PAIN AND FATIGUE SEVERITY AND FREQUENCY: CONGRUENCE BETWEEN CANCER PATIENTS AND THEIR FAMILY CAREGIVERS

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ABSTRACT

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Family caregivers are asked to provide patient care, specifically assisting symptom management, at home, but their reliability of symptom management and assessment for patients is challenged because of the low agreement between patients' and caregivers' symptom reports. There is a gap in the knowledge in that a lack of a theory or model has been used to illustrate the scenario of a low level of congruence of symptom perception between patients and caregivers. The study developed the framework of Empathic Accuracy of Symptom Perception (EASP) based on Davis's Empathy Model and Ickes's Empathic Accuracy. Given's Family Care Model was used to support empathic accuracy in the context of the caregiving environment. EASP was conceptually defined as the similarities in the cognitive appraisal of patients' cancer symptom experiences between family caregivers and patients. Empathetic accuracy was operationally defined as congruence of pain and fatigue severity and frequency. The specific aim of this research was to examine how caregivers' emotionality (caregiver depression) and caregivers' threats of caregiving (caregiver burden) predict EASP (congruence of pain and fatigue severity and frequency), when taking into account contextual factors of caregivers (age, sex, education, relationship to patients, observation of the total number of patients' symptoms, and living arrangement).

This is a cross-sectional, descriptive study adopting the data from the study entitled Family Home Care for Cancer- A Community-Based Model (# R01Ca-79280). A total of 225 cancer patient-caregiver dyads were examined regarding their reports on severity and frequency of patients' pain and fatigue in the seven days prior to the baseline interview.

The results show that congruence of pain and fatigue severity and frequency between patients and caregivers was at a fair-to-moderate level (ICC = 0.3 ~ 0.5). The Odds Ratio (OR) of caregivers' congruence versus noncongruence of pain severity was decreased by a higher score of caregiver depressive symptoms, a greater number of patient symptoms, and caregivers living with patients, while congruence was increased by caregiver self-esteem. The OR of caregivers' underestimation versus congruence of pain frequency was decreased by 46% when one point of schedule interruption increased (95% CI of exp [-0.62] = 0.4 - 0.83). The OR of caregivers' underestimation versus congruence of fatigue severity was increased 10% by caregivers perceiving one more patient symptom (95% CI of exp [-1.02] = 0.81 - 1.01). The OR of caregivers' underestimation versus congruence of fatigue frequency was decreased by 23 % when caregivers recognized one more patient symptom (95% CI of exp [-0.14] = 0.77 - 0.97). Developing the EASP framework can enrich knowledge of family caregivers' empathy related to symptom management. Clinical care providers need to acknowledge that caregivers' awareness of patient symptoms and their congruence of symptom perception may be a sign of caregiver burden and caregiver depressive symptoms; therefore, caregiver burden and depression may be detected early. Nursing research is encouraged to integrate the EASP framework that can develop the approaches for caregivers' empathic accuracy and also to strengthen the generalization of this framework. Health policies are needed to advocate for family caregivers as partners in the health care system to ensure that care resources are available and the coordination for patients and their families occurs.

DEDICATION

This work is dedicated to my parents who were family caregivers for my grandfather who passed away because of non-small cell lung cancer. It is also dedicated to all the cancer patients and their family members whom I took care of and communicated with. Their experiences have inspired me to enter into the research area of family cancer care.

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Overview

Purpose

The purpose of this research is to examine how caregivers' emotionality and perceived threats of caregiving impact empathic accuracy of symptom perception (EASP) between caregivers and their cancer patients. This research also explores empathic accuracy of patients' symptom perception between family caregivers and cancer patients, which the primary investigator operationally defined in this study as congruence of symptom perceptions. This study begins to create a theoretical framework examining the relationships among caregivers' emotionality, caregivers' threats of caregiving, and empathic accuracy while considering the effect of caregivers' characteristics.

The purpose of this chapter is to provide a brief overview of the cancer caregiver population and care demands related to cancer symptoms, of empathic accuracy (congruence) of symptom perception in the study, and of the factors influencing empathic accuracy (congruence) of symptom perception between caregivers and their cancer patients. The specific aims and hypotheses of this study are introduced at the end of this chapter. Likewise, this study illustrates how the conceptual framework of EASP and these findings may contribute to new nursing knowledge, to new research perspectives, and to the implementation of the framework of EASP for cancer family care, all of which demonstrate this study's significance for nursing science.

Background

Cancer caregiver population. Family caregivers generally are family members who provide care for patients without medical training or payments (Family Caregiving Alliance, 2011). Family caregivers of patients with cancer provide vital and continued physical and emotional support for patients, helping them to endure the cancer experience at home. According to the National Alliance for Cancer and the American Association of Retired Persons [NAC and AARP] (2009), more than 65.7 million informal caregivers take care of their family members, who have had diagnoses varying across all chronic conditions in the United States. In the general caregiver population, caregivers are predominantly female (66%) and are 48 years of age on average. In addition, 7% of adult family caregivers are providing care for their adult family members with cancer. In cancer families, involvement of family caregivers is essential for optimal treatment and treatment compliance, continuity of care, and social support (Glajchen, 2004). Most family caregivers of adult cancer patients are spouses, partners, or adult children. Relatives, close friends, or neighbors may take this role when the primary family caregiver is not available (ACS, 2010; Mintz, 2007; Paul, Kurtz, & Mentzer, 2007).

For patients with illnesses or disabilities, the majority of care demands are daily life activities and instrumental activities (56%). Their caregivers spend 20 hours per week on average providing care, and 13% of caregivers provide 40 hours or more. Seventy-four percent of caregivers have continued working while managing caregiving responsibilities. On average, the length of caregiving is 4.3 years (NAC & AARP, 2009). According to the American Cancer Society [ACS] (2010), cancer families provide about 80% of home-care services. Most caregivers whose patients were diagnosed with cancer spent more than 15 hours per week providing care at home in the first year (Van Houtven, Ramsey, Hornbrook, Atienza, & van Ryn, 2010; van Ryn et al., 2011). Kim, Baker, Spillers, and Wellisch (2006) also found that cancer and dementia family caregivers spend approximately 30 hours per week providing patient care at home. Performing cancer care at home is time-consuming, and time demands increase along with patients’ changing dependency needs.

Cancer is a life-threatening disease: Malignant neoplasm has been the second leading cause of death in the United States for five years, according to the Centers for Disease Control and Prevention mortality report (CDC, 2009), despite the declining mortality in the cancer population (Jemal, Center, DeSantis, & Ward, 2010). Typically, when the cancer-related symptoms appear, symptom management becomes a major part of family caregivers' responsibilities. However, cancer patients and their families are usually not familiar with their dynamic characteristics during the course of treatment. (ACS, 2010; Fan, Filipczak, & Chow, 2007). Caregivers are required to pay more attention to new care demands related to patients' symptoms. van Ryn et al. (2011) focused on the caregivers who provided at least 50% of informal care for patients who were diagnosed with lung and colorectal cancer, and found that family caregivers provided cancer-specific clinical care, including monitoring side effects of treatments (68%), managing symptoms (47%), administering medication (34%), making decisions for contacting doctors (30%) and for providing medicine (29%), and changing wound dressing (19%). Regarding the reports of van Ryn et al., symptom management is the most prevalent caregiving activity aside from assisting with patients' daily activities. Therefore, most care requirements for caregivers occur during patients' in the treatment phase. In this circumstance, caregivers become not only proxies for cancer patients in reporting cancer patients' symptoms to formal care providers and in assisting with symptom management at home, but also partners with professional health care providers.

The experience of cancer can introduce various threats into the family. The threat of death from cancer is perceived not only by patients, but also by most family caregivers. Family caregivers may also image threats from providing care because care demands can interrupt caregivers' lives, which has been recognized as *caregiver burden* (Grunfeld et al., 2004).

Perceiving patients' symptom burdens in order to provide symptom management for patients can impact caregivers' own lives (Palos et al., 2011). Caregivers have to readjust their lives for those caregiving situations. In addition, perceiving patients' symptoms and assisting with symptom management are acknowledged as ongoing care demands placed on caregivers. Caregivers may project a threat from providing patient care to their living quality. There may be a relationship between caregivers' accurate perceptions of patients' cancer symptoms and their perceptions of the threats of caregiving. Developing the conceptual framework of EASP can contribute to supporting nursing research in symptom management.

Congruent levels of symptom perception as a measure of empathic accuracy. This study develops a conceptual framework of EASP (see Figure 1) using theoretical support from three theories: empathic accuracy (Ickes, 1993), the empathy model (M. H. Davis, 1996), and the family care model (FCM; B. Given, 1995). The concept of empathic accuracy refers to the "perceivers' capability to accurately infer the actors' thoughts and feelings" (Ickes, 1993). The present research, inspired by Ickes's definition of empathic accuracy, examines caregivers' accurate perceptions of patients' cancer symptoms while caregivers use their cognitive appraisals to be accurate in perceiving patients' symptoms**.** Therefore, in this study, *empathic accuracy of symptom perception* is conceptually defined as family caregivers' and patients' similarities in the cognitive appraisal of patients' cancer symptom experiences. Furthermore, empathic accuracy has a parallel definition as "interpersonal accuracy." According to the empathy model (M. H. Davis, 1996), having "interpersonal accuracy" is one of the results from empathic processes that can determine perceivers' behavior toward other persons. Having interpersonal accuracy is referred to as the largely cognitive outcomes through processing cognitive and affective empathy.

Ickes (1993) suggested that a straightforward way to measure empathic accuracy is to compare the actor's actual experience with that of the perceiver's corresponding inferred perceptions of him or her , EASP is operationally defined as the "congruence of symptom perception," which measures the caregiving situation where family caregivers and patients have similar perceptions of patients' symptoms, specifically focusing on severity and frequency of pain and fatigue.

Several studies measuring congruence between caregivers and care receivers have found that caregivers' reports of cancer-related symptoms were low in congruence (Kurtz, Kurtz, Given, & Given, 1996, 2006; C. Lin, 2001; McPherson, Wilson, Lobchuk, & Brajtman, 2008; Tu & Chiou, 2007; Wennman-Larsen, Tishelman, Wengstrom, & Gustavsson, 2007). In a few studies on congruence of symptom perception, researchers have reported the specific caregiver characteristics– such as caregiver burden, male caregivers, and older caregiver–which are correlated with low congruence (Broberger, Tishelman, & von Essen, 2005; McPherson, et al., 2008; Wennman-Larsen, et al., 2007).

Factors related to empathic accuracy (congruence of symptom perception). Theoretically, a perceiver will be less able to empathize with the target person and also feel less empathic accuracy if the individual perceives a threat in his or her situation, such that perceiving threats may decrease empathic accuracy (Ickes, 1993; M. H. Davis, 1996). For family care situations, the threats of caregiving in the present study are conceptually defined as caregivers perceiving threats from providing care. Indeed, some studies have reported that caregivers with feelings of burden have lower likelihood of congruent perception of patients' symptoms (McPherson, et al., 2008; Wennman-Larsen, et al., 2007). Because caregiving is demanding and impacts caregivers' lives, some caregivers may perceive these caregiving circumstances as threats. Glajchen (2004) emphasized that cancer caregivers often operate within caregiving situations and without preparation. Given, Sherwood, and Given (2011) reinforced the necessity of caregiver involvement in patient care after patients received cancer treatment because symptom management can be a core responsibility of care through treatment and into to post-treatment. Caregivers may feel burdened when their lives are continually interrupted because they are providing care to meet patients' demands. In that manner, a caregiver may perceive this burdensome caregiving situation as a threat. In the present study, the threats from providing care that caregivers perceived are represented by caregiver burden.

Caregiver emotionality. Empathy may be influenced by emotionality and perceivers' negative emotionality, such as sadness and anger, which can lessen their abilities for cognitive empathy (M. H. Davis, 2006; Eisenberg & Eggum, 2009; Eisenberg, Eggum, & Di Giunta, 2010). In the current study, *caregiver emotionality* is defined as caregivers' mood expressions, such as anxiety and depression. Depression is frequently recognized in the family caregiver population as an indicator of caregivers' poor mental health resulting from long-term, stressful caregiving circumstances in which caregivers have not developed sufficient knowledge or strategies to cope with dynamic care demands (National Family Caregivers Association, 2010; Pellegrino et al., 2010; Rivera, 2009). Therefore, in the current study, emotionality is referred to as caregiver depression. Primary investigator hypothesizes that increasing caregivers' depression levels may decrease their ability to accurately perceive patients' symptoms.

Furthermore, feelings of burden that are related to providing care may generate negative emotions, such as depression, in caregivers. Studies found that a high correlation (r= 0.3- 0.6) between caregivers' reports of caregiving burden and depression (Clark & Diamond, 2010; Grunfeld, et al., 2004; Y. Kim, Duberstein, Sorensen, & Larson, 2005; Kurtz, Kurtz, Given, &

Given, 2004). In this regard, caregivers' emotionality and threats of caregiving may be covariants and may have an effect on caregivers' EASP. Therefore, it raises the critical question of whether caregivers' emotionality (depression) can predict low empathic accuracy (congruence of symptom perception) for nursing science. In the meantime, this study presumes that the congruence of symptom perception is an important factor in determining how caregivers provide appropriate symptom management. Exploring how caregivers' emotionality (depression) and their perception of threats (caregiver burden) are related to caregivers' empathic accuracy (congruence of symptom perception) may help to understand the phenomenon of caregivers' EASP in nursing science and may also help nursing practice in assisting caregivers to perform symptom management for patients. The issue has not been tested in previous research, but this study will fill that gap.

Caregiver demographics. Caregivers' demographics are related to caregiver depression and caregiver burden (Family Caregiving Alliance, 2009). Caregivers' demographics may indirectly affect EASP. Previous studies have shown that caregivers who are older and female tend to have perceptions about symptoms that are congruent with patients' perceptions (Broberger, et al., 2005; Wennman-Larsen, et al., 2007). However, the effects of these characteristics on congruent levels of symptom perception were inconsistent between studies. Caregivers with low education have correlated with noncongruence, which may be because education is related to the ability of understanding and receiving information (C. Lin, 2001; Yeşilbalkan & Okgün, 2010). While laypersons might suspect that spousal caregivers would be most likely to have congruence when compared with nonspouses, this has not been supported by research findings (Broberger, et al., 2005; McPherson, et al., 2008; Wennman-Larsen, et al., 2007). Therefore, this research will examine the impact of caregivers' age, sex, and relationship to patients on empathic accuracy (congruence of symptom perception).

Cancer-related symptoms. The current study uses pain and fatigue to represent cancer-related symptoms. Although different cancer diagnoses may generate different symptoms, pain and fatigue are the most common symptoms of cancer and cancer treatments (National Institutes of Health State-of-the-Science, 2004). Cancer patients commonly report pain as the most unpleasant symptom, and unrelieved pain interrupts a patient's quality of life. The multidimensional nature of pain can make effective pain management more difficult (Delgado-Guay & Bruera, 2008; McGuire, 1995; van den Beuken-van Everdingen et al., 2007). Furthermore, fatigue is the most prevalent symptom in patients' daily lives and is related to receiving aggressive treatment and/or cancer malignancy (Bower, 2007; Diaz et al., 2008; Ryan et al., 2007). In the studies that identified symptom clusters, pain and fatigue commonly shared the same related symptoms, such as depression and sleeping problems (Donovan & Jacobsen, 2007; Fan, Hadi, & Chow, 2007; B. A. Given, Given, Sikorskii, & Hadar, 2007; E. Kim et al., 2009), and these related symptoms are commonly identified as the ones that most influence patients' physical functioning (B. Given, Given, Azzouz, & Stommel, 2001; B. A. Given, et al., 2007; Miaskowski, 2010). Therefore, pain and fatigue should be a priority to be measured for empathic accuracy of symptom perception.

In addition, the present study examines symptom severity and frequency. Symptom experiences are multidimensional and consist of the following characteristics: distress, which is highly correlated to intensity (severity); occurrence, which includes duration, prevalence, and frequency; and quality, which includes interference (Armstrong, 2003; Dodd et al., 2001). Severity and distress have been commonly measured to represent symptom burden, because the levels of severity and distress have the most interference with a patient's quality of life; but symptom severity is suggested to positively determine the patient's distressful perception of symptoms (H. J. Kim & Abraham, 2008; Kirkova et al., 2010). Some studies have also reported that an increase in frequency and severity of symptoms can impact a patient's performance of daily physical functioning and worsen a patient's quality of life (Lutz et al., 2001; Mercadante, Casuccio, & Fulfaro, 2000). Meanwhile, severity and frequency are convenient measurable symptom characteristics for caregivers to use at home when assessing patients' symptom burden. In the present study, EASP will be measured by comparing cancer patients' and caregivers' perception of pain and fatigue severity and frequency.

Furthermore, congruence of symptom perception has been suggested as a guide for caregivers in providing appropriate symptom management. Unrelieved pain and fatigue can limit patients' physical functioning and lower patients' quality of life (B. A. Given, et al., 2007; Miaskowski, 2010), which may indicate that EASP is important for patients' quality of life. Silveira, C. Given, B. A. Given, Rosland, and Piette (2010) have published the only study examining the relationship between congruence of symptom severity and frequency and health outcomes of patients and caregivers. They reported that patients whose caregivers' symptom perceptions were congruent with the patients' self-reports were more likely to have better quality of life. Their findings may imply that helping caregivers to achieve congruent perceptions of patients' symptoms may theoretically improve patients' quality of life. The gaps influencing the development of empathic accuracy in the family care environment are (a) prior studies have not oriented by theoretical perspectives, (b) prior studies have also not examined any of the relationships among EASP, appropriate symptom management, and the impact patients' quality of life; (c) EASP in family care has been neither described in the caregiving theories or supported by nursing theoretical perspectives; and (d) it has not been tested empirically.

Therefore, a long-term goal of this research is to build on the EASP conceptual framework to design studies that can enrich the understanding of empathic accuracy in cancer family care.

This present study, however, will focus only on exploring EASP (congruence of pain and fatigue severity and frequency), and how caregiver emotionality and caregiver perceptions of threats of caregiving predict EASP, as depicted in the conceptual framework of EASP.

Specific Aims

The purpose of this research is to examine how caregivers' emotionality and perceived threats of caregiving impact EASP between caregivers and their cancer patients. This research will also explore empathic accuracy of patients' cancer symptom perceptions. As stated above, caregivers' empathic accuracy is operationally defined as congruence of symptom perception, severity, and frequency of pain and fatigue between cancer patients and family caregivers. The congruent levels of pain and fatigue severity and frequency will be measured in this study by examining the value of the difference between patients' scores and caregivers' scores of patients' pain and fatigue severity and frequency. If the score difference is close to zero, indicating similar scores between patients and caregivers, then congruence of pain and fatigue and frequency between patients and caregivers is high, and vice versa. Noncongruence is also categorized as overestimation when a caregiver's score is higher than a patient's and underestimation when a caregiver's score is lower than a patient's. Emotionality is operationally defined as caregivers' depressive symptoms, and perception of threats related to caregiving is represented by caregiver burden.

This study used a secondary data analysis for 225 pairs of cancer patients and family caregivers, adopted from the parent study entitled Family Home Care for Cancer—A Community-Based Model (# R01Ca-79280). The specific aim of this research is to examine how caregivers' emotionality (caregiver depression) and caregivers' threats of caregiving (caregiver burden) predict EASP (congruence of pain and fatigue severity and frequency), when taking into account contextual factors of caregivers–including caregivers' age, sex, education, relationship to patients, and total number of patients' symptoms that caregivers observe, as well as living arrangement–as they can influence caregivers' emotionality and threats resulting from caregiving.

Hypotheses. The two hypotheses for this study are:

1. Increased caregiver depression and caregiver burden will be related to lower congruent values of pain and fatigue severity and frequency.

2. Caregivers who are female, older, patients' spouses, better educated, perceiving a lower number of patients' symptoms, and living with patients will have greater congruence of pain and fatigue severity and frequency than will caregivers, who are male, younger, nonspouses of patients, less educated, perceiving a higher number of symptoms, and not living with patients.

Significance for Nursing Science

This conceptual framework of EASP has the potential to make a significant contribution to nursing science in the areas of theoretical nursing knowledge, new strategies for research, and implementation of cancer care. The framework of EASP depicts that both emotionality and threats of caregiving can influence caregivers' perceptions of patients' symptom experiences, thereby affecting the congruent levels of symptom perception between patients and caregivers.

New knowledge for nursing. The EASP framework has been developed by applying the theoretical perspectives of Ickes's empathic accuracy in psychological therapy, Davis's empathy model in psychology, and Given's family care model in nursing science. Most prior studies, aimed at identifying discrepant symptom perceptions between cancer patients and caregivers, have not oriented themselves with theories or models, but mainly have addressed the unreliability of caregivers' perception of patients' symptoms. This focus kept most of these studies at the level of description for caregivers' accurate perception of patients' symptoms. Therefore, the present study will extend the science by synthesizing empathy theories in caregiving research.

The EASP framework has been established to understand the caregiving situation in the family. M. A. Davis (1994) described empathy as people's general temperament, and Ickes (1993) described empathic accuracy as the nature of everyday mind reading, so that being empathic naturally happens in people's daily lives. The perspective of this research is that caregivers' empathy may lead caregivers to be more likely to accurately perceive patients' symptoms because, today, most cancer care has shifted to home and provided by family caregivers; caregivers' empathy may encourage them to make an effort to understand patients' symptom burdens. Patients' symptom burden often refers to their physical, psychological, social, and spiritual problems related to cancer and anticancer treatments. Testing this set of relationships is the focus of this study, and sets the stage for future work aimed at examining empathic accuracy of patients' symptom experience.

Although the perspective of empathic accuracy came from Ickes, Ickes's own study applied this conceptualization of empathic accuracy in order to differentiate various statuses of relationships–such as dating relationship, spousal relationship, and friendship–between the perceiver and the target person. Few studies have used the concept of empathic accuracy in the symptom perception of caregiving dyads. More research in the area of empathic accuracy within the relationship of caregiving dyads will extend the science of empathy.

New strategies for nursing research. This study has developed the framework of EASP to conceptualize empathic accuracy that includes the influence of the factors of emotionality and perceived threats of caregiving. At least 30 previous studies have shown congruence or noncongruence of cancer patients' symptoms by comparing patients' self-reports and caregivers' report about patients' symptoms; however, congruence of symptom perception has not been conceptually defined. The framework of EASP allows researchers to develop hypotheses that can account for variations in EASP between cancer patients and their caregivers. The present study also defines congruent levels of symptom perception as a measure of EASP in a caregiving situation, in which family caregivers and patients have similar perceptions of patients' symptoms, specifically focusing on pain and fatigue severity and frequency.

Previous studies also commonly have identified low congruent levels of symptom perception and often have concluded that the reliability of caregivers' reports of patients' symptoms may be questionable. Very few of the previous studies that tested family caregivers' accurate reports of patients' symptoms have extended their investigations to identify how caregivers' characteristics, such as emotionality and perceived threats of caregiving, may pose risks to empathic accuracy. The present study will test the predictive relationship between congruence of symptom perception, caregivers' emotionality, and threats of caregiving. It also will consider the influence of caregiver demographics and has the potential to generate knowledge of empathy accuracy in family care.

Furthermore, the EASP framework shows that there is a logical sequence between empathic accuracy and patients' health outcomes. These sequential relationships between empathic accuracy and outcomes of patients and caregivers have been tested in the subsequent studies. Nursing research can begin to establish research evidence for the relationship between empathic accuracy and caregivers' helping behaviors. Establishing the evidence for empathic accuracy of symptom perception can enrich family cancer care research.

Implementation in cancer care. The EASP framework takes into account the contributions of the affective components of the empathic process to the cognitive outcome of empathic accuracy. This conceptualization acknowledges the fact that caregivers use both cognitive and affective empathic processes to provide daily care for patients, including symptom management and assistance with daily activities. Examining the hypotheses in the present study may support existing research that has emphasized the negative impact of caregiver burden and caregiver depression on cancer caregiving. Several studies have investigated the different strategies to reduce the risk of caregiver burden and/or caregiver depression for caregivers (Honea et al., 2008; Rivera, 2009). However, the present study presumes that both caregiver burden and caregiver depression not only may represent caregivers' health outcomes, but also are important factors that influence caregivers' accurate perceptions of cancer patients' symptom experiences.

The EASP framework shows that accurately perceiving patients' symptoms is an essential caregiver ability that is presumed to lead caregivers to provide appropriate symptom management. The EASP framework may help nurses to recognize family caregivers' characteristics, such as caregivers with depression and burden, and to take into account caregiver demographics in order to deliver effective nursing interventions for patients and caregiver in expressing symptoms. Caregivers with greater empathic accuracy of patients' symptom experience may help patients alleviate symptom burdens by determining appropriate symptom management. Additionally, empathic accuracy may help caregivers to feel more confident in symptom management, thereby decreasing their burdened feelings from providing care. In conclusion, improving empathic accuracy may benefit cancer patients and their family caregivers.

Limitations of the Present Study. Several limitations exist in the present study. First, the study is a cross-sectional study using baseline data. Caregiver emotionality, threats of caregiving, and empathic accuracy may change because of the dynamic nature of symptoms and caregivers' perception of caregiving. A longitudinal study should be conducted to understand the dynamic relationship among those three concepts. Second, this study focuses on patients who have been newly diagnosed with cancer and who are receiving chemotherapy for the first time. The results may not be generalized to other cancer patients who are not newly diagnosed, are not the first-time recipients of chemotherapy, or have received anticancer treatments different from chemotherapy. Third, this study focuses on identifying how caregivers experience depression and how caregiving burden can impact their ability of empathic accuracy of patients' symptoms. Further research will test the effect of EASP on caregivers' helping behavior and both patients' and caregivers' outcomes. Fourth, this study only selects negative caregiving characteristics (caregiver depression and caregiver burden) to predict low empathic accuracy. There is a lack of knowledge on whether or not caregivers who have positive perceptions about providing care can enhance EASP. Fifth, this present study does not test the entirety of the empathic process as defined by Davis and others in the framework of EASP. Davis's empathy model has demonstrated that both cognitive and affective empathy occur simultaneously, which may imply that it is difficult to determine which empathic outcomes were produced from one process but not from the other. For example, Lobchuk et al (2002) identified five cues (patient-oriented, caregiver-oriented, generalized other, feeling distanced, and other) for different types of perceptive processes that may link with congruence of symptom perception. However, when the studies used those five cues in developing interventions to guide caregivers' perspective-taking process, congruence did not improve (Lobchuk & Degner, 2002; Lobchuk, Degner, Chateau, & Hewitt, 2006). Further study about caregivers' empathic accuracy is needed to examine empathic processes within verbal and nonverbal communication, and consequences and influencing factors of empathic processes in order to develop effective interventions for specific caregiver populations to improve EASP.

Purposes of Chapters

Chapter 2 establishes the model of EASP using theoretical literature in different fields to identify and explore the factors impacting caregivers' EASP (congruence) within a caregiving situation. Chapter 3 reviews the relationships among the concepts within the EASP model by examining the state of science, providing the background for the conceptual framework of the study, including the factors influencing congruent levels of symptom perception and the expected outcomes generated by the concept. The methodology in chapter 4 describes the design of the present study using secondary data and includes a brief introduction of the parent study. Chapter 5 shows the result of analyses regarding the two hypotheses. The discussion of congruence and the discrepancy between the results of the present study and previous studies will be illustrated in Chapter 6.

CHAPTER 2

Theoretical Framework and Rationale

This chapter will establish a conceptual framework for the phenomenon that occurs when family caregivers accurately perceive cancer patients' symptom experiences. The phenomenon describing "the observer's accurate perception toward the other person" has been conceptually illustrated by Ickes (1993) as the concept of empathic accuracy (p.558). *Accurate perception* has been termed as congruence in the prior literature. Because congruence is understood as the quality or levels of agreeing or corresponding, *congruent viewpoint* occurs when two or more people or groups achieve the same opinion or perspective through understanding, negotiating, or communicating (M. A. Davis, 2009; Lobchuk, 2006).

Perception has been described as a capability of understanding by receiving stimulation from the environment and also has been defined as an observation of receiving impressions of the sense or of the mind; synonyms include awareness, sense, and recognition (Bunting, 1988). Armstrong (2003) has described *symptom perception* as the ability to understand symptom experiences that are the perception of the frequency, intensity (severity), distress, and meaning occurring when symptoms are produced and expressed.

Symptom perception is defined in this research as the cognitive activity of recognition of the physical and psycho-social-spiritual state of another person's symptom experiences, including symptom severity, symptom frequency, duration of symptoms, and personal belief system. In this research, the *cognitive ability* of symptom perception includes the dimensions of severity and frequency. In sum, a caregiver perceiving a patient's symptoms is meant as the caregiver's ability to recognize the patient's symptom experiences.

When patient care is provided at home, a family caregiver may live in a caregiving circumstance that is distinctively different from a noncaregivers' living situation. EASP between patients and caregivers has been presumed to be influenced by their characteristics. Given's middle-range model, the Family Care Model (FCM; B. Given, 1995), has been applied to discover the patients' and caregivers' factors of EASP in the home-based care. The FCM describes the caregiving circumstances within the nature of the care demands for patients, such as symptom management and assistance for daily life activities, and how these demands can influence patients' quality of life. The FCM was applied to support the importance of empathic accuracy (congruent symptom perception) in caregiving situations.

Therefore, theoretical concepts were examined and derived from three theories, including Ickes's (1997) empathic accuracy, Davis's (1994) empathy model, and B. Given's (1995) family care model. A conceptual framework was also established for family caregivers' perceptions of patients' symptoms. The following section will use theoretical literature in psychology and nursing to define the concept of empathic accuracy and explore the factors that support or inhibit empathic accuracy.

Philosophical Underpinnings for the Concept of Empathic Accuracy

Perceiving the other's experience has been illustrated and argued to be sympathy or empathy. *Sympathy* is the shared feeling that results when a person observes another person in an emotional state, such that sympathy has a greater component of passive and emotional reactions. *Empathy* is an attempt to understand others' feelings rather than a sharing of them, such that empathy can be accomplished by viewing and interpreting other people's actions, movements, and physical cues. Therefore, empathy is the general attempt to get inside the other in an intellectual capacity (M. H. Davis, 1994; Stueber, 2008). Philosophically, E. Husserl described the phenomenon of empathy as putting one's self into another one's shoes, whereby people make conscious attributions of intentional acts to other subjects. Husserl further has explained that this process involves a perceiver who observes the target person’s situation and projects his or her image of himself or herself in the same situation in order to achieve an understanding of the target person’s feelings. Philosophically, Husserl has stated this empathic experience is an intersubjective one (Beyer, 2011). In sum, a caregivers perceiving a patient’s symptom experience is an expression of empathy.

In psychology, perceiving another person’s feelings or thoughts has been referred to as empathy (M. H. Davis, 1996; Ickes, 1993). Although sympathy may also be inferred to perceive others feelings or thoughts, it simply shows sorrow for another person’s distress, whereas empathy is to understand within cognitive perspectives (Stueber, 2008). Decety and Jackson (2004) also have defined empathy as “a sense of similarity in feelings experienced by the self and the other, without confusion between the two individuals” (p. 71). Decety and Ickes (2009) have stated that empathy consists of affective and cognitive constructs. In addition, empathy includes fully communicating that experience back to the other in an objectively explicit manner (M. A. Davis, 2009; Giacalone et al., 2008).

