

Do Beliefs and Feelings about Lung Cancer Effect Patient's and Informal Caregiver's
Perceptions of Symptom Experiences?

By

Tammy D. Murdoch

A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfillment of the requirements of the degree of

MASTER OF NURSING

Faculty of Nursing
University of Manitoba
Winnipeg

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ABSTRACT

Lung cancer patients experience higher levels of symptom distress than those with other types of cancer. Accurate symptom assessment is becoming an increasing responsibility of the family, requiring an open line of dyadic communication. Negative cognitions and emotions may strain communication, impacting caregiver ability to accurately assess symptoms. Results from this study will lay the foundation for understanding potential conflicts associated with illness attributions by patients and family caregivers.

The focus of this descriptive-comparative study was to explore the relationships and differences between dyadic member smoking history, illness attributions, perceptions of caregiver perspective-taking, and assessments of patient pain, dyspnea, and fatigue. This study was guided by Weiner's (1995) Theory of Social Conduct. Thirty-four lung cancer patient-family caregiver dyads were recruited from a cancer care outpatient setting in the City of Winnipeg.

Findings from non-parametric analyses revealed that both patients and their family caregivers attributed 'the patient' as having 'control' over the cause and management of the disease. Discrepant patterns on dyadic illness attribution reactions and perceptions of caregiver perspective-taking had an impact on dyadic agreement on patient symptoms.

There is a need for future research to identify dyads at risk for dysfunctional communication that can impact symptom management in the home setting. Interventions to target modifiable negative illness attributions and perspective-taking behaviours should be designed to assist caregivers in providing optimal symptom management.

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DEDICATION

TO MY HUSBAND GEOFF
FOR HIS LOVE, FAITH, AND SUPPORT.

TABLE OF CONTENTS

	<u>Page</u>
Abstract	i
Acknowledgements.....	ii
Dedication	iii
List of Tables	viii
List of Figures	ix
Chapter I: Statement of the Problem	1
Purpose of the Study	4
Definition of Terms	5
Research Questions.....	6
Summary	6
Chapter II: Literature Review.....	8
Lung Cancer	8
Incidence & Prevalence	8
Etiology	9
Types, staging, and treatment	10
Symptom Experience	16
Fatigue	20
Dyspnea	21
Pain	23
Informal caregiver perceptions and Empathic processes	27
Stigma and Illness Attribution	34

Conceptual Framework	44
Summary	52
Chapter III: Methodology	54
Population and Sample	55
Procedures for Data Collection	57
Recruitment of Subjects	57
Data Collection Protocol	59
Instruments	59
Folstein Mini-Mental Status Examination	60
Demographic Data Forms	60
Memorial Symptom Assessment Scale	62
Measurement of Onset and Offset Reactions	64
Caregiver Perspective-Taking Tool	65
Protection of Human Subjects	65
Data Analysis	67
Summary	68
Chapter IV: Results of Data Analysis	69
Description of the patient and caregiver samples	70
Demographic Characteristics of Patients	70
Demographic Characteristics of Family Caregivers	73
Instrument Reliability	81
Analysis of the Research Questions	82
Research Question #1	83

Smoking histories	83
Onset Reactions	87
Supplemental within-group analysis for onset reactions	96
Offset Reactions	101
Supplemental within-group analysis for offset reactions	115
Caregiver Perspective-Taking	120
Symptom Experiences	125
Pain	128
Shortness of Breath	130
Fatigue	131
Research Question #2	132
Onset reactions	133
Offset Reactions	137
Caregiver Perspective-taking	141
Summary	148
Chapter V: Discussion	151
Limitations of the Study	167
Implications for Practice	169
Recommendations for Future Research	171
Conclusion	172
References	175
Appendices	
A. Letter of Support	188

B. Invitations to Patients and Caregivers	189
C. Patient Consent Form	190
D. Caregiver Consent Form	194
E. Mini-Mental Status Examination of Patients and Caregivers	198
F. Patient Demographic Survey	201
G. Caregiver Demographic Survey	206
H. Memorial Symptom Assessment Scale – Patient version	210
I. Memorial Symptom Assessment Scale – Caregiver version	211
J. Onset Reactions – Patient	212
K. Onset Reactions – Caregivers	216
L. Offset Reactions – Patient	220
M. Offset Reactions – Caregivers	224
N. Caregiver Perspective-taking Scale – Patient version	228
O. Caregiver Perspective-taking Scale – Caregiver version	231

List of Tables

	<u>Page</u>
Table 1 - Reasons for non-participation of patients/caregivers	71
Table 2 - Demographic and Medical Characteristics of Patients and Family	
Caregivers	76
Table 3 - Caregiving Relationship Characteristics of Patients and Family	
Caregivers	79
Table 4 - Smoking Histories	86
Table 5 - Rank order of mean scores related to cause of cancer	88
Table 6 - Onset Reactions	95
Table 7 - Rank order of mean scores related to control over course of cancer...	103
Table 8 - Offset Reactions	107
Table 9 - Caregiver Perspective-Taking	121
Table 10 - Symptom Presence.....	127
Table 11 - Symptom dimensions and total symptom scores	129
Table 12 - Correlations between discrepancy scores on onset attributional	
responses and patients' symptom experiences	134
Table 13 - Correlations between discrepancy scores on offset attributional	
responses and patients' symptom experiences	138

List of Figures

	<u>Page</u>
Figure 1 – Weiner (1995) Theory of Social Conduct Diagram	48

CHAPTER I

Statement of the Problem

Lung cancer is a devastating disease that reaches deep into our society. While once considered a rare disease, lung cancer has become the most virulent and lethal cause of cancer mortality in the 21st century (Cooley, Kaiser, Abrahm, & Giarelli, 2001). It is the second most commonly diagnosed cancer in Canada and the leading cause of cancer deaths nationwide (Canadian Cancer Society, 2007). With a large percentage of patients presenting with advanced disease, the overall five-year survival rate, even with treatment, is a dismal 14% (Cooley et al., 2001). Without treatment, the median survival of lung cancer patients is less than six months (Cooley et al., 2001). Not surprisingly, the focus of treatment is often palliative rather than curative in nature, underscoring the importance of symptom management (Tanaka, Akechi, Okuyama, Nishiwaki, & Uchitomi, 2002; Tishelman, Degner, & Mueller, 2000a).

Symptom management within this population can be a daunting task as research has shown that lung cancer patients experience higher levels of symptom distress than those suffering from other types of cancer (Degner & Sloan, 1995). The disease is associated with a host of physical symptoms related to natural disease progression and treatment-related sequelae (Lobchuk & Kristjanson, 1997). Tanaka and colleagues (2002a) found pain, fatigue, and dyspnea to be the most commonly reported symptoms within this patient population.

