., 1993); caregivers answered a modified version of this scale (with permission from FACIT.org) to report their own

quality of life (Northouse et al., 2002; 2013). The FACT-G is a valid and reliable scale used to measure health related quality of life (Brucker, Yost, Cashy, Webster, & Cella, 2005; Brucker et al., 2005; Cella et al., 1993; Overcash, Extermann, Parr, Perry, & Balducci, 2001; Winstead-Fry & Schultz, 1997) with four different dimensions of quality of life: physical, social, emotional, and functional. Scoring for this validated scale followed established instructions for creating subscale and overall summary scores. This 27-item measure has a 5-point response scale ranging from (0) “not at all” to (4) “very much.” The items were coded/reverse-coded such that higher scores indicated better quality of life. The internal reliability alpha for the overall scale was .893 among patients and .899 among caregivers. Patients’ and caregivers’ quality of life scores were included as single item observed variables in this analysis.

**Covariates.** Measures of age, sex, race (white vs. other), income, cancer type, patient treatment (chemotherapy vs. other; hormone therapy vs. other), patient-caregiver relationship type (spouse vs. other) and length of time since patient diagnosis were obtained from patients’ medical records and the Risk for Distress Scale, adapted from the original Omega Clinical Screening Interview (Mood & Bickes, 1989; Northouse et al., 2007; Northouse et al., 2013). Caregiver burden was measured using a summary score from two subscales of the Caregiver Reaction Assessment (CRA), which assesses responses to tasks and problems associated with caregiving (Given et al., 1992), and six additional items added by study researchers (16 items total). The measure has a 5-point response scale ranging from (1) “strongly disagree” to (5) “strongly agree.” Validity of the CRA has been reported (Snyder, 2005).

### **Data Analysis Strategy**

This study investigated meaning-based coping as a mediator and moderator of the relationship between number of comorbidities/conditions and quality of life. The hypotheses

were examined using the actor-partner interdependence model (APIM; Kenny et al., 2006; Rayens & Svavarsdottir, 2003). The APIM captures actor effects, partner effects, and the interdependence between members of a dyad. Actor effects refer to the effect that the patient or caregiver has on his or her own outcomes. Partner effects refer to the effect that one individual's characteristics or behavior has on the outcome of the other. The presence of partner effects is an example of interdependence. Interdependence is often of great interest to researchers who are studying dyadic data and ignoring it can bias results while overlooking important data about interpersonal processes and influence (Gonzalez & Griffin, 1999; Kashy & Snyder, 1995; Popp, Laursen, Kerr, Stattin, & Burk, 2008).

Study hypotheses H1-H4 were tested using an expanded form of the APIM known as the actor-partner interdependence mediation model or APIMeM (Ledermann, 2011). Figure 4.1 depicts the base APIMeM model for this study. This model consists of a pair of predictor variables (patient and caregiver number of comorbidities/conditions); a pair of mediator variables (patient and caregiver meaning-based coping); and, a pair of final outcome variables (patient and caregiver quality of life). The APIMeM model was used to test for direct effects (H1-H3) and mediation effects (H4). Full mediation is indicated if mediation effects are significant, but no direct relationship between comorbidities/conditions and quality of life exists; partial mediation is indicated where mediation effects are significant and a direct relationship exists between comorbidities/conditions and quality of life (Zhao, Lynch & Chen, 2010). Bootstrapping and model constraints were used to test indirect effects suggested by the mediator models. Moderation (H5) was tested by adding an interaction term to the standard actor-partner interdependence model. The use of interaction terms allowed for the testing of specific hypothesized paths. All models also included covariances between predictor variables, and error

terms of the mediator and outcome variables. The following variables were included as covariates in the multivariate analysis: age, sex, race, income, cancer type, patient treatment, length of time since patient diagnosis and caregiver burden (not shown in the figures).

Structural equation modeling (SEM) was used to estimate the model parameters using MPlus version 6.1 (Muthén & Muthén, 2011). A standardized dataset was created in SPSS version 21 and used to conduct SEM in MPlus because of the inefficiency of standardized solutions provided by path analysis software when dyadic data are used (Kenny, Kashy & Cook, 2006). The chi-square statistic, comparative fit index (CFI), and the root mean squared error of approximation (RMSEA) were used to determine the adequacy of model fit. The indicators of adequate model fit for these indices (i.e. the indication that the model fits the sample data well) are a non-significant chi-square statistic or a chi-square to degrees of freedom ratio of less than 2; a CFI above .90; and a RMSEA value of .05 or less (Hu & Bentler, 1999). A key advantage of SEM is the ability of actor and partner effects to be tested simultaneously, which allows for a more comprehensive understanding of an entire model compared to the estimation of individual effects (Kline, 2011).

## **Results**

Background demographic information obtained from patients and caregivers at baseline are presented in Table 4.1. The average age at baseline of patients was 60.5 years (SD: 11.5; range: 26-95) and of caregivers 56.5 years (SD: 13.4; range: 18-88). A majority of patients (62%) and caregivers (56.8%) were female. Patients were predominantly White (79.3%) and the next largest racial group was African American (15.3%); Asians (1.0%), American Indian/Alaskan Natives (0.2%), Pacific Islanders (0.2%) and individuals who reported multiple races (3.9%) comprised the rest of the sample. This distribution was very similar among



caregivers. Patients reported an average of 14.5 years of education (SD: 2.7; range 7-22) and caregivers, an average of 14.6 years (SD 2.8; range 7-22). Most of the patients (75.6%) and caregivers (82.9%) were married or living as married. Most caregivers were the spouse of the patient (70%) and most caregivers lived with the patient (82.6%).

Table 4.2 provides information about the comorbidities/conditions reported by the sample. Patients and caregivers reported up to five comorbidities/conditions. The average number of comorbidities/conditions reported was 1.82 among patients (SD: 1.44; range 0-5) and 1.48 among caregivers (SD: 1.35; range 0-5). Most patients (77.5%) and caregivers (68.1%) reported at least one comorbidity/condition and one-third of patients (32.3%) and almost one-quarter of caregivers (23%) reported three or more comorbidities/conditions. The most commonly reported were hypertension (39.9% patients; 30.0% caregivers), heart problems (30.4% patients; 26.4% caregivers), depression (26.2% patients; 21.9% caregivers), arthritis (18.0% patients; 16.5% caregivers), and diabetes (14.0% patients, 9.3% caregivers). There were significant differences between the number of patient and caregiver comorbidities/conditions ( $p < .001$ ).

#### **Hypotheses 1-4: Mediation Model**

Figure 4.2 provides the standardized estimates for the mediation model tested. The model included the number of comorbidities/conditions (X); meaning-based coping as a mediator (M); and, quality of life as an outcome (Y). Hypothesis 1 (H1) tested the direct effects of comorbidities/conditions on quality of life ( $X \rightarrow Y$ ); hypothesis 2 (H2) tested the direct effects of comorbidities/conditions on meaning-based coping ( $X \rightarrow M$ ); hypothesis 3 (H3) tested the direct effects of meaning-based coping on quality of life ( $M \rightarrow Y$ ); and, hypothesis 4 (H4) tested for meaning-based coping as a mediator of the relationship between comorbidities/conditions and

quality of life (partial or full mediation). Independent (actor) and interdependent (partner) effects were tested for each of the hypotheses.

### **H1: Influence of Comorbidities/Conditions on Quality of Life (X→Y)**

Supporting the study hypothesis, two significant actor effects were found when examining the direct relationship between comorbidities/conditions and quality of life. More comorbidities in patients ( $\beta=-0.12$ ;  $p=0.005$ ) were associated with lower patient quality of life. Similarly, more caregiver conditions were associated with lower caregiver quality of life ( $\beta=-0.12$ ;  $p=.003$ ). One significant partner effect was observed. More conditions among caregivers was associated with lower quality of life among patients ( $\beta=-0.11$ ;  $p=0.02$ ).