In the early studies of empathy research, the cognitive activity known as role-taking and its products were examined. Expanding on the cognitive definition of empathy, Hogan (1969, p. 308) has defined empathy as “the act of constructing for oneself another person's mental state.” (as cited in M. H. Davis, 1996, p. 17). Hogan’s definition restricts empathy to the cognitive realm and places the focus on both the outcome and the process. This is the line of research from which this present conceptual model will be developed. Below, the cognitive ability of empathy and the related concept of empathic accuracy will be described and synthesized into this present research. While this research is about caregivers’ perceptions of cancer symptom experiences, I will begin my conceptualization of empathic accuracy with definitions proposed by Ickes and Davis. Then, I will reposition the definitions to focus on perceptions of cancer experiences.

Empathic accuracy. Empathic accuracy has been defined as “a perceiver or an observer is able to accurately infer the specific content of another person’s thoughts and feelings” (Ickes, 1993, p. 388). Empathic accuracy has been used in the study of interpersonal perception in European psychology and philosophy in the late 1940s (Ickes, 1997). M. H. Davis (2006) has described interpersonal accuracy as the successful estimation of other people’s thoughts, feelings, and characteristics that largely results from cognitive empathic processes. Ickes has explained that the ability to have empathic accuracy reflects a person’s capability of complex psychological inferences consisting of observation, memory, knowledge, and reason, which combine to yield insights into the thoughts and feelings to others (Ickes, 1997). From Ickes’s perspective, empathic accuracy is a product of cognitive empathic processes. Ickes et al.’s research on empathic accuracy has assumed that every perceiver has a distinct ability for empathy, so that the determination of the empathic accuracy depends only on the different characteristics of perceivers. Empathetically accurate perceivers are those who are consistently good at “reading” other people’s thoughts and feelings, while empathically inaccurate perceivers are those who are consistently poor at reading other people’s thoughts and feelings.

Furthermore, Ickes’s perspective of empathic accuracy has focused on the accuracy of dyadic interpretation that the observer can recognize and perceive the target person’s thoughts and feelings (Ickes, 1997). Ickes (1993) has reviewed previous studies and found that empathic accuracy can be seen as including four dimensions: (a) perceivers’ accuracy in judging others’ personality traits by relying on inter-rater consensus; (b) dyad members’ accurate perception or understanding of each other’s attitudes, and values that compare partner perspectives within the dyad; (c) perceivers' accuracy or affective sensitivity in inferring emotional states of the target persons; and (d) perceivers' empathetic accuracy related to their abilities to infer the specific content of another person's thoughts and feelings. These empathic accuracy dimensions are cognitive abilities. The present research uses this perspective of empathic accuracy to examine family caregivers' perception of patients' symptoms.

Ickes's research has measured empathic accuracy directly without presumption about the processes that underlie a perceiver's empathy (Ickes, 2009), which may imply that each perceiver is assumed to have empathy for the target person. Ickes and his colleagues' previous studies found that relationship of the dyad is a major factor that can influence the levels of accuracy. A close relationship between the observer and the target person also has been considered a factor that influences empathic accuracy. The observers who have a close relationship with the target person—for example, a dyad of a partner and close friend—are more likely to accurately recognize the changes of the target person's behavior than the stranger. The dyads with close relationships may have better communication, which improves the perceiver's ability of accurate recognition (Ickes, 2007). That may suggest that caregivers' relationships to patients, such as spouse and nonspouse, may influence the level of accuracy. It may also suggest that caregivers who live with patients may have better communication, so that caregivers are more likely to have empathic accuracy. Therefore, relationship to patient will be considered as a personal factor influencing empathic accuracy in the present study.

Likewise, individuals' emotional statuses, such as depression and anxiety, may partially block their affective sensitivity toward the others' feelings (Decety & Jackson, 2004; Decety & Meyer, 2008; Gadassi, Mor, & Rafaeli, 2011). For example, a study examining spouses experiencing moderate levels of depression and perceiving their partners' emotion has found that spouses who were depressed were less likely to accurately perceive their partners' emotions (Tranmer et al., 2003). In that case, the perceiver's emotionality can influence that individual's own affective ability and can also impact cognitive ability to interpret the target person's experience. Based on these results, caregivers' relationship to patients and emotionality can influence caregivers' empathic accuracy. The present study will use the findings of the studies based on Ickes's empathic accuracy model to support the theoretical hypothesis that caregivers' depression can be a negative factor influencing them to be unable to accurately perceive patients' symptoms.

Ickes (1997) has argued that another central impediment to empathic accuracy is when perceivers feel highly threatened. Perceiving threats is specifically related to concerns by the perceiver about the consequences that would likely result from accurately inferring the partner's thoughts and feelings. Ickes's previous studies have shown that when a dyad is in highly threatening circumstances, the members tend to have low empathic accuracy, or they become less congruent (Ickes, 1997). Although Ickes and Simpson's studies have focused on relationship-threatening situations that lead to inaccurate empathy (Simpson, Orina, & Ickes, 2003), Preston and de Waal (2002) have addressed the issue that perceiving threats in any circumstances can make empathy unwieldy. Therefore, empathic accuracy may decrease as a result of perceived threats in certain situations. For example, a caregiver may feel threatened when a loved one receives a cancer diagnosis, especially because cancer is the second-leading cause of death in United States. Family caregivers may also feel threatened if they have very high stress loads in dealing with complex cancer situations, or if they do not have adequate support for their caregiving activities. The issue of threat in the conceptual framework of the EASP (Figure 1) focuses on caregivers' threats from their stressful caregiving lives. The theoretical hypothesis that threat of caregiving can decrease empathic accuracy will be examined in this research.

Ickes's (1993) review also has shown that the empathy process should be understood as having three components: *empathic understanding* (accurately inferring the thoughts and feelings of another person), *empathic expression* (accurately expressing inferred thoughts and feelings that match the actual experience of the other person), and *empathic communication* (the dialogic and dialectical aspect of the empathy process, in which communicative relationships can help in developing empathic understanding). Ickes has presumed that the relationship among these three components is circular, and empathic accuracy is a theoretical term close to empathic understanding and is beneath this circular empathic process. However, in this research, only the cognitive aspect of empathic understanding will be examined. M. H. Davis (1994) has expanded on these processes and also has developed the empathy model, which links personal characteristics, situations, processes, and outcomes to empathic accuracy. In Davis's perspective (1994 & 2006), empathic accuracy is a cognitive outcome of complex empathic processes.

Empathy model. The empathy model (M. H. Davis, 1994, 2006) has described empathy as a process occurring when a person perceives other people, which generates the perceiver's behaviors toward the target person. There are four constructs in the model: antecedence, process, intrapersonal outcomes, and interpersonal outcomes. When a perceiver observes the target person in a certain situation, the perceiver's cognitive and affective empathic processes are activated to generate two levels of outcomes in which the proximal outcomes (intrapersonal outcomes) are cognitive and affective reactions, and the distant outcomes (interpersonal outcomes) are advanced performances of social-relationship behaviors. The present study understands empathic accuracy of patients' symptom perceptions to be a cognitive intrapersonal outcome. In the following section, I will examine the construct of intrapersonal outcomes, specifically focusing on interpersonal accuracy, because interpersonal accuracy has been used by Davis as a parallel term for empathic accuracy.

Davis (1994) has defined *interpersonal accuracy* as the successful estimation of other people's thoughts, feeling, and characteristics, and has described it as one of the cognitive intrapersonal reactions that largely result from the perceiver's role-taking processes. Other cognitive responses include attributional judgment and cognitive representations, which are linked with empathy-related processes of observing the actors' behavior and perspective-taking, respectively. In particular, the perspective-taking process is the observer's cognitive representation of the target person's self (M. H. Davis, 1994). Later, Davis used empathic accuracy as a parallel to his concept of interpersonal accuracy and explained that empathic accuracy is a consequence of an observer using perspective-taking in order to have accurate insights into the target person's thoughts and feelings (M. H. Davis, 2006). Both role-taking and perspective-taking are the attempts of one individual to understand another by imagining the other's perspectives (M. H. Davis, 1994).

In other words, empathic accuracy is interpersonal accuracy, in which the observer cognitively takes the target person's perspective. According to M. H. Davis's perspective of empathic accuracy to caregiving situations, caregivers may use the intrapersonal ability of cognitively taking the cancer patients' perspective about their symptoms, so that they can accurately estimate patients' symptoms. Therefore, empathic accuracy of symptom perception is related to both sides of patients' and caregivers' symptom perception. The communication between caregivers and patients is important in order to understand or accurately perceive patients' symptoms. The importance of communication has been reflected in Davis's model, which addresses the language-mediated association in the cognitive empathic process. Therefore, in the framework of EASP, the communication or negotiation between caregivers and patients will be considered.

In addition, intrapersonal outcomes of empathic processes in Davis's model include affective outcomes (Davis, 2006). *Affective outcomes* are perceivers' emotional expressions in responding to their experiences of the target persons. The most common example is an infant's mimicry (M. H. Davis, 1994; 2006). Feelings of compassion and feelings of discomfort for the target person's experience has been referred to as emotional concern and personal distress, both of which may be associated with sympathy (M. H. Davis, 1994). Affective outcomes in caregiving situations may refer to those caregivers who have depressive symptoms or negative emotions after providing care.

The construct of antecedents of empathic processes in Davis's empathy model consists of personal factors and situational factors (M. H. Davis, 1994; 2006). Perceivers' personal characteristics are related to their emotionality, whereby perceivers tend to become upset or distressed in the face of threatening or annoying situations. The strength of these situations can evoke an emotional response from the observer (M. H. Davis, 2006). Davis (2006) also has stressed that the explanation of empathy within a specific situation must examine features of caregiving environments and of the individuals involved. Affect intensity, a dimension of individual differences, characterizes perceivers' tendencies to experience strong emotional reactions. High affect-intensity perceivers respond with more anger and become more depressed by frustrating stimuli, but also can respond more joyfully to pleasant situations (M. H. Davis, 1996). Given that this emotionality may be important in the caregiving circumstance, caregivers' depression may be construed as a factor that may influence affect intensity. This present research will examine the personal factors of emotionality (measured as caregiver depression) in the empathy process.

The construct of empathic process is important in determining perceivers' reactions when they observe target persons' performances. The empathic process that affects the perceiver's viewpoint in Davis's model (1996) includes noncognitive process (e.g., mimicry) and cognitive process (verbal and nonverbal communication). Applying this perspective of empathy processes to caregivers' perceptions of patients' symptoms, the present study will examine EASP that infers an intrapersonal outcome from complex empathic processes between the caregiving and care-receiving dyad. Although Davis (2006) has pointed out that most cognitive empathic outcomes result from cognitive empathic processes, it is difficult to ignore the contribution of noncognitive processes in empathic outcomes. In other words, both cognitive and noncognitive empathic processes occur simultaneously. In the EASP framework, I will address communication and negotiation to represent empathic processes. Because the present study aims to identify the impact of caregivers' characteristics on EASP, empathic process issues will be examined in future research.

The last construct of importance in Davis's empathy model is the interpersonal outcomes of the observers' behaviors toward the target persons. Being empathic can increase helping behaviors and decrease aggressive behaviors, resulting in cooperation, active support for others, and improved communication; as a consequence, those helping behaviors can improve social relationships in observers and target persons (M. H. Davis, 2006). Regarding the phenomenon of congruence of symptom perception, caregivers who are empathic with patients' symptoms may have empathic accuracy (congruent perception of patients' symptoms), such that they may engage in helping behaviors, such as symptom management or daily activities assistance, for patients. Therefore, patients can generally benefit from caregivers' empathic accuracy (congruent perceptions). However, M. H. Davis also has indicated that aggressive behavior by caregivers sometimes occurs even in cases where high empathic accuracy is displayed. Consequently, the perceivers' empathy or empathic accuracy does not always guide them to perform helping behaviors. In other words, EASP in the home environment does not guarantee that family caregivers will successfully provide symptom management. However, caregivers who did not have empathy or EASP will be unable to carry out an appropriate symptom management programs to help patients.

In sum, the theoretical conceptualization of empathic accuracy relevant to this current research includes the family caregiver's relationship to the patient, caregivers' emotionality, and the perception of threats in the caregiving situation. From Davis's perspective, empathic accuracy is an intrapersonal outcome of elements of the empathy process. People have abilities to comprehend other people in their daily life and specific circumstances. In turn, these experiences can encourage perceivers to perform helpful behaviors or social behaviors. Perceivers' emotional states and perceptions of threats around them is an important antecedent in empathic accuracy. In caregiving situations, family caregivers who have empathic accuracy (congruent symptom perceptions) with their patients may act to relieve those symptoms with helping behaviors; these behaviors can be understood within the interpersonal outcomes of Davis's model. Again, empathic accuracy, the theoretical concept in this research, will use congruence of symptom perception as an operational definition. The full, complex, and dynamic empathic processes that take place in caregiving situations will be examined in future research.

In the current study**,** empathic accuracy is a cognitive act of the caregivers in perceiving patients' symptom experiences through accurate recognition and assessment, so that patients' symptom experiences can be understood. Congruence of symptom perception is used to represent a measure of the caregiver's empathic accuracy**.** A straightforward way to measure empathic accuracy, which has been suggested by Ickes (1993), is to compare the content of the target person's actual thoughts and feelings with the content of the perceiver's corresponding inferred thoughts and feelings. EASP in this present study is operationally defined as the congruent levels of symptom perception, which is a measure of a caregiving situation in which family caregivers and patients have similar perceptions of patients' symptoms, specifically focusing on pain and fatigue severity and frequency. Less congruent symptom perceptions when comparing patients' and caregivers' symptoms scores are differentiated as overestimation and underestimation. Symptom experiences are subjective experiences in which the patient's own symptom perceptions are always used as the referents. Therefore, overestimation occurs when caregivers' symptom scores are higher than patients', and underestimation occurs when caregivers' symptoms scores are lower than patients'.

The theoretical model providing empathy research and the conceptualization of empathic accuracy used in this study illustrate that this research study will focus on the caregiver's perception of the patient's symptoms and will examine the influences of the caregiver's emotionality and perception of threats. In the next section, B Given's middle-range FCM is used to contribute to the development of the conceptual model of EASP.

Middle-Range Nursing Care Model

The FCM has been developed by B. Given (1995) for families of patients with chronic illnesses who are living in the community. In general, the FCM describes the antecedents and consequences of supporting patients' care demands and requirements for family care. Care demands are patients' needs that include usual daily care, such as bathing and dressing;

instrumental daily care, such as transportation and shopping; and symptom management. Antecedents are the characteristics of both patients and caregivers–such as age, sex, and socioeconomic status (SES)–as well as the patients’ disease status and social supports. Consequences of family caregivers involved in patient care fall into health outcomes for both patients and family caregivers (B. Given, 1995).

Typically, cancer symptom management has been the most common care demand for family caregivers who provide care at home (van Ryn, et al., 2011). In the present research, the FCM will be applied to support the framework of EASP (congruent symptom perception) to identify consequences of empathic accuracy in conducting symptom management and maintaining patient health. Because symptom management in the FCM is one of the care requirements that can generate caregiver burden, which may influence patients’ health outcomes, caregivers’ EASP will be regarded here as an influencing factor to determine appropriate symptom management. EASP may fit in the construct of care demands as a source of information that family caregivers can use to provide symptom management.

Other sources for caregivers include formal support (e.g., visiting nurses) informal social support, friends, or secondary family caregivers (B. Given, 1995). Therefore, EASP is important for the family caregivers of cancer patients, and congruence of symptom perception may contribute to patients’ quality of life. The present study will examine caregivers’empathic accuracy (congruence of symptom perception), and will specifically measure caregivers’empathic accuracy of patients’ pain and fatigue severity and frequency, because pain and fatigue are the most burdensome symptoms for cancer patients in their daily lives.

Furthermore, the FCM conceptualizes caregiver burden as a potential consequence of a caregiving situation with multiple care demands and requirements. B. Given’s research (1995) has hypothesized that the strength of care demands and requirements depends on patients' physical, functional, and psychological capacity, which is directly correlated with patients' physical and functional performances and also causes increased loads of care demands placed upon family caregivers (B. Given, 1995). Once the patient's capacity has deteriorated, family members become more involved in patients' lives to provide care, such as symptom management and assistance of daily life activities. As described in B. Given's model, care demands, including symptom management, can be considered threatening caregiving situations for caregivers, because supporting care demands can interfere with caregivers' lives, causing caregiver burden. In this regard, caregiver burden can be considered a threat to caregivers, which may potentially decrease caregiver's empathic accuracy with patients. Caregiver burden describes caregivers' negative subjective perceptions about their healthy strength, their support from other family members, the interruption of their social lives, and their changes in employment status. The description of caregivers' responses to providing care in B. Given's perspective has included a postive aspect—self-esteem in providing care. Those five caregiver reactions have resulted from dealing with care demands that include symptom management (B. Given, 1995).

Caregivers' feelings of burden may also be related to the concept of *compassion fatigue*. The term compassion fatigue was first used by Johnson (1992) to describe a situation whereby health care providers had either become apathetic or experienced helplessness and anger in response to the stress they felt in witnessing patients go through devastating illness or trauma. Because family caregivers replace a part of the health care providers' role in patient care, compassion fatigue may occur in family caregivers. However, compassion fatigue may only describe extremely negative emotional reactions resulting from caregiving, and not every family caregiver experiences extreme burden. Typically, some family caregivers can derive positive meaning from caregiving, although they feel caregiver burden (B. Given, 1995; Y. Kim, Schulz, & Carver, 2007). Therefore, caregivers who have caregiver burden are more likely to have compassion fatigue, so they may be unlikely to perceive patients' symptoms accurately. Both Ickes and Davis have argued that there are situations that can influence the accuracy of empathic perception. Threatening situations are hypothesized to decrease empathic accuracy (Ickes, 1997). The strength of the situation in Davis's (1994) model is assumed to influence the empathy process. Because cancer care is a source of stress for caregivers and the families of cancer patients, and given that caregiver burden is one threat of a caregiving situation, this research hypothesizes that a threat of caregiver burden can decrease accurate perceptions of cancer patients' symptoms. The concept of caregiver burden is critical for reflecting caregivers' abilities to manage patient symptoms. However, the caregivers who already provide symptom management for patients may perceive threats. Caregivers may be worried about their abilities to dealing with patients' variable symptoms and also afraid of additional changes in their lives when caregiving becomes an endless situation. This threatening feeling may reflect in their caregiver reactions; in particulary, caregiver burden. Therefore, the present research conceptualizes caregiver burden as a threat to the caregiver and also assumes this threatening feeling is an impediment to caregivers' accurate empathy or congurent perceptions.

Additionally, the FCM has shown that patients' and caregivers' individual characteristics influence how care requirements and demands are experienced and dealt with, which also indirectly determine patients' outcomes. Caregivers, especially female family members and spouses, often take responsibility for those care requirements. Caregivers who live with patients are more likely to report a higher level of caregiver depression and caregiver burden (B. Given, 1995). Caregivers who live with patients, such spouses, may be more familiar with patients' cues about symptoms than caregivers who do not live with patients. The links between social support and care demands and requirements have indicated that caregivers can obtain the assistance to deal with care demands, such that families who have broader social networks may have access to a wider range of relatives, friends, and formal health care providers to support care demands and requirements, thereby lightening a caregiver's burden of care.

In conclusion, regarding the empathy model, the concept of empathic accuracy, and the FCM, EASP between cancer patients and their family caregivers describes a caregiving situation in which family caregivers are capable of peceiving patients' symptoms and accurately assess patients' symptom experiences. Empathic accuracy may guide caregivers to provide appropriate symptom management. These three theories in the current study will be applied to support the theoretical framework of EASP.

Ickes's empathic accuracy has demonstrated that similar perceptions of patient symptoms between patients and caregivers (empathic accuracy) is influenced by caregivers' perceptions of threat in the caregiving situations. Davis's empathy model proposes that empathic accuracy, as congruence of symptom perception, is a proximal cognitive outcome of empathy processes influenced by emotionality and the threats of the situations. Emotionality may be represented by caregivers' depression as an antecedent, such that caregivers' depression may decrease empathic accuracy and may lead to inappropriate perceptions of patients' symptoms. Briefly, these two theories can support the hypothesized relationships among emotionality, threat of caregiving, and empathic accuracy; therefore, this research hypothesizes that caregiver depression and caregiver burden may decrease empathic accuracy.

The FCM has supported the importance of symptom perception for symptom management and has established the rationale for hypothesizing the relationship between accurately perceiving symptoms and patients' quality of life. The perspective from FCM can help intergrate the concept of EASP into caregiving research to enrich an understanding of the caregiving situation, thereby advancing the science of family cancer care.

In addition, regarding Davis's empathy model, two important elements should be considered in the present conceptual framework of EASP. The first is communication (verbal and nonverbal), which is an essential empathic process as an intersubjective interaction beween the perceiver and the actor that can affect caregivers' perception of cancer patients' symptoms. The second is the concept of *helping behaviors*, which are the distant consequence of having empathic perception. However, communication and helping behaviors, related to the changes within the dyadic relationship, in family cancer care are beyond the scope of this current study. This study will focus on identifying the relationships among caregivers' emotionality, threats, and empathic accuracy (congruence) of pain and fatigue severity and frequency. Therefore, communication and helping behaviors are merely added to the conceptual framework of EASP for a complete depiction of the processes and variables.

Conceptual Framework of EASP

For the present study, the EASP conceptual framework represents an aspect of empathy that may be relevant to the caregiving situation for cancer patients and their caregivers (Figure 1). Three theories orient the model with concrete theoretical support oriented: empathic accuracy, the empathy model, and the FCM. The EASP depicts the influence of caregivers' emotionality (depression) and threats of caregiving (caregiver burden) on the main concept of empathic accuracy (the congruence of pain and fatigue severity and frequency) while considering the influences from patients' and caregivers' demographics. The EASP framework also shows the expected outcomes of EASP in caregivers' helping behaviors and the quality of life of patients and caregivers.

The theoretical concepts being examined in this study are the impact of caregivers' emotionality and threats of caregiving on EASP. Caregivers–instead of physically feeling the same symptom experience that patients do–can cognitively appraise patients' symptom experiences. The EASP framework depicts that both emotionality and threats of caregiving can influence caregivers' perceptions of patients' symptoms experiences, thereby affecting the congruence levels of symptom perception between patients and caregivers. Therefore, EASP in this study, which is inspired by Ickes's and Davis's perspectives of empathic accuracy, is conceptually defined as the similarity of family caregivers' cognitive appraisals of their patients' cancer symptom experiences. Symptom experience, is described as a cognitive symptom perception, including severity, time (duration and frequency), distress, and quality (Armstrong, 2003). The current study will operationally examine severity and frequency of pain and fatigue to represent symptom perception.

Based on the operational definition of empathic accuracy as congruent levels of symptom perception, empathic accuracy is obtained from both patients and caregivers. In this regard, the characteristics of caregivers and patients influencing the EASP should not be ignored. The contextual factors in the EASP framework include patients' and caregivers' demographics, such as age and sex, as well as the caregivers' relationship to the patient, living arrangement, and awareness of the total number of patients' symptoms. However, because the present study will focus on examining how caregivers' emotionality and threats of caregiving can impact empathic accuracy, caregivers' demographic characteristics, which are expected to affect emotionality and

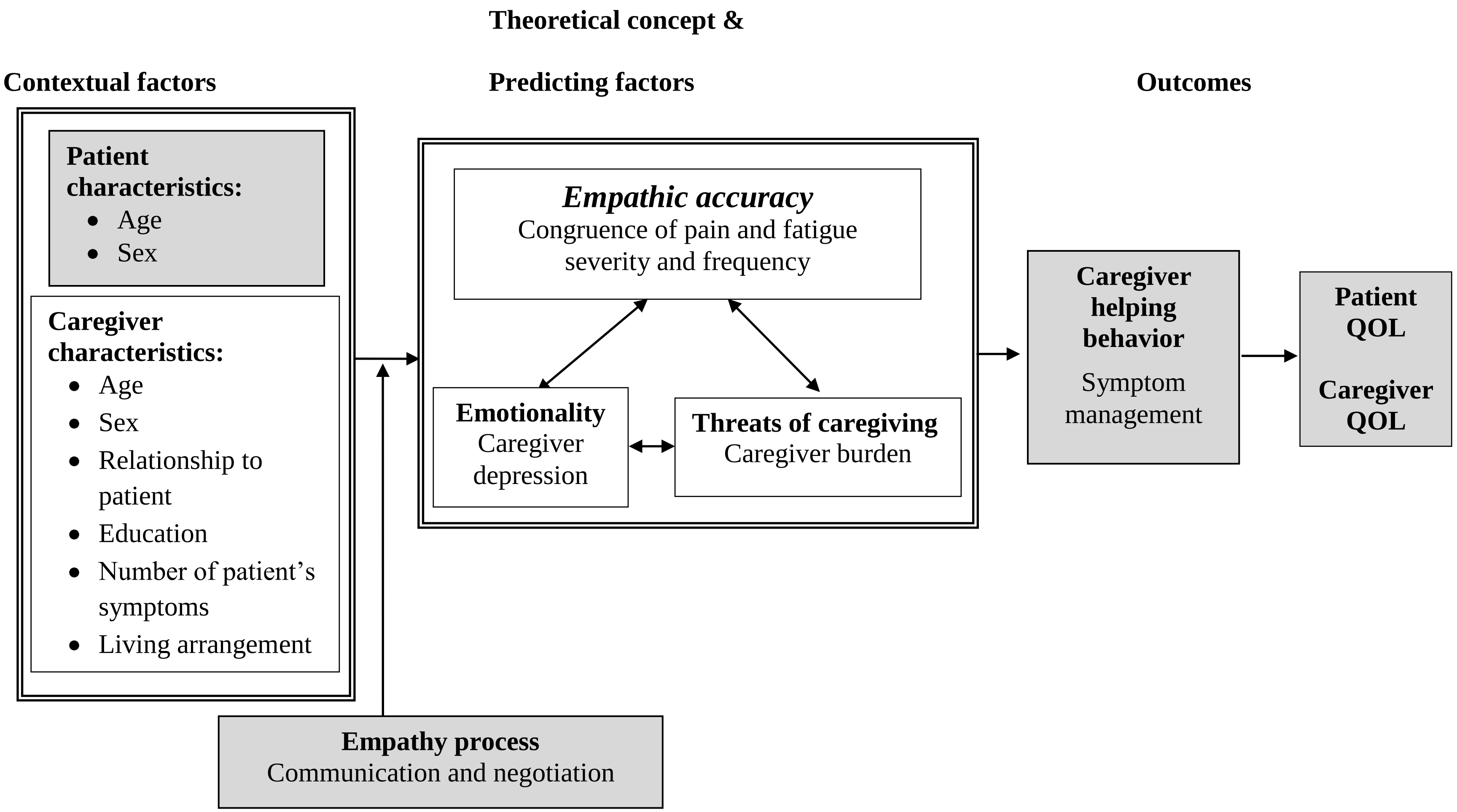


Figure 1. Theoretical framework of Empathic Accuracy of Symptom Perception (EASP). QOL = quality of life. The relationships among the concepts in the boxes with double-line are tested. The concepts in the gray boxes were not tested in the current research.

threats of caregivers, will be taken into account, but patients' factors will not be included in the analysis.

In the current study, caregiver emotionality is defined as caregivers' mood expression, such as anxiety and depression. Depression is frequently recognized in the family caregiver population when caregivers have insufficient knowledge and insufficient support for care (National Family Caregivers Association, 2010). Accordingly, caregivers' depression, perhaps, leads caregivers to believe that patients are suffering from pain or fatigue; depressed caregivers may be more likely to rate a higher score of severity and frequency for their patients' symptoms than the patients' self-rating of symptoms, thereby decreasing empathy accuracy (congruence of symptom perception).

The current study describes the threats of caregiving as perceived by caregivers. Threat has often been described as an indication of imminent harm, danger, or pain. In a family, cancer diagnosis is a threat because family caregivers believe that they are losing a patient, and they may also believe that patients must be suffering from cancer. Threats of caregiving to caregivers can refer to negative expectations of life challenges resulting from patients' cancer and cancer treatment. Some cancer dyads have revealed that they were unprepared for symptom management, and didn't know how to cope with the unpredictable nature of life (Harden et al., 2002; Pickett, Barg, & Lynch, 2001). Caregiver appraisal of providing care has been interpreted by using the following terms: threat, benign, benefit, and challenge (Bakas & Burgener, 2002; Oberst, Thomas, Gass, & Ward, 1989). Threats of caregiving do not describe actual physical harm or danger to caregivers, but infer the negative perception of potential life challenges.

Caregiver burden has been described as caregivers' negative reactions from the imbalances that are created in their social, psychological, and economic living situations, because providing care has interrupted these aspects of their lives (B. Given, Given, & Sherwood, 2012). Often, caregivers may imagine that there will be more unknown or difficult patient care in the future, especially when patients are undergoing anticancer treatment. Caregiver burden may be a reflection of the fact that caregivers are perceiving threats of caregiving.

Therefore, caregiver depression will be used to represent emotionality, and caregivers' feelings of burden from providing care will represent the perceptions of threats in caregiving environments. Both emotionality and threats are theoretically understood as factors that may diminish empathic accuracy within the empathic processes surrounding caregivers' perceptions of the patient.

Contextual factors of the EASP refer to dyadic characteristics. According to the FCM, both patients' and caregivers' demographic characteristics and patients' health conditions can influence care demands related to health outcomes of patients and caregivers. Both Davis's and Ickes's theories on empathic accuracy have emphasized the perceiver's personal factors influencing empathic process, but have not included the target person's characteristics. The present study will examine caregivers' demographic characteristics (age, sex, education, relationship to patients, living arrangement, and number of patient symptoms) and then test their relationships with caregiver emotionality and threats of caregiving. It will also examine the covariant effect of those concepts on empathic accuracy.

Based on the empathy model and FCM, the researcher expects that the conceptual framework of EASP can generate caregivers' helping behavior, such as approaching symptom management, and improve patients' and caregivers' quality of life as well. Providing symptom management may be a helping behavior, which is one of the interpersonal outcomes of empathy processes in Davis's empathy model. Patients' and caregivers' quality of life is the outcome of providing for care demands in Given's FCM. Based on the EASP conceptual framework, increasing congruence of symptom perception is assumed to generate more appropriate symptom management and improve quality of life for patients and caregivers. The concept of symptom management is broad and beyond the scope of this study. Symptom management is the care given to improve quality of life of patients who have a serious or life-threatening disease, and includes any strategies used to prevent and treat the symptoms related to disease, side effects related to anticancer treatments, and any psychological, social, or spiritual problems related to disease and treatment (Cella, Wagner, et al., 2007; Dodd, et al., 2001; Fu, LeMone, & McDaniel, 2004). The data used for this current study does not include sufficient information to differentiate between caregivers' behaviors of symptom management for patients. Further study will evaluate types of caregivers' helping behavior regarding symptom management to support this framework. The present study will focus on predicting the relationship between caregiver emotionality and EASP, and between caregivers' perception of threats of caregiving and EASP.

Specific aim. The specific aim of this research is to examine how caregivers' emotionality (caregiver depression) and caregivers' threats of caregiving (caregiver burden) predict EASP (congruence of pain and fatigue severity and frequency), when taking into account contextual factors of caregivers–including caregiver's age, sex, education, relationship to patients, observation of the total number of patients' symptoms, and living arrangement.

Hypothesis. There are two hypotheses for this study:

1. Increased caregiver depression and caregiver burden will be related to lower congruent values of pain and fatigue severity and frequency.

2. Caregivers who are female, older, patients' spouses, better educated, perceiving a

lower number of patients' symptoms, and living with patients will have greater congruence of pain and fatigue severity and frequency than the caregivers who are male, younger, nonspouses of patients, less educated, perceiving a higher number of symptoms, and not living with patients.

Therefore, this study will examine the predicted relationship that caregivers' emotionality and threats of caregiving impact EASP with and without contextual factors of caregivers' characteristics.