The keen assessment and monitoring of symptoms required for proper management has traditionally been the responsibility of the patient and healthcare professional working in concert. Increasingly, however, the burden of care of patients

afflicted with lung cancer is falling upon families. This is due, in part, to health care cost restraints, severity of the illness, and widespread patient preference for out-of-hospital care, during both treatment and palliative phases (Bakas, Lewis, & Parsons, 2001; Goldstein, Concato, Fried, Kasl, Johnson-Hurzeler, & Bradley, 2004; Lobchuk & Degner, 2002a; Lobchuk & Kristjanson, 1997). Home-based care usually provides the patient with greater emotional and physical comfort and therefore an enhanced quality of life (Kinsella, Cooper, Picton, & Murtagh, 2000).

This shift in the delivery of care greatly increases the stress and responsibility placed on the informal caregiver (caregiver), requiring them to estimate the symptom experiences of the patient, and to understand and interpret symptoms within the context of the patient's point-of-view (Lobchuk, 2001). This caregiver skill is also known as perspective-taking, defined as the imaginative tendency or ability of an observer to place oneself in another person's place in order to understand another's thoughts and feelings (Hogan, 1969).

Perspective-taking is an empathic process that has an important role in informal caregiving. In theory, it allows the caregiver to attain a more accurate understanding of the patient's symptom experiences, enabling them to validate the patient's experiences through reflective communication and help-intended behaviours. However, the ability of the caregiver to exercise empathic understanding can be challenged by many factors such as level of caregiver knowledge about the disease, beliefs regarding the cause of the disease and its progression, previous relationship with the patient, and emotions such as fear or anger (possibly due to the smoking behaviours of the patient). Apart from the work done by Lobchuk and colleagues, factors that impact empathic processes, such as

perspective-taking, have not been systematically tested within the informal caregiving relationship. As such, research is needed in this area to garner a better understanding of this dynamic process within the context of the cancer patient/caregiver relationship.

Research in the area indicates that caregivers (those with a close, personal relationship with the patient either spouse, family member, or friend) attain reasonable perceptual agreement with the patient on patient symptom experiences (Lobchuk & Vorauer, 2003; Lobchuk & Degner, 2002). This ability requires a good line of communication between patient and caregiver and a desire, on the part of the caregiver, to assist the patient (Lobchuk, 2005). There is growing speculation however, that these interpersonal caregiving dynamics are being potentially challenged by the increasing stigmatization of lung cancer (Chapple, Ziebland, & McPherson, 2004; Lobchuk, 2005).

Since research empirically linked smoking to lung cancer over four decades ago, there has been evolving public sentiment against cigarette smoking as a result of mass media that strongly addresses the linkage between cigarette smoking and lung cancer. (Kim & Shanahan, 2003; Gilbert, Ronald, Edward, & Lowe, 1998). Smoking, linked with more than 85% of all lung cancers (Health Canada, 2005), is now socially rejected and considered deviant behaviour with smokers being isolated and stigmatized as “socially unqualified deviants” (Kim & Shanahan, 2003).

This stigmatization of smokers may result in feelings of guilt, isolation and/or embarrassment on the part of the smoker (Kim & Shanahan, 2003). Cooper (1984) found that both lung cancer patients and their informal caregivers blamed the patient for having brought on the disease due to his or her smoking behaviours. Findings also indicated that blaming, avoidance and being angry at the lung cancer patient can alter usual lines of

communication between patient and caregiver. In addition, the well known health effects of second-hand smoke may cause the caregiver, who smoked in the past or continues to smoke, to experience feelings of guilt and self-blame for the cause of the patient's disease. These feelings may also result in an alteration in the lines of communication between caregiver and patient. The by-product of these illness attributions may jeopardize the caregiver's ability to communicate and validate patient symptom experiences. This can result in sub-optimal treatment of symptoms.

Lung cancer stigma and subsequent causal attributions have been examined in a limited scope by researchers (Berckman & Austin, 1993; Chapple et al., 2004; Faller, Schilling, & Lang, 1995). However, to date, no studies have examined the impact of stigma and causal attribution on interpersonal dynamics between informal caregivers and lung cancer patients including perceptions of lung cancer patient's symptoms. Specifically, whether perceptual differences between patient and caregiver with respect to illness attributions - who is to blame for the cause of the disease ('onset reaction') and who is responsible for controlling disease progression ('offset reaction') - and subsequent emotions, challenge caregiver perspective-taking and impact on the perceptual congruence of patient and caregiver reports of patient symptom experiences (Lobchuk, 2005).

Purpose of the Study

The aim of this study is to explore the relationships and differences between patient and caregiver smoking history, illness attributions (through 'onset' and 'offset' reactions), perceptions of caregiver perspective-taking, and assessments of patient pain, dyspnea, and fatigue experiences. To date, these relationships have remained unexplored

by researchers, and as such, preliminary information gleaned from this study will lay the foundation for a beginning understanding of these relationships and subsequently allow for the identification of patient-caregiver dyads at high risk for dysfunctional communication and inappropriate management of symptoms, such as pain, fatigue and dyspnea. This project is part of a larger study funded by the National Cancer Institute of Canada, examining lung cancer stigma and the potential effect it may have on caregiver perspective-taking and perceptual agreement on patient illness experiences, lead by Dr. Michelle Lobchuk (Principal Investigator), Dr. Christine McPherson, and Dr. Susan McClement (Co-Investigators).

Definition of Terms

Perspective-taking – The imaginative tendency to put oneself in another person's place in order to understand what the other person is thinking and feeling without vicariously experiencing the patient's emotions (Hogan, 1969; Long & Andrews, 1990).

Onset Responsibility – A perception of responsibility for the onset or occurrence of a disease (Karasawa, 1991, as cited in Weiner, 1995).

Offset Responsibility- The degree of "perceived control" in relation to disease progression (Karasawa, 1991, as cited in Weiner, 1995).

Stigma - an attribute or undesirable behaviour that results in an individual being disgraced or deeply discredited (Goffman, 1963). For example, as in lung cancer, the association with smoking promotes biased attitudes by individuals towards individuals who smoke.

Research Questions

1. What are the relationships and differences between lung cancer patient and caregiver respective responses on their smoking histories, 'onset' and 'offset' reactions, caregiver perspective-taking, and perceptions on patient pain, fatigue and dyspnea experiences (symptom experiences)?
2. If discrepancies are identified during the analysis of question one, what is the effect of these discrepancy scores for patient and caregiver 'onset reactions', 'offset reactions', and caregiver perspective-taking on levels of patient and caregiver perceptual agreement on patient symptom experiences?