### **H2: Influence of Comorbidities/Conditions on Meaning-Based Coping (X→M)**

Patient number of comorbidities were not associated with patient meaning-based coping; however, significant caregiver actor effects were observed. Among caregivers, having more conditions was associated with lower meaning-based coping ( $\beta=-0.08$ ;  $p=0.02$ ). One significant partner effect was found: more patient comorbidities were associated with lower meaning-based coping among caregivers ( $\beta=-0.06$ ;  $p=0.04$ ).

### **H3: Influence of Meaning-Based Coping on Quality of Life (M→Y)**

As expected, significant actor effects were found when examining the direct relationship between meaning-based coping and quality of life. More meaning-based coping in patients was associated with higher patient quality of life ( $\beta=0.26$ ;  $p<.001$ ). Similarly, more caregiver meaning-based coping was associated with higher caregiver quality of life ( $\beta=0.22$ ;  $p=.006$ ). One significant partner effect was observed. More caregiver meaning-based coping was associated with lower patient quality of life ( $\beta=-0.22$ ;  $p=.019$ ).

#### **H4: Meaning-Based Coping as a Mediator ( $X \rightarrow M \rightarrow Y$ )**

The results from testing H1-H3 indicated that caregiver meaning-based coping might partially or fully mediate the relationship between: caregiver number of chronic conditions caregiver conditions and caregiver quality of life ( $X_c \rightarrow M_c \rightarrow Y_c$ ; partial mediation); patient number of comorbidities and caregiver quality of life ( $X_p \rightarrow M_c \rightarrow Y_c$ ; full mediation); caregiver number of chronic conditions and patient quality of life ( $X_c \rightarrow M_c \rightarrow Y_p$ ; partial mediation); and, patient number of chronic conditions and patient quality of life ( $X_p \rightarrow M_c \rightarrow Y_p$ ; partial mediation). A bootstrapping procedure in MPlus was used to confirm mediation (i.e. indirect) effects.

Three mediation effects were significant. First, the indirect effect of caregiver number of comorbidities on caregiver quality of life, mediated by caregiver meaning-based coping ( $X_c \rightarrow M_c \rightarrow Y_c$ ), was significant ( $\beta = -0.02$ ; 95% CI: -0.054, -0.002). This suggests that caregiver number of conditions had significant indirect effect on caregiver quality of life. Given the evidence of a direct effect between caregiver conditions and caregiver quality of life, these results confirm partial mediation. Second, the indirect effect of caregiver number of comorbidities on patient quality of life, mediated by caregiver meaning-based coping ( $X_c \rightarrow M_c \rightarrow Y_p$ ; partial mediation), was significant ( $\beta = 0.02$ ; 95% CI: .001, .048). This suggests that caregiver number of conditions has a significant indirect effect on patient quality of life. Given the evidence of a direct effect between caregiver conditions and patient quality of life, these results also confirm partial mediation. Lastly, the indirect effect of patient number of comorbidities on caregiver quality of life, mediated by caregiver meaning-based coping ( $X_p \rightarrow M_c \rightarrow Y_c$ ), was significant ( $\beta = -0.01$ ; 95% CI: -0.046, -0.001). There was no observed direct effect between patient number of conditions and caregiver quality of life; therefore, these results suggest a full mediation effect.

### **Hypothesis 5: Meaning-Based Coping as a Moderator**

Meaning-based coping was also tested as a possible moderator of the relationship between comorbidities and quality of life. Four interaction terms were created for these SEM models: 1) an interaction between patient comorbidities and patient meaning-based coping; 2) an interaction between caregiver comorbidities and caregiver-meaning-based coping; 3) an interaction between patient comorbidities and caregiver meaning-based coping; and, 4) an interaction between caregiver comorbidities and patient meaning-based coping. The interaction terms were added to models that included main actor and partner effects between comorbidities/conditions and quality of life and between meaning-based coping and quality of life. None of the interaction terms were significant. These results suggest the effects of comorbidities/conditions on quality of life were not dependent upon patient/caregiver levels of meaning-based coping.

### **Covariates**

Higher patient meaning-based coping was associated with younger patient age, having a male caregiver and higher income. Higher caregiver meaning-based coping was associated with being a female or spousal caregiver and patients receiving chemotherapy (vs. other treatments). Higher patient quality of life was associated with higher income and increased patient age. Higher caregiver quality of life was associated with higher patient age and lower caregiver burden.

### **Discussion**

The purpose of this study was to examine the relationship between pre-existing chronic health problems and quality of life among patients with advanced cancer and their caregivers, while investigating the mediating and moderating role of meaning-based coping on that

relationship. Of particular interest was interdependence between patients and caregivers, namely, the influence of one individual's predictor variables on their own outcomes (i.e. actor effects) and the other person's outcomes (i.e. partner effects).

Findings suggest that as patient and caregiver number of comorbidities/conditions increased, their own quality of life decreased. This aligns with previous research which has found an association between number of chronic conditions and quality of life, but uniquely, this study confirms this relationship within an advanced cancer context. While evidence suggests cancer often contributes more to mortality than patient comorbidities where advanced disease exists (Edwards et al. 2014), findings from the current study suggest it is vital to consider how comorbidities influence quality of life. In addition, study findings suggest the comorbidities/conditions of one member of the dyad negatively influenced the quality of life of the other. That is, as caregivers' number of conditions increased, quality of life reported by patients worsened. Although previous research found a relationship between number of chronic conditions and quality of life (Agborsangaya, Lau, Lahtinen, Cooke, & Johnson, 2013; Fortin et al., 2004), this research focused only on the effect of an individuals' comorbidities on their own outcomes and was not focused primarily on individuals with advanced cancer. Findings from my study extend existing research and indicate that in the dyadic context, the comorbidities/conditions of one member of the dyad have significant effects on their partner's quality of life. This finding also underlines the importance of examining the dyadic process that exists between patients' and caregivers' health status, because each person's preexisting conditions have the potential to affect the wellbeing of the other.

Comorbidities/conditions are likely an additional source of health-related stress, in addition to advanced cancer, that patients and caregivers must manage (Checton et al., 2014).

These comorbidities/conditions may contribute to symptoms or functional limitations that compromise an individual's own quality of life or influence the ability of caregiver to complete caregiving tasks. The burden of chronic disease is multifaceted and individuals with chronic conditions often face continued adaptations over the course of their illness (Clark, 2003; Wagner et al., 2001). Multimorbidity is particularly complex, given the common need for individuals to manage multiple medications, treatment regimens and health care providers (Clark, 2011; Janevic, Ellis, Sanders, Nelson, & Clark, 2013; Ritchie, Kvale, & Fisch, 2011). More assessment of caregiver conditions and the extent to which caregivers are able to manage them are needed (Kim, Kashy, Spillers, & Evans, 2010). Caregivers may need additional support and resources in order to maintain their own health and provide quality care to patients.

Associations were also found between the number of comorbidities/conditions and caregiver meaning-based coping. More comorbidities/conditions among patients and caregivers were associated with lower meaning-based coping among caregivers. Previous research has shown that caregivers exhibit significant levels of psychological distress, especially as the patient's disease progresses (Pitceathly & Maguire, 2003). Because caregivers likely bear the responsibility for managing their health problems, as well as those of the patient, the impact of comorbidities/conditions on their ability to find meaning might be stronger. It is interesting to note that neither patient comorbidities nor caregiver conditions influenced patient meaning-based coping. Previous research has shown that people with cancers and other comorbidities face complex biological, behavioral, and psychosocial challenges (Edwards et al., 2014; NCI, 2014). The significance of advanced disease, and a higher likelihood that the primary cause of patient mortality would be cancer and not the co-existing conditions (Edwards et al., 2014), could help

explain why the comorbidities of the patient or caregiver posed no additional influence on meaning-based coping.