CHAPTER 3

Literature Review

This chapter will review literature to support the framework of EASP. It will begin by introducing the population of family caregivers of cancer patients and describes research about cancer patients' care demands specific to cancer and its symptom management. Next, literature that supports the relationships among the main concept, factors, and outcomes in the theoretical framework of EASP will be discussed. Specifically, the literature reviewed on the following pages will address (a) the family caregivers of cancer patients, and at-home cancer care related to pain and fatigue; (b) EASP and its relationship with caregivers' emotionality and threats of caregiving; and (c) caregivers' demographic characteristics that are relevant to caregivers' emotionality, threats of caregiving, and EASP. The final section in this chapter will illustrate the methods that are designed to identify congruent symptom perception.

Family Caregivers of Cancer Patients

Family caregivers generally are the family members who are unpaid care providers for patients, and who have no medical training (Family Caregiving Alliance, 2011). According to the NAC and AARP (2009), approximate 65.7 million informal caregivers in the United States take care of patients who have had diagnoses across all chronic condition, and 7 % of adult family caregivers were providing care for an adult family member diagnosed with cancer. Also, among those adult caregivers, they are predominantly female (66%), the average age caregivers is 48, and most are married and living with their partners (62%). In addition to this, 74% of adult caregivers continue to work while they manage caregiving responsibilities. Families provide about 80% of at-home care services. Caregivers spend 20 hours per week, on average, providing care for their ill family members, and 13% provide weekly care for 40 hours or more. The average length of caregiving is 4.3 years (NAC & AARP, 2009).

In addition, caregivers who live with patients provide three times as many hours of care per week, and primary caregivers spend more hours giving care than nonprimary caregivers. Female caregivers spend more time providing care than do males, and females also handle most of the time-consuming and difficult care demands (NAC and AARP, 2009; Reinhard, Given, Petlick, & Bemis, 2008). The research reports on family caregivers of adult cancer patients have shown that most of these family caregivers are spouses, partners, or adult children. Relatives, close friends, or neighbors may take this role when family is not available (ACS, 2010; Mintz, 2007; Paul, et al., 2007).

According to the American Cancer Society (ACS, 2010) annual report, the mortality from all cancers in the United States has declined by 60% between 1990 and 2006. The 5-year survival rate from cancer was 68% between 1999 and 2006, which is higher than the survival rate between 1975 and 1986 (Jemal, Siegel, Xu, & Ward, 2010). Today's cancer population has a longer life expectancy. Additionally, a shorter period of hospitalization for treatments is a current medical trend that is shifting cancer care from hospitals to families. In sum, the cancer population is growing in the community. Because of shorter periods of cancer treatment in hospitals and longer life expectancies for cancer patients, it is necessary to have a larger number of family caregivers who can cope with the increasing number of cancer survivors. For caregivers of cancer patients, symptom management is a major care demand when they provide care for patients at home, second in frequency only to assisting with patients' daily activities. Caregivers' perceptions of patients' symptom will be an important influencing factor in deciding how to provide symptom management.

Cancer Care at Home

Family caregivers of patients with cancer provide vital and continued physical and emotional support for patients, helping them to get through the cancer experience. In cancer families, involvement of family caregivers is essential for optimal treatment of cancer patients–ensuring treatments compliance, continuity of care, and social support (Glajchen, 2004; Reinhard, et al., 2008). The B. Given et al. study (2004) examined 152 dyads of cancer patients and their family caregivers, and found that most cancer care demands provided by family members are related to assisting patients with routine activities of daily life. A majority of care demands that require patients to request assistance from family are daily life activities and instrumental activities (56%), including helping feed, dress, and bathe patients, as well as arranging schedules, managing insurance, and providing transportation (NAC & AARP, 2009). When patients are more dependent, performing those daily care demands becomes more time-consuming and intensive.

Meanwhile, family caregivers are expected to assess and report information regarding patients' symptoms, to identify side effects of patients' cancer treatments, and to administer medication for symptom management. Family caregivers are expected to provide emotional support for patients as well (Glajchen, 2004; Reinhard, et al., 2008). Despite a decline in cancer mortality in a report of the National Cancer Institute (Jemal, Siegel, et al., 2010), malignant neoplasm is the second leading cause of death next to the heart disease, which has been the first cause of death in the last decade (CDC, 2009). Additionally, cancer symptoms usually change during the time of receiving treatment and post treatment (Fan, Filipczak, et al., 2007). In particular, the changes of cancer symptoms may generate new care demands related to symptoms. These uncertain situations may require more attention from caregivers, who monitor the changes of symptoms and provide symptom management. Therefore, caregivers who have been providing patient care may perceive more interruption to the family because of patients' care demands.

Nowadays, cancer patients are often discharged to their homes when they just receive the anti-cancer treatment and may still have treatment-related symptoms. Those patients need their family caregivers to remain with them and support their daily activities at home. Family caregivers provide patient care at home as the care partners in the current health care systems. The present study explores congruent levels of cancer patients' pain and fatigue severity and frequency between patient and caregivers. However, because this study only uses the one-time measure of information at the first interview from the parent study, there will not be sufficient information to examine the changes of symptoms.

Generally, family caregivers are not as familiar with clinical cancer care, especially symptom assessment and management, as they are with usual daily care. However, since the cancer treatments can be provided in the clinics, cancer care demands become a major part of caregivers' responsibilities (ACS, 2010). van Ryn, et al (2011) recruited 677 caregivers who provided at least 50% of informal, at-home care for patients diagnosed with lung and colorectal cancer, and then found that those family caregivers provided most of the cancer-specific care, including monitoring the side effects of treatments (68%), assisting with symptom management (47%), administering medication (34%), making decisions for contacting doctors (30%) and for using medications (29%), and changing wound dressings (19%). In their findings, symptom management was the most prevalent caregiving activity that provided by caregivers, except for assisting with patients' daily activities. In conclusion, caregivers' perceiving patients' symptoms and assisting with symptom management are ongoing care demands in patients' cancer trajectories. In these circumstances, family caregivers who provide care for cancer patients become not only advocates in assisting with symptom management and reporting cancer patients' symptoms to formal care providers, but also partners with professional health providers. Therefore, caregivers' accurate perceptions of patients' symptoms may be important for managing symptoms in patients.

Congruent Levels of Symptom Perception as a Measure of Empathic Accuracy

Congruence of symptom perception between patients and caregivers is the operational definition of empathic accuracy in the present study. Congruence in each dyad is measured by comparing the scores of a patient's and a caregiver's perception of patient symptoms. Greater similarity in symptom scores between patients and caregivers indicates greater empathic accuracy (congruence) for the dyad.

Congruence of pain and fatigue severity and frequency. Generally, previous studies examined congruence of symptoms perception to identify whether caregivers can have a accurate symptoms perception to guide them in providing symptom management. Congruence in previous studies is a level of agreement, in which less agreement statistically means non-congruence. Congruent perception of multiple symptoms is measured by correlation coefficient in previous studies ranged widely from fair to moderate (Broberger, et al., 2005; Higginson & Gao, 2008; Kurtz, et al., 1996; Lobchuk & Degner, 2002; Wennman-Larsen, et al., 2007; Yeşilbalkan & Okgün, 2010). Without specific operational definition of congruence, a fair-to moderate level of agreement is recognized as non-congruence. Previous studies also found that caregivers tended to overestimate most patients' symptom distress and severity, but some symptoms, such as dry mouth, constipation, and insomnia, were underestimated by caregivers (Broberger, et al., 2005;

Kurtz, et al., 1996; Lobchuk & Degner, 2002; McPherson, et al., 2008; Molassiotis, Zheng, Denton-Cardew, Swindell, & Brunton, 2010; Wennman-Larsen, et al., 2007).

Researchers interested in pain experiences between cancer patients and caregivers have found that most caregivers tend to overestimate patients' pain severity (Greig, Chow, Bovett, Abdolell, & Gillies, 2005; C. Lin, 2001; Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997). Some studies have evaluated pain frequency, and also have found that caregivers tend to overrate the occurrence of pain (Broberger, et al., 2005; Lobchuk & Degner, 2002; McPherson, et al., 2008). Other studies which measured multiple symptoms also have reported that caregivers commonly overestimate frequency of patients' symptoms (Higginson & Gao, 2008; McPherson, et al., 2008; Molassiotis, Zheng, et al., 2010; Silveira, Given, Given, Rosland, & Piette, 2010; Wennman-Larsen, et al., 2007; Yeşilbalkan & Okgün, 2010).

Furthermore, In those studies on congruence of multiple symptoms, fatigue–but not pain–and its related symptoms, such as lack of energy and weakness, have been identified as the most prevalent, and may also be the most severe, symptoms by both patient and caregivers (Higginson & Gao, 2008; McPherson, et al., 2008; Wennman-Larsen, et al., 2007). Vogelzang et al.'s research (1997) measured both family caregivers' and cancer patients' perceptions of cancer-related fatigue. They found that caregivers overestimated the frequency of patients' daily fatigue, but they did not identify congruence of symptom frequency within the dyad. Stone and Ream (2003) focused on congruence of cancer-related fatigue in 1,370 dyads of patients and their family caregivers in the United Kingdom. Their study showed that 71% of the 454 responding caregivers recognized patients' fatigue, while 56% of 576 responding patients reported fatigue during the same time period.

Family caregivers also had a higher percentage than patients in reporting patients' other fatigue-related feelings and the effects of patients' fatigue on different aspects of patients' lives. Other studies measuring multiple symptoms also have reported a higher score of fatigue from caregivers (McPherson, et al., 2008; Molassiotis et al., 2010; Silveira, et al., 2010). These results also were extended over the long term in longitudinal studies (Hinton, 1996; Molassiotis, Zheng, et al., 2010; Silveira, et al., 2010). Briefly, family caregivers of cancer patients tend to overestimate severity and distress of patients' pain and fatigue. Based on the findings of either low correlation coefficient or the non-zero score differences between caregivers and patient's symptom scores, the researchers typically provided a conclusion that caregivers' symptom perception is not reliable. However, in spite of this conclusion, caregivers are still required to assist symptom management and provide patient care.

Cancer-related symptoms. Cancer-related symptoms have commonly impacted patients' performance of physical functioning as well as quality of life (Butt et al., 2008; Delgado-Guay & Bruera, 2008; Miaskowski et al., 2006; Pud et al., 2008). Symptoms have been referred to as the physical and psychological indicators of the changes in normal functioning that are experienced by an individual who has an illness (Lenz, Pugh, Milligan, Gift, & Suppe, 1997). Cancer–related symptoms, such as pain and fatigue, may occur before the cancer diagnosis is confirmed, and may also alter when patients receive cancer treatments or when the progression of cancer worsens health conditions. As patients get weaker, family caregivers usually take on the patients' care in its entirety, including assisting with patients' daily activities, instrumental daily activity, and symptom management. In order to help patients to manage cancer-related symptom and side effects of cancer treatment, caregivers have to continually adjust their lives for caregiving situations. Dynamic characteristics of cancer-related symptoms, along with treatments in the cancer trajectory often create unfamiliar demands for cancer patients and their family caregivers (Fan, Filipczak, et al., 2007). The National Institute of Health [NIH] (2004) statement for symptom management in the cancer population also reported that although different cancer sites may generate different symptoms, pain and fatigue are the most common symptoms of cancer and cancer treatments.

Cancer pain. Cancer pain has been the focus of most cancer research on symptom management. Pain is the most common and feared symptom of cancer by Americans (ACS, 2010). Cancer patients report pain as the most unpleasant and disruptive symptom because unrelieved pain can interrupt patients' daily lives and limit their capacities to performing physical functioning activities (Vallerand, Templin, Hasenau, & Riley-Doucet, 2007). Specifically, because of its multidimensional nature, pain can be triggered or worsened by other psychological and physical symptoms, such as anxiety and sleep problems. Therefore, it is complicated to alleviate pain distress (Delgado-Guay & Bruera, 2008; McGuire, 1995; van den Beuken-van Everdingen, et al., 2007). Regarding the recognition of multidimensionality of symptoms, several symptom instruments have been developed to evaluate multiple dimensions of multiple symptoms, such as the M. D. Anderson Symptom Inventory [MDASI] and the Memorial Symptom Assessment Scale [MSAS] which are used to evaluate symptom severity, interference, and frequency (Cleeland, 2007; Portenoy et al., 1994).

In addition, cancer patients in the late stage of cancer, especially breast cancer and lung cancer, have a high incidence of bone metastasis. Bone metastasis means that the tumor cells spread into bone and replace the bone tissues. As the bones are replaced with tumors, patients often feel bone pain because nerve endings in and around the bone send pain signals to the brain. Therefore, cancer patients with bone metastasis are usually suffering more from pain than they were in the earliest stages of their disease. Pain management has been in the spotlight of the cancer research on symptoms, since pain experiences are typically uncomfortable for cancer patients. The investigators who were interested in congruent levels of symptom perception between cancer patients and their caregivers typically measured patients' pain severity and distress (Lobchuk, et al., 2006; McPherson, et al., 2008; Molassiotis, Zheng, et al., 2010; Silveira, et al., 2010).

Cancer-related fatigue. Cancer-related fatigue is another multidimensional symptom. Fatigue has been recognized as one of the most prevalent symptoms for cancer patients who receive treatment (Donovan et al., 2004b; Goedendorp, Gielissen, Verhagen, Peters, & Bleijenberg, 2008; Hagelin, Wengstrom, Ahsberg, & Furst, 2009; Hoffman, Given, von Eye, Gift, & Given, 2007). According to a National Cancer Institute report, cancer-related fatigue persists at some level for months or years. Some cancer survivors report long-term complaints of fatigue (Baker, Denniston, Smith, & West, 2005; Bower, 2007). Cancer patients often report fatigue as a major obstacle to maintaining normal daily activities and quality of life, especially for patients who receive cancer treatments (Bower, 2007; Byar, Berger, Bakken, & Cetak, 2006; Diaz, et al., 2008; Ryan, et al., 2007; Stasi, Abriani, Beccaglia, Terzoli, & Amadori, 2003). In addition, fatigue can impact all areas of life function, including mood, physical function, and social interaction (Curt et al., 2000; Donovan et al., 2004a; B. Given et al., 2002). For family caregivers who have been involved in patients' lives, patients' fatigue may indirectly impact caregivers' lives as well (Passik & Kirsh, 2005; Vogelzang, et al., 1997).

Furthermore, cancer patients often report pain and fatigue at the same time. Both pain and fatigue practically have been identified as the core of symptom clusters (Fan, Hadi, et al., 2007; B. A. Given, et al., 2007; Hoffman, et al., 2007; E. Kim, et al., 2009). Fatigue often coexists with insomnia and depression, and these symptoms are also associated with pain (Donovan &

Jacobsen, 2007; Hoffman, et al., 2007; E. Kim, et al., 2009; Redeker, Lev, & Ruggiero, 2000). As mentioned above, pain is the most unpleasant symptom, and fatigue is recognized as the most prevalent symptom by both patients and caregivers. Pain and fatigue are the symptoms that most commonly interfere with patients' physical function (Cella, Yount, et al., 2007; B. Given, Given, et al., 2001). Patients who are suffering from both pain and fatigue may have less capability to perform physical functioning, such that they have to depend more on family caregivers for assistance in their daily activities. Patients' dependence indicates caregiving around these symptoms (Miaskowski, 2010; P. C. Stone & Minton, 2008), which may generate more care demands for caregivers. It is worthwhile to prioritize pain and fatigue before attempting to understand overall cancer-related symptoms.

Symptom characteristics. Symptom experience, in Dodd et al. (2001), is described as the individual's perception of the symptoms, evaluation of symptom meaning, and subsequent responses. Later, Armstrong (2003) defined symptom experience as the perception of the frequency, intensity, distress, and meaning occurring as symptoms are produced. As symptom characteristics including distress (severity and/or distress), occurrence (prevalence, duration, and frequency), and interference are counted, the researcher and caregivers can translate subjective symptom feelings into cognitive perception. Severity and distress commonly have been measured to represent symptom burden, because the high levels of severity and distress create the most interference with patients' quality of life. Kirkova et al. (2006) reviewed the symptom instruments used to measure multiple symptoms, and they found that among those symptom dimensions, symptom prevalence and severity were often used as the main determinant for symptom burden, while frequency and duration were less frequently reported or measured.

Symptom severity has been suggested to positively determine the patients' distressful perception of symptoms (H. J. Kim & Abraham, 2008; Kirkova, et al., 2010). Therefore, severity often has simply been measured for symptoms. Mercadante et al. (2000) showed that 370 cancer patients reported worse functional performance when they had increasingly frequent and intense (severe) symptoms. Lutz et al. (2001) investigated the relationship between symptom experience and quality of life among 69 patients who were diagnosed with lung cancer, and found that the patients who had frequent and severe symptoms reported worse quality of life. Both Mercadante et al.'s and Lutz et al.'s findings have suggested that an increase in both frequency and severity of symptoms can impact cancer patients' performance of daily physical functioning and worsen patients' quality of life (Lutz, et al., 2001; Mercadante, et al., 2000). Meanwhile, family caregivers are named as informal caregivers, because they do not receive formal training for symptom management as professional caregivers do. It is easy for caregivers to assess severity and frequency of symptoms at home to represent patients' symptoms burden.

In summary, measuring the severity and frequency of patients' pain and fatigue is a priority for symptom management, especially for the patients who are receiving chemotherapy (Molassiotis et al., 2009; Sigurdardottir & Haugen, 2008; Soltow, Given, & Given, 2010). Because caregivers play a major role in assisting patients in appropriate symptom management, having empathic accuracy of the severity and frequency of pain and fatigue between patients and caregivers is critical. However, because caregivers have low congruent perception and also commonly overestimate cancer patients' symptoms, caregivers have been considered as unreliable proxies of patients' symptoms (Chau et al., 2010; Greig, et al., 2005; Kirou-Mauro, Harris, Sinclair, Selby, & Chow, 2007). Therefore, it is essential to understand the congruence of symptom perception. In the present study, EASP will be measured by comparing cancer patients' and caregivers' perception of pain and fatigue severity and frequency. In this study, the EASP framework will examine the three congruence levels of symptom perception between patients and caregivers for pain and fatigue severity and frequency, in terms of overestimation, congruence, and underestimation, separately, to identify factors influencing congruence.

Relationship Among Caregiver Emotionality, Caregiver Threats of Caregiving, and Congruence of Symptom Perception

Caregiver emotionality. Emotionality consists of positive and negative affect and is measured or represented by emotional intensity (Eisenberg et al., 1994). Caregiver emotionality is often described with negative mood components in which depression is commonly emphasized. The Family Caregiver Alliance (Family Caregiving Alliance, 2009) has reported that caregivers with depressive symptoms may isolate themselves, and lose interest in people. Lee, Brennan, and Daly (2001) also emphasized that increasing caregivers' depression can prevent them from perceiving the benefits of providing care, and may also decrease caregivers' empathy. Redinbaugh and her colleagues (2002) reported that caregivers are more likely to overestimate patients' pain when they have more negative feelings about patients' pain, when they believe that patients are suffering from great pain, and when they need to provide numerous pain medications for pain relief. Tang, et al. (2006) examined 170 Taiwanese family caregivers of cancer patients at the end of life, and found that the caregivers who were more aware of patients' disease experiences and symptoms reported higher level of depression. Lobchuck and Vorauer (2003) also have suggested that the overestimation of patient worrying may be influenced by caregivers' depressive symptoms and anticipating grief. Accordingly, caregivers who have negative emotionality may be more likely to inaccurately perceive patients' symptoms.

In contrast to the description above about the relationship between caregiver depression and congruence of symptom perception, Kurtz et al. (1996) found that caregiver depression was not correlated with congruence of symptom frequency among 216 dyads of caregivers and cancer patients. Shega, Hougham, Stocking, Cox-Hayley, and Sachs (2004) evaluated 115 dyads of family caregivers and community dwelling persons with dementia and found that caregivers' depression was correlated with congruence of patients' pain severity. Meanwhile, Hung, Pickard, Witt, and Lambert (2007) found that depressed caregivers of stroke patients were more likely to underestimate patients' pain experience but caregivers with pain experience tended to overestimate patients' pain. These inconsistent results may have occurred because the studies dealt with different diseases and different symptoms, or perhaps these patients' pain had been treated before they returned home. The present study will use caregiver depression to represent emotionality in order to examine how caregiver depression predicts empathic accuracy of pain and fatigue severity and frequency.

Threats of caregiving. According to the EASP framework for this study, for a family care situation, the threats of caregiving are conceptually defined as caregivers perceiving threats from providing care because supporting patients' care demands can interrupt caregivers' lives, which has been recognized as caregiver burden (Grunfeld, et al., 2004). Generally, threats of caregiving do not describe actual physical harm or danger to caregivers, but infer the negative perception of potential life challenges. Cancer not only brings the threat of death to the ill family members, but also generates various threats in the family. Family caregivers may feel empathic with patients' symptom burdens, and also feel threats from providing patient care. Supporting care demands can consume caregivers' time and interrupt caregivers' lives, which has been recognized as caregiver burden (Grunfeld, et al., 2004). B. Given, et al (2011) reinforced the necessity of caregiver involvement in patient care after patients received cancer treatments, because symptom management can be a core care demand from treatment to post treatment.

Glajchen (2004) emphasized that cancer caregivers often operate within caregiving situations and without preparation. Caregivers may feel burdened when their lives are continually interrupted to provide care to meet patients' demands. Caregiver burden is described as caregivers' negative reactions from the imbalances that are created in their social, psychological, and economic living consequences, because providing care has interrupted these aspects of their lives (B. Given, et al., 2012). Therefore, caregivers may perceive the threats of providing care that impact their own lives, because caregivers have to readjust their lives for those caregiving situations.

From these scholars, the investigator can derive a equationtion whereby caregiver burden can be described as caregivers' negative anticipations about how their lives will be impacted from providing care. Caregiver burden was defined as a multidimensional bio-psychosocial reaction resulting from an imbalance in care demands relative to the caregiver's personal life, in terms of physical and emotional health, social role, financial recourses, and formal care resources (B. Given, Kozachik, Collins, DeVoss, & Given, 2001). Montgomery, Gonyea, and Hooyman (1985) categorized caregiver burden in two aspects: the subjective aspect describes perception of self-distress from care circumstances, and the objective aspect refers to the numerous kinds of care demands and numbers of caring hours.

Vitaliano and Katon (2006) showed that caregivers with high levels of caregiver burden are less willing to provide care. Caregivers with greater burden may not notice patients' feelings and may avoid involvement in patient care; lower congruent symptom perception is not surprising. Indeed, some studies have reported that caregivers with feelings of burden have a lower likelihood of congruent perception of patients' symptoms (McPherson, et al., 2008; Wennman-Larsen, et al., 2007). Lobchuk et al. (2006) also reported that higher caregiver burden might lead caregivers to be less likely to agree with patients' self-reports of symptom experience. Wennman-Larson et al. (2007) found low congruence of multiple cancer symptoms among 52 dyads of patients and their family caregivers. Three aspects of caregiver burden, including a lack of family support, a negative impact on health, and low self-esteem, were positively correlated with discrepant ratings of patients' emotional functioning. Wennman-Larson et al. (2007) interpreted that the low congruence as resulting from caregivers' stressful situations was because they experienced a low level of caregiving esteem and lack of family support or worsening health.

In addition, caregiver depression and caregiver burden often have been correlated, and caregiver burden has been identified as predictor of caregiver depression (Clark & Diamond, 2010 ; Grunfeld, et al., 2004; Y. Kim, et al., 2005; Kurtz, et al., 2004). Clark and Diamond (2010) examined 112 caregivers of elderly people and found that caregivers' feelings of burden, which were measured using Zarit Burden Inventory (ZBI), were correlated with caregivers' depression, which were measured by using the Center of Epidemiological Study Depression scale (CESD). Similarly, four subscale of caregiver burden measured by the Cancer Reaction Assessment was moderately correlated to caregiver depression measured by the CESD (range = 0.34 - 0.57), except for caregiver self-esteem which was negatively correlated to depression (r = - 0.15 - 0.2; (C. W. Given et al., 1992; Sherwood, Given, Given, & von Eye, 2005). Grunfeld et al. (2004) examined 89 dyads of caregivers and patients with breast cancer and found that caregiver burden (measured by ZBI) was the major predictor of caregivers' psychological distress (depression and anxiety). Kurtz et al. (2004) analyzed 351 caregivers' reports on the relationship between their caregiver burdens and their physical health and depression; they found that higher scores on "schedule interruption" and "family abandonment" predicted higher scores of caregiver depression and lower scores of caregivers' physical health. Therefore, caregivers with a higher burden may have a higher likelihood of being depressed. Likewise, higher levels of depression in a caregiver may imply the existence of co-occurring caregiver burden. Therefore, both emotionality and threats can coexist to influence congruence of symptom perception. For example, McPherson et al. (2008) examined 66 dyads of cancer patients and their caregivers. They identified that depression and anxiety can predict discrepancy of psychological symptoms; meanwhile, greater caregiver burden can predict discrepancy of physical symptoms. Miaskowski et al. (1997) compared caregivers' characteristics between the congruent group and the noncongruent group when they examined the congruent pain intensity among 78 cancer patient-caregiver dyads. They found that caregivers in the noncongruent group were more likely to report having greater caregiver strain than the caregivers in the congruent group. Caregiver strain, along with caregiver burden and depression, has been the major characteristic that negatively correlates to family caregivers' health and physical functioning (Honea, et al., 2008). Therefore, caregivers who have negative emotionality and who perceive threats may have decreased accuracy when perceiving patients' symptoms.

Caregiver Demographics as the Underlying Factors for Caregiver Emotionality and Threats of Caregiving

Sex and age. Caregivers' demographics have been related to depression and caregiver burden. Ferrario, Vitaliano, Zotti, Galante, and Fornara (2003) reported that caregivers over the age of 50 have higher depression scores than those who are younger. Female caregivers are reported to have a higher likelihood of depression than male caregivers (B. Fletcher, Dodd, Schumacher, & Miaskowski, 2008; Rivera, 2009). This finding on female caregivers' depression has been identified as being related to caregiver burden in some studies (B. Given et al., 2004;

Phillips, Gallagher, Hunt, Der, & Carroll, 2009; Pinquart & Sorensen, 2006). Fletcher et al. (2008) specifically reported that younger female caregivers whose patients have prostate cancer and who report low quality of life are more likely to report higher levels of depression, have physical symptoms such as morning fatigue and sleeping disorders. Rhee et al. (2008) studied 60 caregivers of cancer patients and reported that depression was positively correlated with several caregiver characteristics, including being female, being a spouse, having poor health, feeling burdened, having poor adaptation, and demonstrating low functioning, as well as taking care of the patients with low functioning performance. Dumont, Turgeon, & Allard, et al. (2006) recruited 212 advanced-cancer patients with and their caregivers to examine caregivers' psychological distress, including depression. They found that the caregivers who had a greater caregiver burden and were younger females were significantly more likely to have higher levels of psychological distress.

Education. In addition, education has been identified as being related to depression. Previous aggregate-level studies have reported that people with a higher education have less likelihood of being depressed (Kurtz & Brown, 1985; Kurtz, et al., 2004; Kurtz, Martinmorgan, & Graff, 1987). Thus, a higher educational level may protect against the symptoms of depression. In the caregiver population, education also has been associated with fewer symptoms of depression. Family caregivers with higher education have also shown lower caregiver burden (Barrentine, Street, & Kurtz, 1984; Cameron, Franche, Cheung, & Stewart, 2002; Y. Kim, et al., 2005). The reason may be that education is related to the ability to identify resources, such that caregivers who have a higher degree of education may be able to identify more social resources to support their caregiving, so that they have less caregiver burden.

Patient symptoms. Caregivers' demographic characteristics, which are described above, can influence caregivers’ experience of burden and depression, but the number of patient symptoms that caregivers observe also can be a risk factor. B. Given et al. (2004) examined 152 caregivers of cancer patients and found that caregiver reports of higher total number of patient symptoms is positively correlated to caregivers’ depressive symptoms. Specifically, B. Given et al. (2004) also found that most caregivers who identified seven or more patient symptoms reported depression scores greater than 16. Therefore, caregivers who observe more patient symptoms may have a risk of being more depressed.

Overall, caregivers’ demographics–such as female gender, younger age, higher level of education, and being a spouse–and the total number of patient symptoms that the caregiver observed are caregiver characteristics which may influence caregiver depression and burden. Therefore, in this study, these caregiver characteristics may have an indirect effect on congruence of symptom perception and will be used as control variables.

Caregiver Demographics Related to Congruent Symptom Perception

The relationship between caregivers’ demographic characteristics–age, sex and relationship with the care receiver–and congruence of symptom perceptions is recognized in a few studies (Broberger, et al., 2005; McPherson, et al., 2008; Wennman-Larsen, et al., 2007). Other studies have identified these caregiver characteristics in the comparison of two groups of symptom congruence or discrepancy (Kurtz, et al., 1996; C. Lin, 2001; Miaskowski, et al., 1997; Silveira, et al., 2010).

Caregiver age. Two studies which measured congruence of pain severity between cancer patients and caregivers found that caregivers in the noncongruence group were slightly older than those in the congruence group, and that older caregivers tended to overestimate patients’ pain severity (C. Lin, 2001; Miaskowski, et al., 1997). However, the age differences were not statistically significant. Other studies measuring multiple symptoms reported no differences in caregivers' age between congruence and noncongruence groups (Molassiotis, Zheng, et al., 2010; Silveira, et al., 2010). Furthermore, caregivers of different ages might be more aware of some symptoms, but not others. For example, Kurtz et al. (1996) compared cancer patients' family caregivers among three age ranges. They reported that younger caregivers (age < 50) exhibited the most discrepancy with patients in pain occurrence, while middle-aged caregivers (age = 50 - 64) were more discrepant about constipation symptoms, and older caregivers (age ≥ 65) were more discrepant with nausea. In this regard, caregivers in different age ranges may pay attention to different patient symptoms.

Caregivers' sex. Caregivers' sex also has an unclear contribution to congruence. Generally, in past studies, female caregivers have been more likely to be congruent with patients, possibly because women are socialized more than men to focus on caregiving (Berg & Woods, 2009). Gadassi et al. (2011) reported that women's depressive symptoms were specifically associated with lower levels of empathic accuracy for negative feelings. They concluded that depressive symptoms may have a greater impact on interpersonal perception of relationships for women than for men. Perceiving other people's feeling is related to individuals' interpersonal attributes and skills, such as empathy, sympathy and compassion. Female caregivers may be more able to perceive others' emotions and therefore may understand patients better than male caregivers.

In some studies, female caregivers had a higher likelihood of having congruent symptom perception with patients than did male caregivers (Kurtz, et al., 1996; Resnizky & Bentur, 2007). McPherson et al. (2008) also found that being a male caregiver is a major factor in determining the discrepancy of physical symptoms and psychological symptoms. However, the opposite has been reported in other studies. Higginson and Gao's (2008) report has shown that female caregivers have a higher likelihood of noncongruence for patients' pain symptoms than did male caregivers. Wennman-Larsen et al. (2007) reported that female caregivers with male patients are significantly more likely to be noncongruent for symptoms of emotional function. Additionally, other studies have reported no effect of caregivers' sex on congruence of symptoms (Silveira, et al., 2010; Wennman-Larsen, et al., 2007). Overall, studies report inconsistent relationships between female and male caregivers' congruence, finding that females can be more congruent with, but also can overestimate, patients' symptoms when compared with male caregivers.