Summary

Lung cancer is a devastating and stigmatized disease in relation to the perception that the patient brought the disease on oneself because of cigarette smoking. The shift in the care of lung cancer patients from the hospital to the home, as well as the projected growing number of lung cancer patients who will require the participation of informal caregivers in their home-based care, has greatly increased the responsibility placed on the caregiver to effectively manage symptoms. In light of these circumstances, health care professionals will become increasingly reliant on caregiver assistance with the increasing volume of lung cancer patients. As such, it is critical that the caregiver be able to accurately perceive patient symptom experiences and interpret these symptoms within the context of the patient's viewpoint in order to ensure adequate treatment of symptoms and disease management. This caregiver skill may be difficult to undertake however, due to the increasing stigmatization of the disease in relation to tobacco usage and the subsequent illness attributions held by both the patient and caregiver, which in turn, may

have a negative impact on help-intended communication and empathic processes, such as perspective-taking. Empirically-based studies exploring these interpersonal dynamics and their effects on patient-caregiver perceptual agreement for pain, fatigue and dyspnea experiences are needed.

CHAPTER II

Literature Review

The literature reviewed for this study has been grouped into four different areas: lung cancer, symptom experiences, informal caregiver perceptions and empathic processes, and stigma and illness attribution. Each area will be examined separately.

Lung Cancer

This section will present literature that was reviewed related to lung cancer incidence & prevalence, etiology, and types and treatments.

Incidence & prevalence.

At the beginning of the twentieth century, lung cancer was a rare disease. However, over the next forty years it reached epidemic proportions for men, and is now considered to be an epidemic among women due to the increased rates of women using tobacco products, killing more women than any other cancer in North America (Ingle, 2000). Lung cancer is the second most common cancer, and is the leading cause of cancer deaths worldwide for both men and women (Cooley, 2002; Silvestri, Sherman, Williams, Swan-Swan, Flume, & Turrisi, 2002). Recent statistics estimate that in 2007, 23,300 Canadians will be diagnosed with lung cancer resulting in 19,900 deaths (Canadian Cancer Society, 2007). Each week in Canada during 2007 it is estimated that 448 people will be diagnosed with lung cancer and each week 383 people will succumb to the disease (Canadian Cancer Society, 2007). Worldwide statistics are even more grim with deaths from this disease projected to double by the year 2020, resulting in more than 2.4 million deaths every year (Sarna, 1999). Lung cancer will climb from its current position as the tenth leading cause of preventable deaths to a grim 5th place standing by the year

2020 (Sarna, 1999). The highest incidence of lung cancer is in the elderly, peaking at age 75 (Ingle, 2000), however, research indicates this age will steadily drop to closer to middle-age (ages 35-69) over the next ten to fifteen years (Sarna, 1999).

Etiology.

In the 1960s, empirical evidence linked tobacco usage to lung cancer and in 1964, the Surgeon General of the United States declared smoking a health risk (Kim & Shanahan, 2003). Since that time, smoking has been linked to 80%-90% of all lung cancer cases (American Lung Association, 2007; Canadian Cancer Society, 2007; Health Canada, 2005; Ingle, 2000; Williams & Sandler, 2001). The risk of developing lung cancer in smokers is estimated to be 10-25 times the risk of non-smokers (Ingle, 2000). Cigarette smoke is known to contain over 4,000 chemical compounds that insult bronchial epithelium when smoke is inhaled (American Lung Association, 2007; Ingle, 2000). The most carcinogenic compound is tar, which causes basal cell hyperplasia leading to dysplasia, or an abnormal development of tissue. This further leads to the displacement of normal, healthy ciliated and mucus-secreting cells. Repeated exposure to smoke may cause a lung cell to undergo neoplastic (abnormal tissue development as a tumor) transformation (Ingle, 2000; Taber, 1997).

In 1986, two landmark studies were published by the U.S. Surgeon General and The Expert Committee on Passive Smoking, National Academy of Sciences' National Research Council linking environmental tobacco smoke, also known as passive smoke or second-hand smoke, with lung cancer incidence in non-smokers (National Cancer Institute, 2000; Ingle, 2000). Passive smoke contains nearly all of the carcinogens contained in mainstream smoke inhaled by smokers. However, because it is not filtered, a

greater number of carcinogens are inhaled passively (Ingle, 2000). Exposure to environmental tobacco accounts for 17% of lung cancers among non-smokers claiming the lives of approximately 300 Canadians each year (Canadian Cancer Society, 2007), with significantly increased risk for persons living with smoking spouses (Ingle, 2000).

The remaining 10%-20% of lung cancer is caused by asbestos, radon, occupational agents, indoor air pollution and dietary factors (Ingle, 2000). Asbestos and smoking have been proven to compound the effect on lung cancer incidence. "Compared with nonexposed, non-smokers, the incidence of lung cancer is increased five-fold in nonsmokers exposed to asbestos and a startling 80-fold to 90-fold in exposed smokers" (Ingle, 2000, p. 1301).

Types, staging, and treatment.

Lung cancer is divided into two broad categories: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). NSCLC is further subdivided into squamous cell carcinoma, adenocarcinoma, and large cell carcinoma, each having distinct histological characteristics upon which diagnosis and management are based (Ingle, 2000).

Twenty-five percent of all lung cancers are SCLC, an aggressive tumor that is often metastatic at the time of diagnosis due to a doubling time of slightly less than two months, the shortest of all lung cancer types (Ingle, 2000). NSCLC accounts for the remaining 75% of lung cancers, with squamous cell carcinomas being more common in males (Ingle, 2000) and adenocarcinoma most common in women (Sarna, 1999).

Staging of lung cancer is based on the TNM staging system developed in the 1950s by the American Joint Commission on Cancer, commonly used in classifying the

cancer by tumor size (T), presence or absence of nodal involvement (N), and presence or absence of metastases (M). It is also useful in prognosis and planning treatment as well as in predicting surgical resectability in relation to lung cancer (Ingle, 2000). In 1996, the Commission revised the TNM system to include revisions in the International System for Staging Lung Cancer providing greater specificity in identifying patients groups relative to prognosis and treatment options (Ingle, 2000).

While the health care system continues to use the TNM system, lung cancer is now divided into eight rather than six stages, each distinct in relation to treatment and five-year survival statistics (Ingle 2000). Stage I (divided into subcategories IA and IB) involves limited or localized disease ranging from a tumor 3 cm or less for Stage IA to a tumor >3 cm involving the main bronchus, or 2 cm or more distal to the carina invading the visceral pleura, which may be associated with atelectasis, or obstructive pneumonia for Stage IIB. There is no nodal involvement or evidence of metastases in Stage I (Ingle, 2000).

Stage II also consists of two subcategories, Stage IIA and IIB. Stages IIA and IIB are the same as their Stage IA and IB counterparts with the exception of nodular involvement in the ipsilateral peribronchial and/or ipsilateral hilar lymph nodes, including direct extension (Ingle, 2000). Stage IIB may also include the T3 designation which involves a tumor of any size that directly invades any of the following: chest wall, diaphragm, mediastinal pleura, parietal pericardium, or tumor in the main bronchus (Ingle, 2000) with no nodular involvement.