Consistent with theory and other literature (Helgeson, Reynolds, & Tomich, 2006), results suggest the ability of patients and caregivers to find positive meaning in their stressful experiences had a positive influence on their wellbeing. Unexpectedly, however, increased meaning-based coping among caregivers was associated with decreased quality of life among patients. A possible contributor to this finding could be the use of baseline data. While the diagnosis of advanced disease requires psychological adjustment on the part of both patients and caregivers, the time it takes to make that adjustment could differ. A previous study of post-traumatic growth in patients with advanced liver cancer found that, for all but one of the dimensions assessed, patient's posttraumatic growth was unchanged for the first six months following diagnosis (Moore et al., 2011). The caregivers' ability to find growth and benefit, prior to the other partner being able to do so, could be a source of concern for the patient. In their discussion of meaning-making among individuals with advanced cancer, Lethborg and colleagues (2006) describes this process for patients as "dynamic", "bittersweet", and "taxing." Patients may need more time than caregivers to make sense of their advanced disease and prognosis, adapt to the challenges they will face in the present and future, and identify areas of benefit and growth.

Researchers have called for the inclusion meaning and benefit-finding in programs for patients and caregivers, given its positive impact on outcomes (Kim, Baker, et al., 2007; Kim, Schulz, et al., 2007). The ability to find partner effects (e.g., influence of patient meaning-based coping on caregiver quality of life) could be influenced by the structure of the survey items. In this study, all of the items asked about individual level meaning-based coping; conversely, items

that measure individual perceptions about the meaning-based coping of both members could better capture positive partner effects that might exist. Essentially, this would modify the assessment of meaning-based coping from how “the meaning I perceive for *myself*” to “the meaning I perceive for *us*.” Communal coping refers to the perceptions individuals hold when they view a stressful experience as shared (i.e. our problem) and engage in coping processes that reflect a shared orientation (Lewis et al., 2006; Lyons, Mickelson, Sullivan, & Coyne, 1998). Communal coping may more accurately capture the coping processes that occur in social groups (e.g., dyads, families), than stress and coping frameworks developed to capture individual level processes. Future research in this area is warranted.

An unexpected finding was that while meaning-based coping mediated relationships between comorbidities and quality of life, it did not moderate these relationships. Meaning-based coping is often conceptualized as a moderator (Wenzel et al., 2002), and it was expected that the ability of patients and caregivers to find positive meaning or growth in their experiences could help *buffer* the negative impact of comorbidities/conditions on their own quality of life. There were, however, no significant moderating effects. Instead, these findings suggest, that meaning-based coping help to *explain* the relationship between comorbidities/conditions and quality of life (i.e. mediation).

Caregiver meaning-based coping was found to mediate relationships between the caregiver and patient number of conditions and patient and caregiver quality of life; conversely, patient meaning-based coping was not found to mediate these relationships. Previous research has identified caregivers as a primary source of emotional support for patients (Given et al., 2001; Stenberg, Ruland, & Miaskowski, 2010). As such, caregivers may play a significant role in setting the emotional tenor in the care-giving and care-receiving experience. This could be



reflected in the mediating processes observed. Second, the measure of meaning-based coping referred specifically to areas of meaning-making related directly to the cancer. More tangible factors such as symptom distress and medication adherence, which are directly related to the patient's comorbidities, or meaning-based coping related to the comorbidities themselves could be more relevant mediators. Lastly, as previously mentioned, the use of baseline could be influencing these results. Further testing with longitudinal data could shed more light on these mediating processes as the cancer progresses and patients and caregivers continue to adapt to the illness and its influence on their lives. However, the fact that patient meaning-based coping did not help to explain the relationship between patient comorbidities and patient quality of life suggests that other factors should be considered.

### **Limitations**

There are some limitations to this study. The study collected data about the number and type of comorbidities/conditions of patients and caregivers; however, data was not collected on the severity of these conditions, time since diagnosis of the comorbidity/condition nor their experiences with disease management. It is possible that those who are facing severe complications from their comorbidities, those who are newly diagnosed with other chronic conditions and adjusting to them, and those who are not able to manage their chronic diseases successfully may have more challenges that could negatively influence their ability to engage in meaning-based coping and their quality of life and that of their dyadic partner. These associations should be tested. In addition, the use of an open-ended question to collect data on comorbidities/conditions instead of a checklist could have resulted in underreporting of these health problems. Furthermore, the sample also included patients and caregivers who had relatively high levels of education and income. Individuals with lower levels of education and

income may have more difficulties with managing the advanced cancer and adequately managing their chronic conditions due to the quality and availability of resources needed to cope with both types of challenges. In addition, some research indicates that minority populations may suffer more morbidity from chronic diseases (CDC, 2013; Gaskin et al., 2014; Nwankwo, Yoon, Burt, & Gu, 2013). Further analysis testing differences between these groups could help identify areas of risk and need. Another limitation is the cross-sectional nature of the analysis, which precludes a determination of causality. It could be that quality of life has an influence on meaning based coping; this association should be tested in longitudinal research. Lastly, most of the couples in this sample were spouses. Given the observed relationship between relationship type and caregiver appraisal, it is recommended relationship-type be tested as a moderator of the observed relationships.