Caregiver education. Because caregiver education influences caregivers' depression and feelings of burden, it may also be a factor that influences congruence of symptom perception. Prior studies have shown that caregivers whose reports were not congruent with patients' had less education than those who were congruent (Kurtz, et al., 1996; C. Lin, 2001; McPherson, et al., 2008; Miaskowski, et al., 1997; Resnizky & Bentur, 2007). Silveira et al. (2010) found that caregivers who overestimated patients' symptoms were less likely to be high school educated than those who accurately reported and those who underestimated patients' symptoms. Wennman-Larsen et al (2007) found that the caregivers who overestimated cancer patients' symptoms were less likely to have post-secondary education compared to those who were congruent or those who underestimated symptoms. Silveira et al. (2010) have pointed out that education is related to literacy, which can contribute to the abilities of understanding and communication. Schieman and Turner (2001) stressed that education can improve an individual's ability to think, symbolize and communicate, which can improve one's perception of other people's pain. Therefore, it is reasonable that caregivers with higher education levels may have more accuracy in congruent symptom perception. Less education, using a cutoff point of 12 years of education, can predict low congruence that may be related to caregivers' understanding of symptoms and symptoms management. The present study will include caregiver education as a control factor in the EASP model.

Caregivers' relationship to patients. Stinson and Ickes (1992) tested the differences in empathic accuracy between male friends and male strangers, and they found that friends have better empathic accuracy for interpreting the target persons' response than strangers do. In this regard, they believed that the perceiver-target relationship is important in empathic accuracy. In general, most family caregivers of adult cancer patients are spouses or partners. According to the report from the Family Caregiver Alliance, primary family caregivers, in general, are often patients' spouses. In most studies that recruited cancer patients and their family caregivers, spouse caregivers were the majority of caregiver population (ACS, 2010). Spousal caregivers are assumed to understand the patients' behaviors more than nonspousal caregivers. However, no findings have reported that having a spousal relationship is a significant factor affecting congruence of symptom perception for caregivers. As we have seen, spousal relationships can be a factor in caregiver depression and feelings of burden. This study will use caregivers' social role with patients as a covariant factor which may have an indirect effect on congruence of symptom perception.

Living arrangement. Because spousal caregivers and patients are more likely to live together, it is a common expectation that spousal caregivers have greater congruent levels of symptom perception than nonspousal caregivers. A few studies have shown that caregivers who lived with cancer patients were more likely to have congruent reports of patients' quality of life or general health (Magaziner, Simonsick, Kashner, & Hebel, 1988; O'Brien & Francis, 1988; Sneeuw et al., 1997). However, Resnizky and Bentur (2007) identified that living with the patient is a factor for having greater agreement of patient symptoms, when comparing caregivers who lived with and who did not live with cancer patients, regardless of whether they were spouses. Living arrangement may be also related to the caregivers' experience about patients' behavior and life style. Therefore, the current study will examine living with patient as a caregiver's characteristic and test its effect on EASP.

Briefly, based on the findings from previous studies that identified the dyadic factors influencing congruence, caregiver emotionality and threats of providing care may predict congruence, and some caregivers' and patients' demographics have unclear effects on congruence. Those findings support the need to examine these factors in the model of congruent symptom perception in this research. Furthermore, caregivers' demographic characteristics have associations with caregivers' depression and feelings of burden. In this study, these variables will be controlled in order to detect the main effect of caregivers' emotionality and threats on congruence of pain and fatigue severity and frequency between cancer patients and their caregivers.

In sum, caregiver depression and caregiver burden in the previous studies mainly can be identified as common negative perceptions of providing care. These caregivers' negative perceptions may also influence caregivers' perception of patients' symptoms and decrease congruence of symptom perception. Regarding the findings about congruent symptom perception in the prior studies, two issues concerning these hypothesized relationships have to be emphasized for nursing science and nursing practice: (a) prior studies did not use a theory-oriented concept for congruence of symptom perception and (b) the congruent levels of symptom perception may be determined by a combination of cognitive and affective empathic processes.

First of all, most of the previous studies did not apply theories when illuminating the complexities of congruent symptom perception. One notable exception is Lobchuk (2006), who used a concept of *perspective-taking* to describe how caregivers perceive patients' symptoms. With respect to the Davis's empathy model (1994), an empathic process consists of noncognitive and cognitive components, and these two elements respectively generate affective outcomes, such as empathic concern and anger, and non-affective outcomes, such as accuracy and judgments. Thus, Lobchuk's (2002, 2006) concept of perspective-taking describes empathic process to approach congruence. The present study will apply Ickes's concept of empathic accuracy, in which caregivers will be assumed to be empathic with patients' symptom experiences. The present study has selected with caution the theories to support the concept of empathic accuracy in describing the phenomenon of congruent levels of symptom perception in caregiving situations.

Lobchuk et al. (2006) conducted studies based on the concept of perspective-taking to examine how caregivers perceive patients' symptom perceptions and to identify caregivers' perceiving processes by various cues. The results in their preliminary study (2006) have shown that there is no significant difference in caregivers' accuracy in perceiving patients' symptoms after caregivers are guided by different cues. The reason may be because cognitive and affective empathic processes occur simultaneously. Although Davis's empathy model categorized two kinds of empathic processes, cognitive and affective, it is difficult to ask caregivers to choose one kind of empathic process but ignore the other. Therefore, by using Davis's model, caregivers' empathy can be measured by the outcome congruence or helping behaviors. In addition, Lobchuk et al. (2006) suggested that improving patient-caregiver communication may decrease the possibility of discrepant symptom perception. Instead of testing empathic process, the present study will operate within the understanding of the inseparable empathic processes when identifying how the factors, in terms of caregivers' emotionality and the perception of threats, influence congruent levels of symptom perception in caregiving environments.

Methods to Measure Congruent Levels of Symptom Perception Between Cancer Patients and Family Caregivers

Congruent level of symptom perception describes the agreement between caregivers and patients when scoring patients' symptoms and patients' reports of their symptoms as a reference. Discrepancy describes situations where caregivers do not rate the patients' symptoms the same as the patients' do. Among the reviewed studies, congruent levels of symptom perception was identified by subtracting caregivers' reports from patients' reports (C. Lin, 2001; Miaskowski, et al., 1997), and also by using statistics, including reliability analyses and correlation coefficients (Lobchuk & Degner, 2002; McPherson, et al., 2008; Molassiotis, Zheng, et al., 2010; Silveira, et al., 2010), to test agreements between patients and caregivers. The following section introduces the subtraction method and statistical strategies used in previous studies to obtain congruence of symptom perception between cancer patients and their family caregivers. The present study will use the subtraction method and the intraclass correlation coefficient (ICC) to evaluate congruence of pain and fatigue severity and frequency.

Subtraction method. The subtraction method is a simple and convenient strategy to analyze the distance between patients' and family caregivers' scores, such that scores that are closer to zero indicate greater the congruence of symptom perception. For example, Lobchuk et al. (1997) and Resnizky and Bentur (2007) reported the numbers and percentages for dyads in five score distances from -2 to 2 to differentiate dyadic congruency levels for multiple symptoms. The exact same score, indicating perfect congruence, is represented by the zero distance.

Although zero difference between patients' and caregivers' scores (perfect congruence) is expected, having perfectly congruent perceptions for each of the patients' symptoms may be an impossible request for caregivers. Some studies have established congruence with a certain range to distinguish congruent and discrepant groups (C. Lin, 2001; Miaskowski et al., 1997). C. Lin (2001) defined congruent perception of cancer pain by a difference of less than 1 between caregivers' and patients' reports on *pain now,* using an 11-point Likert-type scale on an item from the Brief Pain Inventory (BPI). The scale ranged from 0 (no pain) to 11 (most severe pain). Miaskowski et al. (1997) defined congruence as a range of score difference between caregivers' and patients' rating (± 10 mm) by using a 100-millimeter visual analog scale of pain severity. In both studies, when the distance between symptom scores fells in the established range, there was congruency; when the distances between scores fell outside of the congruent range was discrepancy. In this regard, it may be practicable to establish a range of congruence at either plus or minus1 point (C. Lin, 2001) or at plus or minus 10 mm (Miaskowski et al., 1997) for clinical judgments.

Furthermore, the non-zero score distance between patients and their family caregivers, and the score difference located outside of the congruent range have been referred as noncongruence and discrepancy. The discrepancy can fall into two types: overestimation (higher) and underestimation (lower), to illustrate caregivers' over patients' scores respectively (Hauser et al., 2006; Kurtz, et al., 2006; McMillan & Moody, 2003; McPherson, et al., 2008; Molassiotis, Zheng, et al., 2010; Silveira, et al., 2010). Therefore, subtraction method can show three congruent levels: overestimation, congruence, and underestimation by each dyad. Previous studies often used average score differences of caregivers' over patients' scores for overestimation of cancer patients' symptoms (McMillan et al. 2003; Molassiotis et al. 2010).

However, those studies show a typical congruent symptom perception at group-level. The fact is that some caregivers can accurately report patients' symptoms, while others overestimate and underestimate symptom level. The present study reported the number of dyads in three congruent levels.

Statistical value. Statistical methods, including the paired *t*-test, independent *t*-test, ICC, Kappa, Pearson's correlation, Spearmen's correlation, and Lin's concordance coefficient (LCC), can also be used to evaluate agreement in the levels of congruent symptom perception between family caregivers and cancer patients. In this regard, statistical congruence represents the group-level congruence, but not individual dyadic congruence.

Pearson's correlation, ICC, and LCC are used to test relationships between two or more raters' scores. The correlation, which ranges from 0 to 1, represents the similar patterns between patients' and caregivers' scores. Higher correlation indicates a greater similarity in the pattern between caregivers' and patients' scores. ICC interprets agreement based on five levels: 0 to0.2 as poor, 0.3 to 0.4 as fair, 0.5 to 0.6 as moderate, 0.7 to0.8 as strong, and > 0.8 almost perfect agreement (Cicchetti, 2001; Portney & Watkins, 2000). LCC represents the agreement between two raters' scores and uses the Lin's correlation line passing through the origin and when it has a slope of 1.0 (L. Lin, Hedayat, & Wu, 2007; L. Lin & Torbeck, 1998). The Kappa statistic shows the ratio of percentages for two or more raters' categorized answers for the same questions. High agreement is represented by a higher ratio of the same answer between caregivers and patients.

In sum, both subtraction and statistics (reliability analyses and correlation coefficients), are necessarily applied in the congruence studies. Subtraction is a basic strategy to show differences between patients' and caregivers' perceptions of symptom scores. Statistical methods are advanced strategies used to identify congruent values by comparing entire patterns of symptom scores. For understanding group-level congruence, using subtraction will allow the researcher to compare mean score differences, and using statistics can identify similar patterns of symptoms between patients and caregivers. The present study will use subtraction to identify the individual congruent values of each dyad and test the number of caregivers who overestimate, congruent, and underestimate patients' symptoms. This study also will use statistical strategies to identify the group-value dyadic congruence.

CHAPTER 4

Methodology

The purpose of this research was to examine how caregivers' emotionality and threats of caregiving impact their empathic accuracy of symptoms perception (EASP) between them and their cancer patients. The specific aim of this research is to examine how caregivers' emotionality (caregiver depression) and caregivers' threats of caregiving (caregiver burden) predict EASP (congruence of pain and fatigue severity and frequency), when taking into account contextual factors of caregivers, including caregivers' age, sex, education, and relationship to patients, as well as total number of patients' symptoms that caregivers observe and living arrangement. These caregiver characteristics can influence caregivers' emotionality and threats of caregiving, both of which influence congruence of pain and fatigue severity and frequency.

This study used secondary data analysis with 225 pairs of cancer patients and family caregivers. Two hypotheses for this study were:

1) Increased caregiver depression and caregiver burden will be related to lower congruent values of pain and fatigue severity and frequency.

2) Caregivers who are female, older, patients' spouse, better educated, perceiving a lower number of patient symptoms, and living with patients will have a greater congruence of pain and fatigue severity and frequency than the caregivers, who are male, younger non-spouse of patients, less educated, perceiving a higher number of symptoms, and not living with patients.

Therefore, this study examined the predicted relationship that caregivers' emotionality and threats of caregiving impact EASP with and without contextual factors of caregivers' characteristics. These predictive relationships among three main theoretical concepts, emotionality, threats of caregivers, and EASP, tested the main parts of the theoretical framework of EASP. This study did not test the effect of empathic accuracy on caregivers' helping behavior and quality of life of patients and caregivers.

Study Design

This study was a secondary analysis of a de-identified dataset to examine the relationship between empathic accuracy of the severity and frequency of pain and fatigue, caregivers' emotionality, and caregivers' threats of caregiving as depicted in the conceptual framework of EASP. The parent study for this project is entitled "The Family Home Care for Cancer—A Community-Based Model (# R01Ca-79280)", and was funded by National Institute of Health. This data was selected because it collected information about the perception of patients' symptoms from both patients and caregivers, which allowed the current study to examine congruent pain and fatigue severity and frequency as the operational concept of EASP between patients and caregivers. The present study tested the factors of caregivers that affect congruent symptom perception between patients and caregivers, and the relationship of congruence of pain and fatigue severity and frequency with caregivers' depression and caregiver burden.

Parent study design. The parent study was a longitudinal experimental study with a randomized controlled trial that guided patients and caregivers to manage cancer symptoms. The study was conducted from 1998 to 2003. Consented dyads of patients and their family caregivers received a baseline interview and were then randomly assigned into two groups to receive interventions based on the Symptom Management Toolkit. Patients in one group received the "Patient Intervention for Management of Symptoms and Support (PIMSS)" which was delivered by a trained cancer nurse; the patients in the other group received the self-management attention control (SMAC) delivered by a non-nurse coach. The PIMSS was a stepped-approach cognitive behavioral intervention that taught disease acquired skills to patients who were receiving cancer treatments. The parent study also investigated patients' behaviors and emotion and also involved their family caregivers in managing patients' pain, fatigue, and other commonly occurring cancer symptoms, including constipation, dyspnea, anorexia, inability to concentrate, dry mouth, nausea, cough, emotional distress, and insomnia. Briefly, in the PIMSS group, nurses offered symptom-specific advice about self-care available though a website. The content of the PIMSS included problem solving and self-care management of the symptoms, the impact on physical role and social function, and emotional distress. In the SMAC group, the coach did not offer specific advice, but referred patients to a written symptom management guide containing the same content as the website. Patients were expected to apply the strategies on their own.

The nurse and coach contacted participants by six phone calls in eight weeks (Weeks 1, 2, 3, 4, 6, & 8). The family caregivers were called at Weeks 1, 4 and 8 to discuss concerning symptoms and were referred to the symptom management guide for caregiving strategies. The purpose of contacting family caregivers was to assist them to better manage patients' problems.

Two follow-up interviews for data collection were conducted at Week 10 and 16 via phone contact. The content of interviews included patients' symptom experiences, depressive symptoms, mastery of care, and health-related quality of life, as well as caregivers' caregiving experiences. The duration of participation in the parent study was 16 weeks. Both patients and caregivers were expected to develop the strategies for communication, obtaining support, acquiring information, carrying out self-care behaviors, and coping with emotional distress (C. W. Given et al., 2004).

Design of present study. The present study was a secondary analysis of a de-identified data set, and was a cross-sectional study. Specifically, the current study only used the data from dyadic participants' first interview from the parent study. The parent study was a randomized clinical trial with cognitive-behavioral intervention, and the intervention had been tested to efficiently improve patients’ cancer symptoms experience (C. W. Given, et al., 2004; Sikorskii et al., 2007; Sikorskii, Given, Given, Jeon, & McCorkle, 2006). Because the patients in the PIMSS and the SMAC groups received guidance for symptom management, their symptoms may have improved at the two follow-up interviews. The patients in the PIMSS also had learned strategies to communicate with family caregivers about their symptoms. In this regard, the patients at the two follow-up interviews may have expressed their symptoms more precisely than they did at the first interview. Therefore, the present study only examined the data of patients and caregivers at the first interview, in order to avoid the potential effects of the cognitive-behavior intervention on the patients’ symptom expressions in the second and third interview.

The relationship among caregiver burden, caregiver depressive symptoms, and congruence of pain and fatigue severity and frequency between cancer patients and their family caregivers was the primary process being investigated. Congruent levels of symptom perception was operationally defined as the difference between patients’ scores and caregivers’ score on patients’ pain and fatigue severity and frequency, in which the scores of pain and fatigue severity and frequency were measured by using the modified MD Anderson’s symptom inventory. When the score difference was close to zero indicates similar scores between patients and caregivers, and congruence of pain and fatigue severity and frequency between patients and caregivers was high; and vice versa. Furthermore, this study examined the relationships among caregivers’ emotionality, threats and congruence.

Sample

The parent study recruited participating dyads of patients and caregivers from six healthcare systems in Michigan. Inclusion criteria for the patients in the parent study were: (a) being age 21 or older; (b) having a new diagnosis of solid tumors, such as lung cancer, breast cancer or non-Hodgkin lymphoma, which have been recurrent or have metastasis; (c) having underwent the first course of cancer chemotherapy and completed no more than the first two cycles before the first interview; (d) understand and speak English; (e) being able to communicate by phone; (f) having experienced at least a two-point score on his or her pain severity in the last 24 hours; and (g) having a recognized primary family caregiver. Both patients and their caregivers were at least 21 years old, cognitively intact, English-speaking, able to speak and hear for telephone interviews, and willing to take part in the study. Patients may have had new or recurrent diseases. The parent study excluded patients who were diagnosed with hematological malignancy, received bone marrow or stem cell transplant, and received hospice care, or had diagnosed emotional or psychological disorders because these patients had different needs for symptom management from those patients who were diagnosed with solid tumors and the patients who received cancer treatments (C. W. Given, et al., 2004).

The present study used the same inclusion and exclusion criteria as the parent study. In addition, this study selected all of the dyadic participants where both the patient and family caregivers reported severity and frequency of patients' pain and fatigue in the last seven days at the first interview in the parent study. The parent study at baseline interview had a total number of 225 dyadic participants who met these criteria, which was the sample size for the present study.

Power analysis. Statistical power analysis examines the relationship among the four elements involved in statistical inference: sample size (N), significance criterion (α), population effect size (ES), and statistical power ($1-\beta$) (Cohen, 1992). Effect size is often used in practice to estimate a likelihood of having a clinical significant difference between two treatment groups or having any other numerical-comparison contrasts when the study has a specific sample size. A higher effect size indicates a higher likelihood that the study can have a clinical significant difference.(Faraone, 2008; Ferguson, 2009; Kelley, 2007). Cohen (1988) suggested that for regression and correlation, an effect size at least 0.02 is small, at least 0.15 is moderate, and at least 0.35 is large. The parent study used the results of 15-item symptom severity as a primary outcome to examine the effect of intervention, and targeted 122 patients per study arm and detected a similar effect size of approximately 0.35 between the two groups after weeks 10 and 20, with at least 80% power at 5% level of significance (C. W. Given, et al., 2004). Therefore, a collected sample size of 122 in each study arm of the parent study would be sufficient to show the significant effect differences between the experimental group and control group.

In the present study, which was conducted as a cross-sectional study with a fixed sample size of 225, the statistical sample power was examined by following three questions:

1. What sample size is expected for the current study, if the study assumed a moderate effect size (which is 0.15 and represents 0.36 Pearson's correlation between dependent variable and independent variable for simple linear regression modeling), alpha is 0.05, and sample power is 80% within the 8 predictors (age, sex, education, relationship to patients, living arrangement, number of observed patient symptoms, depression, and caregiver burden), and congruence of symptoms will be an outcome variable?
2. How much sample power will result based on the fixed sample size of 225 pairs, if the study assumed that median effect size is 0.15, alpha is 0.05, and the number of predictors is seven, and congruency of symptoms will be an outcome variable?
3. How much effect size could this model capture by given the sample size of 225 pairs, if the study assumed that power is 80%, alpha equals 0.05, and the number of predictor

of seven?

The present study operated the G*power software to examine statistical power analysis. The G*power performs high-precision statistical power analyses for the most common statistical tests: *t*-test, *F*-tests, and *chi-square* tests in behavioral research. (Erdfelder, Faul, & Buchner, 1996). The G*power has been used in many other disciplines, including biology, genetics, ecology, pharmacology, and medical research (Faul, Erdfelder, Lang, & Buchner, 2007).

The main research concern in the present study was to detect any correlation between congruent symptom perception variables. The G*power setting used *F*-test with linear multiple regression procedure with null hypothesis of squared multiple correlation coefficient deviated from zero. Squared multiple correlation coefficient ranges (R^2) from 0 to 1 and represents how much variance of the dependent variable (here congruence of symptom perception) could be explained by the independent variables (Shieh, 2008). Thus, the deviation of R^2 from zero means that the independent variables can explain 0% of the variance of the dependent variable, so that the dependent variable cannot be predicted by the independent variables.

For Question 1, the sample size would be at least 55 when this study has standard sample power as 80%, alpha as 0.05, and effect size as 0.15. For Question 2, the sample power of predicting a significant factor is 99.9% when the study has the samples size as 225, alpha as 0.05, effect size as 0.15. These two results show that the present study had a sufficient sample size and sample power when the study has a moderate effect size.

For Question 3, the result by used G*power showed that the desired effect size 0.06 was minimum, with a sample size as 225, power as 80%, alpha as 0.05, and seven predictors. A cross-sectional, descriptive study with a fixed sample size and a small effect size, like the current study, would be less likely to find a significant difference or correlation coefficient among the variables.

Measurements

The present study tested the EASP conceptual framework, which focused on congruent symptom perception of pain and fatigue severity and frequency. The theoretical concepts in this study were the caregivers' emotionality, threats of caregiving, and EASP. Based on two hypotheses, caregivers' emotionality and caregivers' threats of caregiving are assumed to predict congruence of pain and fatigue severity and frequency between cancer patients and their family caregivers. Both patients and caregivers' demographics, caregivers' depression and burden and congruent levels of symptom perception will be described for the profile of the dyadic samples (see Table 1 & Table 2).

Demographic characteristics. Demographic characteristics of cancer patients and caregivers including patients' and caregivers' age, sex, education, caregivers' relationship to patients, and living arrangement, which were considered based on the results of reviewed studies. Age of patients and caregivers was based on the date of birth at the time of collecting data and was a continuous variable. Sex, Education, Relationship to patients, and Living arrangement were categorized as binomial variables. Sex was naturally coded in male and female. Caregivers' education was split into two levels: the caregivers who attended college or some technical training, and those who had no formal education and who were educated but did not attend college. The categorical variable 'relationship to patients' focusing on caregivers' role to patients, but not quality of relationship, was coded 1 for spousal caregivers and 0 for non-spousal caregivers. Caregivers' Living arrangement was coded in caregivers living together with patients and those living in separately. Other patients' clinical characteristics also included the site of cancer, stage of cancer, metastasis and recurrence of cancer.

When the analysis was processed the test of the general linear modeling for two hypotheses, only caregivers' demographic variables were treated as control variables. These caregiver variables were reported in the previous studies to be associated with caregivers' emotionality, caregiver burden, and congruence of symptom perception, and included caregivers' age, sex, education, relationship to the patient, and living arrangement, as well as the total number of patients' symptoms that caregivers observed.

Caregiver perception. Caregiver perceptions-caregivers' emotionality and their perception of threats, in the theoretical framework have been hypothesized to affect congruent levels of symptom perception. Emotionality has been operationally defined as caregivers' depressive symptoms. Threats have been understood to be features related to care demands, for example, caregiver burden. Caregiver burden has been operationally defined as caregivers' subjective reactions about how providing patient care impacts them. For the current study, the CESD) was used to measure caregivers' depression and the Caregiver Reaction Assessment (CRA) was used to measure caregiver burden. The modified MD Anderson Symptom Inventory (MDASI) tested pain and fatigue severity and frequency in order to measure congruence.

Caregiver depression. The CESD **(**van Dam **&** Earleywine, 2010**)** consists of 20 items which was developed by Radloff (1977) to evaluate the frequency of depressive symptoms experienced in the preceding week. Each item is scored on a four-point scale (0-3) to represent the range of frequency of experiencing depressive symptoms in the past week, in which 0 represents not at all or less than one day, 1 is for 1-2 days, and 2 is for 3-4 days, and 3 is for 5-7 days. The total score of the CESD has a range from 0 to 60 with higher scores indicating greater depressive symptoms. The reliability, validity and factor structure have been tested in the general population (Radloff, 1977). The inter-item and item-scale correlations were higher in the patient sample (0.9) than in the general population (0.85). Lower test-retest reliability ($r < 0.5$) may result from the life events that occurred in the measured time interval; therefore, the CESD is also sensitive to the occurrence of life events. The validity has been obtained by comparing the CESD score of the sample patient to the individual's score on the Positive Affect Scale; the correlation was highly negative (Radloff, 1977). By comparing the general population with patients who had a depression diagnosis, researchers have identified the cutoff score of 16 or higher as the clinical criterion for having depressive symptoms (Radloff, 1977; Schein & Koenig, 1997). The score of 16 has shown a high sensitivity (100%) for clinical depressive symptoms in different populations (Dozeman et al., 2010; Li & Hicks, 2010).

The CESD scale has been used to detect caregivers' depressive symptoms with good reliability and validity. Cronbach's alpha was approximately 0.9 in the studies that used the CESD scale to measure caregivers' depressive symptoms (Y. Kim, et al., 2005; Sherwood et al., 2007). Kim, Kashy, and Evans (2007) found that 25% of the caregivers of patients with colon/rectal cancer diagnosed within the past 2 month had moderate depressive symptoms with CESD scores of 16 or above (see Table 1).

In this study, the score of CESD represented the caregiver depressive symptoms and was tested as an independent variable in the congruent model of pain and fatigue severity and frequency when examining the two hypotheses. Caregivers were also categorized in two groups by a cut-off point score on the CESD of greater than or equal 16. The categorization allowed the researcher to examine the differences of caregiver demographic characteristics, hours of providing symptom management, total number of patient symptoms, caregiver burden, caregivers' reports of patients' pain and fatigue severity and frequency, and congruence of pain and fatigue severity and frequency.

Caregiver burden. The CRA was developed to measure types of caregivers' responses and changes in the reaction over time (C. W. Given, et al., 1992). The CRA has 24 items falling into five dimensions: self-esteem, family abandonment, schedule interruption, health burden, and financial burden. Self-Esteem subscale (seven items) assesses whether or not caregiving is enjoyable and rewarding, or whether it cause resentment. Family Abandonment subscale (five items) measures the extent to which families support and work together with caregivers, and also asks caregivers' perception of being abandoned by other family members. Schedule Interruption subscale (five items) assesses the degree to which caregiving interrupts caregivers' usual activities, causes the elimination of some activities, and interferes with relaxation times. Health Burden subscale (four items) measures caregivers' physical capability and energy to provide care. The last subscale, Financial Burden (three items) looks at the adequacy, the difficulty, and the strain of financial situation on the caregivers and the family (C. W. Given, et al., 1992; Stommel, Wang, Given, & Given, 1992).

Each item is scored on a 5-point scale, from 1 (*strongly agree*) to 5 (*strongly disagree*). Scores for items in the Self-Esteem subscale need to be reversely coded when a total score of the CRA is calculated. A higher total score of the CRA refers to higher burden. The inter-scale correlations have shown a fair independence (0.02- 0.45), which means that each subscale can be independently used for measurement (C. W. Given, et al., 1992). The test-retest reliability of the five subscales ranges from 0.62 to 0.86 over 12 months (Persson, Wennman-Larsen, Sundin, & Gustavsson, 2008). The construct validity was tested by comparing with the patients' scores for Activities of Daily Life (ADL) and the CESD. Both the ADL and CESD have been shown to be negatively correlated to caregiver self-esteem (-0.11 with ADL, and -0.23 with CESD), and positively correlated to burden of finances, lack of family support, health and schedule interruption (*r* = 0.34 to 0.57). Researchers have also found the higher correlations between the ADL and the subscale "schedule interruption" (*r*= 0.52), and between the CESD scale and Health Burden subscale (B. Given & Given, 1992; C. W. Given, et al., 1992).

Cronbach's alpha scores have shown a high degree of reliability for the five subscales (0.62 to 0.90). The homogeneity of the items in each subscale of the CRA has been found to represent high internal consistency (C. W. Given, et al., 1992; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Using the CRA in face-to-face interviews has been demonstrated to take 10 minutes or less (Nijboer, et al. 1999). There have been no studies reporting the CRA's sensitivity and specificity, possibly because it may be difficult to find a comparison group of family caregivers who are not experiencing caregiving stress, which would be needed to determine a clear cutoff score. The ceiling/floor effects of the CRA scale have also not been tested, but the 5-point level scale for each item may give the range of the score needed to decrease the possibility of ceiling/floor effects (see Table 1).

Although the CRA consists of five subscales, each of them can be independently used to measure theses five characteristics of caregivers' reactions of caregiving (C. W. Given, et al., 1992). The present study used only three subscales from the CRA—Schedule Interruption, Family Abandonment, and Self Esteem, to evaluate caregiver burden (Table 2). Both Schedule Interruption and Family Abandonment depicted negative caregiver reactions that directly resulted from care involvement, including symptom management. The Self Esteem subscale represents positive caregiver reaction that may directly contribute to a caregiver's perception of helping patients. These three caregiver reactions may be recognized as soon as caregivers start dealing with care demands. Sherwood et al. (2005) stated that these three caregiver reaction subscales were thought to represent the portions of caregiver burden that would be more affected by the exogenous factors, such as the number of caregiving demands.

Although the items of Health Burden subscale and Financial Burden subscale are relevant to providing care, caregivers' health and financial issue are not impacted by caregiving involvement. Caregivers' health in physical capability and energy in performing caregiving may also be influenced by their pre-existing health conditions. The Finance Burden subscale examines whether there is a financial difficulties resulting from providing care for caregivers and the families, so that financial burden may only influence caregivers and family to pay for utilizing social supports and to maintain households. Therefore, current study selected three subscales—Schedule Interruption, Family Abandonment, and Self Esteem, to measure caregiver burden in three separated domains and did not apply these two subscales in representing caregiver burden (See Table 1).

Symptom. The MDASI (Cleeland et al., 2000) was modified in the parent study to measure cancer patients' symptom severity and frequency, so that the present study used them to represent the severity and frequency of pain and fatigue in the present study. The parent study selected the 15 most prevalent symptoms of patients during the time when patients received active cancer treatments. The MDASI has demonstrated an internal consistency of 0.85. The construct validity has shown similar factor loadings between two outpatient samples. The MDASI has been also sensitive to detect high scores of symptom severity and interference for patients with poor performance and for patients undergoing active treatments (Cleeland, et al., 2000; Soltow, et al., 2010).

In the parent study, both patients and caregivers report patients' pain and fatigue severity and frequency which were measured by using the modified MDASI. Symptom severity was examined by separately asking the patients and their caregivers to rate patients' average pain and fatigue severity within the past seven days by using an 11-point scale (0-10), where 10 indicated the worst pain and fatigue severity. The MDASI was also modified to measure frequency of the same 15 symptom, as perceived by the patients and caregivers. Symptom frequency examined how many days that patients felt pain and fatigue in the past week. The frequency was recorded by using a 8-point scale (0-7), in which 0 meant to no feelings of pain or fatigue on any day, and 7 meant feelings of pain and fatigue happening daily in the last seven days (Appendix A). Therefore, for severity of both pain and fatigue, greater score indicated the more severe pain and fatigue. Likewise, for frequency of patients' pain and fatigue, which ranged from 0 to 7, greater scores indicated the more frequently feelings of pain and fatigue. The present study tested pain and fatigue severity and frequency between patients' and caregivers' symptom reports to represent congruence of symptom perception.

Congruence. Congruence of pain and fatigue severity and frequency has been operationally defined as the congruence of symptom perception, which is a measure of a caregiving situation in which family caregivers and patients have similar perceptions of patients' symptoms, specifically focusing on pain and fatigue severity and frequency. In the current research, congruence of pain and fatigue severity and frequency was obtained by comparing caregivers' perception of patients' pain and fatigue severity and frequency with patients' self-reports, thereby, examining family caregivers' accurate perception of patients' symptoms as a measure of empathic accuracy. The comparison for congruent symptom perception will be presented by statistical and mathematical methods (see Table 2).