Stage III involves extensive disease and is categorized into Stages IIIA and IIIB. Each subcategory involves extensive tumor development with nodular involvement.

Stage IIIB can include a tumor of any size that invades structures such as the mediastinum, heart, great vessels, trachea, esophagus or carina with extensive nodular involvement (Ingle, 2000). Stage IV lung cancer involves tumor of any size, extensive nodular involvement and distant metastases for example to the brain (Ingle, 2000).

The TNM staging system is not routinely used with respect to SCLC since most individuals with SCLC have metastatic disease at the time of diagnosis (Ingle, 2000). As such, SCLC is described as either “limited” or “extensive”. Limited stage refers to disease that can be encompassed in one radiation field ((Dr. S. Navaratnam, personal communication, August 13, 2007). “Extensive-stage disease refers to tumor that has spread beyond the boundaries of limited disease” (Ingle, 2000, p. 1312).

Lung cancer is often in an advanced stage upon diagnosis as it has undergone approximately thirty doublings or three-quarters of its natural history by the time it is large enough to be detected, with many tumors metastasizing in the preclinical phase (Ingle, 2000). Prognosis for this disease is often very dismal, with SCLC having the poorest survival rates of all lung cancer types. If left untreated, survival averages approximately 6-12 weeks. If treated for limited and extensive-stage disease, two year survival rates of 12%-21% and 1%-4% respectively can be expected (Ingle, 2000). Survival rates for NSCLC depend on the stage of disease at the time of diagnosis and the treatment modalities employed (Ingle, 2000). Five-year survival for resectable tumors may exceed 70%, with rates for advanced and metastatic NSCLC ranging from 0%-3% at best (Ingle, 2000). Advances in treatment combinations have been recently made with respect to surgery and adjuvant chemotherapy (therapy given to assist in the prevention,

amelioration or cure of disease) that may significantly impact survival outcomes for early-stage NSCLC patients (Dunant, Pignon & Le Chevalier, 2005).

Treatment strategies are dependent upon many important prognostic factors including histology, tumor extent, and the physical condition of the patient (Lobchuk, 1995). With respect to NSCLC, surgery is usually the first line treatment for stage I and II disease (Ingle, 2000; Melville & Eastwood, 1998). In addition, several recent studies, including a landmark study by Winton and colleagues (2005), have reported significant benefits of administering adjuvant chemotherapy treatment after surgical resection in early stage NSCLC (Belani, 2005; Dunant et al., 2005; Gurubhagavatula & Lynch, 2005, Winton, Livingston, & Johnson, 2005). Winton and colleagues' (2005) randomized control trial included 482 patients with surgically resected stage IB or stage II NSCLC and was the first of its kind to treat all patients with a newer third generation chemotherapy agent, omit postoperative radiation therapy, and only include a narrow subgroup of patients with operable tumors (Pisters, 2005). After a median follow-up of greater than five years, the results indicated that those receiving adjuvant chemotherapy improved their five-year overall survival rate by 15 percentage points when compared with observation alone (69% vs. 54%) and decreased the risk of death by 31% (Pisters, 2005). In response to favourable results from this and other studies, adjuvant chemotherapy has been recommended to become part of the standard management of operable NSCLC (Belani, 2005; Dunant et al., 2005; Gurubhagavatula & Lynch, 2005, Pisters, 2005, Winton et al., 2005).

Fifty percent of all lung cancers are inoperable upon diagnosis, and another twenty-five percent of patients have tumors that cannot be completely resected (Ingle,

2000). Radiation therapy plays an important role in the treatment and management of individuals with NSCLC (Ingle, 2000). It has been considered a potentially curative alternative in stage I and stage II patients who either refuse surgery or are not surgical candidates (Ingle, 2000). It can also be used pre-operatively, in combination with chemotherapy, to down stage the tumor potentially rendering it operable or postoperatively in combination with chemotherapy (Ingle, 2000; Maghfoor & Perry, 2005).

Chemotherapy is most often used to treat stage III and stage IV NSCLC patients; it has shown a 50%-70% response rate in stage III patients when used in combination with surgery or radiation therapy (Ingle, 2000). There is some question as to the merits of using chemotherapy in advanced stage patients with metastases due to some of the side-effects. However, according to Ingle (2000), chemotherapy has been shown to extend survival and also improve symptoms such as cough, hemoptysis, bone pain, weight loss, and malaise, and can be administered pre-operatively, post-operatively or as a stand alone regime.

With regards to SCLC, surgical resection is usually not an option due to its often metastatic presence at the time of diagnosis (Ingle, 2000). However, SCLC is known to be quite sensitive to both radiation and chemotherapy (Ingle, 2000; Melville & Eastwood, 1998). Often thoracic radiation therapy in combination with chemotherapy for limited-stage disease is the standard of care (Ingle, 2000). Combined-modality treatment results in a decrease in recurrence rates and appears to give a modest advantage in relation to survival over chemotherapy alone (Ingle, 2000). Maghfoor and Perry (2005) reported that SCLC confined to one lung may be curable when treated with a combination of

chemotherapy and thoracic irradiation followed by prophylactic cranial irradiation. However, if the malignancy has spread beyond the confines of one lung, it is considered incurable (Maghfoor & Perry, 2005).

For the vast majority of lung cancer patients there will come a point in their illness trajectory where the disease is no longer responsive to curative treatment, and palliative care will become the focus of care (Silvestri, Sherman, Williams, Swan-Swan, Flume, & Turrisi, 2002). Palliative care was defined by the World Health Organization in 2007, as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. The goal of palliative care is to achieve the best quality of life possible for patients and their families. According to Silvestri and colleagues (2002) an integral component of palliative care is to relieve symptoms, as such, care must be taken to ensure the therapy is not worse than the disease. Therefore, the chosen palliative treatment should be as brief and as effective as possible in an attempt to minimize any untoward effects (Silvestri et al., 2002). This may prove difficult in certain situations as different treatment modalities can be toxic and troublesome in relation to symptoms, side-effects, and long term sequelae (Silvestri et al., 2002). In light of these facts, research is needed to facilitate the development of supportive interventions for lung cancer patients and their families as they cope with cancer, its treatment, and its impact on quality of life (Lobchuk, 1995).