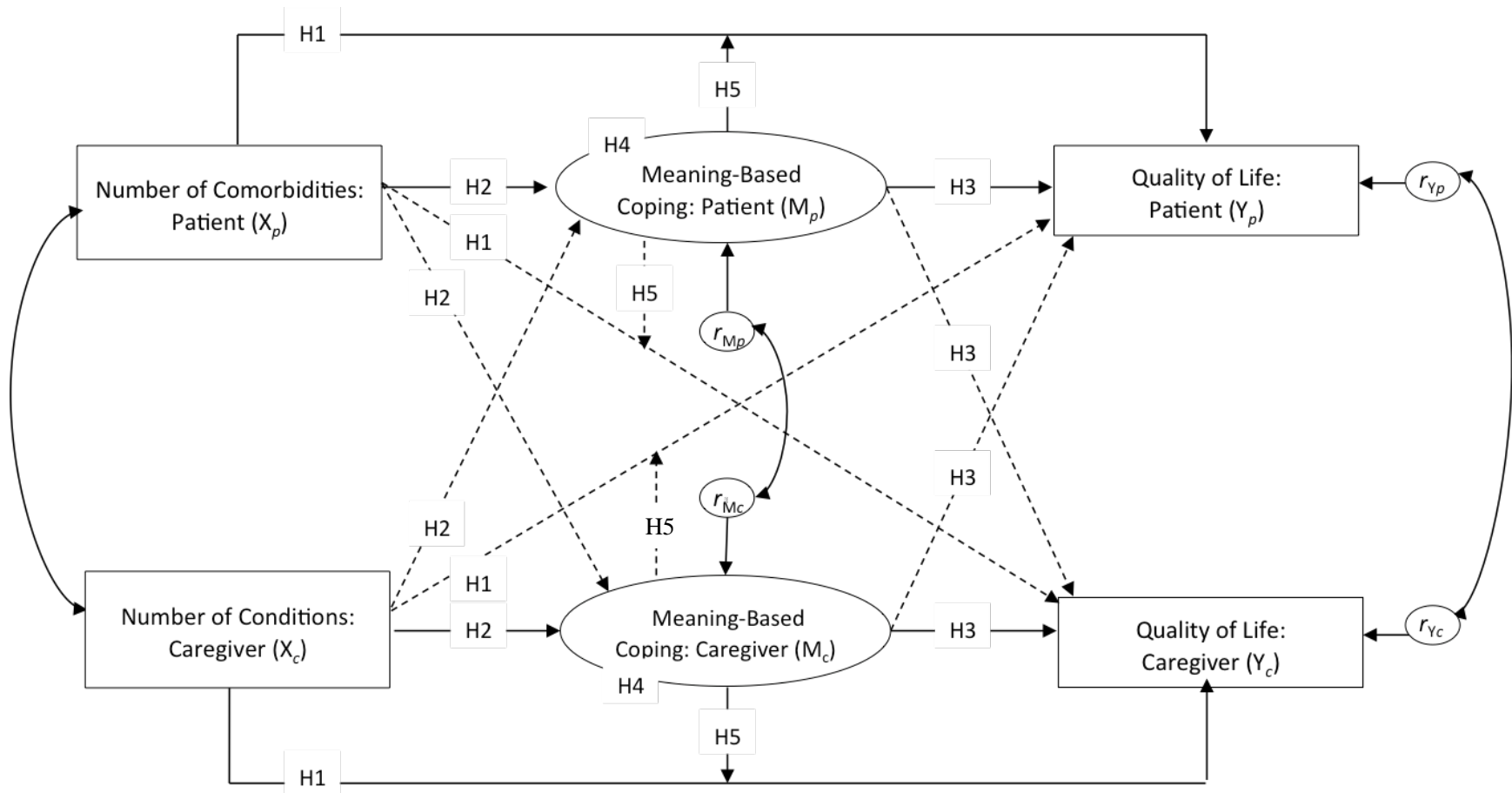
## **Conclusion**

A unique contribution of this study to the literature is the consideration of how patient comorbidities *and* caregiver chronic conditions influenced their quality of life in the context of advanced cancer. Quality of life is important at all phases of a cancer experience. At advanced stages of disease, where curative treatment is no longer the goal, supporting and maintaining patient quality of life grows ever stronger. Thus, while advanced cancer may contribute more to patient mortality than their comorbidities, this study suggests that efforts to improve patient quality of life should not ignore patient comorbid conditions – or the chronic conditions of their caregivers. Future research should consider how the *number* comorbidities/conditions, as well as the ability of patients and caregivers to *manage* those conditions influences their wellbeing. From an intervention perspective, it may be useful to help patients and caregivers in skill-building and resource-finding that will help them manage their conditions individually, as a unit,

and as often the case with multimorbidity, with multiple medical providers. In practice, the assessment of both patient and caregiver number of chronic conditions could help to identify dyads who might benefit from interventions; however, more resources for caregiver assessment at the patient's care settings may be necessary for this to occur. Existing cancer-related interventions and chronic disease management programs could be useful for tailoring resources specifically for patient/caregiver dyads managing advanced cancer and other illnesses.

Another unique finding of this study was that caregiver meaning-based coping helped to explain the relationship between chronic conditions and patient *and* caregiver quality of life. While meaning-based coping (i.e. benefit finding, identification of growth) is often a component of cancer support interventions, my findings suggest that understanding how caregivers' own health issues influence their meaning-based coping is an important factor to consider. In addition, future research could investigate *how* meaning-based coping influences quality of life, including whether factors such as patient/caregiver communication or depression further explain this association. In addition, longitudinal studies of meaning-based coping and measures of cancer progression, could help to elucidate how these factors play out in patients and caregivers over time.

Figure 4.1. Hypothesized Model: Patient and Caregiver Number of Comorbidities/Conditions, Meaning-Based Coping, and Quality of Life



*Note:* Subscript  $p$  refers to patients and subscript  $c$  refers to caregivers. The hypotheses relevant to each path in the model have been noted (i.e. H1 refers to Hypotheses 1). H5 also considered the moderating role of one dyad member's meaning based coping on the relationship between comorbidities/conditions and quality of life of the other (paths not shown). Independent effects (i.e. actor effects) are represented by solid lines. Interdependent effects (i.e. partner effects) are represented by dashed lines. Error covariances are represented by curved double-headed arrows.

Table 4.1. Patient and Caregiver Demographic Information at Baseline

	Patients (N=484)	Caregivers (N=484)	Difference Tests <sup>a</sup>
Age in years			
Mean (SD)	60.5 (11.5)	56.5 (13.4)	*
Range	26-95	18-88	
Sex (%)			
Female	62.0	56.8	NS
Male	38.0	43.1	
Race (%)			
American Indian/Alaskan Native	0.2	0	NS
Asian	1.0	1.2	
Black	15.3	15.9	
Pacific Islander	0.2	0	
White	79.3	79.6	
Multiracial	3.9	2.5	
Highest level of education in years			
Mean (SD)	14.5 (2.7)	14.6 (2.8)	NS
Marital Status (%)			
Married/Living as married	75.6	82.9	*
Divorced/Separated	13.2	8.1	
Widowed	6.0	2.3	
Never married	5.2	6.8	
Relationship to patient (%; caregiver only)			
Spouse	--	70.0	--
Daughter	--	12.0	
Son	--	3.3	
Sister/Brother	--	0.2	
Other relative	--	5.6	
Friend	--	4.3	
Unknown/Coding error	--	4.5	
Currently living with patient (caregiver only)			
% Yes	--	82.6	--

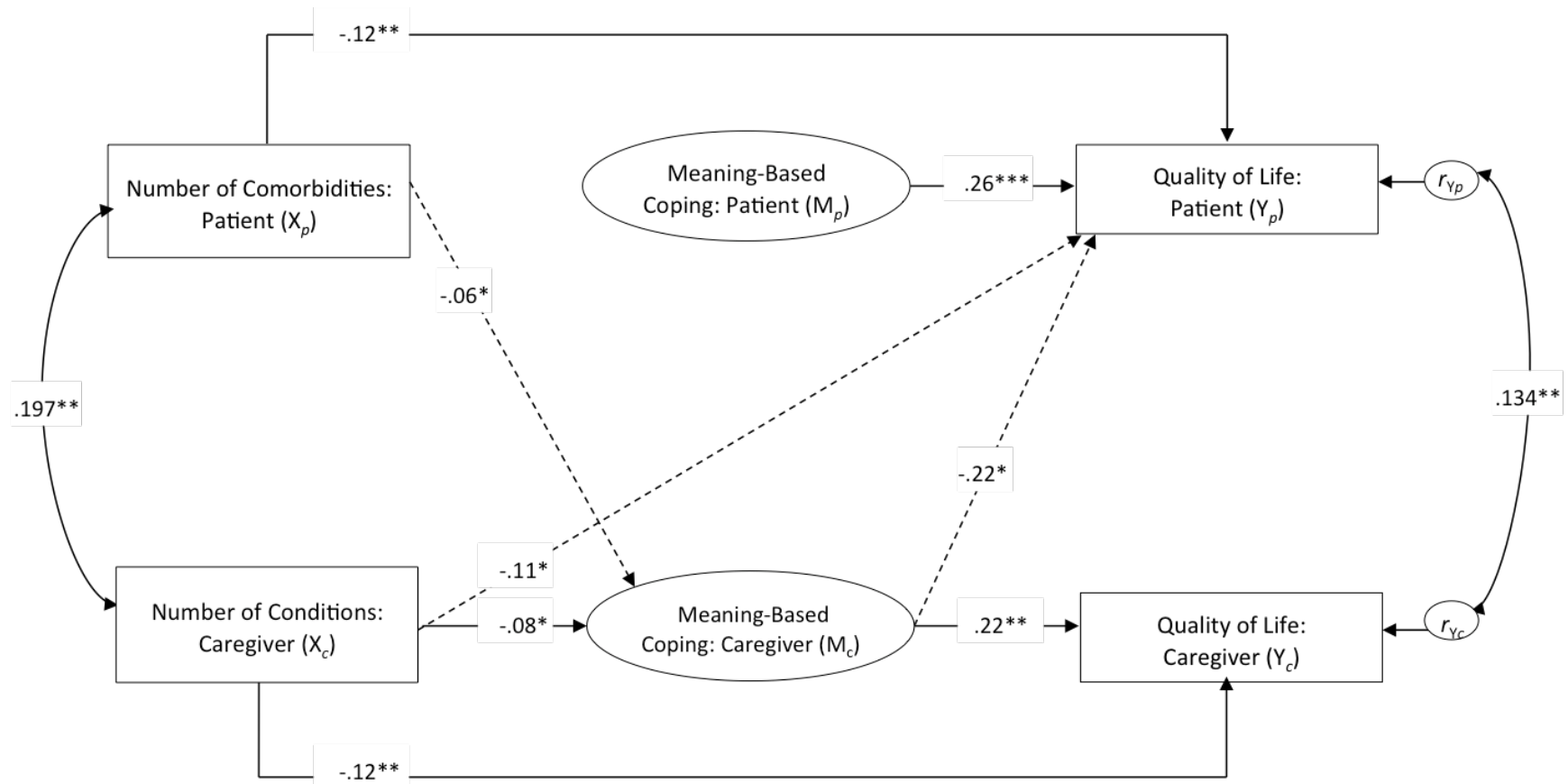
<sup>a</sup>Paired sample t-tests, McNemar's Test, or Wilcoxon Signed-Rank Test. \* $p < .05$ ; NS: not significant.