The mathematical methods for obtaining congruence of pain and fatigue severity and frequency were to subtract caregivers' reports of patients' symptoms from patients' self-reports, calculated as the value of the difference between patients' scores and caregivers' score on patients' pain and fatigue severity and frequency, with patients' reports as reference. When the value of the difference was close to zero, indicating similar scores between patients and caregivers, this also indicated high congruence of pain and fatigue severity and frequency between patients and caregivers; and vice versa.

The symptom score difference via the mathematical approach was recalculated into two forms to represent the congruent level, in which one was the absolute value, and the other encompassed three levels of original natural scores of each symptom variable. The absolute value of the distance between patients' and caregivers' score of patients' pain and fatigue severity and frequency represent congruent severity ranged from 0 to 10, and congruent frequency ranged from 0 to 7. An absolute value of the difference close to zero designates similar scores between patients and caregivers, indicated that the congruent degree of pain and fatigue severity between patients and caregivers was high. The absolute value of congruent symptom perception was used to test the two hypotheses.

The original natural score differences of these four symptom variables: pain and fatigue severity and frequency were categorized into three levels: overestimation, congruence, and underestimation. Operationally, overestimation describes that caregivers rate a higher score for patients' symptoms than patients (the scores differences was greater than 1); underestimation describes that caregivers rate a lower score for patients' symptoms than patients (the score difference was less than -1), and congruence depicts caregivers gave a similar score of symptom characters as patient do (the score differed in the range from -1 to 1). Therefore, each symptom characteristic had three congruency categories.

The statistical method measured congruence, which was scored by continuous variables of pain and fatigue severity and frequency, representing the levels of agreement between patients and caregivers. The agreement was tested by the ICC (see description in the data analysis section).

Meanwhile, the MDASI was used in the current study to measure the number of patients' symptoms that the caregivers perceived. There were 15 total symptoms in the MDASI. The variable for the number of patients' symptoms was obtained by counting the symptoms that caregivers had reported in the parent study, creating range of 0 to 15 for the total number patients' symptoms that caregivers perceived. However, the inclusion criteria for the dyad selection in the present study stated that both caregivers and patients must at least report patients' pain and fatigue severity and frequency, so each dyad had at least 2 points for the number of symptoms at the first interview (see Table 2).

Human Subjects Protection

The current study obtained two approvals: the approval of Institutional Review Board (IRB) from Michigan State University, and the approval of dataset utilization from the principle investigator of the Family Home Care for cancer. Because this data has been de-identified, the IRB application was deemed by the IRB as not pertaining to Human Subjects research and has been exempted. The variables were selected based on the conceptual framework (Figure 1). The current study obtained the approval of utilizing the data set from the principle investigators of the parent study.

Table 1

Instruments Used to Measure Caregiver Depressive Symptoms, Caregiver Burden and Cancer Symptom Perception of Patients and Caregivers

Measurements	Authors	Subscale	Items	Score	Psychometrics
CESD	Radloff 1977	N/A	20	4 levels: 0-3 0= 0 day, 1= 1-2 days, 2 = 3-4 days, & 3 = 5-7 days	Cronbach' α =0.9 Inter-item & Item-scale correlation = 0.9
CRA	Given, et al. 1992	Health impact (4) Family abandonment (5) Schedule interruption (5) Financial burden (3) & Self-esteem (7)	24	1-5 points (strongly agree to strongly disagree)	Cronbach' α 0.62- 0.9 for 5 subscales Health, α= 0.80 Self-esteem, α= 0.90 Schedule, α= 0.82 Abandonment α= 0.85 Finance, α= 0.81 Construct validity 0.23- 0.57 for 5 subscales
MDASI	Cleeland, et al. 2000	Present Severity Interference with life	19	0-10 (severity)	Internal consistency = 0.85

Note: The center for Epidemiologic studies depression (CESD), Caregiver Reaction Assessment (CRA), The *MD Anderson Symptom Inventory* (MDASI)

Data Management

Merging data files. Because the congruent levels of symptom perception use both patients' and caregivers' information at the same time, these two datasets were merged into one in order to identify the dyadic sample. After the researchers defined the missing values, the datasets from the cancer patient side and the family caregiver side in the parent study were merged by the same subject ID number. Each dyad had the same research ID number for the patient and his or her family caregiver. The procedure of merging was as follows: (a) sort the research ID number from small to large for patient and caregiver datasets; (b) based on the same ID number, the variables of two datasets were merged into one dyad's information, and (c) the variables were selected for the present study based on the theoretical framework (see Figure 1). Additionally, selection of the dyads for the present study was based on the inclusion and exclusion criteria (see Sample section in this chapter).

Data recode. In order to identify the factors for congruence of pain and fatigue severity and frequency, this study has to obtain congruent levels of pain and fatigue severity and frequency between caregivers and cancer patients. At the first step, we merged the patients' and caregivers' information into one data set regarding their same research identification number. The second step was to reorganize caregivers' demographic characteristics, including sex, relationship to patients, education, and living arrangement. We recoded female caregiver as '1' and male caregivers as '0'. The original data of variable 'Relationship to patients' was coded for spouse caregivers as '1' and non-spouse caregivers as '0.' Caregivers in the parent study who completed college education are recoded as '1'and other caregiver who had secondary education or less are recoded as '0'. Caregivers' living arrangement was recorded '1' if they *lived with patients* when they were interviewed and '0', if they did not live together. The literature recommended that *CESD score of 16 or higher* may indicate the potential of having clinical depressive symptoms. This study also recoded caregivers' depression score that CESD score is 16 or higher as '1' and CESD score is lower than 16 as '0,' to examine the differences between two CESD groups in binomial caregiver demographics, total number of patients' symptoms, caregiver burden, caregivers' perception of pain and fatigue severity and frequency, and congruence of pain and fatigue severity and frequency

Data Analysis

The current study used the conceptual framework in order to understand the predictors of empathic accuracy of pain and fatigue severity and frequency between cancer patients and their family caregivers. The Statistical Package for the Social Sciences (SPSS) version 18 (IBM, Inc. Armonk, NY) was used for descriptive analysis, Pearson's correlation, independent *t*-test, chi-square, ANOVA, the generalized linear models (GLM), and multinomial loglinear regression.

Descriptive analysis of sample. The data were examined according to the characteristics of all variables. The continuous variables (e.g. age and pain severity), were represented by mean, standard deviation, range, and confidence intervals. The categorical variables (e.g., sex, level of education, relationship to patient, and cancer site) were shown by the percentage and frequency (see Table 2).

ICC. ICC was used to identify the overall levels of congruence of pain and fatigue perception. ICC is a statistical method that has been used to measure the correlation between pairs of observations that do not have obvious order, and it has also been used to measure the agreement between assessors, rather than between two methods (White & van den Broek, 2004). A class of variables refers to metric (scale) and the variance of variables. When researchers are interested in the relationship among variables of a common class, they can look for the ICC. The

Table 2

Variables and Their Measurements Used for Data Analysis

Theoretical domain	Measurement	Variables	Score	Statistical analysis
Control variable				
		Caregiver age	≥ 21	Descriptive analysis
		Caregiver sex	0,1	
		Caregiver education level	0.1	
		Caregiver relationship to patient	0,1	
		Living arrangement	0,1	
		Number of patients’ symptoms	0-15	
Theoretical variable				
Emotionality	CESD	Caregiver depression	0-60	Descriptive analysis
Threat	CRA	Family Abandonment (5)	5-25	Descriptive analysis
		Schedule Interruption (5)	5-25	
		Self-Esteem (7)	7-35	
Congruent level of symptom perception	MDASI	Pain severity in the last 7 days Fatigue severity in the last 7 days	0-10	Descriptive analysis (1) Caregiver’s score - patients’ score (2) Intraclass correlation coefficient (ICC)

Note: A total of 17 items were chosen in the CRA for three subscales: Family Abandonment, Schedule Interruption, and Self-Esteem (see Appendix A: Caregiver Reaction Assessment Instrument). CESD = The Center for Epidemiologic studies depression; CRA = Caregiver Reaction Assessment; MDSAI = The MD Anderson Symptom Inventory.

ICC represents the ratio of each symptom score that divides the rated variances of each dyad of patients and caregivers by overall variance (McGraw 1996). Statistically significant results indicated meaningful congruence between patients and caregivers. The following guidelines in ICC were used for interpretation of the level of similarity or agreement: 0.81-1.00 is excellent agreement; 0.61-0.80 is good agreement; 0.41-0.60 is moderate agreement; ≤ 0.40 is poor to fair agreement (Cicchetti, 2001; Kramer & Feinstein, 1981). The ICC values between patients and caregivers' scores by the statistical method represents congruence levels of symptom perception, which means that a higher ICC values represented higher levels of agreement between patients and caregivers' scores, which also indicated higher levels of congruence.

Pearson correlation. Pearson correlation was used to examine the relationship strength among the variables, in order to choose variables for the tests of the GLMs. The Pearson correlation is a measure of the strength of the relation between two or more variables. Using Pearson's correlation assumes that two variables are measured on at least interval scales, and determines the extent to which the values of two variables are proportional to each other. Correlations can range from 1.0 to -1.0 where a value close to 0 represents no relationship between the variables; the value of -1 refers negative to a correlation, and 1 refers to a positive correlation. However, the correlation only proves the strength of the relationship between variables, and cannot show cause and effect (Bewick, Cheek, & Ball, 2003; Hill & Lewicki, 2011). The contextual factors (caregivers' characteristics) were re-coded to 0 and 1 as dummy variables in order to score the correlation between congruence and those contextual factors.

GLMs. General linear regression which solves the equation fits a straight line to a number of points. The line represents the correlation between the dependent variable and the independent variables corrected by the ratio of standard deviations of these variables. GLMs were used to measure the regression of depressive symptoms and caregiver burden regarding the caregiver demographics as independent variables.

Loglinear regression. In order to test this study's hypotheses, the researcher used the categorized three congruent levels: overestimation, congruence, and underestimation as dependent variables. Because the dependent variable is categorical, loglinear regression was used to test the analysis model (see Figure 2). Loglinear regression is a multiple regression, which is typically used to test models when the dependent variables are categorical or dichotomous. The factors (independent variables) used in the loglinear regression can be continual variables or categorical variables. The multinomial loglinear regression identified caregiver characteristics which predicted congruence/non-congruence of pain and fatigue severity and frequency. Multinomial logistic regression is used to model nominal outcome variables, in which the log odds of the outcomes are modeled as a linear combination of the predictor variables. Exp (parameter) or exp (β) represents the odds ratios for the predictors. They are the exponentiation of the coefficients.

For hypothesis 1, the dependent variable was three congruent levels of pain and fatigue frequency and severity, and independent variables are caregiver depression and caregiver burden. For hypothesis 2, caregiver demographic characteristics were tested to identify whether they are covariates of caregiver depressive symptoms and caregiver burden the independent variables or they are also the predictor of these three congruent levels. Caregiver demographics included age, sex, education level, relationship to patient, living arrangement and the total number of patients' symptoms that were perceived. These two hypotheses generated eight equations. The first four equations tested Hypothesis 1 that increasing caregiver depression and caregiver burden can decrease congruence. The other four equations tested Hypothesis 2 that considering caregivers' demographic characteristics as confounding variables with depression and burden affects congruence (see Table 3).

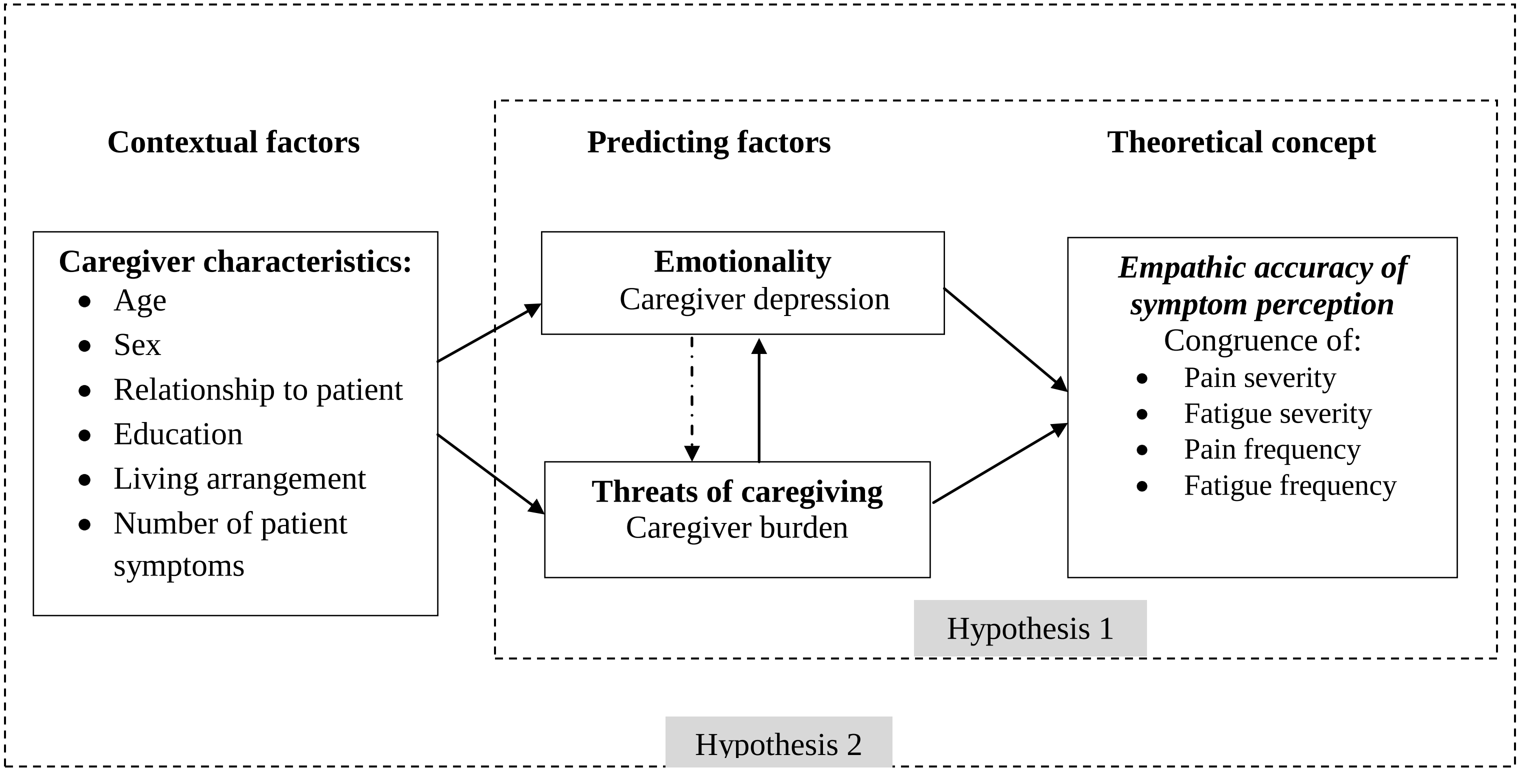


Figure 2. Analysis model for predicting factors and empathic accuracy in the theoretical framework, Empathic Accuracy of Symptom Perception. The boxes with dotted line are the two hypotheses.

Table 3

Linear Regression in Testing Hypothesis

	Equation	Symptom perception
Hypothesis 1	Congruence of *pain* severity = a_1 + b_{11} caregiver depression + b_{12} caregiver burden + b_{13} caregiver depression * caregiver burden+ b_{14} contextual variables + e_1	PS
	Congruence of *pain* frequency = a_2 + b_{21} caregiver depression + b_{22} caregiver burden + b_{23} caregiver depression * caregiver burden+ b_{24} contextual variables + e_2	PF
	Congruence of *fatigue* severity = a_3 + b_{31} caregiver depression + b_{32} caregiver burden + b_{33} caregiver depression * caregiver burden+ b_{34} contextual variables + e_3.	FS
	Congruence of *fatigue* frequency = a_4 + b_{41} caregiver depression + b_{42} caregiver burden + b_{43} caregiver depression * caregiver burden+ b_{44} contextual variables + e_4.	FF
Hypothesis 2	Congruence of *pain* severity = a_5 + b_{51} caregiver depression + b_{52} caregiver burden + b_{53} caregiver depression * caregiver burden + e_5	PS
	Congruence of *pain* frequency = a_6 + b_{61} caregiver depression + b_{62} caregiver burden + b_{63} caregiver depression * caregiver burden + e_6	PF
	Congruence of *fatigue* severity = a_7 + b_{71} caregiver depression + b_{72} caregiver burden + b_{73} caregiver depression * caregiver burden + e_7	FS
	Congruence of *fatigue* frequency = a_8 + b_{81} caregiver depression + b_{82} caregiver burden + b_{83} caregiver depression * caregiver burden + e_8	FF

Note. *a*=incept, *b*= parameter, *e*= error, PS = pain severity, FS= fatigue severity, PF= pain frequency, & FF= fatigue frequency

Chapter 5

Results

This descriptive secondary data analysis examined how caregivers' emotionality (caregiver depressive symptoms) and caregivers' threats of caregiving (caregiver burden) predict EASP (congruence of pain and fatigue severity and frequency). Based on the theoretical framework of EASP, the contextual factors, including caregivers' age, sex, education, relationship to patients, the total number of patients' symptoms that caregivers observe, and living arrangement were covariants of caregivers' emotionality and threats of caregiving. The covariants were hypothesized to influence congruence of pain and fatigue severity and frequency. In this chapter, the analysis model (Figure 2) will be tested, as will the study's two hypotheses: (1) that increased caregiver depressive symptoms and caregiver burden will be related to lower congruent values of pain and fatigue severity and frequency, and (2) that caregivers who are female, middle aged or older, a spouse of the cancer patients, have higher education, perceive lower numbers of patients' symptoms, and who live with patients will have greater congruence of pain and fatigue severity and frequency.

Sample Size and Power

The present study only selected 225 dyads of cancer patients and their identified family caregivers who both reported patients' pain and fatigue severity and frequency. This sample size contributed an effect size of 0.06. Effect size refers to the possibility of significant variance between the groups. According to the criteria of effect size for the regression model provided by Cohen (1988), the effect size of 0.06 is close to the minimum of at least 0.02. This small effect size illustrates that a significant relationship among the variables is less likely and that a low likelihood of identifying a significant relationship is expected.

Table 4

*Cancer Patients' Demographic Characteristics (*N *= 225)*

Demographic characteristic		Mean (*SD*)	
Age		58.35	(11.6)
Comorbidity		2.10	(1.6)
Average total # of patient symptoms		8.32	(3.1)
		N (%)	
Age	<45	23	(10.2)
	45 ≤ age <65	133	(59.1)
	≥65	69	(30.6)
Sex	Female	134	(59.6)
Education	No education or primary school	3	(1.3)
	High school	77	(34.3)
	College	107	(47.5)
	College graduate	38	(16.9)
Race	Caucasian	201	(90.1)
	African American	17	(7.6)
	Other	5	(2.1)
Marital status	Single (never married, widowed, separated/divorced)	51	(22.7)
	Married & partner	173	(77.2)
Employment	Currently work for pay (Yes	58	(25.8)
	/No)	167	74.2)
	Retired (if not working for pay)	100	(60.6)
Comorbidity	0 comorbidity	41	(18.2)
	1 comorbidity	49	(21.8)
	At least 2	135	(60.0)
Cancer site	Breast cancer	55	(24.4)
	Colon	16	(7.1)
	Lung (non-small	54	(24.0)
	/small cell)	14	6.2)
	Genitourinary	23	(10.2)
	Gastrointestinal	16	(7.1)
	Gynecological	12	(5.3)
	Others	32	(14.2)
Cancer stage	Early	18	(8.0)
	Late	201	(89.3)
Recurrent	Yes	63	(28.0)
Metastasis	Yes	139	(61.8)

Table 5

*Caregivers' Demographic Characteristics (*N *= 225)*

Demographic characteristic		Mean (*SD*)	
Age		54.8	(13.1)
Comorbidity		1.7	(1.5)
Average total # of patient symptoms		8.0	(3.1)
Hours of symptom management		10.6	(5.3)
Caregiver depressive symptoms (CESD)		11.9	(7.8)
		N (*%*)	
Age	<45	48	(21.3)
	45 ≤ age <65	125	(55.5)
	≥65	52	(23.1)
Sex	Female	135	(60)
Relationship to patient	Spouse	161	(71.6)
	Adult child	19	(8.4)
	Other	36	(20)
Education	No education or primary school	1	(0.4)
	High school	75	(33.3)
	College	111	(49)
	College graduate	38	(16.9)
Race	Caucasian	207	(92.0)
	African American	12	(5.3)
	Other	4	(2.7)
Marital status	Single (never married, widowed, separated/divorced)	36	(16.1)
	Married & partner	184	(83.7)
Employment	Currently work for pay (Yes)	130	(57.8)
	Retired (if not working) for pay	66	(29.3)
Living arrangement	Together	189	(84)
Comorbidity	0 comorbidity	49	(21.8)
	1 comorbidity	71	(31.6)
	At least 2	105	(46.7)
Hours of symptom management	At least 4 hours	88	(52.1)
	≥ 11 hours	46	(54.7)
Caregiver depressive symptoms (CESD)	≥12	103	(45.8)
	≥16	56	(24.9)
Caregiver burden (CRA)	Schedule interruption	2.9	(0.8)
	Self-esteem	4.5	(0.5)
	Family support	1.7	(0.6)

Note. CESD = The center for Epidemiologic studies depression; CRA = Caregiver Reaction Assessment

Descriptive Analysis of Participants' Demographic Characteristics

A total of 225 dyadic cancer patients and their caregivers were included (see Tables 4 and 5). This study used descriptive analysis to examine the dyadic participants' demographic characteristics, including patients' and caregivers' age, sex, education, and comorbidities, hours caregivers spent providing symptom management, caregivers' living arrangements, patients' cancer diagnoses, cancer stages, as well as caregivers' emotionality (depressive symptoms) and threats of caregiving (caregiver burden—family abandonment and schedule interruption, and positive caregiver reaction of self-esteem) in the conceptual framework of EASP (see Tables 4 and 5). In the tables, the continuous and ordinal variables are represented by their means and standard deviations, while the categorical and nominal variables are represented by their total numbers and percentages.

Age. Overall, patients were older than their family caregivers. The average age of these cancer patients was 58.35 (*SD* ± 11.59), and of caregivers was 54.80 (*SD* ± 13.14). There were 125 (55.5%) caregivers and 133 (59.1%)patients in the age range of 45 to 65. Participants whose age was 65 or older were 52 (23.1 %) for caregivers and 69 (30.6%) for all cancer patients.

Sex. This study had 134 (59.6 %) female patients and 135 (60.0 %) female caregivers. There were 79 (48.0%) female caregivers among the 161(71.0%) spousal caregivers.

Education. More than half of caregivers and patients at least had a college degree. There were 111 (49.0 %) caregivers and 107 (47.5%) patients having a college degree. Seventy-five (33.3%) caregivers and 77 (34.3%) patients had only a secondary education.

Race. Among 225 dyads, 207 (92.0 %) caregivers and 201 (90.1%) patients were Caucasian. There were 12 (5.3%) caregivers and 17 (7.6%) patients who were African American. The remaining minority categories, included Mexican (Latina), Asian, and Native American, were represented by 4 (2.7%) caregivers, and 5 (2.1%) patients.

Marital status. A majority of patients and caregivers were married. Fifty-one (22.7%) patients and 36 (16.1%) caregivers were single (never married, widowed, separated, and divorced).

Employment. There were 58 (25.8%) employed cancer patients. Among 167 unemployed cancer patients, 100 of them (44.4% of 225 cancer patients and 60.6 % of 167 unemployed cancer patients) were retired. Among 225 family caregivers, 130 (57.8%) were employed and 95 (42.2%) were unemployed at the time of interview. There were 66 unemployed caregivers (29.3% of 225 caregivers, 69.5% of 95 unemployed caregivers) that were retired.

Living arrangement. There were 189 (84%) of family caregivers living with patients at the time of interview. All spousal caregivers (*N* = 161) lived with patients (not shown in the table).

Cancer diagnosis. Among 225 cancer patients, 68 (30.2 %) were diagnosed with lung cancer, which included 54 (24%) patients diagnosed with non-small cell lung cancer and 14 (6.2%) patients diagnosed with small cell lung cancer. Fifty-five (24.4%) patients were diagnosed with breast cancer. Thirty-nine (14.2%) patients had cancer related to the gastrointestinal system (colon and other gastrointestinal organs cancer). There were 201 (89.3%) patients at the late stage of cancer when received the cancer diagnosis, which is greater than those who were at the early- staged cancer. Sixty three (28%) patients were recurrent and 139 (61.8%) patients were metastatic at the time of diagnosis.

Comorbidity. The average number of comorbidities reported by patients' was 2.1 (*SD* ± 1.61) and by caregivers was 1.71 (*SD* ± 1.52). The number of caregivers who reported no comorbidity was 49 (21.8%), who had one comorbidity was 71 (31.6%), and who had at least two comorbidities was 105 (46.7%). All comorbidites were reported for the time they took care of cancer patients. More than half of the patients (*n* = 135, 60.0%) reported that they had at least two comorbidities at the time of interview.

Hours of providing symptom management. The hours of providing symptom management measured how many hours that caregivers spent providing symptom management for patients in the week before the interview. The average hours of symptom management in prior week was 10.61 (*SD* ± 15.27) hours. Eighty-nine percent of family caregivers who spent at least 4 hours in the last week providing symptom management, and 46 % caregivers spent more than 11 hours in the last week providing symptom management.

Caregivers' emotionality. The investigator used the CESD, which has 20 items, to examine the individual depressive symptoms. The total score ranged from 0 for no depressive symptoms to 60 for the worst depression. A cut-point score of 16 was used to determine whether or not a person had clinical depressive symptoms (CESD $\geq$ 16). An average CESD score for caregiver depressive symptoms was 11.89 (*SD* ± 7.83). One-hundred-three (22.3%) of 225 caregivers reported their depressive symptoms equal to or greater than 12, while 46 (54.7%) of them reported their depression scores equal to or greater than 16.

Caregivers' threats of caregiving. Caregivers' threats of caregiving were represented via caregiver burden. Caregiver burden was reported by using three subscales of the CRA: family abandonment, schedule interruption, and self-esteem. Each item is scored by using a 5-point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). *Schedule interruption* and F*amily abandonment* are used to evaluate caregivers for their negative responding to the caregiving situations. Both have 5 items, so that each has a score range from 5 to 25.

Table 6

Differences in Caregivers' Depression, Feelings of Burden, Age, Hours of Symptom Management, and Total Number of Patient Symptoms by Sex, Education, Relationship to Patient, and Living Arrangement (t test)

Caregiver Characteristic	Mean (*SD*)	Mean (*SD*)	*df*	*t*
	Male (*N* = 90, 40%)	Female (*N* = 135, 60%)		
Age	55.63 (12.76)	54.24 (13.39)	223	-0.78
Depression	10.95 (7.48)	12.52 (8.02)	223	-1.47
Schedule interruption	2.94 (0.68)	2.80 (0.84)	223	-1.31
Family abandonment	1.70 (0.62)	1.72 (0.65)	223	0.19
Self-esteem	4.54 (0.41)	4.47 (0.49)	223	-1.09
Total number of symptoms	7.92 (3.07)	8.11 (3.16)	223	0.44
Hours of providing symptom management	11.70 (16.07)	9.84 (14.71)	167	-0.78
	≤ High school (*N* = 76, 33.8%)	≥ College (*N* = 149, 66.2%)		
Age	58.17 (12.06)	53.08 (13.36)	223	-2.79 *
Depression	13.48 (8.64)	11.08 (7.28)	223	-2.20 *
Schedule interruption	2.80 (0.82)	2.88 (0.76)	223	0.78
Family abandonment	1.69 (0.65)	1.72 (0.64)	223	0.33
Self-esteem	4.46 (0.54)	4.52 (0.42)	223	0.86
Total number of symptoms	7.96 (3.33)	8.07 (3.02)	223	0.25
Hours of providing symptom management	17.10 (21.25)	7.88 (10.91)	167	-3.71 *
	Non-spouse (*N* = 55, 28.4%)	Spouse (*N* = 161, 71.6%)		
Age	46.12 (14.11)	58.03 (11.02)	214	6.42 *
Depression	14.29 (9.73)	11.13 (6.97)	214	2.60
Schedule interruption	2.79 (0.82)	2.88 (0.76)	214	0.77
Family abandonment	2.03 (0.68)	1.58 (0.57)	214	4.74 *
Self-esteem	4.45 (0.58)	4.52 (0.41)	214	1.00
Total number of symptoms	8.45 (3.51)	7.91 (3.00)	214	11.11
Hours of providing symptom management	10.90 (14.06)	10.96 (16.02)	160	-0.19
	Do not live together (*N* = 29, 16%)	Live together (*N* = 189, 84%)		
Age	43.21 (13.64)	56.82 (12.04)	216	5.57 *
Depression	15.44 (9.36)	11.45 (7.50)	216	-2.57

Table 6 (cont'd)

Caregiver Characteristic	Mean (*SD*)		Mean (*SD*)		*df*	*t*	
	Male (*N* = 90, 40%)		Female (*N* = 135, 60%)				
Schedule interruption	2.76	(0.84)	2.87	(0.76)	216	0.72	
Family abandonment	2.07	(0.68)	1.64	(0.61)	216	-3.51	*
Self-esteem	4.44	(0.53)	4.51	(0.45)	216	0.75	
Total number of symptoms	8.03	(3.57)	8.06	(3.08)	216	0.04	
Hours of providing symptom management	9.10	(7.53)	11.16	(16.26)	161	0.56	

*$p < .05$

A higher score resulting from the scales for schedule interruption and family abandonment indicates a higher level of caregiver burden. Self-esteem is a subscale examining positive reactions of caregivers. It consists of 7 items and a score range from 7 to 35, in which a higher score refers to a higher level of self-esteem. In this study, an average score for schedule interruption was 2.86 (*SD* ± 0.78), family abandonment was 1.71 (*SD* ± 0.64), and self-esteem was 4.50 (*SD* ± 0.46).

Differences in Caregiver Scores by Their Demographics

By using the independent *t* test, the current study tested the differences of caregivers' age, depression, three types of caregiver burden, hours of providing symptom management, and the total number of patient symptom regarding caregivers' binomial demographic characteristics: sex (female vs. male), education (< college vs. ≥college), spouse (spouse vs. non-spouse), and living arrangement (live together with patients vs. live separately). See Table 6 for all results.

Sex. There were no significant differences between female and male caregivers in their ages, depressive symptoms, caregiver burden scores, total number of patient symptoms, and hours of symptom management between (see Table 6). Male caregivers reported a higher score of schedule interruption (2.94 ± 0.68) than female caregivers (2.80 ± 0.84). Male caregivers also spent more hours providing symptom management (11.70 ± 16.07) than female caregivers (9.84 ± 14.71). The average age of female caregivers (54.24 ± 13.39) was younger than that of male caregivers (55.63 ± 12.76). Female caregivers in this study reported higher levels of depression (12.52 ± 8.02) and family abandonment (1.72 ± 0.65), but lower scores of self-esteem (4.47 ±0.49) than males. These female caregivers also recognized a greater number of patients' symptoms (8.11 ± 3.16) and spent fewer hours (9.84 ± 14.71) in providing symptom management as compared to male caregivers in the last seven days.