In summary, lung cancer is a serious disease that has reached epidemic proportions and is only rising in incidence, particularly among women. Empirically

linked to tobacco usage in the 1960s, smoking is believed to be responsible for approximately 80%-90% of all lung cancer cases. This devastating disease is separated into two broad categories, non-small cell lung cancer (accounting for 75% of all lung cancers), and small-cell lung cancer (accounting for 25% of all lung cancers). Treatment depends largely on the stage of the disease upon diagnosis. Even with aggressive treatment (surgery, chemotherapy, radiation therapy), survival rates are often less than favourable. However, new post-surgical adjuvant chemotherapy treatment may offer hope to patients with early stage NSCLC. For the vast majority of patients, palliative care will be the focus of their care, necessitating the development of supportive interventions for lung cancer patients and their families as they cope with this disease, treatment modalities and its impact on quality of life.

Symptom Experience

Cancer has been cited as the most feared of all diseases (Lin, Lin, & Stein, 1982). It is not only viewed by many as a terminal situation, but is also associated with a host of unpleasant, life-altering symptoms. As such, symptom assessment and management are integral components of cancer treatment, and in no other group is this more compelling than in the lung cancer population.

In their groundbreaking study, Degner and Sloan (1995) discovered that those suffering from lung cancer reported the highest levels of symptom distress, with only 6% of patients asymptomatic at the time of diagnosis (Ingle, 2000). In addition, research has shown that adult lung cancer patients often experience multiple symptoms which may change over their illness trajectory and among various treatments (Cooley, Short, & Moriarty, 2003; Degner & Sloan, 1995). If not properly managed, uncontrolled

symptoms have been associated with a loss of physical functioning, an increase in psychological distress, and a decrease in quality of life (Cooley et al., 2003). This assault on emotional wellbeing not only impacts the patient, but also the family (Tanaka, Akechi, Okuyama, Nishiwaki, & Uchhitomi, 2002a). On a positive note, symptom distress has proven amenable to intervention within this population (Degner & Sloan, 1995), thus emphasizing the importance of not only a clear understanding of the symptoms that adults with lung cancer experience over the course of their illness, but also of accurate assessment and subsequent management by the informal caregivers (Cooley et al., 2003).

Numerous studies have examined which symptoms are most troublesome for lung cancer patients at various disease stages (Bakas et al., 2001; Cooley et al., 2003; Degner & Sloan, 1995; Dodd & Miaskowski, 2001; Tanaka et al., 2002a). Degner and Sloan (1995) found that in newly diagnosed patients, the most distressing symptoms were fatigue, pain, cough, lack of appetite, and insomnia. Cooley and colleagues (2003) reached similar findings when they conducted a secondary analysis of three different data sets (N= 117) comparing symptoms in lung cancer patients at three time intervals – entry into study, at three months and at six months. They found that fatigue was the most prevalent distressing symptom at each time interval, with pain frequency coming in second. Dyspnea and cough were found to become problematic for approximately one-third of patients at the six month mark. Fatigue and pain were also the most commonly noted symptoms when looking at prevalence of distressing symptoms within patients receiving active treatment (surgery, radiation, chemotherapy and combined therapy).

Lobchuk and colleagues (1997) found in their study on the congruence between patients' and primary family caregivers' perceptions of patient symptom distress that

difficulty breathing was rated as one of the most distressing symptoms from both the patients' and caregivers' perspective. Tanaka and colleagues (2002a) also reported that within the palliative care setting, lung cancer patients found pain, dyspnea and anorexia to be the most distressing symptoms. Thus, fatigue, pain, and dyspnea appear to be the most distressing symptoms within the lung cancer population across the illness trajectory.

Fatigue, dyspnea and pain were chosen as the focus for this study due in part to the previous discussion, but also because pain has been recognized by the U.S. Joint Commission on Accreditation of Healthcare Organizations as a symptom that is inadequately managed and under-treated by health care professionals (JCAHO, 2000). The Canadian Council on Health Facilities Accreditation (CCHFA) have included documentation of pain assessment and management as an integral component of its revised accreditation evaluation for Canadian hospitals, emphasizing the need for health care organizations and institutes to address the problem of lack of accountability for quality pain management (Canadian Pain Mechanisms, Diagnosis and Management Consortium, 2005). The Canadian Pain Mechanisms, Diagnosis and Management Consortium (2005) have stressed that research is critical to examine the contextual issues involved in managing pain. In addition, fatigue and dyspnea have been identified, by an expert in the diagnosis and treatment of lung cancer, as clinically relevant and highly prevalent symptoms requiring the attention of health care providers (Dr. S. Navaratnam, personal communication, April 25, 2005). As such, these three symptoms will form the symptom experience component of this study, looking at the potential impact stigma and illness attribution have on caregiver perspective-taking and perception of patient symptom experiences.

Examining three symptoms simultaneously also follows recommendations made by Dodd and Miaskowski (2001) who suggest breaking away from the tradition of examining symptoms in isolation in favour of the exploration of “symptom clusters” defined as “three or more concurrent symptoms (e.g. pain, fatigue, and sleep insufficiency) that are related to each other” (Dodd & Miaskowski, 2001, p. 465). This is also a particularly relevant approach within the lung cancer population as it is estimated that these patients may experience an average of 4.1 highly distressing symptoms at any given time (Cooley et al., 2002). Dodd and Miaskowski (2001) found that “the presence of three concurrent symptoms may have a synergistic effect as a predictor of the patient’s future morbidity” (p. 466).

Tanaka and colleagues (2002b) examined the impact of dyspnea, pain and fatigue on daily life activities of advanced stage lung cancer patients in Tokyo. They found that fatigue and dyspnea interfered with at least one daily life activity in over 50% of patients, with pain interfering with at least one daily life activity in about 40% of patients. They also found that fatigue and dyspnea predominantly interfered with physical activities whereas pain interfered with all activities almost equally. Activities of daily life in this study included such things as walking, work, mood, enjoyment, sleep and relaxation (Tanaka et al., 2002b). A disruption of these activities may have a direct impact on the quality of life of the patient, and as this is the only study of its kind, further investigation is warranted. In order to have a better understanding and appreciation of the magnitude and importance of each of these three symptoms, they will be briefly reviewed on an individual basis in relation to cancer in general.

Fatigue.

Fatigue is characterized by difficulty concentrating, anxiety, a gradual decrease in stamina that is out of proportion to energy expended; difficulty sleeping; increased sensitivity to light, noise, taste, and touch; a feeling of being cold and off-balance; an increase in nausea and diarrhea; and the limiting of social interactions to activities of particular significance” (Olson, 2007, p.5). Cancer-related fatigue differs considerably from acute or chronic fatigue experienced by the general population, being described as more intense, chronic and disruptive, and typically unrelieved by rest (Viskovsky & Schneider, 2003). The prevalence of fatigue in patients with advanced lung cancer has been reported as high as eighty percent (Okuyama, Tanaka, Tatsuo, Kugaya, Kugaya, & Okamura et al., 2001). As fatigue is not directly observable in most of its forms, its recognition and treatment are often overlooked. The manifestations of this symptom can include lack of motivation, exhaustion, weakness, sleep disturbance, irritability and sadness (Viskovsky & Schneider, 2003).