Table 4.2. Comorbidities of Patients and Chronic Conditions of Caregivers

		M (SD) or %	Difference Tests <sup>a</sup>
Number of comorbidities (Range 0-5)	PT	1.82 (1.44)	
			**
Number of conditions (Range 0-5)	CG	1.48 (1.35)	
Type of comorbidity/condition (yes/no)			
Hypertension	PT	39.9	**
	CG	30.0	
Heart Problems	PT	30.4	NS
	CG	26.4	
Depression	PT	26.2	NS
	CG	21.9	
Arthritis	PT	18.0	NS
	CG	16.5	
Diabetes	PT	14.0	*
	CG	9.3	

<sup>a</sup>Paired sample t-tests or McNemar's Test. \* $p < .05$ ; \*\* $p < .001$ .; NS: not significant

Figure 4.2. Mediation Model Results – Hypotheses 1 - 3



*Note:* Estimates are standardized; only significant parameter estimates are reported. Interdependent effects (i.e. partner effects) are represented by dashed lines. Error covariances are represented by curved double-headed arrows. X= predictor variable; M=mediator variable; Y=outcome variable. Subscript  $p$  refers to patients and subscript  $c$  refers to caregivers. Independent effects (i.e. actor effects) are represented by solid lines. The following variables were included as covariates in the multivariate analysis: age, sex, race, income, cancer type, patient treatment, relationship type, length of time since patient diagnosis and caregiver burden. Model fit:  $X^2/df=1.625$ ; CFI=.93, RMSEA=.04.  $+p < .10$ ;  $*p < .05$ ;  $**p < .01$

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## **CHAPTER V**

### **Key Dissertation Findings and Implications for Research, Practice and Policy**

Despite the progress made in cancer screenings and treatments, many individuals face the challenges of advanced disease. Over 1.6 million people are expected to be diagnosed with cancer in 2015, a significant portion of which will have advanced disease (ACS, 2015). The four most commonly diagnosed non-skin cancers are breast, colorectal, lung and prostate cancers. Between 2003 and 2009, approximately 37% of breast cancers, 56% of colorectal cancers, 79% of lung cancers, and 16% of prostate cancers were diagnosed at regional or distant stages (ACS 2014). Given the consequences and complications of their disease (Barnes & Bruera, 2002; Walsh, Donnelly, & Rybicki, 2000), patients with advanced cancer often rely on family caregivers for support. The work of these caregivers is complex and multifaceted: medication administration, emotional support, communication with health providers and symptom management are just a few of their tasks (Given, Given, & Kozachik, 2001). Thus, research on the experiences of individuals with advanced cancer – and their caregivers - has the potential to benefit a significant portion of patients and families affected by the disease.

#### **Dissertation Aim**

The primary aim of my dissertation work was to investigate how the pre-existing health problems that patients and caregivers have at the onset of the advanced cancer/caregiving experience influenced a number of health-related outcomes. This work sought to answer questions about patients and caregivers that I was unable to identify in available literature.

Though cancer has been associated with the severity of patient comorbidities, and evidence suggests patient comorbidities influence cancer treatment (Ogle, Swanson, Woods, & Azzouz, 2000), I noticed a lack of studies that considered how patient comorbidities influenced non-clinical outcomes (Extermann, 2000). While considerable research investigates how caregiving influences caregivers' future health challenges (Pearlin, Mullan, Semple, & Skaff, 1990; Pinquart & Sörensen, 2003), I noticed that this literature did not examine associations between cancer caregivers' own chronic conditions and patient and caregiver outcomes. Informed by multimorbidity research (Fortin et al., 2004; Vogeli et al., 2007), I was particularly interested in how the number of patient and caregiver comorbidities/conditions influenced their wellbeing. Addressing these gaps is useful for designing supportive patient/caregiver interventions.

I conducted secondary data analyses using data from a randomized clinical trial (RCT) with 484 patient/caregiver dyads (Northouse et al., 2013). Patients in the RCT had advanced breast, colorectal, lung, or prostate cancers and a limited 5-year life expectancy; family caregivers were identified as primary sources of emotional and physical support for patients. Across three separate studies, I focused on independent effects and interdependent effects of comorbidities/conditions (e.g. heart disease, diabetes, arthritis, etc.) and other key study variables on patient and caregiver outcomes. Independent effects referred to the influence a patient/caregiver had on their own outcomes (also known as actor effects); interdependent effects referred to the influence a patient/caregiver had on each other's outcomes (also known as partner effects). Stress and coping theory (Lazarus & Folkman, 1984) and interdependence theory (Van Lange & Rusbult, 2012) provided the theoretical and conceptual framing for this work (see Figure 1.1). In this final chapter, key findings from each study are summarized and I discuss implications for research, policy and practice.

## **Study 1: Comorbidities, Chronic Conditions and Health-Promoting Behaviors**

In my first study, I examined the influence of the number patient comorbidities and caregiver chronic conditions on their engagement in exercise, diet, and sleep behaviors at three time points. I focused on health-promoting behaviors as an outcome for three main reasons. First, engagement in adequate diet, exercise and sleep behaviors has been associated with improved health among cancer survivors; however, much of this work does not include individuals with advanced cancer (Berger et al., 2005; Courneya & Friedenreich, 2007; Rock et al., 2012). Second, across many types of caregiving situations, the health of caregivers has been identified as a public health concern (Talley & Crews, 2007); but very few studies have examined engagement in health behaviors among advanced cancer caregivers (Kim & Schulz, 2008). Third, given the variability of patient and caregiver experiences over time (Giesinger et al., 2011; Glajchen, 2004; Teno, 2001), I wanted to examine these relationships at multiple time points (over a six-month period).

Prior to examining the influence of patient comorbidities and caregiver chronic conditions on behaviors, I assessed the frequency of behavior engagement among this population. I found that many patients with advanced cancer and their family caregivers are already engaging in diet, exercise, and sleep behaviors. At baseline, a majority of patients and caregivers reported eating a balanced diet (78.6% of patients; 72.2% of caregivers) or getting adequately sleep (74% of patients; 62% of caregivers) at least 3 days a week; and, over one-third reported engaging in moderate or vigorous exercise at least 3 days a week (36% of patients; 43.9% of caregivers). Given their shared social and physical environment (Gordon-Larsen, 2006; Lewis et al., 2006; Muzet, 2007; Umberson, Crosnoe, & Reczek, 2010), I hypothesized that there would be interdependent effects - that the health behaviors of one dyad member would positively



influence health behaviors of the other. Indeed, more patient exercise and better sleep were associated with more exercise and better sleep among their caregivers at a later time point. In addition, more caregiver exercise was associated with more patient exercise at a later time point.