Education. Caregivers who did not have college degrees were younger and reported significantly higher scores of depressive symptoms than the caregivers who had college or advanced degrees. The former caregivers spend significantly more hours for symptom management than the latter (see Table 6). In comparisons between two education groups of caregivers, there were no significant differences in caregiver reactions and the total number of patient symptoms. The caregivers without college degrees had lower scores of schedule interruption, family abandonment, and self-esteem than the caregivers who had higher education degrees. They also reported a lower number of patient symptoms.

Relationship to patient. Spouse caregivers, compared to non-spouse caregivers, were significantly older and reported lower scores of depressive symptoms and family abandonment (Table 6). Spouse caregivers also reported higher scores of schedule interruption and self-esteem. The spouse caregivers spent more time providing symptom management for patients, although they recognized fewer symptoms. Spouse caregivers may feel more obligated to patient health than non-spouse caregivers; therefore, they may spend more time providing symptom management and report higher scores on schedule interruption than non-spouse caregivers. Meanwhile, spouse caregivers have higher scores on self-esteem, which could imply that taking care of patients is valued as an accomplishment for them.

Living arrangement. Caregivers who were living with patients spent significantly fewer hours supporting patients with symptom management than the caregivers who did not live with patients (Table 6). The caregivers living with patients also were older and reported lower scores of depression and family abandonment, but had higher scores of schedule interruption and self-esteem. All spouse caregivers in the current study lived with their patients. For caregivers living with patients, one can infer that their lives revolve around their patients; therefore, it is possible that they spend more time in providing symptom management and thus have higher scores of schedule interruption.

Description of Congruent Levels of Pain and Fatigue Severity and Frequency

In this study, congruence of symptom perception was represented by comparing the score differences of pain and fatigue severity and frequency between patients and caregivers. Pain and fatigue severity was measured on an 11-point scale (0-10), and pain and fatigue frequency was measured on an 8-point scale (0-7). Both patients and caregivers had to score the severity of patient pain and fatigue in the last seven days and list the number of days in last seven that patients felt pain and fatigue. Overall, both patients' and caregivers' scores on pain severity and frequency were lower than fatigue severity and frequency. Patient-reported scores of pain severity (mean = 2.74, *SD* ± 2.69) and pain frequency (mean = 2.89, *SD* ± 2.85), were lower than caregivers' ratings for pain severity (mean = 3.41, *SD* ± 2.89) and pain frequency (mean = 3.33, *SD* ± 2.96). Patients' reports on their fatigue severity (mean = 5.15, *SD* ± 2.47) and fatigue frequency (mean = 5.10, *SD* ± 2.23) were higher than their own reports on pain severity and frequency. Patients' scores on fatigue severity and frequency were lower than caregivers' ratings of fatigue severity (mean = 5.68, *SD* ± 2.35) and fatigue frequency (mean = 5.47, *SD* ± 2.14). Therefore, average of scores of pain and fatigue severity and frequency from caregivers were higher than those from patients. Regarding the MDASI used to measure 15 patient symptoms, the average total number of patient symptoms was eight for both patients' (mean = 8.32, *SD* ± 3.12) and caregivers' (mean = 8.03, *SD* ± 3.09) repots (Table 4 and 5). Both patients and caregivers reported the same number of patient symptoms

ICC. The ICC was used to examine the agreement (congruence) of pain and fatigue severity and frequency between cancer patients and their family caregivers. The ICC is used to measure the reliability of measurements or ratings by identifying the similarity between two raters by testing correlation strength between the two raters' scores, which determined the level of agreement (congruence). The higher the value of the ICC, the greater was the congruence. ICC criteria range from poor (< 0.2), fair (0.21 - 0.40), moderate (0.41 - 0.60), substantial (0.61 - 0.80), to excellent or perfect (0.81 - 1.0). ICC will approach 1.0 when there is no variance within the targets (Cicchetti, 2001; Kramer & Feinstein, 1981).

Four models of congruence of pain and fatigue severity and frequency had ICCs lower than 0.5. The highest congruence level was pain severity (ICC = 0.46), and the lowest was fatigue frequency (ICC = 0.26). Furthermore, the congruent level of pain severity and frequency was greater than the level of fatigue severity and frequency (Table 7). According to the ICC criteria above, this study had fair to moderate levels of ICC for four congruencies. Members of cancer dyads may pay more attention to pain, because pain may be more observable than fatigue. The congruence of perceiving pain severity and frequency, therefore, is better than that of fatigue.

Subtraction. The score differences of pain and fatigue severity and frequency between cancer patients and their family caregivers was calculated by subtracting patients' scores from caregivers'. The original value of score differences ranged from -10 to 10 for severity and from -7 to 7 for frequency. To calculate the absolute value, the original value was re-coded so that the negative values became as positive. For example, -10 was re-coded as 10, and -5 was re-coded as 5. By using the original value, the score closest to the center (zero) indicated better congruence. Using the absolute value of congruencies, the smaller score indicated higher congruence. Therefore, 0 score difference of both original and absolute values indicates perfect congruence. Among these 225 dyads, there were 60 (27%) cancer dyads in perfect congruence on pain

Table 7

Means with SD and ICCs for Examining CongruentLlevels of Pain Severity, Fatigue Severity, Pain Frequency, and Fatigue Frequency Between Caregivers And Patients

Measurement	Pain severity	Fatigue severity	Pain frequency	Fatigue frequency
	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)
Total number of dyads	N= 222	225	224	225
Patient score	2.74 (2.69)	5.15 (2.47)	2.89 (2.85)	5.10 (2.23)
Caregiver score	3.41 (2.89)	5.68 (2.35)	3.33 (2.96)	5.47 (2.14)
Intraclass Correlation Coefficient (ICC)	0.46*	0.38*	0.43*	0.26*

*$p < 0.05$,

Table 8

*The Substation for Examining Congruent Levels of Pain Severity, Fatigue Severity, Pain Frequency, and Fatigue Frequency Between Caregivers and Patients (*N *= 225)*

Measurement	Pain severity (-10 ~10)	Fatigue severity (-10 ~10)	Pain frequency (-7~7)	Fatigue frequency (-7~7)
	N	*N*	*N*	*N*
Total number of dyads	222	225	224	225
	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)	Mean (*SD*)
Original value of score difference	0.68 (3.32)	0.53 (2.98)	0.43 (3.50)	0.37 (2.84)
Absolute value of score difference	2.51 (2.28)	2.32 (1.94)	2.50 (2.48)	1.97 (2.07)
	N (%)	*N* (%)	*N* (%)	*N* (%)
Underestimate	50 (22.5)	49 (21.8)	53 (23.7)	44 (19.5)
Congruence	87 (39.2)	93 (41.3)	100 (44.6)	110 (48.9)
Overestimate	85 (38.3)	83 (36.9)	71 (31.7)	71 (31.6)
Perfect congruence (0 score difference)	60 (27.0)	36 (16.0)	76 (33.9)	83 (36.9)
1 score difference	27 (12.2)	57 (25.3)	24 (10.7)	27 (12.0)
2 score difference	31 (14.0)	44 (19.6)	28 (12.5)	38 (16.9)
>2 score difference	105 (46.8)	88 (39.1)	97 (42.9)	67 (34.2)

Note. Score difference = caregivers-patients; Underestimate = score difference < -1; Congruence = score difference -1~1; Overestimate = score difference >1.

*$p < 0.05$

severity, 36 (16%) in congruence on fatigue severity, 76 (33.9%) in congruence on pain frequency, and 83 (36.9%) in congruence on fatigue frequency (Table 8).

The original value of score difference of pain and fatigue severity and frequency was operationally counted in three congruent levels: underestimation, congruence, and overestimation so that each symptom characteristic had three congruent categories. Underestimation was a score difference less than -1, and overestimation was a score difference greater than 1, while congruence was a score difference ranging from -1 to 1. Table 7 shows that there are more cancer dyads that were categorized in the congruence group for four symptom variables than there were in the two noncongruence groups. Forty to 50% cancer dyads were congruent for those four symptom variables, whereas 30 to 40% of caregivers overestimated these symptoms. The findings about pain and fatigue severity and frequency are described below:

1. The number of caregivers who were congruent or overestimated the patients' symptoms (score difference ≥ -1) was greater than the number of caregivers who underestimated patient symptoms (score difference < -1).
2. Among three congruent levels of pain and fatigue severity and frequency, the group of congruence (score difference -1~ 1) had the greatest number of cancer dyads, and the group of underestimation (score difference < -1) had the fewest.
3. In comparing the number of cancer dyads in three congruent groups for pain and fatigue, the percentage of cancer dyads in the group of congruence (-1~1) of fatigue severity and frequency was greater than that of pain severity and frequency. Fatigue, however, had a lower ICC level than pain.
4. In comparing the number of cancer dyads for severity and frequency among three

congruent levels (underestimation, congruence, and overestimation), the number of cancer dyads in the congruence on frequency of both pain and fatigue was greater than the number in the congruence on severity of both pain and fatigue. Likewise, the groups of overestimation of pain and fatigue severity had a greater number of cancer dyads than the groups of overestimation of pain and fatigue frequency.

In summary, the ICC levels and subtraction showed the different results in determining which symptom variables had greater congruence. The ICC showed that congruence of pain is higher than that of fatigue, while subtraction showed that congruence on fatigue had a greater number of dyads than did congruence on pain. Subtraction showed congruence by counting the score differences of each dyad as individuals, while the ICC operated on data structured as groups, not individuals. In this study, ICC presented the congruent levels of symptoms of entire samples, and subtraction showed the sizes of caregiver-patient score differences for each symptom characteristic.

The distributions of congruence of pain and fatigue severity and frequency showed that cancer dyads with zero score difference were greater than the dyads without zero score differences. This study used three congruent levels (underestimation, congruence, and overestimation) of four symptom variables (pain severity, fatigue severity, pain frequency, and fatigue frequency) as dependent variables. The multinomial log-linear regression was used to test the factors of caregivers for three congruencies of four symptoms variables.

Differences of Caregiver Characteristics by Three Congruent Levels of Pain and Fatigue Severity and Frequency

A Chi-square and an ANOVA was used to examine the differences in caregivers' characteristics among these three congruent levels of pain and fatigue frequency and severity

(Table 9 and 10). Overall, caregivers' sex, education, relationship to patient (spouse or non-spouse), and living arrangement were not significantly different among the three congruent levels (see Table 9). However, other caregiver characteristics age, depressive symptoms, three caregiver reactions, perceiving total number of patient symptoms, and hours of providing symptoms management were significantly different among three congruent levels of four symptom variables.

Congruence of pain severity. Comparing the three congruent levels of pain severity (see Table 10), significant differences between congruence and overestimation were found in self-esteem, family abandonment, and total number of patient symptoms; the only significant difference between underestimation and overestimation was found in total number of patient symptoms (see Table 10). Caregivers in the congruent group were the youngest and reported the highest score of self-esteem, and they also reported the lowest scores on the CESD, schedule interruption, family abandonment, the total number of patient symptoms, and hours of providing symptom management, when compared to the other two noncongruent groups. Caregivers in the overestimation group were the oldest and reported the greatest number of patient symptoms and most hours providing symptom management.

Congruence of fatigue severity. Comparing the three congruent levels of fatigue severity, there was only a significant difference between the underestimation group and the overestimation group in the total number of patient symptoms, in which caregivers in the overestimation group reported higher scores on patients' total symptoms than did the caregivers in the underestimation group (see Table 10). The caregivers in the congruence group also reported the highest scores on self-esteem and the greatest number of hours providing symptom management. Caregivers in the overestimation group for fatigue severity were the oldest and reported the highest scores of family abandonment, schedule interruption, and total number of patient symptoms. Caregivers in the underestimation group for fatigue severity reported the highest scores of depressive symptoms.

Congruence of pain frequency. Comparing the three congruent levels of pain frequency, a significant difference was found only in caregivers' family abandonment between congruence and underestimation groups, in which caregivers in the congruence group reported a higher average score of family abandonment than those in the underestimation group (see Table 10). Caregivers in the congruence group were older and reported higher scores of CESD, schedule interruption, self-esteem, and family abandonment. They also spent the most hours providing symptom management. Caregivers in the overestimation group reported the greatest number of patient symptoms.

Congruence of fatigue frequency. Comparing the three congruent levels of fatigue frequency, the only significant difference was the total number of patient symptoms between congruence and underestimation, in which caregivers in the congruence group of fatigue frequency perceived a greater number of patient symptoms than did the caregivers in the underestimation group (see Table 10). Caregivers in the overestimation group were the oldest and reported the highest scores of self-esteem. Caregivers in the congruence group had higher scores of CESD, schedule interruption, and family abandonment, and they reported more hours of providing symptom management than did the caregivers in the other two groups.

Table 9

Differences Among Three groups—Underestimation, Congruence, and Overestimation in Testing Characteristics (binomial variables) of Caregiver (Chi-Square)

Caregiver characteristic		Underestimation *N* (%)	Congruence *N* (%)	Overestimation *N* (%)	$df_{bg/wg}$	X^2
Pain severity		50 (22.5)	87 (39.6)	85 (38.3)		
Sex	Female	33 (66.0)	50 (57.5)	50 (58.8)	2/222	1.03
	Male	17 (19.1)	37 (42.5)	35 (42.1)		
Education	≥ College	33 (66.0)	60 (69.0)	55 (64.7)	2/222	0.36
	≤ High school	17 (34.0)	27 (31.0)	30 (35.3)		
Relationship	Spouse	33 (70.2)	63 (73.3)	63 (78.8)	2/222	1.29
to patient	Nonspouse	14 (29.8)	23 (26.7)	17 (21.3)		
Living	Together	39 (81.3)	71 (82.6)	76 (93.8)	2/222	6.00
arrangement	Not together	9 (18.8)	15 (17.4)	5 (6.2)		
Fatigue severity		49 (21.8)	93 (41.3)	83 (36.9)		
Sex	Female	27 (55.1)	62 (66.7)	46 (55.4)	2/222	2.94
	Male	22 (44.9)	31 (33.3)	37 (44.6)		
Education	≥ College	29 (59.2)	67 (72.0)	53 (63.9)	2/222	2.70
	≤ High school	20 (40.8)	26 (28.0)	30 (36.1)		
Relationship	Spouse	33 (70.2)	64 (71.1)	64 (81.0)	2/222	2.76
to patient	Nonspouse	14 (29.8)	26 (28.9)	15 (19.0)		
Living	Together	41 (85.4)	76 (83.5)	72 (91.1)	2/222	2.22
arrangement	Not together	7 (14.6)	15 (16.5)	7 (8.9)		
Pain frequency		53 (23.7)	100 (44.6)	71 (31.7)		
Sex	Female	33 (62.3)	60 (60.0)	41 (57.7)	2/222	0.26
	Male	20 (37.7)	40 (40.0)	30 (42.3)		
Education	≥ College	37 (69.8)	64 (64.0)	48 (67.6)	2/222	0.58
	≤ High school	16 (30.2)	36 (36.0)	23 (32.4)		
Relationship	Spouse	35 (67.3)	73 (76.0)	53 (79.1)	2/222	2.29
to patients	Nonspouse	17 (32.7)	23 (24.0)	14 (20.9)		
Living	Together	41 (78.8)	86 (88.7)	61 (89.7)	2/222	3.62
arrangement	Not together	11 (21.2)	11 (11.3)	7 (10.3)		
Fatigue frequency		44 (19.6)	110 (48.9)	71 (31.5)		
Sex	Female	26 (59.1)	70 (63.6)	39 (54.9)	2/222	1.38
	Male	18 (40.9)	40 (36.4)	32 (45.1)		
Education	≥ College	29 (65.9)	73 (66.4)	47 (66.2)	2/222	0.00
	≤ High school	15 (34.1)	37 (33.6)	24 (33.8)		
Relationship	Spouse	29 (69.0)	76 (71.0)	56 (83.6)	2/222	4.25
to patients	Nonspouse	13 (31.0)	31 (29.0)	11 (16.4)		

Table 9 (cont'd)

Caregiver characteristic		Underestimation *N* (%)	Congruence *N* (%)	Overestimation *N* (%)	$df_{bg/wg}$	X^2
Living arrangement	Together	36 (85.7)	92 (84.4)	61 (91.0)	2/222	1.63
	Not together	6 (14.3)	17 (15.6)	6 (9.0)		

Note. df = degree of freedom; bg/wg = between group/within group.
* $p< 0.05$,

Table 10

Differences Among Three Groups—Underestimation, Congruence, and Overestimation-in Testing Characteristics (continual variables) of Caregiver (ANOVA)

Characteristic	Underestimation Mean (*SD*)	Congruence Mean (*SD*)	Overestimation Mean (*SD*)	$df_{bg/wg}$	*F*
Pain severity					
Age	55.30 (14.36)	55.48 (12.97)	53.88 (12.59)	2/219	0.36
CESD	13.70 (9.19)	10.50 (6.52)	12.23 (8.14)	2/219	2.78
Schedule interruption	2.88 (0.84)	2.84 (0.76)	2.85 (0.78)	2/219	0.03
Self-esteem[a]	4.50 (0.47)	4.58 (0.42)	4.40 (0.48)	2/219	3.16*
Family abandonment[a]	1.77 (0.66)	1.56 (0.62)	1.83 (0.63)	2/219	4.08*
Total # of symptoms[a,b]	7.68 (3.31)	7.19 (3.24)	9.06 (2.57)	2/219	8.59*
Hours of providing symptom management	11.02 (15.09)	10.03 (16.67)	11.08 (14.35)	2/219	0.89
Fatigue severity					
Age	53.93 (13.86)	54.07 (13.14)	56.12(12.74)	2/222	0.66
CESD	12.30 (8.34)	11.45 (7.32)	12.14 (8.13)	2/222	0.25
Schedule interruption	2.80 (0.67)	2.80 (0.83)	2.95 (0.79)	2/222	0.94
Self-esteem	4.46 (0.56)	4.51 (0.44)	4.49 (0.43)	2/222	0.19
Family abandonment	1.68 (0.55)	1.66 (0.63)	1.78 (0.70)	2/222	0.93
Total # of symptoms[b]	7.00 (5.27)	7.98 (2.99)	8.71 (3.05)	2/222	4.81*
Hours of symptom management	6.80 (7.33)	12.03 (18.48)	10.79 (13.73)	2/222	1.29
Pain frequency					
Age	54.12 (14.42)	55.82 (2.08)	53.70 (13.64)	2/221	0.61
CESD	10.02 (7.00)	12.72 (7.91)	12.15 (8.22)	2/221	2.12
Schedule interruption[c]	2.62 (0.75)	2.99 (0.76)	2.83 (0.80)	2/221	0.18
Self-esteem	4.50 (0.47)	4.54 (0.42)	4.43 (0.52)	2/221	1.10
Family abandonment	1.66 (0.55)	1.73 (0.70)	1.72 (0.62)	2/221	4.01*
Total # of symptoms	7.56 (3.33)	7.95 (3.12)	8.53 (2.20)	2/221	1.55
Hours of symptom management	9.10 (16.89)	10.61 (7.61)	8.53 (10.06)	2/221	0.76
Fatigue frequency					
Age	52.63 (11.26)	54.42 (14.03)	56.72 (13.13)	2/222	1.40
CESD	10.20 (5.90)	12.85 (8.30)	11.45 (8.00)	2/222	1.98
Schedule interruption	2.71 (0.75)	2.91 (0.84)	2.86 (0.71)	2/222	1.06
Self-esteem	4.45 (0.46)	4.49 (0.46)	4.53 (0.46)	2/222	0.37
Family abandonment	1.70 (0.67)	1.75 (0.63)	1.65 (0.64)	2/222	0.56

Table 10 (cont'd)

Characteristic	Underestimation Mean (*SD*)	Congruence Mean (*SD*)	Overestimation Mean (*SD*)	$df_{bg/wg}$	*F*
Total # of symptoms[c]	7.18 (3.79)	8.54 (3.13)	7.77 (3.46)	2/222	3.43*
Hours of symptom management	6.16 (9.06)	12.74 (17.57)	9.87 (13.88)	2/222	2.16

Note. *df* = degree of freedom; bg = between group; wg = within group

[a] Congruence versus Overestimation. [b] Underestimation versus Overestimation. [c] Underestimation versus Congruence.

* $p < 0.05$.

In summary, most caregivers in the congruence group of these four symptom variables had a higher average score of self-esteem and spent more hours on symptom management than did the caregivers in the other two noncongruence groups. Caregivers in congruence of pain severity and fatigue severity reported the fewest depression symptoms, whereas caregivers in the congruence groups of pain and fatigue frequency had the most depressive symptoms. Caregivers who were categorized in the overestimation group for pain severity and fatigue severity reported higher levels of family abandonment and greater numbers of patient symptoms. Caregivers in the underestimation groups of pain frequency and fatigue frequency tended to have lower scores on CESD, schedule interruption, family abandonment, and total number of patient symptoms.

Results of Testing Two Research Hypotheses

This study had two hypotheses:

1) Increased caregiver depressive symptoms and caregiver burden will be related to lower congruent values of pain and fatigue severity and frequency**.**

2) Caregivers who are female, older, patients' spouses, better educated, perceiving a lower number of patient symptoms, and living with patients will have greater congruence of pain and fatigue severity and frequency.

The dependent variables were four congruencies of pain severity, pain frequency, fatigue severity, and fatigue frequency. Independent variables included caregiver depressive symptoms (CESD), caregiver burden of schedule interruption, family abandonment, self-esteem (CRA), and six caregiver demographics: age, sex, education, relationship to patients, living arrangement, and total number of patient symptoms. We used the Independent *t* test (*t*) and Pearson's correlation *(r)* to identify the significant relationships among the independent variables. The GLM was used to determine the factors of caregiver depressive symptoms and caregiver burden for the four regression models of congruence of symptom perception. Multinomial log-linear regression was employed to test the model of congruent pain and fatigue severity.

Pearson's correlation. Pearson's correlation tests the relationship between two continuous variables. This study used Pearson's correlation to test the relationships between caregiver depressive symptoms, caregiver age, total number of patient symptoms, and perception of patients' pain and fatigue, and the relationships between caregiver burden and these caregiver characteristics (see Table 11). The correlations between caregiver depressive symptoms and caregiver characteristics including age, total number of patient symptoms, and their perception of pain and fatigue severity and frequency were lower than 0.20. The correlations between caregiver burden and the same caregiver characteristics were lower than 0.30, except for the correlation between family abandonment and total number of patient symptoms ($r = 0.68$, $p > .05$).

Table 10 shows that caregivers who had higher scores of depressive symptoms and caregiver burden were more likely to report higher scores of patients' symptom severity and frequency. The score of caregiver depressive symptoms was significantly correlated with caregivers' perception of patients' fatigue severity and frequency. Caregivers' schedule interruption was significantly correlated with caregivers' perception of patients' pain and fatigue severity and frequency. Family abandonment was significantly correlated to caregivers' perception of patient pain severity and pain frequency and fatigue severity. Caregiver self-esteem, however, had no significant correlation with these caregiver characteristics.

Table 11

Pearson's Correlation Coefficient for Caregiver Characteristics and Caregiver Perception of Pain and Fatigue Severity and Frequency

Caregiver characteristics	CESD	Schedule interruption	Family abandonment	Self-esteem
Caregiver age	-0.29**	- 0.17**	0.68	- 0.29**
Total number of symptom management	0.22**	0.22**	0.26**	0.00
Caregiver perception				
Pain severity	0.08	0.14*	0.21**	0.03
Fatigue severity	0.17*	0.25**	0.18**	- 0.02
Pain frequency	0.11	0.14*	0.15**	- 0.03
Fatigue frequency	0.17**	0.19**	0.05	- 0.02

* $p < 0.05$. ** $p < .001$

The *t* Test for Differences of Caregivers' Characteristic Between Caregiver Whose CESD ≥16 and CESD<16.

Because the CESD score of 16 was used to determine screening clinical depressive symptoms, caregivers' CESD scores were separated into two groups (CESD ≥16 and CESD <16). This study used the *t* test and cross tabulation to identify the differences between two CESD groups for caregiver characteristics, including caregiver age, hours of symptom management, total number of patient symptoms, and caregiver burden of schedule interruption and family abandonment (Table 12). Caregivers who had a risk of clinical depressive symptoms (CESD ≥16), as compared to the caregivers who had depression scores lower than 16, were younger, spent double hours in providing symptom management in the last 7 days, recognized a greater number of patients' symptoms, and also reported a higher score on caregivers burden (schedule interruption and family abandonment). However, four binomial caregiver characteristics (sex, education, relationship to patient, and living arrangement) did not have significant differences between two depression groups.

Table 12

Differences of Caregiver Demographics, Caregiver Scores of Patients Pain and Fatigue Severity and Frequency, Congruence of Pain and Fatigue Severity and Frequency between CESD ≥ 16 and CESD <16 (t *test,* N *= 225)*

Caregiver characteristic		CESD ≥ 16 *N* (%)	CESD <16 *N* (%)	*df*	*t*
		56 (24.89)	169 (75.11)		
		Mean (*SD*)	Mean (*SD*)		
Age		49.59 (15.14)	56.53 (11.96)	223	-3.51*
Hours of symptom management		1.18 (0.81)	0.55 (0.81)	223	3.68*
Total # of symptoms		8.92 (2.92)	7.74 (3.14)	223	2.45*
Caregiver burden					
Schedule interruption		3.34 (0.67)	2.70 (0.76)	223	5.65*
Family abandonment		1.99 (0.79)	1.62 (0.56)	223	3.84*
Self-esteem		4.46 (0.50)	4.51 (0.45)	223	-0.63
Caregiver score					
Pain severity		3.53 (2.88)	3.37 (2.90)	223	0.37
Pain frequency		3.62 (3.04)	3.23 (2.94)	223	0.86
Fatigue severity		6.16 (2.36)	5.53 (2.34)	223	1.76
Fatigue frequency		5.84 (1.81)	5.36 (2.23)	223	1.47
Congruence					
Pain severity		2.87 (2.41)	2.38 (2.23)	223	1.39
Pain frequency		2.64 (2.55)	2.45 (2.47)	223	0.50
Fatigue severity		2.23 (1.80)	2.35 (1.99)	223	- 0.41
Fatigue frequency		1.62 (1.87)	2.09 (2.13)	223	- 1.45
		N (% of total)	*N* (% of total)		X^2
Age	<45	22 (9.8)	26 (11.6)	2	14.16*
	45≤ age <65	25 (11.1)	100 (44.4)		
	≥65	9 (4.0)	43 (19.1)		
Sex	Female	18 (8.0)	72 (32.0)	1	1.92
	Male	38 (16.9)	97 (43.1)		
Education	≤High school	23 (10.2)	53 (23.6)	1	1.77
	≥College	33 (14.7)	116 (51.6)		
Relationship to patients	Spouse	19 (8.8)	36 (16.7)	1	3.58
	Non-spouse	35 (16.2)	126 (58.3)		
Living arrangement	Together	10 (4.6)	19 (8.7)	1	1.52
	Separate	45 (20.6)	144 (66.1)		

* *p* < .05

GLM. The present study examined the predictors of caregiver depression and caregiver burden by using GLM. This examination was conducted to determine if there was the multicollinearity of the context factors (caregiver age, sex, education, relationship to patient, living arrangement, and total number of patient symptoms) and caregiver depression and caregiver burden for the four symptom congruence models. Multicollinearity is a statistical phenomenon in which two or more predictive variables in a multiple regression model are highly correlated. In this situation the coefficient estimates may change erratically in response to small changes in the model or the data.

Factors of caregiver depressive symptoms. Not only were caregivers' demographic characteristics (caregiver age, sex, education, relationship to patient, living arrangement, and total number of patient symptoms) used to determine the predictor of caregivers' depressive symptoms, but also caregiver burden (schedule interruption, family abandonment, and self-esteem) was included in the regression test of depression because caregiver burden had been identified as a possible component of caregiver depression. The equations (1) below shows that the factors of caregiver depressive symptoms included caregiver education, age, family abandonment, and schedule interruption. An increase in caregiver depressive symptoms was predicted for caregivers who were younger, had college or advanced degrees, and reported higher scores of family abandonment and schedule interruption.

$$\begin{aligned}\text{Caregiver depressive symptom} = {} & 7.12 + 2.86^{*}\ \text{education} + (-0.16)\ \text{caregiver age} \\ & + 1.97^{*}\ \text{caregiver family abandonment} + \\ & 3.14^{*}\text{schedule interruption}\end{aligned} \tag{1}$$

Factors of caregiver burden. This analysis model considered binomial caregiver demographics (age, sex, education, relationship to patient, living arrangement, and the total number of patient symptoms) as predictors of caregiver schedule interruption, family abandonment, and self-esteem.

Caregiver schedule interruption was predicted by one variable: the total number of patient symptoms. The equations (2) below shows that a higher score of schedule interruption was only directly predicted by an increase in the total number of patients' symptoms. Therefore, caregivers who perceived a greater number of patient symptoms were more likely to report schedule interruption.

$$\text{Schedule interruption} = 2.42 + 0.05 * \text{total number of patient symptoms} \qquad (2)$$

Family abandonment was predicted by caregiver age, relationship to patient, and the total number of patient symptoms. The equations (3) below shows that a higher score on family abandonment is predicted by a non-spouse caregiver, an increase in caregiver age, and an increased number of patient symptoms. Therefore, caregivers who were patients' spouses, were younger, and recognized more patient symptoms were more likely to report a higher score of family abandonment.

$$\begin{aligned}\text{Family abandonment} = {} & 1.69 + 0.33 * \text{spouse} + (-\ 0.08) * \text{caregiver age} + \qquad (3)\\ & 0.05 * \text{total number of patient symptoms}\end{aligned}$$

This study found that binomial caregiver demographic characteristics and the total number of patient symptoms did not predict self-esteem. As seen in Table 6, there was also no significant difference in self-esteem between binomial caregiver characteristics.

In summary, caregivers who were younger, a spouse of the patient, educated with a college or advanced degree, and reported a larger number of their patients' symptoms were more likely to report a higher score of caregiver depression and caregiver burden. Caregivers' characteristics were tested as confounding variables of caregiver depression and caregiver burden in the multinomial log-linear regression that examined whether or not caregivers' characteristics directly influenced the three levels of congruence of pain and fatigue severity and frequency.

Multinomial Loglinear Regression

The investigator study used the multinomial loglinear regression because the data displayed non-normality and because the investigator categorized each outcome variable (congruence of pain and fatigue severity and frequency) with three congruent levels. The investigator tested the main effect of independent variables— caregiver depressive symptoms, caregiver burden and caregiver demographic characteristics—using the four congruence models shown below. The investigator also tested interactions of main effects and their confounding variables on these four models. The positive relationship between cancer depressive symptoms and caregiver burden has been found in previous studies (Daly, Douglas, Lipson, & Foley, 2009; Grunfeld, et al., 2004; Sherwood et al., 2006). Given et al. (1992) have reported the inter-relationships among three caregiver reactions in developing the CRA instrument for caregivers who provide patient care. The present study found that caregiver education, age, and burden can influence caregiver depressive symptoms. Caregivers' age, relationship to patients and total number of patient symptoms can predict caregiver burden. If caregiver depressive symptoms and caregiver burden, and their factors cannot directly impact congruence of pain and fatigue severity and frequency, the multicollinearity has to be considered regarding the associations among these caregiver characteristics.

Hypothesis 1

This study examined the effect of caregiver depressive symptoms and three caregiver reactions—family abandonment, schedule interruption, and self-esteem—as independent factors to explain three levels: overestimation, congruence, and underestimation of pain and fatigue severity and frequency.

When one examines the main effect of those independent factors, the findings show that congruence of pain severity was influenced by depressive symptoms and self-esteem, and congruence of pain frequency was influenced by schedule interruption. Congruence of fatigue severity and frequency were not influenced by depressive symptoms or caregiver reactions.