Although often disregarded by healthcare professionals, fatigue has been found to be a major life concern of cancer patients (Viskovsky & Schneider, 2003). A study done by Vogelzang and colleagues (1997), found that professional caregivers believed that patients were experiencing pain more frequently than fatigue therefore judging it to be of more concern. However, patients felt that fatigue was the symptom causing the greatest difficulty, with high levels of fatigue leading to a decrease in quality of life, functional status, and symptom management (Viskovsky & Schneider, 2003).

Fatigue can be ascribed to a number of causative factors. It can be a result of the disease itself, for example due to dyspnea, pain, emotional distress, and sleep

disturbances, or the result of indirect disease effects such as cachexia and anemia. Also, treatment modalities such as pain medication and radiation therapy cause can fatigue. Cooley and colleagues (2002) reported that 100% of their subjects receiving radiation therapy complained of high distress associated with fatigue. In addition, chemotherapy can cause anemia leading to fatigue. Co-morbidities unrelated to the disease such as infection, or endocrine, pulmonary or cardiac dysfunction can contribute to fatigue (Viskovsky & Schneider, 2003).

Like pain and dyspnea, “fatigue is perceived in a multidimensional manner including sensory, affective, behavioural, and cognitive dimensions” (Viskovsky & Schneider, 2003, p. 2). Studies have linked fatigue with pain (Dodd & Miaskowski, 2001). Miaskowski and Lee (1999) found that cancer patients suffering from intense pain also had increased levels of fatigue. In addition, they found that pain disturbs sleep leading to increased fatigue. Suffering from fatigue may also be a predictor of other symptom experiences. According to Cooley and colleagues (2003) beginning evidence suggests that fatigue and pain may influence a number of other symptoms in cancer patients. In a previous study conducted by Cooley and colleagues (2002), when fatigue and pain were reported together, patients were found to experience 6.3 other concurrent symptoms and those who reported fatigue alone reported having, on average, 4.5 other symptoms, stressing the importance of accurate assessment and management of this burdensome symptom.

Dyspnea.

Dyspnea is a complex and distressing symptom that is difficult to manage (Houlihan, Inzeo, Joyce, & Tyson, 2004). The American Thoracic Society (1999) defines

dyspnea as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The symptom derives from interactions among multiple physiologic, psychologic, social, and environmental facts and may induce secondary physiologic and behavioural responses” (p. 321).

Dyspnea has been associated with a primal fear of death by suffocation and as such, evokes a strong visceral response that begs for intervention by patients, caregivers and healthcare professionals alike (Houlihan et al., 2004). Not surprisingly, dyspnea is more common among lung cancer patients. Dudgeon and colleagues (2001) examined dyspnea in a variety of cancer groups and found an 84% prevalence rate in lung cancer patients at various stages of the disease, both in and out of treatment compared to 41.9% among the general cancer population.

The causes of dyspnea in lung cancer patients can be a direct result of the cancer due to an intrinsic or extrinsic airway obstruction by the tumour, pleural effusion, pulmonary parenchymal involvement or superior vena cava syndrome, or an indirect result of the cancer due to cachexia, anemia, pneumonia or pulmonary emboli. Dyspnea in lung cancer can also be due to treatment-related causes from surgery, radiation pneumonitis and subsequent radiation fibrosis, chemotherapy induced pulmonary toxicity, cardiomyopathy, or as a result of a problem unrelated to the cancer such as chronic obstructive pulmonary disease (COPD), asthma, or the result of continued tobacco usage (Dudgeon et al., 2001). Tanaka and colleagues (2002b) cautioned however that the pathophysiology of dyspnea is not yet well understood, despite its high prevalence. As a result, dyspnea remains one of the most difficult symptoms to treat in advanced and terminal stages of lung cancer.

Assessment of dyspnea remains a real challenge for nurses due to not only its multiple causes, but also its highly subjective nature (Houlihan et al., 2004). In this regard, dyspnea has been described as a pain equivalent (Wickham, 2002). Both are “complex, sensory and affective subjective experiences that result from the interplay of modulating factors” (Wickham, 2002, p. 926).

It has been found that cancer patients often experience pain and dyspnea simultaneously; both often worsening with progressive disease. As with pain, the language of dyspnea is imprecise and the severity of dyspnea does not necessarily correlate with objective measures e.g. pulse oximetry, or stage of cancer (Wickham, 2002).

Pain.

Pain has been described as a multidimensional phenomenon with sensory, affective, and cognitive dimensions. As previously discussed, pain has been recently recognized by the CCHFA as a key component of its accreditation evaluation of hospitals and institutes, requiring stringent documentation of pain assessment and management including patient response to the treatment of pain (Canadian Pain Mechanisms, Diagnosis and Management Consortium, 2005) with the U.S. Joint Commission on Accreditation of Healthcare Organizations declaring pain to be the fifth vital sign in health care (JCAHO, 2000).

The expression of pain is influenced by numerous individual (ie.gender), experiential (i.e. past pain experiences), and situation (i.e. stage of disease) variables. “Pain cannot be measured directly, but can be assessed only indirectly by others’ evaluation of an individual’s report of pain or through manifested behaviours” (Puntillo

& Tesler, 1993, p. 303). Cancer-related pain is estimated to afflict 20-50% of patients at the time of diagnosis and can escalate to 55%-95% of patients in advanced or terminal stages depending on the kind of cancer; posing a serious emotional challenge for the patient going beyond the physical and medical problems it presents (Sela, Bruera, Conner-Spady, Cumming, & Walker, 2002). Pain is estimated to affect at least 40% of lung cancer patients (Tanaka et al., 2002a).

The association between cancer diagnosis and pain is so pronounced that the sense of dread experienced by most patients upon diagnosis is compounded by an anticipatory fear of pain and suffering. Lung cancer is one of the most common cancers to cause pain (Potter & Higginson, 2003). The etiology of pain in lung cancer can usually be attributed to (a) tumor location and nerve involvement for example: Pancoast tumor, chest wall invasion, pleural effusion or brachial plexus involvement (Houlihan et al., 2004; Potter & Higginson, 2003); (b) metastatic involvement which may include such things as back pain related to spinal cord compression, bone pain, or headache (Houlihan, et al., 2004; Potter & Higginson, 2003); or (c) the result of treatment or treatment related sequelae including incisional pain from surgery or chemotherapy related peripheral neuropathies (Houlihan, et al., 2004; Potter & Higginson, 2003).