Next, I included the main predictor variables of interest, patient comorbidities and caregiver conditions. I hypothesized that patient comorbidities and caregiver chronic conditions would be negatively associated with their own health behaviors (i.e. independent or actor effects) as well as behaviors of their dyadic partner (i.e. interdependent or partner effects). In some cases, my hypothesis was confirmed. As patient number of comorbidities increased, patient and caregiver exercise and caregiver sleep behaviors at certain time points worsened. Similarly, as caregiver number of conditions increased, caregiver and patient engagement in exercise at certain time points worsened. Conversely and unexpectedly, there were some instances in which more comorbidities/conditions were associated with better exercise, diet and sleep behaviors. This suggests that comorbidities/conditions may act as both a barrier and facilitating factor for health-promoting behavior engagement. This study contributes to the literature by demonstrating that patient and caregiver comorbidities/conditions have independent and interdependent influences on their health-promoting behaviors.

## **Study 2: Dyadic Comorbidity Burden, Symptom Distress, Threat Appraisals, and Self-Efficacy**

In the second study, I used baseline data to examine the influence of two physical-health related variables – symptom distress and dyadic comorbidity burden - on the threat appraisals and self-efficacy of patients and caregivers. Symptom distress – which included how often they experienced a range of symptoms, including pain, digestion problems, and fatigue – was included as a measure of their physical health status. While symptom distress is not a proxy for a

measure of how well patients and caregivers manage their chronic conditions, it could be seen as an indicator of the day-to-day health challenges they face. After identifying whether patients and caregivers (individually) had a low number of chronic conditions (0-1) or high number of chronic conditions (2 or more), I created four comorbidity burden groups: patient-low/caregiver-low; patient-high/caregiver-low; patient-low/caregiver-high; and, patient-high/caregiver-high. For all of my study hypotheses, I expected to see differences by dyadic comorbidity burden.

I hypothesized that more symptom distress among patients and caregivers would be associated with higher threat appraisals and lower self-efficacy for themselves (independent effects) and the other member of the dyad (interdependent effects). Across all groups, I found evidence of independent effects: patient and caregiver symptom distress were associated with their own higher threat appraisals. Interestingly, I only saw evidence of interdependent effects - where one dyad member's symptom distress influenced the threat appraisals of the other - in the total sample and when the caregivers' comorbidity burden was low. I suggested that this finding could be related to caregiver experience managing health problems. That is, caregivers with a low number of chronic conditions may have less experience dealing with health concerns, and as a result, may perceive more potential threats associated with cancer caregiving.

Though some studies have examined patient and caregiver self-efficacy in relation to the confidence they have in themselves or each other to manage the cancer experience (Keefe et al., 2003; Lev, Paul, & Owen, 1999), I considered patient and caregiver self-efficacy as it related to the broader family. Specifically, I investigated how symptom distress and threat appraisals influenced their confidence in their ability to cope with disease (individually) and their confidence to help their family as a whole cope with the disease. Results indicated that patients and caregivers with higher threat appraisals had lower individual- and family-related self-

efficacy. In some cases, the strength of this association differed by the dimension of self-efficacy. While there were no direct associations between the threat appraisals of one dyad member and the efficacy of the other, threat appraisals helped explain the relationship between symptom distress and self-efficacy for some groups (i.e. mediation effects).

Results from the multigroup analysis showed that across all groups, an individual's own threat appraisals mediated the relationship between their own symptom distress and self-efficacy. However, in dyads that included a caregiver with a low comorbidity burden, caregiver symptom distress had an indirect effect on patient self-efficacy through patient threat appraisals. I suggested that patients might feel more threatened when they do not have much evidence that caregivers can manage physical health problems. In turn, this could negatively influence their self-efficacy. This study contributes to the literature by bringing attention to the ways patient and caregiver health concerns influence the self-efficacy they have to cope (individually) and help their family cope with the illness and its consequences.

### **Study 3: Comorbidities, Chronic Conditions, Meaning-Based Coping and Quality of Life**

While a number of negative outcomes are associated with having or caring for someone with advanced cancer (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Cameron, Franche, Cheung, & Stewart, 2002; Delgado-guay, Parsons, Li, Palmer, & Bruera, 2009), patients and caregivers often identify positive meaning in their challenges, such as increased personal strength and relationship quality (Kramer, 1997; Wise & Marchand, 2013). In this final study, I examined the mediating and moderating role of meaning-based coping on the relationship between the number of patient and caregiver comorbidities/conditions and their quality of life.

First, I found that as the number of patient and caregiver comorbidities/conditions increased, *caregiver* meaning-based coping decreased; however, comorbidities/conditions did

not have a direct association with *patient* meaning-based coping. Second, results indicated that comorbidities/conditions were negatively associated with quality of life. As the patient number of comorbidities increased, patient quality of life decreased. However, as caregivers' number of conditions increased, patient *and* caregiver quality of life decreased. Thus, independent and interdependent effects were observed. I argued that these effects could be related to a) the additional stress imposed by managing comorbidities/conditions and/or b) symptoms or limitations related to the health problems that decrease quality of life and the ability of caregivers to complete caregiving-related tasks.

Next, I examined the direct effect of meaning-based coping on quality of life. I found that as patient meaning-based coping increased, patient quality of life increased. Similarly, as caregiver meaning-based coping increased, caregiver quality of life increased. However, contrary to my hypothesis, as caregiver meaning-based coping increased, patient quality of life decreased. One possible reason for this could be the use of baseline data. Compared to their caregivers, patients may need more time to find positive meaning from their experiences and the challenges that they face (Lethborg, Aranda, Bloch, & Kissane, 2006; Moore et al., 2011). Further study of these effects over a longer period of time is warranted.

Additional analyses indicated that caregiver meaning-based coping mediated the relationships between patient and caregiver number comorbidities/conditions and quality of life. It is very interesting to note that caregiver meaning-based coping emerged as a mediator while patient meaning-based coping did not. One possible reason for this finding is that caregivers are often a primary source of emotional support for patients (Given et al., 2001; Stenberg, Ruland, & Miaskowski, 2010). In this role, they may set the emotional tenor for the caregiving/care-receiving experience. This may be especially true early in the caregiving experience, when

patients and caregivers are adjusting to their new roles. Contrary to stress and coping theory, there was no evidence of meaning-based coping as a moderator. Overall this study also underscores that negative (i.e. comorbidities/conditions) and positive (i.e. meaning-based coping) aspects of the patient/caregiver experience are important to consider.

### **Implications for Research**

**Measurement.** Individuals with multiple chronic conditions often experience more health challenges than others with fewer or no chronic conditions (Fortin, Dubois, Hudon, Soubhi, & Almirall, 2007; Valderas, Starfield, & Roland, 2007). A key contribution of this dissertation is the analysis of the influence of multiple chronic conditions within a dyadic framework. Condition type (e.g. diabetes, heart disease, arthritis) and severity may also contribute to differences in dyadic experiences with illness and resources needed for disease management (Fultz, Ofstedal, Herzog, & Wallace, 2003; Rijken, van Kerkhof, Dekker, & Schellevis, 2005); however, this was not included in this analysis and is an important area of future research.

In 2012, the National Quality Forum, under contract with the US Department of Health and Human Services, published a framework for the measurement of multiple chronic conditions (NQF, 2012). The report notes that counts of number of chronic conditions – the most basic way to determine where multiple conditions exist – should be supplemented with a consideration of disease severity. This would allow for greater attention conditions that may be harder to treat and manage and help highlight where potential interactions between conditions (e.g. medication, regimens, physiological interactions) would be useful to prioritize in an intervention context. Other priority areas identified in the report include effective communication and coordination of care, optimizing functioning, and taking a person- and family-centered approach to care. These

priority areas could also be included in measures of patient and caregiver experiences managing multiple chronic conditions as a way to identify dyads in need.