Using the congruence group of pain severity as a reference, two significant results were found for the Odds Ratios (OR) of overestimation versus congruence and underestimation versus congruence groups. The OR of the overestimation group versus congruence group of pain severity could have increased by increasing the scores of family abandonment and family and caregiver depressive symptoms, and simultaneously decreasing the score of self-esteem. The OR of underestimation compared with congruence could have increased if the score of CESD increased and the score of self-esteem decreased.

Schedule interruption was found to significantly influence the congruence of pain frequency, where the OR of congruence versus underestimation of pain frequency increased if the score of schedule interruption also increased. Caregiver depressive symptoms and caregiver reactions did not contribute effect for the congruence of pain frequency.

The values of R square in these regression examinations for these congruence models of pain and fatigue severity and frequency, however, were significant. This means that these models cannot be explained by either caregiver depressive symptoms or three caregiver reactions alone. Other factors determined congruent levels of pain and fatigue severity and frequency besides caregiver depressive symptoms and caregiver burden.

Hypothesis 2

In Hypothesis 2, the caregiver demographics—age, sex, education, relationship to patients, living arrangement, and caregivers' perception of total number of patient symptoms were included and tested as factors of congruence of pain and fatigue severity and frequency. Exp (parameter) or exp (β) represents the odds ratios for the predictors. They are the exponentiation of the coefficients.

Congruence of pain severity. This study tested the main effect of the independent variables on congruence of pain severity (the equations 4-7). The equations (4) and (5) used the congruence group as reference to compare with two noncongruence groups while the equations (6) and (7) used the underestimation group as reference compared with congruence and overestimation.

The equations (4) and (5) showed that total number of patient symptoms, living arrangement, caregiver depressive symptoms, and caregivers' self-esteem can influence this model. Caregivers were more likely to be not congruent with patients' pain severity than be congruent with patients' pain severity if caregivers reported a greater number of patient symptoms, a higher score of caregiver depressive symptoms, and a lower score of self-esteem, and if the caregiver lived with patient.

Both the equations (4) and (5) illustrated that caregivers were more likely to display congruence rather than noncongruence (overestimation and underestimation) for patients' pain severity when they felt fewer depressive symptoms and more self-esteem, recognized fewer patient symptoms, and did not live with patients. The effects of caregiver depressive symptoms and caregiver self-esteem on congruence can support the hypothesis that increasing caregiver depression can decrease congruence of symptom perception. Family abandonment and schedule interruption, however, did not contribute a significant effect to the model of congruence of pain severity.

$$\begin{aligned}&\text{Log}\ [p(\text{Overestimation of PS} / \text{Congruence of PS})] = \\ &\quad 2.71 + 0.02 * \text{CESD} + (-1.01) * \text{Self-esteem} + 0.20 * \text{total number of} \\ &\quad \text{patient symptoms} + \exp\,(-1.49) * \text{not living with patient}\end{aligned} \tag{4}$$

$$\begin{aligned}&\text{Log}\ [p(\text{Underestimation of PS} / \text{Congruence of PS})] = \\ &\quad 0.61 + 0.06 * \text{CESD} + (-0.44) * \text{Self-esteem} + 0.20 * \text{total number of patient} \\ &\quad \text{symptoms} + \exp\,(-0.22) * \text{not living with patient}\end{aligned} \tag{5}$$

Meanwhile, the findings of the equations (4) and (5) showed that caregivers who did not live with patients were more likely to be congruent with patients' pain severity, and caregivers who perceived greater patient symptoms were more likely to be noncongruent with patients. These two caregiver characteristics are in opposition to the hypothesis that caregivers perceiving more symptoms or living with patients have greater congruent symptom perception.

$$\text{Log}\ [p(\text{Overestimation of PS} / \text{Underestimation of PS})]= (-0.44)+ (-0.03)^{*}\ \text{CESD} + (-0.18)^{*}\ \text{total number of patient symptoms} + \exp\ (-1.22)\ \text{not live with patient} \tag{6}$$

$$\text{Log}\ [p(\text{Congruence of PS} / \text{Underestimation of PS})]= 1.36+ (-0.06)^{*}\text{CESD} + (-0.02)^{*}\ \text{total number of patient symptoms} + \exp\ (0.15)\ \text{not live with patient} \tag{7}$$

The equations (6) and (7) used the group of caregiver underestimation of pain severity as the reference to find the factors. In the equation (6), when comparing two noncongruent groups of pain severity, a higher OR of caregivers who overestimate patients' severity rather than underestimate was be predicted by a lower score of caregiver depressive symptoms and fewer patient symptoms, and also by the caregivers living with patients. In the equation (7), an increase in the OR of caregivers that are congruent versus those that underestimate patients' pain severity was predicted by a lower score of caregiver depressive symptoms and the total number of patients' symptoms, and also by the caregivers not living with patients. Therefore, the equation (6) and (7) showed that caregiver depression, the total number of patient symptoms, and caregivers' living arrangement are important factors influencing caregivers to accurately perceive patients' pain severity.

Among these four pain severity equations (4-7) caregiver depressive symptoms and caregiver self-esteem were main factors for congruence of pain severity, and caregiver living arrangement and total number of patient symptoms contributed to the main effect for this model. Caregivers who had fewer depressive symptoms were more likely to be congruent with patients' pain severity. This means caregivers could more accurately perceive patients' symptoms if they had fewer depressive symptoms. A greater number of patient symptoms and living together firmly contributed to decreasing the likelihood of congruent pain severity. When the model used different categories as references, the effect of self-esteem was only significant in the equations PS 1and PS 2, which used congruence as the reference. Caregiver self-esteem only produced an effect for caregivers who had congruence greater than non-congruence.

Congruence of fatigue severity. This study tested how caregiver characteristics determined three levels of congruence of fatigue severity and then obtained three equations (8-10). The results showed that the total number of patient symptoms was the only factor determining whether the dyads of caregivers and patients had congruence or noncongruence for fatigue severity. The equation (8) showed that the OR of caregivers who overestimated versus the caregiver who were congruent with patients' fatigue severity could increase by 20% when caregivers perceived one more patient symptom than before (95% Confidence Interval [CI] of exp (0.08) = 0.98 - 1.20). The equation (9) showed that the OR of underestimation rather than congruence for patients' fatigue severity decreased by 10% when caregivers perceived one more patient symptom than before (95% CI of exp (-1.02) = 0.81-1.01). The equation (10) showed that the OR of overestimation versus underestimation increased by 20% when caregivers perceived one more patient symptoms than before (95% CI of exp (0.18) = 1.06 - 1.31). Only the equation (9) showed a significant effect of the total number of patient symptoms on congruence of fatigue severity, which indicated that when caregivers became increasingly aware of the total number of patients' symptoms, they were more likely to be congruent with patient fatigue severity rather than underestimate it.

$$\text{Log [p (Overestimation/ Congruence of FS)]} = (-0.78) + 0.08 * \text{total number of patient symptoms} \qquad (8) \qquad (p > .05)$$

$$\text{Log [p (Underestimation/ Congruence of FS)]} = 0.12 + (-0.10) * \text{total number of patient symptoms} \qquad (9) \qquad (p < .05)$$

$$\text{Log [p (Overestimation/ Underestimation of FS)]} = (-0.90) + 0.18 * \text{total number of patient symptoms} \qquad (10) \qquad (p > .05)$$

Regarding Hypothesis 2, the association between caregiver characteristics and caregiver burden was considered as a factor in the test. This study also found that the interaction between the total number of patient symptoms and family abandonment could contribute to the model of fatigue severity. As the study examined the predictors of family abandonment above, the total number of patient symptoms was a predictor of family abandonment. Therefore, the reason that family abandonment did not directly affect this congruence model, perhaps, was because of the multicollnearity. The total number of the patient's symptoms may have been more important than the caregiver's family abandonment in affecting congruence of fatigue severity.

Congruence of pain frequency. Based on finding in the equations (11-13) to test the main effect and interaction of the factors, schedule interruption was the only factor influencing the model of congruence of pain frequency. The equation (11) showed that the OR of caregivers who overestimated patients' pain frequency compared to those who were congruent with pain frequency decreased by 24% when one point of schedule interruption increased (95% CI of exp (-0.27) = 0.51 - 1.13). The equation (12) showed that the OR of caregivers who underestimated rather than were congruent with patients' pain frequency decreased by 46% when one point of schedule interruption increased (95% CI of exp (-0.62) = 0.4 - 0.83). The equation (13) shows that the OR of caregivers who overestimated versus underestimated patients' pain frequency increased by 42% when one point of schedule interruption increased (95% CI of exp (0.35) = 0.89- 2.25). Specifically, only the equation (12) showed a significant effect of schedule interruption on congruence.

$$\text{Log}\,[p\,(\text{Overestimation/ Congruence of PF})] = 0.45 + (-0.27) * \text{schedule interruption} \qquad (11) \quad (P > .05)$$

$$\text{Log}\,[p\,(\text{Underestimation/ Congruence of PF})] = 1.11 + (-0.62) * \text{schedule interruption} \qquad (12) \quad (P < .05)$$

$$\text{Log}\,[p\,(\text{Overestimation/ Underestimation of PF})] = (-0.66) + 0.35 * \text{schedule interruption} \qquad (13) \quad (P > .05)$$

This study also tested the effect of the interaction between schedule interruption and its confounding variables (spouse relationship to patients, caregiver depressive symptoms, and caregiver feelings of abandonment and self-esteem) on the model of congruent pain frequency. Schedule interruption was the only factor contributing a significant effect to the model, which was consistent with the test for the main caregiver characteristic effect in the model of congruent pain frequency.

In sum, caregivers who felt more schedule interruption were more likely to have an accurate report of patients' pain frequency; this finding, however, did not support the first hypothesis. This study also found that schedule interruption from care involvement (including symptom management) was predicted by the total number of patient symptoms, which may indicate that caregivers must be aware of symptom frequency. Therefore, caregivers who reported more schedule interruption could be more congruent on patients' pain frequency.

Congruence of fatigue frequency. After testing both the main effect and interaction, total number of symptoms was the only variable which influenced the congruence of fatigue frequency. The equation (14) showed that the OR of caregiver who overestimated fatigue frequency compared to a congruent caregiver decreased by18% when caregivers perceived one more patient symptom than before (exp (-0.08), 95% CI of exp (β) = 0.84 - 1.02). The equation (15) showed that the OR of caregivers who underestimated patient fatigue frequency rather than being congruent decreased by 23 % when caregivers recognized one more patient symptom than before (exp (-0.14), 95% CI of exp (β) = 0.77 - 0.97). The equation (16) showed that the OR of caregivers who overestimated fatigue frequency rather than underestimated it increased by 6% when caregivers perceived one more patient symptom than before (exp (0.06), 95% CI of exp (β)= 0.94- 1.20). Caregivers who recognized more patient symptoms were more likely to have a congruent report of patients' fatigue frequency. Still, only the equation (15), by comparing the underestimation group with the congruence group, showed a significant effect on the total number of patient symptoms to congruence of fatigue frequency. Briefly, an increase in the total number of patients' symptoms may imply that caregivers become increasingly aware of patients' symptoms, and that they are more likely to be congruent than to underestimate patients' fatigue frequency.

$$\text{Log [p (Overestimation/ Congruence of FF)]} = 0.23 + (-0.08) * \text{total number of patient symptoms} \qquad (14) \quad (P > .05)$$

$$\text{Log [p (Underestimation/ Congruence of FF)]} = 0.21 + (-0.14) * \text{total number of patient symptoms} \qquad (15) \quad (P < .05)$$

$$\text{Log [p (Overestimation/ Underestimation of FF)]} = 0.22 + 0.06 * \text{total number of patient symptoms} \qquad (16) \quad (P > .05)$$

Conclusion

In this study, caregivers, on average, were 52.8 (SD± 13.1), spouses of cancer patients (*n* = 161, 71.6%), and Caucasian (*n* = 207, 92%). Also, 149 (65.9 %) of the caregivers had a college degree (Table 2), and 189 (84%) lived with their patients, which accounted for all the spouse caregivers. Comparing the mean scores of pain and fatigue severity and frequency between cancer patients and caregivers, caregivers overestimated these four symptom variables. The ICCs of pain and fatigue severity and frequency were from low to moderate. The ICCs of pain and fatigue severity between cancer patients and their family caregivers were lower than 0.5, and the ICCs for fatigue severity and frequency were lower than 0.4 (Table 7). The ICC score for pain and fatigue severity was higher than pain and fatigue frequency. Because the ICC criteria has stated that a score of 0.3 to 0.4 indicates fair congruence and scores of 0.5 to 0.6 indicates moderate congruence, the 225 cancer dyads have a fair to moderate level of congruence.

This study categorized each score difference of four symptom variables (pain and fatigue severity and frequency) between cancer patients and caregivers into three levels of congruence:

congruence (-1~1), underestimation (< -1), and overestimation (>1). More than 40% of caregivers were categorized in the group of congruence for these four symptoms variables, and that was higher than the other two noncongruent groups. Less than 25 % of caregivers (*n* = 53) were categorized in the underestimation group for these four symptoms. In brief, most caregivers were congruent with patient symptoms or overestimated them.

The first and second hypotheses were supported when the results showed that an increase in depressive symptoms and a decrease in self-esteem predicted less congruence of pain severity. However, a higher score of schedule interruption predicted more congruence of pain frequency rather than noncongruence. Neither caregiver depression nor caregiver burden affected the model of fatigue severity and fatigue frequency, which is inconsistent with the first hypothesis.

The second hypothesis included caregiver demographics (age, sex, education, and relationship to patients), but demographics did not have a significant effect on congruence. However, two caregiver characteristics not found in previous studies (the total number of patient symptoms and caregivers' living arrangement) were identified for congruence. However, in contrast to this hypothesis, increasing the total number of patients' symptoms can independently raise the OR of caregivers' congruence rather than noncongruence for pain severity, fatigue severity, and fatigue frequency. Also, caregivers who did not live with their patients had a greater likelihood of being congruent with patients' pain severity, but this caregiver characteristic did not impact congruence of pain frequency, fatigue severity, or fatigue frequency.

Overall, caregiver depressive symptoms and caregiver self-esteem were identified as the two factors which affect congruence of pain severity, as hypothesized. Caregivers' demographic characteristics–including age, sex, and education–did not affect the congruence of pain and fatigue severity and frequency as the covariants of caregiver depression and caregiver burden. Therefore, because the finding on the relationships among caregiver depression, caregiver burden, and caregiver characteristics did not completely support the two hypotheses, the EASP model needs to be adjusted.

CHAPTER 6

Discussion and Implications

The purpose of the current study was to examine the concept of EASP in caregiving situations and to identify how this concept can be influenced by caregiver characteristics. Specific aims were to examine whether caregiver depression and caregiver burden can decrease congruence of pain and fatigue severity and frequency, and how caregiver demographic characteristics affect this concept. The findings of this study were compared to prior studies for the similarities and differences of congruent levels and factors of congruence of cancer symptoms between patients and caregivers. This chapter presents those comparisons and the implications of the conceptual framework of EASP and of the results of this study for clinical practice, nursing research, and health policy.

Effect Size

The power analysis in Chapter 4 showed that the sample size of 225 dyads of cancer patients and family caregivers was adequate. Within a fixed sample size of 225 dyads of cancer patients and their family caregivers, this study obtained an effect size of 0.06, standard sample power of 80%, and significance of 0.05. Effect size of 0.06 in a regression model is higher than the minimum effect size of 0.02 and lower than moderate effect size of 0.15, according to Cohen’s (1988) suggestion for "conventional" values of effect size. This study used four symptom score differences (pain severity, fatigue severity, pain frequency, and fatigue frequency) between cancer patients and their family caregivers as dependent variables, and eight independent variables (caregiver’s age, sex, education, relationship to patient, living arrangement, total number of patient symptoms, caregiver depression, and caregiver burden). Effect size addresses the magnitude of the effect under the alternate hypothesis between groups, or of the relationship between variables. A small effect size, therefore, indicated that this study would be less likely to find a statistically significant relationship between the dependent variables and those eight independent variables.

In spite of the small effect size, this study found that caregiver depression, caregiver self-esteem, total number of patients' symptoms and caregivers' living arrangement had significant effects on congruence of pain severity; caregivers' schedule interruption can influence congruence of pain frequency. Therefore, caregivers' emotionality and perceived threats of caregiving environment can influence congruence of symptom perception between cancer patients and their caregivers. These two factors impact only pain severity and frequency but not fatigue severity and frequency, while the total number of patient symptoms that caregivers perceive can impact congruence of fatigue severity and fatigue frequency.

Congruent Levels of Pain and Fatigue Severity and Frequency

This study obtained a fair-to-moderate level (0.3 - 0.5) of congruence for pain and fatigue severity and frequency between cancer patients and their family caregivers. This has been a typical finding: that family caregivers and patients had low agreement for patients' symptoms, and caregivers overestimated their cancer patients' symptoms (McPherson, et al., 2008; Resnizky & Bentur, 2007; Silveira, et al., 2010; Wennman-Larsen, et al., 2007).

Meanwhile, the ICC level of cancer pain was greater than that of fatigue, which means that congruence between caregivers and patients for patients' pain is better than for patients' fatigue. Caregivers may pay more attention to patients' pain responses than to patients' fatigue, because pain management has been emphasized in nursing lectures to caregivers. Compared to cancer fatigue, patient responses to cancer pain may also be easier for caregivers to recognize. Cancer patients may express cancer pain more often because they want to lessen unpleasant feelings, especially when cancer pain can limit patients' capabilities for daily activities. Cancer patients, however, may have become accustomed to feeling fatigue, so that they don't specifically point out these feelings to family caregivers (Wennman-Larsen, et al., 2007).

This study, additionally, categorized the dyads' congruence into three levels (groups), and found that the number of caregivers who were congruent with patients' pain and fatigue severity and frequency was greater than those who overestimated and underestimated it. Therefore, although the agreement level was low, caregivers were capable of accurately perceiving patients' symptoms within the range of core difference from -1 to 1. Also, the number of caregivers who overestimated patient symptoms was greater than those who underestimated them. In that case, most caregivers tended to believe that patients were suffering from symptoms burden, which was supported by previous studies that also found that patients' symptoms were overestimated by their family caregivers (Broberger, et al., 2005; Greig, et al., 2005; Lobchuk & Degner, 2002; Redinbaugh, et al., 2002).

Therefore, the current study reveals that many caregivers of cancer patients can accurately perceive patients' symptoms, and that some may overestimate patients' symptoms. Another important finding is that caregivers who either were congruent with or overestimated patient symptoms tended to provide symptom management, whereas caregivers who underestimated patients' symptoms delayed symptom management or provided insufficient symptom management.

Hypothesis 1: Caregiver Depression and Caregiver Burden Relevant to Congruence Model

Table 9 shows that among three congruent levels (underestimation, congruence, and overestimation) of four symptom variables (pain and fatigue severity and frequency), caregivers who were in the congruence groups of pain severity and fatigue severity reported the lowest scores of caregiver reactions, and caregivers who were in the congruence groups of pain frequency and fatigue frequency reported the highest scores of three caregiver reactions. Also, the caregivers in the two congruence groups of pain and fatigue severity had the lowest scores of depressive symptoms, and those in the underestimation group reported the highest scores of depression, in regards to CESD score differences. However, the caregivers in the congruence groups of pain and fatigue frequency had the highest score of depressive symptoms and three caregiver reactions than the other two noncongruence groups (Table 9).

Hypothesis 1 tested whether increasing caregiver depression and caregiver burden can decrease congruence of symptom perception between cancer patients and their family caregivers. Three results show that (a) increasing caregiver depression decreased congruence of symptom perception, but this study showed that decrease only for pain severity; (b) increasing caregiver self-esteem also increased the likelihood of congruence of pain severity; (c) increasing schedule interruption generated a higher likelihood of congruence on pain frequency; (d) family abandonment did not generate effects on any congruence of these four symptom variables; and (e) neither caregiver depression nor caregiver burden impacted the three congruent levels of fatigue frequency and fatigue severity. Previous studies have suggested that higher caregiver burden and caregiver emotions can diminish caregivers' empathic accuracy (congruence) of patients' symptoms (Higginson & Gao, 2008; McPherson, et al., 2008; Resnizky & Bentur, 2007; Wennman-Larsen, et al., 2007).

For the result "a," Miaskowski et al. (1997), who used the CESD to measure caregiver depression, found higher scores reported by caregivers who were not congruent with patients' pain severity. McPherson et al. (2008) used the Profile of Mood States, which evaluates individuals' affective status, such as depression, anxiety, and sadness. They found that caregiver mood can predict the discrepancy of psychological cancer symptom. The current study extended the original findings to show that caregivers in the underestimation group reported higher scores than those in the overestimation group of pain severity. Accordingly, caregivers who were at risk of depression may have had one of two behaviors toward patient symptoms and themselves. If caregivers had depressive symptoms and projected them to patients' symptoms, they might highly overestimate patients' pain severity. If caregivers' depression led them to be self-centered (Bieling & Alden, 2001), caregivers would mind their own symptoms more than they would take care of patients'. In that case, they would be likely to underestimate patients' pain severity.

For the result "b," self-esteem enhanced the possibility of congruence of pain severity. Wennman-Larsen et al. (2007) also suggested that caregivers who have greater self-esteem are more likely to have congruence with patients on fatigue severity, but not on pain. The Wennman also used fatigue for recognizing caregivers' congruence because it was the most frequently occurring symptom. Therefore, improving caregivers' self-esteem for providing care may increase their accurate perceptions of patients' symptom severity.

The result "c" shows that caregivers with more schedule interruption tended to be congruent with patients' pain frequency. In contrast with the results of a and b, the result c is opposite from the hypothesis. This finding was identified in the previous studies. However, caregivers who have been experiencing schedule interruption are assumed to spend time involved in the patient's life and care; accordingly, caregivers can notice or hear patients expressing symptoms. Among all symptoms, cancer pain is more often expressed by patients, although fatigue is the most commonly occurring symptom. In this regard, that might be why caregiver schedule interruption can contribute to congruence of pain frequency.

The current study found that different caregiver reactions were associated with different congruencies of symptoms and influenced pain but not fatigue. The reason for that may be because dealing with different symptoms is related to different caregiver reactions. Persson et al (2008) used the perspectives of stress theories and illustrated that these five dimensions of CRA are related to different stressors of care. Caregivers who lack resources for caregiving often reported family abandonment, while those who have an amount of resources reported schedule interruption, and those who feel self-achievement on providing care reported self-esteem. In this regard, when perceiving one patient symptom, caregivers may generate the care demands for this symptom that are different from the other symptoms. That results in generating different caregivers' reactions. For example, accurately perceiving patients' pain severity may depend on caregivers' self–esteem for pain evaluation and management. In another words, caregivers who have higher self-esteem are more likely to accurately perceive patients' pain severity**.** Accurately perceiving patients' pain frequency may indicate caregivers pay attention on the occurrence of pain, which also means that caregivers spend time observing patient's symptoms, so that they are more likely to report schedule interruption.

Caregivers carefully paid attention to patients' symptoms, especially cancer pain, in this study so that they could accurately recognize pain occurrence and provide pain management in time. However, that required caregivers to constantly ignore their own life events or rearrange their life schedules in order to cope with patients' symptom management. Therefore, they may have felt their schedules were significantly interrupted (schedule interruption). In sum, greater congruencies of these symptoms may indicate that caregivers had to involve themselves in providing symptom management for patients' pain and fatigue, and that also imbued greater caregiving reactions. It is possible that congruent perception of patients' pain severity and pain frequency indicated that caregivers participated more in patients' pain management, and that also reflects the circumstance that those caregivers dealing with patients' pain were more likely to have an increase in caregiver burden.

The reason for the different results between the current study and the prior studies on the effect of caregiver burden on congruence may be the measurements for caregiver burden and different counting strategies for the outcome variable, congruence. The present study used three subscales of the CRA–Family Abandonment, Schedule Interruption, and Self-Esteem–to detect the influence of each caregiver reaction on these four congruencies of symptoms. Higginson and Gao (2008) used the Zarit Burden Interview to measure caregiver burden and examine the severity of pain and related palliative symptoms for congruence.

In turn, although two studies (Wennman-Larsen, et al., 2007 and McPherson, et al. 2008) used the Caregiver Reaction Assessment (CRA) to measure caregiver burden as did the present study, the congruence of patients' variables affected by caregiver reactions were different. Wennman-Larsen et al. (2007) reported that family abandonment and health impact predicted only congruencies of emotional function and quality of life, while McPherson, et al. (2008) obtained an average of the five subscales (schedule interruption, family abandonment, health impact, financial impact, and self–esteem) together to predict congruence of psychological symptoms. Therefore, those findings support Hypothesis 1: Caregiver burden can decrease caregivers' ability to be congruent with patients' perception on symptoms and quality of life. It might also indicate that accurately perceiving patients' responses to their cancer may give rise to different caregiver reactions.

For the results "d" and "e," the prior studies lack information for family abandonment and fatigue perception. Family abandonment was not specified as a factor for congruence of symptom perception, but it was identified for the congruence of patients' quality of life

(Wennman-Larsen et al., 2007). The Wennman-Larsen study also found that patients' sex and age can determine the discrepancy of fatigue severity, but that caregivers' characteristics cannot. Many variables can trigger fatigue in cancer patients, for example, cancer treatments and cancer itself, that lead patients to commonly feel fatigue more than pain. Also, cancer patients often perceive fatigue earlier than they perceive pain, so they may tolerate fatigue without expressing it. That might be the reason for Wenmman-Larsen et al.'s (2007) result. That might also be why caregiver depression and caregiver burden in the current study did not affect congruence of fatigue severity and fatigue frequency.

In addition, the current study is a descriptive study with a cross-sectional design. The predictive relationship from one variable to anther found in a cross-sectional descriptive study may simply explain a correlation, which means that the predictive relationship can be reversible. In the current study, by applying the previous statement, caregiver depressive symptoms, self-esteem, and schedule interruption can also be impacted by caregivers' congruence of patients' symptoms. Caregivers who can accurately perceive patients' pain severity are more likely to have fewer depressive symptoms and higher self-esteem that the caregivers who cannot; caregivers who can accurately perceive symptom frequency are more likely to have more feelings of schedule interruption. In this regard, congruence of patients' pain severity may be a marker of caregivers who are less depressed and have a growing self-esteem, while congruence of pain frequency may indicate schedule interruption. A longitudinal study would be valuable to examine the variation of the relationship between caregiver burden and congruence of patient symptoms perception in the caregiver's long-term care experience.

Hypothesis 2: Caregiver Characteristics Relevant to Congruence

Hypothesis 2 tested how caregivers' demographic characteristics affected the congruence of symptom perception if these characteristics were also tested with caregiver depression and caregiver burden in the regression models. Still, caregiver depressive symptoms, caregiver self-esteem, and schedule interruption had the same contribution to congruence as the finding for Hypothesis 1 above, even though the caregiver demographic characteristics were included in the model. Caregivers who had fewer caregiver depressive symptoms were more likely to have congruence of pain severity, rather than noncongruence; in addition, they also are more likely to have overestimation or congruence, rather than underestimation. Caregivers who had more self-esteem tended to have congruence of pain severity rather than noncongruence. Schedule interruption still was shown as a single factor for congruence of pain frequency.

The examination of Hypothesis 2 identified that both caregivers' living arrangement and total number of patients' symptoms can affect congruence of pain severity. Caregivers who lived with patients were more likely to not be congruent with patients' pain severity. The total number of patient symptoms can influence congruence of fatigue severity and fatigue frequency. The fewer patient symptoms that a caregiver perceives, the greater likelihood of having congruence on pain severity, fatigue severity.

Living arrangement. Living arrangement was described as caregivers who lived with cancer patients and those who did not. The variable only contributed to the model of congruence of pain severity, but it did not affect the other three congruent models of symptoms. Resnizky and Benur (2002) emphasized that a caregiver's living arrangement is a way to learn about a caregiver's involvement in patient care, and their findings have shown that caregivers who live with their cancer patients can more accurately report patients' symptoms than could the caregivers who did not live with patients. However, the findings in the present study are opposite from the findings of Resnizky et al. (2002). In the present study, the equation (4) and (5) show that caregivers who did not live with patients were more likely to have congruence of patients' pain severity, and the equation (6) shows that caregivers who did not live with patients were also more likely to underestimate patients' pain severity rather than to overestimate it. Regarding the equations (4) and (5), those caregivers who did not live with patients may have provided symptom assessment every time they visited patients. They could have more accurately perceived patients' symptoms; in this regard, they may have been more likely to objectively assess patients' reactions from symptoms. The equation (6) may imply that if the caregivers who did not live with patients did not provide symptom assessment when they visited patients, they would have underestimated, but not overestimated, patient symptoms. Therefore, symptom assessment may be an important approach to accurately perceive patient symptoms. Further study is needed to retest the effect of living arraignment and caregivers' symptom assessment to determine the congruence of symptom perception.

Total number of patient symptoms. The total number of patient symptoms contributed to the models of congruence of pain severity, fatigue severity, and fatigue frequency. Those results are supported by the conceptual framework of patient suffering and caregiver compassion developed by Schulz et al.'s (2007) conceptual model for patient suffering. They (2007) determined that patient suffering from symptom distress is the unique and independent factor of caregiver health and is mediated by caregiver compassion and helping behavior. However, this variable and the findings have not been investigated in the most prior studies on cancer.

Furthermore, the influences of the total number of patient symptoms on pain perception and on fatigue perception were in opposition. Increasing the awareness of total number of patient symptoms was directly related to the decrease in possibility of caregivers' congruence of pain severity, but it was also related to the increase in likelihood of congruence of fatigue severity and fatigue frequency (see Chapter 5, Multinomial Log-Linear Regression).

Caregivers who observe more patient symptoms can generate two responses on pain severity. Some caregivers may have witnessed patients suffering from multiple symptoms; they may view these experiences as a sign and overestimate the patients' pain severity. Others may not focus on dealing with patients' pain severity because they were distracted by other patient symptoms; in this regard, these caregivers are more likely to give inaccurate perceptions for patients' pain severity. Therefore, caregivers recognizing greater numbers of patient symptoms are more likely to be noncongruent with patients on pain severity.

In turn and in contrast to pain, caregivers who observe greater numbers of patient symptoms can generate more accurate perceptions on patient's fatigue but not underestimate it. A greater number of patient symptoms makes an impression on family caregivers that patients feel fatigue because their energy is being consumed by experiencing those symptoms. Caregivers who recognize more patient symptoms, thus, may pay more attention to how often patients' fatigue occurs. In that case, caregivers tend to more accurately perceive patients' fatigue but not to underestimate it.

Furthermore, in the equations of pain severity, congruence levels were determined by caregiver depressive symptoms, caregiver self-esteem, the total number of patient symptoms and living arrangement. Caregivers' awareness of total number of patients' symptoms was positively correlated to schedule interruption and family abandonment. A greater number of patient symptoms usually generate more care demands related to symptom management. In that case, caregivers have to spend more time or require support from other family members to deal with patients' symptoms. In turn, a greater number of patient symptoms can generate a higher likelihood for caregivers to feel family abandonment.

Therefore, according to the results of two hypotheses, accurately perceiving pain, especially pain severity, was determined more by caregivers' characteristics than by fatigue. That may imply that caregivers paid more attention to patients' pain than to patients' fatigue. Cancer pain is often the focus in cancer symptom management. Cancer patients, furthermore, are able to more specifically describe pain in location, timing, and frequency than they are able to describe fatigue. Meanwhile, the previous section also described a possibility of a reversible relationship between caregiver depression, caregiver burden, and congruence of symptom perception regarding the cross-sectional descriptive study. In that case, caregivers' perception on patients' cancer pain, compared to patients' fatigue, can have more influence on caregivers' depression, self-esteem, and schedule interruption. Besides, caregivers' attention to total number of patients' symptoms is a vital factor in perceiving fatigue. Observing patients' fatigue may project an image to caregivers that patients are having many symptoms that cause fatigue.