Pain is generally classified as either nociceptive (which includes somatic and visceral) pain, or neuropathic pain (Librach & Squires, 2000). While not the focus of this study or this review, it is important to note that each type of pain can have many different causes and requires a tailored approach to treatment. Pain is a somatic expression that can be mediated by the patient's emotional status, personality, family, environment, past pain experiences and beliefs about the disease (Librach & Squires, 2000). It is estimated

that up to one-third of cancer patients experience four or more different types of pain (Librach & Squires, 2000). As such, regular and accurate pain assessments are paramount. If the patient is being cared for in the home, the informal caregiver must be highly in-tune with the patient and be able to accurately interpret their symptom expressions, underscoring the importance of the role of the caregiver and their help-intended behaviours.

It is important to accurately measure pain, fatigue, and dyspnea within the meaning context of experiencing symptoms. In the past, symptoms have often been considered in a one-dimensional fashion, usually considering symptom frequency or symptom intensity in isolation. However, Rhodes, Johnson, and McDaniel (1995) declared that accurate assessment and interpretation of symptoms require a concise and clear meaning of symptoms. Rhodes and Watson (1987) defined symptom as a subjective phenomenon perceived by individuals as a departure from normal function, sensation, or appearance or as perceived indicators of change in normal functioning. Lenz, Supple, Gift, Pugh, and Milligan (1995) developed the Theory of Unpleasant Symptoms which advanced symptom theory by conceptualizing each symptom to be a multidimensional experience that can be measured separately or in combination with other symptoms. According to Lobchuk (2001) “the multidimensionality of symptoms refers to a range of content including physiological, sensory, affective, cognitive, behavioural, and sociocultural factors” (p. 53).

In order to properly measure a symptom, each facet of the symptom must be considered which generally includes measuring symptom occurrence (or the individual’s perception frequency, severity, location, timing, quality, and duration) and symptom

distress or the affective dimension that relates to how the symptom makes the individual 'feel' versus how the symptom is experienced (Rhodes & Watson, 1987). Symptom distress refers to the distress evoked by a specific symptom and accompanying feelings (i.e. fear, anger, sorrow) (McClement, Woodgate, & Degner, 1997).

To recap, cancer is associated with a large number of unpleasant, debilitating symptoms. Symptom assessment and management are integral components of cancer treatment, especially in the home environment where increasingly more cancer patients are being treated. This is salient issue for those suffering from lung cancer, it has been cited as having the highest levels of symptom distress, greater than any other type of cancer. Ninety-six percent of patients have experienced at least one symptom at the time of diagnosis, for example dyspnea. Lung cancer patients are reported to experience multiple symptoms concurrently such as pain, fatigue, and dyspnea.

Overall, pain, fatigue, and dyspnea, chosen as the focus of this study, were found to be the most troublesome symptoms for lung cancer patients over the course of their illness. With pain assessment and management being highlighted by the CCHRA as an essential component of its revised accreditation evaluation for Canadian hospitals, it was chosen as one of the three symptoms comprising the symptom experience component of this study. Expert advice also highlighted the importance of examining fatigue and dyspnea as they are considered highly prevalent symptoms within this patient population. The multidimensionality of these symptoms, including their presence, frequency, severity and distress were measured to ensure the full impact and meaning of these symptoms was captured for this study.

Informal caregiver perceptions and Empathic processes

Clipp and George (2000) said that cancer is best understood as a journey, shared by the patient and those who love and care for them. The informal caregiver has historically provided love, support, nurturance, and comfort to the patient in his or her time of need. In recent times however, due to healthcare cost restraints and an aging patient population, the dynamic role of the caregiver has expanded. There has been a shift in caregiving responsibilities from medical personnel to spouses, family and friends. Family members are now being expected to assume responsibility for complex home health care during treatment and advanced stage of illness (Goldstein, et al., 2004; Lobchuk & Kristjanson, 1997; von Essen, 2004). Numerous studies have also found an increase in patient preference for out-of-hospital care, particularly in the terminal stage (Goldstein et al., 2004; Kinsella, et al., 2000). This type of care typically gives patients greater emotional and physical comfort, thereby enhancing quality of life (Kinsella et al., 2000).

The increase in the responsibility of caregivers to provide a more sophisticated level of care requires a high level of knowledge and caregiving skill in relation to symptom assessment and management (von Essen, 2004). Lobchuk and Kristjanson (1997) suggested that successful management of symptoms within the home required a certain level of motivation on the part of the family caregiver. This motivation is important, giving the caregiver the strength and perseverance needed to undertake empathic processes such as help-intended communication. Evidence to date suggests that the empathic perspective-taking process plays a key role in good communication,

perceptual accuracy and enhanced caregiver skill to meet the needs of patients (Lobchuk, 2006).

These are particularly salient issues within the lung cancer population. As previously discussed, this disease is associated with harsh and debilitating symptoms. Therefore, accurate assessment and prompt intervention in response to symptoms to enhance optimal quality of life is of the utmost importance (Lobchuk & Kristjanson, 1997). In addition, due to the often advanced stage of disease at diagnosis and rapid rate of decline, patients may, at times, be unable to communicate meaningfully in regard to their symptom experiences. In such situations, health care professionals must rely on the informal caregiver to provide an alternate or complementary report on the patient's symptom experiences (Lobchuk & Degner, 2002; Tang & McCorkle, 2002), making the family caregiver a key member of the treatment team. Previous research indicated that proxy judgments of patient symptom experiences and quality of life may have important implications for the type of care and treatment provided, and in evaluating the success of that care and treatment (Tang & McCorkle, 2002; von Essen, 2004).

The ability of an informal caregiver to accurately estimate a patient's symptom experiences requires employment of help-intended communication and behaviours (Lobchuk & Vorauer, 2003). Pistrang and Barker (1995) suggested that empathy and disclosure are two central components of informal help-intended behaviours. These researchers found that good communication with the cancer patient was characterized by high empathy toward and low withdrawal from the patient by the caregiver.

According to Long and Andrews (1990), empathy has both cognitive and affective dimensions. In relation to the work of Mehrabian and Epstein (1972), these

researchers found that the affective component of this concept usually involves taking on the feelings of another whereas the cognitive component involves “identifying and understanding another’s feelings and perspectives while maintaining an objective stance by deliberately distancing oneself from the vicarious emotions” (Lee, Flatley, Brennan, & Daly, 2001 p. 45) It is believed that when caregivers possess a balance between affective and cognitive empathy they are the most helpful in the caregiving situation (Lee et al., 2001). Long and Andrews (1990) defined cognitive empathy as “the accurate perception of others, and is often denoted by such terms as perspective-taking (p. 126). Perspective-taking is defined as “the imaginative tendency to put oneself in another person’s place” (Long & Andrews, 1990, p. 126).