Thus, research that seeks to build upon the dissertation findings could include both a count of the number of conditions as well as another variable that controls for the combined severity of the conditions. While a number of existing measures account for disease type and severity (de Groot, Beckerman, Lankhorst, & Bouter, 2003; Diederichs, Berger, & Bartels, 2011), a possible limitation of these measures is the focus on individual-level morbidity burden. The measurement of multiple chronic conditions should include an assessment of the potential for adverse interactions, above and beyond what may be seen individually. For example, in a dyadic context, this would involve attention to where the presence of certain conditions among members of the dyad could lead to additional challenges with disease management.

It has been noted that social networks should also be considered in the assessment of multimorbidity (Diederichs et al., 2011) and I would argue that my dissertation findings support the consideration of the health of social network members in these assessments. As another assessment of dyad member health concerns, I created a measure of *dyadic comorbidity burden*. Further examination of the correlates of dyadic comorbidity burden, alternative methods of assessments, the inclusion of severity of conditions (individual and interactively), and its impact on other patient/caregiver outcomes by dyadic comorbidity burden group is warranted. This research could help practitioners working with this population to identify populations most at risk for adverse psychosocial and behavioral outcomes and tailor information and resources to their specific needs.

**Populations of color.** A focus on patient and caregiver competing health concerns may be particularly critical for improving the health of populations of color. Populations of color

often suffer disproportionate levels of morbidity and mortality from cancer and other chronic conditions compared to Whites (Hayward, Miles, Crimmins, & Yang, 2000; Montague & Green, 2009; Ward et al., 2004; Williams & Jackson, 2005). Some research suggests that comorbidities may help to explain the racial disparities in cancer mortality that exist (Tammemagi, Nerenz, Neslund-Dudas, Feldkamp, & Nathanson, 2005; Yancik et al., 1998). More research in this area is needed which takes into account how comorbidities influence not only mortality rates, but also the lived experiences of this population in order to identify points and priorities for intervention.

Citing the disproportionate burden of cancer on non-White populations, Kim & Schulz (2008) note that the subsequent burden on families remains largely unknown. It has been noted that African American caregivers tend to be older, are less likely to be married, have lower income and wealth, are less likely to use formal services, and often provide more assistance to their care recipients than caregivers of other racial and ethnic groups (NAC, 2009; Dilworth-Anderson, Williams, & Gibson, 2002). How racial disparities in caregiver chronic disease burden influence patient and caregiver outcomes is an important area of future research. A life course approach to this research could provide insight into how the cumulative experiences of patients and caregivers of color over the course of their lives influences their health-related beliefs and practices (Pearlin, Schieman, Fazio, & Meersman, 2005; MaloneBeach, Skeel, & Inungu, 2004). This orientation should also give appropriate attention to the social and familial contexts where health and illness occur (Jackson, Knight, & Rafferty, 2010; Pearlin et al., 2005). This information would be useful for advocacy and programmatic efforts to improve the health of this population before, during, and after disease occurrence.

**Multiple health behavior change.** The findings from my dissertation studies lead me to consider a number of additional research questions. For example, my first study examined the

influence of conditions/comorbidities on exercise, diet and sleep behaviors. There is growing attention to research and interventions that focus on multiple health behavior change within individuals. This work highlights the co-occurrence that often exists between health behaviors and commonalities in theoretical principles of behavior change (Noar, Chabot, & Zimmerman, 2008; Prochaska, Spring, & Nigg, 2008). A parallel line of research could examine multiple health behavior change within a dyadic context. That is, how might an increase in patient exercise influence their caregivers' attention to diet? This work may be especially informative where patient and caregiver prioritization of certain health behaviors may differ, but their shared social and familial contexts provide opportunities for mutual influence and support.

**Family and collective efficacy.** The hypotheses and results from my second study could be extended to consider how family-related self-efficacy influences collective coping efforts. Existing frameworks of dyadic and communal coping take into account appraisal and coping processes at the familial level (Bodenmann, 1995; Lyons, Mickelson, Sullivan, & Coyne, 1998). These frameworks highlight individual and collective efforts to manage stress or adversity and the mechanisms that facilitate shared coping experiences. Future research could examine the use of these frameworks to design cancer interventions that consider other member of the family system. Especially where caregivers have their own significant health challenges, these frameworks could guide research that investigates the extent that other family members participate in caregiving tasks for the patient and caregiver.

**Meaning-based coping and post-traumatic growth.** In my third study, I identified caregiver meaning-based coping as a mediator of the relationship between comorbidities/conditions and quality of life. Some research has begun to consider how caregiver meaning-based coping contributes to their post-traumatic growth during the bereavement period (Bernard-



DuBenske et al., 2008; Wong, Ussher, & Perz, 2009). Another line of research could examine how patient *and* caregiver meaning-based coping during illness/caregiving experiences contribute to caregiver post-traumatic growth. That is, does patient meaning-based coping influence caregiver post-traumatic growth during bereavement? What is the impact of patient and caregiver meaning-based coping on the grief process of the broader family system? How does the meaning-based coping of the caregiver and broader family system influence their individual and collective coping during bereavement? Lastly, how might this research be used to better support caregivers and families during this time?

**Depression.** In this dissertation, patient and caregiver reports of depression as a health problem were included in the count of their number of chronic conditions. Though a small number of patients and caregivers reported additional health problems during the follow-up data collection periods (Time 2 & Time 3), most often, the “new” problem reported was depression. In addition, the measure of symptom distress included two items related to depression and psychological functioning. These items assessed the frequency and severity of both mental distress and fatigue. Past research indicates that poor mental health is significantly associated a number of important patient and caregiver health outcomes, including engagement in exercise, diet and sleep behaviors (Seime & Vickers, 2006; Blaine, 2008; Riemann, Berger, & Voderholzer, 2001), cognitive appraisals and quality of life (Kershaw et al, in progress). Thus, future research should examine depression independently as a patient and caregiver health condition of interest and/or as a moderator of the study findings presented here.

**Gender.** Across each of my dissertation studies, gender was significantly associated with study outcomes. In the first study, being a female patient was associated with less patient exercise (Time 1); being a female caregiver was associated with worse patient sleep (Time 1);

and being a female caregiver was associated with better patient exercise (Time 2). In the second study (total sample analysis), having a female patient was associated with less caregiver threat; however, the effects of gender on threat and self-efficacy differed across comorbidity burden groups. In the third study, *having* a female caregiver was associated with lower patient meaning-based coping; however, *being* a female caregiver was associated with higher caregiver meaning-based coping.

Though the gender-related findings are mixed, as with many other health issues, the results suggest that gender is an important influential factor. Gender has been defined as a socially constructed category that is associated with certain roles, expectations, and behaviors based upon societal beliefs (Brayboy Jackson & Williams, 2006). Overall, research has shown that women are more likely to be caregivers than men (Lin, Fee, & Hsueh-Sheng, 2012) and this was also true in this study sample where approximately 6 out of 10 caregivers were women. The family environment serves as a key context in which individuals learn about expectations of men and women. Evidence suggests that women are socialized to be nurturers and to be more relationship oriented, and thus, they may identify more with the caregiving role than men and devote more time to caregiving related tasks (Lin, et al., 2012; Gerstel, 1994). From this perspective, serving as a family caregiver is viewed as a way for women to confirm social norms and as a way of generating social approval (Lin, et al., 2012). However, the reasons men have historically been less likely to serve as family caregivers also extend beyond socialization processes. Historically, women caregivers did not work outside of the home (Talley and Crews 2004). A strong argument can be made that the broader social context, as well as opportunities in education and employment have influenced the unequal proportion of men and women who serve in this role (Bird & Rieker, 2008).