The Fitness of Theoretical Framework of EASP

The framework of EASP was developed based on three theories. The factors were selected and supported by the findings in the previous studies related to congruence of cancer symptoms. However, the framework is still immature. First, cancer symptoms are many, but this study selected severity and frequency of pain and fatigue to represent symptom perception. Whether the factor *total number of patient symptoms* can influence congruence of other symptoms is unknown. Besides, the current study shows that the factors which influenced congruence of pain perception were different from those which influenced congruence of fatigue perception. Using symptoms other than pain and fatigue to represent congruence of symptom perception may reveal different caregiver characteristics which can influence congruence. Also, the factors—caregivers' schedule interruption, caregivers' awareness of number of patient symptoms, and their living arrangements—did not following the hypotheses. Those findings indicate there is lack of knowledge of how caregivers project their own perceptions on patients' symptoms.

Next, patients' and caregivers' characteristics were considered in the contextual factors of the framework to influence the concept of EASP because the congruence of symptom perception was obtained by comparing the symptom reports from both patients and caregivers. However, the current study only selected caregiver characteristics to predict the empathic accuracy. A complete examination needs to include patients' characteristics as contextual factors influencing the concept of EASP.

Furthermore, caregivers' psychological perceptions are restricted to their negative perspectives as influences on their perceptions of patient symptoms. The current study only used caregiver depressive symptoms to represent caregiver emotionality and used caregiver burden to represent threats of caregiving that the caregiver perceived. Emotionality includes several kinds of emotional expression such as anxiety and sadness. Meanwhile, there is little information about the threats of caregiving from the caregivers' perspective. The threats of caregiving that caregivers perceived can be more precisely represented by caregivers' fear and worry, and those threats of caregiving can result not only from patients' symptoms, but also from household and financial hardship.

With respect to the findings above, the EASP framework is still in development. The framework needs to be tested and revised, so that it can reveal the details of the relationship between cancer patients' and caregivers' characteristics on congruence of symptom perception. The whole framework also includes two outcomes—caregivers' helping behavior and quality of life of patients and caregivers–resulting from EASP. These relationships were not tested in the current study.

Limitations

Regarding the discussion above, the present study has the following limitations:

1. This study was a cross-sectional study. Caregiver emotionality, threats from providing care, and empathic accuracy may change because of the dynamic nature of symptoms and caregivers' perceptions of caregiving. A longitudinal study should be conducted to understand the dynamic relationship among those three concepts and their contribution on the health outcomes of both patients and caregivers.
2. This study focused on patients who were newly diagnosed with cancer and who were receiving chemotherapy for the first-time. The result may not be generalized to other cancer patients who are not newly diagnosed, who are not the first-time recipients of chemotherapy and who are not receiving chemotherapy. Also, caregivers of those patients who receive follow-up treatments may have different caregiving experiences in recognizing patients' symptoms, which may improve congruence of symptom perception.
3. This study used caregiver depressive symptoms to represent caregiver emotionality, and it only showed a major effect on the congruence of pain severity. Caregiver emotionality is described as a family caregiver's emotional reactions toward providing cancer care, including other individual emotions, such as worry, fear, and anxiety. In order to support the current framework of EASP, further studies need to apply an emotion scale, for example, the Profile of Mood States, which consists of six subscales for mood status, including depression, fatigue, anxiety- tension, anger-hostility, vigor-activity, and confusion-bewilderment. If this is done, caregivers' emotionality will be evaluated more thoroughly in order to test the effect of each emotional dimension on caregivers' EASP.

4. Caregivers' empathic accuracy is more likely to go through the cognitive process for patients' pain and fatigue because these symptom perceptions were represented by scores. Davis's empathy model shows that both cognitive and affective empathy occur simultaneously, which may imply that it is difficult to determine which empathic outcomes were produced from one process but not from the other. Further study of caregivers' empathic accuracy will specify cognitive and affective empathic processes and their consequences and influencing factors in order to develop effective interventions for specific caregiver populations that will improve their EASP.

Summary

The present study identified that family caregivers of cancer patients had fair-to-moderate congruence of patients' pain and fatigue severity and frequency, which was similar to the congruence levels of symptom perception in prior studies. In spite of a small effect size, this study shows that some factors significantly influence congruence of pain and fatigue severity and frequency. The hypotheses were partially supported because of the fact and that caregiver depression and caregiver self-esteem influenced congruence of pain severity, a result that supports Hypothesis 1 of the framework. However, schedule interruption, living arrangement, and total number of patient symptoms were in opposition with the hypotheses. Schedule interruption can improve the accuracy of caregivers' perceptions of patient symptoms. Living with patients decreases the possibility of caregivers being congruent with patients on pain severity. Caregivers' awareness of total number of patient symptoms is a new and important finding; it is the only variable which can influence congruence of all four symptom variables. Caregivers who recognize a greater number of patient symptoms tend to be noncongruent with patients' pain severity, but they tend to be congruent with patients' pain frequency, fatigue severity, and fatigue frequency.

Because those findings did not completely fit the hypotheses, it is necessary to develop more studies to examine the associations among the concepts and factors in the EASP framework, including remaining questions. For example, how are caregivers' helping behavior between congruence and noncongruence groups of pain and fatigue severity and frequency related to congruence of symptom perception? How are the patients' and caregivers' quality of life related to congruence of symptom perception? Further studies also need to apply other symptoms when examining this framework to identify the factors influencing EASP. The communication between patients and family caregivers will be important in order for caregivers to have accurate perception of patient symptoms. Answering those questions about the association between the concepts related to EASP will have an important contribution for the understanding of cancer family care.

Implications

For knowledge in nursing science. The gaps in the prior studies aimed at identifying congruent symptom perceptions between cancer patients and caregivers have been a lack of oriented theories or models. The studies mainly emphasized the unreliability of caregivers' perception of patients' symptoms because of low levels of congruence of symptom perception. Approximately 30 studies showed noncongruence of cancer patients' symptoms by comparing patients' self-reports and caregivers' reports about patients' symptoms; however, congruence of symptom perception has not been conceptually defined. The current study has developed the EASP framework by applying the theoretical perspectives of Ickes' Empathic Accuracy in psychological therapy and Davis' Empathy model in psychology, and has engaged these two perspectives of empathy with Given's Family Care Model in nursing research. Davis (1994) described empathy as people's general temperament and Ickes (1993) described empathic accuracy as the nature of everyday mind reading, so that being empathic naturally happens in people's daily lives. In addition, the conceptualization of empathic accuracy in Ickes' study was used to differentiate various relationships between the perceiver and the target person. Few studies have used the concept of EASP for caregiving dyads.

For nursing clinical practice. Specifically, because caregiver burden and caregiver depression are typical negative perceptions that result from caregiving, several studies have investigated different strategies to reduce the risk of these two perceptions for caregivers (Honea, et al., 2008; Rivera, 2009). The examination of the EASP framework in the present study revealed that both caregiver burden and caregiver depression not only may represent caregivers' outcomes, but also are important factors associated with caregivers' accurate perception of cancer patients' symptoms. This conceptualization of the EASP that caregivers use both cognitive and affective empathic processes in symptom management for patients can be extended to assist daily activities.

The EASP framework shows that the greater empathic accuracy for patients' symptom experience, the higher likelihood for caregiver to help patients to alleviate symptom burden, in that caregivers can better determine appropriate symptom management. The EASP framework may drive nurses' attention toward recognizing family caregivers' characteristics, such as caregiver depressive symptoms and caregiver burden, and caregiver demographics as well. Therefore, nurses can deliver effective nursing interventions for caregivers to decrease their own depressive symptoms and caregiver burden in order to to deal with patient symptoms. Eventually, improving EASP can benefit at patients' and caregivers' quality of life.

Results of this study, in turn, showed that caregiver depression, caregiver schedule interruption and self-esteem can impact congruence of pain severity and frequency. Because this study only used data information collected at baseline interview, this result may reveal a point of view that congruence of symptom perception may have indicated caregivers were less depressed and had higher self-esteem but experienced schedule interruption for care involvement as well. Therefore, congruence and overestimation may be a sign of caregiver burden. Clinical nurses may utilize this result for early detection of caregiver depression and caregiver burden. When nurses find that caregivers are congruent with or overestimate patients' symptoms perceptions, nurses need to be aware of caregiver depressive symptoms and caregiver burden.

For future research. This study has developed the framework of EASP to conceptualize empathic accuracy for nursing research that includes the influence of the factors of emotionality and perceived threats of caregiving. However, the EASP framework is still in development, and needs further study to support the relationships among the concepts. Future research can be conducted:

(1) To develop the EASP framework.

The framework of EASP can guide the investigator to develop hypotheses that can account for variations in EASP between cancer patients and their caregivers. Although approximately 30 studies identified family caregivers' reports of patients' symptoms, few extended their investigations to identify how caregiver characteristics, such as emotionality and perceived threats of caregiving, may point out the risk factors of empathic accuracy. The present study tested the predictive relationship between congruence of symptom perception, caregivers' emotionality and threats to caregiving. This study also considered the influence on caregiver demographics, and has the potential to generate knowledge of empathy accuracy in family care.

Furthermore, the EASP framework shows that there is a sequential correlation between empathic accuracy and patients' health outcomes. These sequential relationships between empathic accuracy and outcomes of patients and caregivers should be tested in the subsequent studies. Nursing research can begin to establish evidenced research to examine the relationship between empathic accuracy and caregivers' helping behaviors, enriching family cancer care research.

Based on the theoretical framework of EASP, although it has not been tested yet, the investigator assumes that communication and negotiation between patients and family caregivers and between health care systems and families can influence the empathic accuracy. The Schulz (2007) study also pointed out that communication can modulate the effect of patient symptom burden on caregiver physical and psychological health. Further research must be developed to test how caregivers use verbal and nonverbal communication with patients, as well as communication with health care teams, in order to promote patient care. Because caregiver health is positively correlated with patient health, intervention developed to alleviate patients' symptom burden will help improve caregivers' health.

(2) To design interventions to support the empathic accuracy.

Nursing researchers focused on cancer care also have suggested that interventions should be delivered for both patients and caregivers to advocate patients' self-management and caregivers' training, which will be beneficial for their health and quality of life (Northouse, et al, 2010 & Selviria, C Given, and B. Given, et al., 2012). The Schulz (2007) study also suggested that research should develop interventions to decrease patient suffering and improve caregiver compassion to contribute to caregiver health, based on its conceptual framework which illustrates the relationship between patient suffering and caregiver compassion.

Hopkinson et al. (2012) reviewed the studies which conducted interventions for cancer patients and their family caregivers to identify effects of interventions, delivering to the patient-caregiver pairs and separately delivering to patients and their caregivers to improve health outcomes of cancer patients. They found that couple-based interventions may assist emotional support and improve dyadic coping. Therefore, future research regarding the EASP framework should collect dyadic participants of cancer patients and caregivers in order to test the effect of interventions related to alleviating patient symptom burden and caregiver burden.

3) To extend the concept EASP from cancer patients and their family caregivers to the patients who are diagnosed with diseases other than cancer.

The EASP framework is in development and focuses on the caregiving circumstance of cancer symptom perception between patient and caregivers. Pain and fatigue severity and frequency were selected because they are typical symptoms in the cancer population. On the other hand, different patient populations have their own typical symptoms which may need more assistance from family caregivers. For example, patients diagnosed with Alzheimer’s disease need more family caregiver assistance with their daily activities when they have memory retardation and physical disabilities. In that case, EASP is a typical phenomenon in the caregiving circumstance. Given the statement above about the different symptoms between two diseases, the factors of the concept EASP will be different. The same determinants of the concept EASP among the diseases will indicate the generalization of the EASP framework. Therefore, further studies should utilize this framework in examining the different patient populations to strengthen the generalization.

For health policy. Caregiver health issues receive little attention in public health, social service policy and research because these areas focus on improving the health of populations who have illnesses and who are disabled. Family caregivers are an invisible and potential patient population because their health is impacted by patients’ symptom burden and care demands.

The EASP framework (Figure 1) emphasizes that caregivers' EASP is influenced by their psychological perceptions, modulates their helping behaviors in assisting patient symptom management, and can consequently impact their own and patients' health. Schulz and his colleagues (2007) have pointed out that patient suffering and caregiver compassion often impact family caregiver health. Caregivers who are more involved in caregiving performance generate more caregiver burden and caregiver depression (Palos et al., 2010; Sherwood, et al., 2006). The document of the Institute of Medicine (IOM) illustrates that 90% of long-term care is provided by family caregivers because the health care systems encourage minimum hospital days, and life expectancies are longer than before. Symptom management occupies most of the caregivers' time (von Ray et al., 2011). Family caregivers still report that they are not prepared to provide patient care. Few of them receive the training or have sufficient resource for providing patient care.

The IOM document **"**Retooling for An Aging America: Building the health care workforce" (2008) suggests that the health care workforce must include every individual who provides patient care, including formal health care providers, paid care workers, and informal caregivers (family members and friends), as well as patients themselves. This document also suggests that all of these individuals must have the essential resources, knowledge, and tools that are required to provide high-quality health care. In sum, the focus of these two documents is the necessity of supporting adequate knowledge related to patient care for family caregivers to ensure high quality of care for patients.

Therefore, although health policy may not directly improve caregiver burden and caregiver depression, it might change the clinical environment in providing care resources for family caregivers. Health policy may also focus on advocating for caregiver health in the health care system because caregivers' empathic accuracy in providing symptom management can alleviate patient symptom burden, and may also decrease caregiver depression. Congress should assign the IOM to conduct an aggregate level study to understand the difficulties and factors that influence caregivers who provide symptom management in home-based environments. Moreover, family caregivers are the main providers for most patient care at home. The National Family Caregivers Association's (NFCA, 2008-2009) has recommended establishing family-centered health care, and regulating comprehensive assessments of home-based caregiving situations to determine what family assistance caregivers may require. Therefore, the health policy related to supporting entire family care will be encouraged as well.

Conclusion

The EASP framework was developed with the inspiration of psychological perspectives of empathy and empathic accuracy in the caregiving circumstance to displays the factors and outcomes of caregivers and patients related to congruence of patient symptoms. Some caregivers were able to be congruent with patients' pain and fatigue perception, although some of them typically overestimated those symptoms. Caregivers who have depressive symptoms and caregiver burden may be more aware of patients' pain than fatigue, because their depressive symptoms and caregiver reactions related to patient care can influence their accurate perception of patients' pain. Caregivers' living with patients may influence caregivers' objective perception of patients' symptoms. Caregivers who perceive a greater number of patients' symptoms tend to accurately perceive patients' pain and fatigue rather than to underestimate these symptoms.

This study can compensate for the gaps in the past and extend nursing science by engaging psychology field (empathy theories) with caregiving research to provide a new perspective on caregiver congruence. Because the EASP framework was in early development and the investigator only examined one part of this framework, an essential task is to completely test the EASP framework. Meanwhile, testing the EASP in different ill populations and their family members will improve the generalization of this framework. More research in the area of empathic accuracy within the relationship of caregiving dyads will extend the science of empathy of family caregivers.

APPENDICES

APPENDIX A

Instruments

Table A1

Patient Demographics

1. Gender of patient	Male (1)	Female (2)
2. What is your birthday (write in):	____ /___ /____ month/ day/ year	
3. What is your highest level of education completesd? (circle one)	1) No formal education 2) Completed grade school 3) Completed some high school 4) Completed high school 5) Compelted some college or technical training 6) Completed college 7) Complete graduate/professional degree (post baccalaureate degree)	
4. What is your race or ethnic background?	1) Caucasion/white 2) Afraican American/Black 3) Mexican American/Hispanic/Chicano 4) Native American/Alaskan 5) Oriental/Ascian/Pacific Islander 6) Other (Specify): _______________	
5. What is your current marital status?	1) Never married 2) Married 3) Divorce/Separated 4) Widowed 5) Living together	

Table A1 (cont'd)

6. Including yourself, how many people live in your house?_____________	a. How many younger than 13 years old?______ b. How many between the ages of 13 and 17 ? ______ c. How many 18 years or older?_________
7. Site of Cancer	1. Breast 2. Colon 3. Lung (non-small) 4. Lung (small cell) 5. GU 6. Gastrointestinal 7. Gynecological 8. Pancreas 9. Non-Hodgkin's 10. Menothelioma 11. Other
8. Stage of Cancer	1. Early 2. Late
9. Recurrence of Cancer	1. Yes 2. No
10. Metastatic Cancer	1. Yes 2. No

Table A2

Caregiver Demographics

1 Gender of patient (1)Male (2)Female

2. What is your birthday (write in): ____ /___ /___________

month/ day/ year

3. What is your relationship to ________________________, (patient's name) who has cancer? You are his/her…. (check one.)

1) Spouse
2) Parent
3) Daughter/ son
4) Daughter/ son-in- law
5) Sister/brother
6) Sister/brother-in-law
7) Granddaguther/son
8) Neice/nephew
9) Aunt/uncle
10) Other relative ____________________
11) Friend or companion with hwom you live
12) Other non-relative____________________

4. What is your highest level of education completesd? (circle one)

1) No formal education
2) Completed grade school
3) Completed some high school
4) Completed high school
5) Compelted some college or technical training
6) Completed college
7) Complete graduate/professional degree (post baccalaureate degree)

Table A2 (cont’d)

Caregiver Demographics

5. What is your race or ethnic background?	1) Caucasion/white
	2) Afraican American/Black
	3) Mexican American/Hispanic/Chicano
	4) Native American/Alaskan
	5) Oriental/Ascian/Pacific Islander
	6) Other (Specify): ______________
6. What is your current marital status?	1) Never married
	2) Married
	3) Divorce/Separated
	4) Widowed
	5) Living together
7. Including yourself, how many people live in your house?_____________	a. How many younger than 13 years old?______
	b. How many between the ages of 13 and 17? _______
	c. How many 18 years or older?_________

8. Did you move into _____________________’s home or did ____________ move into your home so that you could assist him/her with his/her cancer care? (check one)

(1) Caregiver moved

(2) Patient moved

If a move occurred, what was the date of the move? (write in): ____/_______/__________

Moth/ day / year (4-digit needed)

Table A 3

Patient symtpoms

Patient version (cut)

1 During *the past 7 days*, on how many days did you experience pain?

0 1 2 3 4 5 6 7

Not present Number of days

2 On a scale of 0 is not present to 10 is the worst it could be, ***how severe*** in pain (for you) *in the past 7 dyas*?

0 1 2 3 4 5 6 7 8 9 10

Not present Worst possible

3 During *the past 7 days*, on how many days did you experience fatigue?

0 1 2 3 4 5 6 7

Not present Number of days

4 On a scale of 0 is not present to 10 is the worst it could be, ***how severe*** in fatigue (for you) *in the past 7 dyas*?

0 1 2 3 4 5 6 7 8 9 10

Not present Worst possible

5. The total number of Patients' symptoms was reported by patients? ________________

Table A3 (cont’d)

Patient symtpoms

Caregiver version (cut)

1 During *the past 7 days*, on how many days did you experience pain?

0 1 2 3 4 5 6 7

Not present Number of days

2 On a scale of 0 is not present to 10 is the worst it could be, ***how severe*** in pain (for you) *in the past 7 dyas*?

0 1 2 3 4 5 6 7 8 9 10

Not present Worst possible

3 During *the past 7 days*, on how many days did you experience fatigue?

0 1 2 3 4 5 6 7

Not present Number of days

4 On a scale of 0 is not present to 10 is the worst it could be, ***how severe*** in fatigue (for you) *in the past 7 dyas*?

0 1 2 3 4 5 6 7 8 9 10

Not present Worst possible

5 The total number of Patients’ symptoms was reported by CG? ________________

CES-D SCALE

Below is a list of the ways you might have felt or behaved. How often have you felt this way during the past week? Please circle the answer that fits your situation best.

Table A4

CES-D Scale

	Items	Rarely or none of the time (<1 day)	Some or little of the time (1-2 days)	Moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1	I was bothered by things that usually don't bother me.	0	1	2	3
2	I did not feel like eating; my appetite was poor.	0	1	2	3
3	I felt that I could not shake off the blues even with help from my family and friends.	0	1	2	3
4	I felt that I was just as good as other people.	0	1	2	3
5	I had trouble keeping my mind on what I was doing.	0	1	2	3
6	I felt depressed.	0	1	2	3
7	I felt that everything I did was an effort.	0	1	2	3
8	I felt hopeful about the future.	0	1	2	3
9	I thought my life had been a failure.	0	1	2	3
10	I felt fearful.	0	1	2	3
11	My sleep was restless.	0	1	2	3
12	I was happy.	0	1	2	3
13	I talked less than usual.	0	1	2	3
14	I felt lonely.	0	1	2	3
15	People were unfriendly.	0	1	2	3
16	I enjoyed life.	0	1	2	3
17	I had crying spells.	0	1	2	3
18	I felt sad.	0	1	2	3

Table A4 (cont'd)

	Items	Rarely or none of the time (<1 day)	Some or little of the time (1-2 days)	Moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
19	I felt that people dislike me.	0	1	2	3
20	I could not get "going."	0	1	2	3

FCRP Research Instruments
Caregiver Reaction Assessment Instrument (CRA)

Table A5

Caregiver Reaction Assessment Instrument (CRA)

	Items	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1.	I feel privileged to care for (patients' name) _____________.	1	2	3	4	5
2.	Others have dumped caring for ___ onto me	1	2	3	4	5
3.	My activities are centered around care for ___.	1	2	3	4	5
4.	It is very difficult to get help from my family in taking care of ___.	1	2	3	4	5
5.	*I resent having to take care of ___.	1	2	3	4	5
6.	I have to stop in the middle of work	1	2	3	4	5
7.	I really want to care for ___.	1	2	3	4	5
8.	I visit family and friends less since I have been caring for ___.	1	2	3	4	5
9.	I will never be able to do enough caregiving to repay ___.	1	2	3	4	5
10.	*My family works together at caring for ___.	1	2	3	4	5
11.	I have eliminated things from my schedule since caring for ___.	1	2	3	4	5
12.	Since caring for ___, I feel my family has abandoned me.	1	2	3	4	5
13.	Caring for ___ makes me feel good.	1	2	3	4	5
14.	The constant interruptions make it difficult to find time for relaxation.	1	2	3	4	5
15.	Caring for ___ is important to me.	1	2	3	4	5
16.	My family (brothers, sisters, and children) left me alone to care for ___.	1	2	3	4	5
17.	I enjoy caring for ___.	1	2	3	4	5

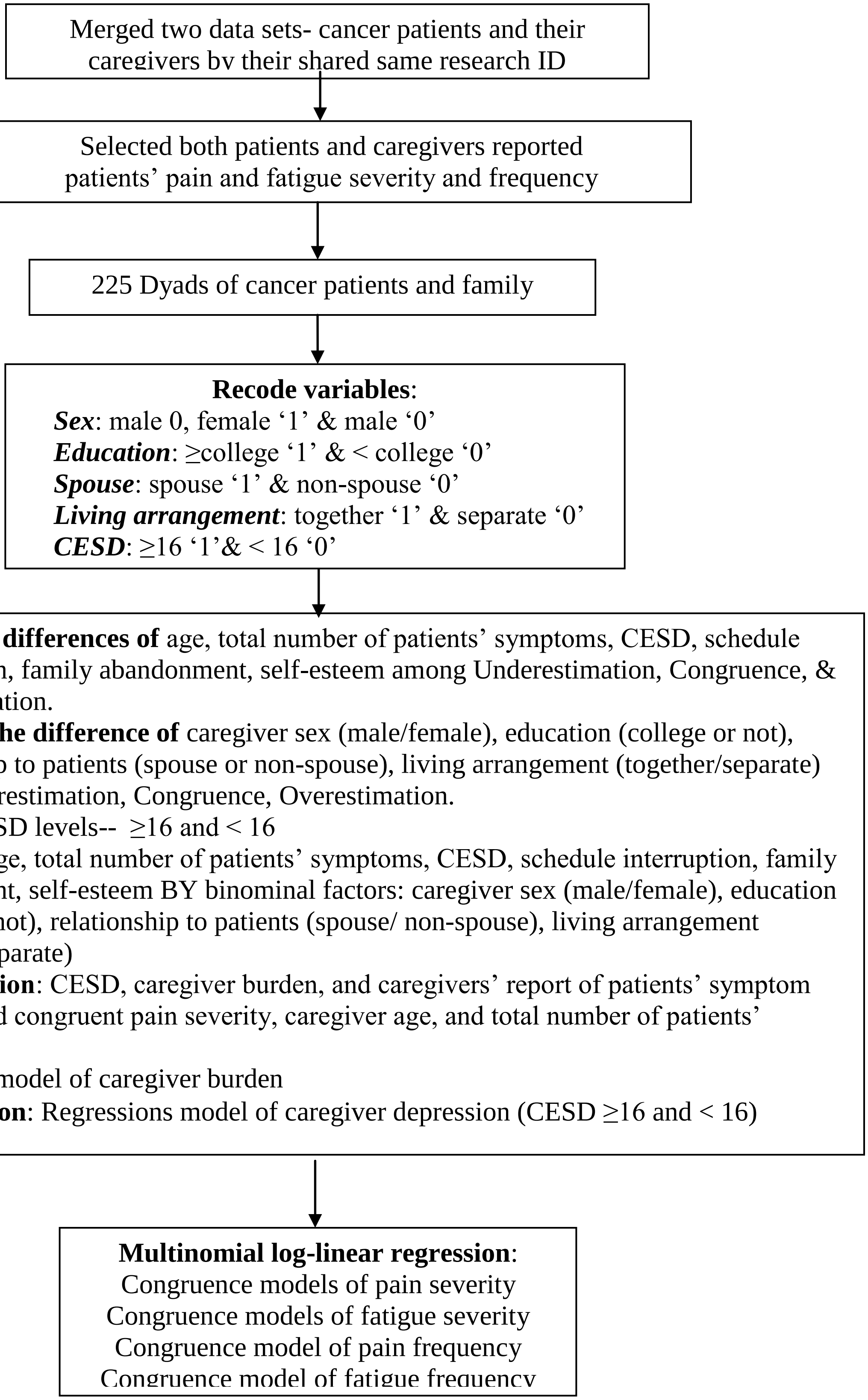
Table A5 (con’d)

Note: * These questions are to be reversely;
Two subscales did not be presented in this study: the health impact and the financial burden.
Items of the Schedule Interruption: 3, 6, 8, 11, & 14; Items of the Family abandonment: 2, 4, 10, 12, & 16 ; Items of the Self-esteem:1, 5, 7, 9, 13, 15, &17
Additional information about this tool can be found at: Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Research in Nursing and Health, 15(4), 271-283.
Note: No further information is available on this tool beyond what is included in the article referenced above.

Appendix B

Data Analysis Flow Chart

Data Analysis Flow Chart



Merged two data sets- cancer patients and their caregivers by their shared same research ID

Selected both patients and caregivers reported patients' pain and fatigue severity and frequency

225 Dyads of cancer patients and family

Recode variables:

Sex: male 0, female '1' & male '0'
Education: ≥college '1' & < college '0'
Spouse: spouse '1' & non-spouse '0'
Living arrangement: together '1' & separate '0'
CESD: ≥16 '1'& < 16 '0'

ANOVA: Test the differences of age, total number of patients' symptoms, CESD, schedule interruption, family abandonment, self-esteem among Underestimation, Congruence, & Overestimation.

Chi-square: Test the difference of caregiver sex (male/female), education (college or not), relationship to patients (spouse or non-spouse), living arrangement (together/separate)

1) By Underestimation, Congruence, Overestimation.
2) By 2 CESD levels-- ≥16 and < 16

T test: Caregiver age, total number of patients' symptoms, CESD, schedule interruption, family abandonment, self-esteem BY binominal factors: caregiver sex (male/female), education (college or not), relationship to patients (spouse/ non-spouse), living arrangement (together/separate)

Pearson's correlation: CESD, caregiver burden, and caregivers' report of patients' symptom severity, and congruent pain severity, caregiver age, and total number of patients' symptoms

GLM: Regression model of caregiver burden

Loglinear regression: Regressions model of caregiver depression (CESD ≥16 and < 16)

Multinomial log-linear regression:

Congruence models of pain severity
Congruence models of fatigue severity
Congruence model of pain frequency
Congruence model of fatigue frequency

APPENDIX C

IRB Approval Letters

Renewal
Application
Approval

November 16, 2009

To: Charles GIVEN
B510 W. Fee Hall
MSU

Re: **IRB# 08-963** Category: EXPEDITED 2-5
Renewal Approval Date: November 13, 2009
Project Expiration Date: November 12, 2010

Title: Concordance between caregivers and recipients perceive cancer-related symptoms impacts on caregiver burden.

The Institutional Review Board has completed their review of your project. I am pleased to advise you that the renewal has been approved.

The review by the committee has found that your renewal is consistent with the continued protection of the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: IRB approval is valid until the expiration date listed above. If you are continuing your project, you must submit an Application for Renewal application at least one month before expiration. If the project is completed, please submit an Application for Permanent Closure.

Revisions: The IRB must review any changes in the project, prior to initiation of the change. Please submit an Application for Revision to have your changes reviewed. If changes are made at the time of renewal, please include an Application for Revision with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify the IRB office promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Sincerely,

Ashir Kumar, M.D.
BIRB Chair

c: Chia Tai Hung
1537 Spartan Village, Apt.B
East Lansing
MI

Closure of
Protocol

October 18, 2011

To: Denise Saint Arnault
B-510 West Fee Hall

Re: **IRB# 08-963** Category: EXPEDITED 2-5
Project Expiration Date: November 10, 2011

Title: Caregiver-patient congruent symptom perception of pain and fatigue {CGA 118534)

Thank you for submitting a closure form for your project. The Institutional Review Board has accepted the information you have provided and your protocol has been officially **closed**.

Closure: Closure indicates that all research activities (including data collection and analysis) are complete and have stopped. If your database is completely de-identified, you can continue to perform data analysis, as the research no longer meets the definition of human subject research. Guidance on de-identified data: http://www.humanresearch.msu.edu/regs/regs_index.htm

Storage of Archived Data: The confidentiality of identifiable information must be maintained even after the research is complete. If you are maintaining data with identifiers, it is your responsibility to continue to maintain the privacy and confidentiality of the subjects and to store and protect the data in accordance with university and federal policy.

When individuals involved in research projects at Michigan State University leave the University, they may take copies of research data for project on which they have worked. The PI must, however, retain original data at Michigan State University.

If a PI leaves Michigan State University, and a project is to be moved to another institution, ownership of the data may be transferred with the approval of the Vice President for Research and Graduate Studies and with written agreement from the PI's new institution that guarantees 1) its acceptance of custodial responsibilities for the data and 2) MSU's access to the data should that become necessary.

IRB records relating to research must be retained for at least 3 years after research is completed or longer as required by law. *45 CFR 46.115(b), 21 CFR 56.109(f).* This includes documents under the investigator's) control, such as the signed informed consent forms and approval letters. To satisfy IRB requirements, IRB records for this project must be retained until at least 3 years. If your research is subject to other laws or requirements that impose a longer record retention period, records must be retained for the longer period.

Future Use of Archived Data: If the data is de-identified, further use of this data by students or colleagues does not require IRB approval. If your stored data contains personal identifiers, future use may require IRB approval - please contact the IRB office for advice when needed.

Problems: While your research is complete and closed, you may still encounter unanticipated problems, adverse events, or other problems that may increase the risk to the human subjects. In this event please notify the IRB office promptly - forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

Thank you for your cooperation. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu.

Sincerely,

Ashir Kumar, M.D.
BIRB Chair

c: Chia Tai Hung, Charles Given

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