According to Risman (2004), gender creates different opportunities and constraints based upon the biological and physiological characteristics that define men and women. Some dyad studies have found that women report more distress than men regardless of whether they occupy the caregiver or care recipient role (Segrin, Badger, & Harrington, 2012). This may be partially due to the desire of men to adhere to traditional forms of masculinity, which promote ideals about strength and may make it difficult for them to acknowledge “vulnerable” emotions such as anxiety and worry (Davis-Ali, Chesler, & Chesney, 1993). This has implications assessing the burden that men face in the caregiving role and evaluating research evidence that suggests that women experience more burden as caregivers.

Though a substantial amount of evidence shows that women seem to have larger social networks than men, some studies have found that men may receive more help in their roles as family caregivers than women (Sandberg, 2006). This may be due to gendered expectations about caregiving. Men may be viewed as needing more help because the caregiving role is not one that they are expected to be able to handle. Gender differences in approaches to caregiving among married couples have also been noted. Men tend to be more task-oriented and authoritative while women may strive to help their husbands maintain their autonomy (Sandberg, 2006). In this way, men and women can be seen as striving to help men maintain the traditionally masculine and autonomous role as head of their relationship whether they are caregivers or care recipients.

It would be useful to examine gender as a moderator of the conceptual relationships examined in my dissertation. Data from the study suggest that in many dyads, both patient *and* caregivers are battling health challenges. As a result, men and women may at times be simultaneously playing the roles of both caregiver and care-recipient. This stands in contrast to

previous research, which looked at the influence of gender on one role or the other. It could be that where men and women are engaging in both patient and caregiver roles, the gender differences usually observed in these roles may be less distinct.

### **Implications for Practice**

The study findings suggest that practitioners who support the wellbeing of patients with advanced cancer and their caregivers should consider how their pre-existing health problems influence their health-related outcomes. Based on stress and coping theory, I hypothesized that the influence of comorbidities/conditions on the outcomes of interest would be negative. In many cases this hypothesis was confirmed. Barriers to self-management include decreased physical functioning, financial constraints, low self-efficacy, and inappropriate social support (Bayliss, Ellis, Steiner, & Main, 2005). It is possible that these barriers are driving some of the results; in a practice setting, an assessment of these barriers could lead to more effective interventions with patients and caregivers to help them work through these obstacles.

In the first study (Ch.2), however, the results suggest that having more chronic conditions was associated with better health behaviors at the second and third time point. It was noted that increased medical encounters, as a result of having more conditions (and more health professionals to visit to manage those conditions) could lead to more opportunities for interventions and support. It should be noted, however, that the strategies used to manage chronic conditions (e.g. medication adherence, engagement in healthy behaviors) are similar across a range of health problems (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). As a result, it could be that having just *one* health professional who works effectively with patients or caregivers on improving self-management behaviors contributes to the observed results. A great opportunity exists for clinicians to engage with both members of the dyad regarding their health

issues and disease self-management during medical encounters. Doing so could help the individual improve chronic disease management - which help across a range of health issues – and in the case of the patient/caregiver dyad, contribute to self-care improvements for both individuals.

There are a number of successful interventions for patients and caregivers with cancer. While a strength of these interventions is a focus on the psychosocial impact of cancer and caregiving (Northouse, Katapodi, Song, Zhang, & Mood, 2010), the extent to which they focus on the additional stressors and functional limitations involved with pre-existing patient and caregiver chronic conditions is unknown. It may be helpful to consider how existing chronic disease management frameworks and interventions can be used to enhance interventions focused primarily on the cancer/caregiving experience. For example, in their framework for the study of self-and family management, Grey and colleagues (2006) describe how individual and familial risk and protective factors influence their disease management, quality of life, behaviors and use of health resources. Moreover, attention to comorbidities/conditions may provide opportunities for practitioners to build upon the strengths that already exist within dyads as a result of their previous and ongoing health challenges.

Patient/caregiver dyads may also benefit from practitioners who understand that patients and caregivers may be helping other family members cope with the illness and its consequences. Where patients and caregivers are providing this support, it may be useful to support their efforts with interventions that include other members of the family system. According to Gallant (2003), family coping should be considered as a part of chronic disease self-management. Practitioner support of family coping could focus on improving communication, relationship quality, and their ability to work as a team in support of each other's wellbeing. Furthermore, in addition to a

“primary caregiver,” other family members may take part in care tasks (Stommel, Given, & Given, 1998). Their inclusion in interventions could strengthen the work of family caregiving teams. Given the variability that exists between patient and caregiver dyads (e.g. age, functional limitations, health status, income, relationship type) and their families, it will be useful for practitioners to take their individual and collective needs into consideration.

Lastly, it is important to note that while families are often a source of support for patients and caregivers, no family system is without challenges. For some patient/caregiver dyads and their broader family systems, communication problems and ongoing family conflicts may exacerbate the stress of an advanced cancer diagnosis and caregiving. In these cases, family interventions with social workers, psychologists, clergy or other professionals trained in supporting families during challenging times may be beneficial. This type of work may need to precede or happen alongside the implementation of other interventions focused on family disease management or coping.

### **Implications for Policy**

The benefits of palliative care for patients and families include better symptom management, strengthened coping efforts and increased quality of life (Gaertner, Weingartner, Wolf, & Voltz, 2013; Yoong et al., 2013). Palliative care can begin from the point of cancer diagnosis; however, many patients do not begin using services at that time (Gaertner et al., 2013). A number of key barriers to the use of palliative care include the separation of palliative care from hospice services and lack of comprehensive coverage for palliative care in many insurance policies (Foley & Gelband, 2001). In addition, misconceptions about the use of palliative and hospice care services by families are also believed to contribute to decrease usage (Foley & Gelband, 2001). For patients and families managing multiple chronic conditions, in

addition to advanced cancer, palliative care services can assist with multidimensional concerns and help coordinate care between physicians (Ritchie, Kvale, & Fisch, 2011). Improved reimbursement for palliative care services, and better integration of palliative care into existing care programs, could improve patient quality of life and subsequently, that of the caregiver (Foley & Gelband, 2001).

Palliative care could also be expanded to include a more explicit focus on caregiver health. Caregiver assessments have been identified as a useful technique for understanding and addressing caregiver needs in order to improve the health of caregivers and the individuals for whom they provide care (FCA, 2006). There are number of challenges to caregiver assessment in health settings. First, in comparison to diseases that progress slowly over time, a cancer diagnosis is unexpected. Though the period of time for cancer caregiver may be more limited, the time spent caregiving is often more demanding than other types of care situations (Kim & Schulz, 2008). As a result, early intervention is highly important. In addition, caregiver assessments are not a standard part of patient care. Policies regarding timely caregiving assessment, and the provision of palliative care to address their needs, could be useful. While many assessment tools exist, not all of them ask specifically about caregivers' physical health (Northouse, Williams, Given, & McCorkle, 2012; Snyder, 2005). These study findings suggest that a measure of caregiver chronic conditions may be an important item to include in such assessments.

## **Conclusion**

The importance of supporting patients and caregivers throughout the trajectory of advanced cancer cannot be understated. The challenges of the disease and its consequences are substantial. Unfortunately, for many families, advanced cancer is not the only health problem

that they face. The conceptual framework designed for this dissertation research was built upon the presumption that patient and caregiver health and wellbeing after a cancer diagnosis is intertwined. It is guided by the notion that an understanding of the health of one member of the dyad is incomplete without considering the health of the other. This interdependent orientation is not novel; however, the challenges of translating this research into practice remain. The complexity of interventions seem to grow exponentially when moving from a focus on single individuals and solitary health outcomes to groups of individuals with multiple and competing needs and concerns. Yet this type of work is a reflection of the lived experience of many families. As a whole, the findings from this dissertation study suggest that a comprehensive view of patient and caregiver health may be useful for understanding factors that influence their wellbeing and designing interventions to support them.



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