Long and Andrews (1990) examined perspective-taking as a predictor of marital adjustment. They specifically looked at perspective-taking, dyadic perspective-taking, defined as “the use of perspective taking within the context of a specific relationship” (Long & Andrews, 1990, p. 127), and the perceptions of the partner’s dyadic perspective taking (known as other dyadic perspective-taking) in predicting marital adjustment in 159 dyads. Results indicated that both the husbands’ and wives’ own perspective was significantly predictive of their spouse’s marital adjustment (Long & Andrews, 1990). With respect to dyadic perspective taking, or “the degree to which individuals reportedly took the perspective of their spouse” (Long & Andrews, 1990, p. 128) and other dyadic perspective-taking, the study found they were both predictive of marital adjustment. Long and Andrews (1990) concluded that understanding a spouse’s point-of-view was important in marital adjustment, stating that perspective-taking evidenced a spouse’s understanding and sensitivity toward their partner

Empathy, through research on the impact of perspective-taking on informal caregivers, has been brought into the area of psychosocial oncology through research on its impact on informal caregiver estimation of patient symptom experiences. Recent reviews have described that informal caregivers provide reasonable estimates of patients' symptoms, with only a slight tendency to overestimate (Lobchuk & Degner, 2002b; McPherson & Addington-Hall, 2003). Lobchuk (2001) compared family caregivers' and advanced-stage cancer patients' perceptions of patients' multidimensional symptom experiences on presence, frequency, severity and distress. Responses from 98 patient and caregiver dyads that completed the Memorial Symptom Assessment Scale (MSAS) revealed that caregivers tended to overreport on symptom experiences, although only to a small degree (1 unit on a theoretical range of 0 to 4 units) (Lobchuk & Degner, 2002b). Lobchuk (2001) also found that levels of patient and caregiver agreement were better on specific questions about symptom frequency, severity and distress rather than global questions about the presence of symptoms. Better levels of agreement were also achieved between patients and informal caregivers on physical versus psychological symptoms. Lobchuk (2001) concluded that family caregivers can provide reasonable proxy or complementary reports on patient symptom experiences especially related to frequency, severity, and distress.

To further the knowledge base on caregiver assessment skills and to ascertain the extent to which caregivers use perspective-taking to arrive at their estimations, Lobchuk (2001) administered to caregiver participants an abbreviated version of the Memorial Symptom Assessment Scale (MSAS) specifically targeting lack of energy and worrying in four instructional set conditions which included: (a) a neutral instructional set where

caregivers were neither encouraged nor discouraged to engage in perspective-taking; (b) self-report condition where caregivers reported on how they themselves think and feel; (c) imagine-self perspective-taking condition where caregivers identified their own thoughts and feelings as they imagined themselves with the patient's diagnosis and responded as if the symptom events were happening to them; and (d) an imagine-patient perspective-taking condition, where caregivers are encouraged to take the patient's perspective and to imagine how the patient feels and thinks in relation to the symptoms experienced (Lobchuk, 2001). The caregivers' reports in these instructional set conditions were compared with reports provided by the patients who completed the MSAS based on their own symptom experiences.

The results indicated that the imagine-patient instructions appeared to be the most effective in assisting caregivers to achieve enhanced alignment with patient self-reports on patient symptom experiences, with the imagine-self instructions producing responses that were the most discrepant from the patient's self-reports related to lack of energy and worrying (Lobchuk, 2001). Lobchuk's (2001) dissertation results highlighted the integral role that perspective-taking plays in caregiver estimations of patient symptom experiences. However, a major limitation of this study was that it was comprised of a convenience sample of caregivers who appeared to already engage in help-intended communication. As such, researchers now need to target situations where it is believed help-intended communication may be compromised or absent, such as may be the case with lung cancer patients and their caregivers who are impacted by the stigma related to tobacco usage.

Being able to achieve reasonable perceptual agreement with the patient on patient symptom experiences is a personal and complex undertaking on the part of the informal caregiver. Research has found that perspective-taking is not a skill possessed equally by all, and there are various degrees in which caregivers engage in perspective-taking (Hogan, 1969; Kasch & Dine, 1988; Lobchuk, 2006). A number of variables were cited in the literature as having the potential to influence patient and caregiver agreement levels on patient symptom distress. They included such things as the age of the patient, gender of the patient, patient's marital status, ethnicity, occupation of caregiver, cancer treatment received, and socioeconomic background (Kristjanson, Nikoletti, Porock, Smith, Lobchuk, & Pedler, 1998). However, Kristjanson and colleagues' (1998) findings were largely inconsistent depending on the type of symptom being assessed as well as the symptom dimension targeted. To date, there has been little exploration of interpersonal dynamics as factors that impact caregiver perception, necessitating further investigation in this area.

Of particular relevance to this study with lung cancer patients and their informal caregivers, Weiner (1995) suggested that illness attributions of responsibility for disease and the accompanying feelings of guilt or anger may moderate help-intended communication involving empathic processes, like perspective-taking. In turn, these factors may impact the ultimate outcome of congruent perceptions between patients and informal caregivers on patient symptom experiences. A search of the literature revealed that there have been no studies done to date examining the relationship among illness attributions and informal caregiver perspective-taking, highlighting the importance of research in this area.

In summary, the traditional role of the informal caregiver was to provide love, support, nurturance, and comfort to the patient. In current times, the informal caregiver is now assuming a key front-line role in the provision of complex home health care during treatment and in advanced stages of illness as more lung cancer patients are being cared for in the home setting. This is due in part to healthcare cost restraint and patient wishes for care in the home setting. This increased responsibility on the caregiver requires a high level of knowledge and motivation on the part of the caregiver to undertake empathic processes such as perspective-taking, reflective communication, and help-intended behaviours necessary for congruent perceptions on patient symptom experiences by patients and informal caregivers.

Research to date indicates that caregivers serve as reasonable proxies for patient symptom experiences, with only a slight tendency for over-estimation. It must be recognized however, that a major limitation of the work in this area to date is the self-selecting samples of caregivers who appeared to be already engaging in help-intended communication. It is imperative that researchers target situations where it is believed help-intended communication may be compromised or absent, such as may be the case with lung cancer patients and their caregivers who are impacted by the stigma related to lung cancer and tobacco.

Perspective-taking on the part of the caregiver has shown to increase patient and caregiver perceptual agreement on patient symptom experiences in comparison to other techniques such as projection (forcing ones own thoughts or beliefs) or imaging oneself in the same situation. To date, little exploration has been done to examine caregiver perspective-taking ability within the context of lung cancer, lung cancer stigma, and

subsequent illness attributions held by both the patient and caregiver. Weiner (1995) suggested that the emotions triggered by the patient's and the caregiver's beliefs about the causal factors of lung cancer may jeopardize or inhibit the caregiver's ability to perspective-taking, and threaten patient symptom management. Further research is needed to gain a more complete understanding of the relationships among these variables.

Stigma and Illness Attribution

Stigma is a complex phenomenon that originated with The Greeks, who used the term to refer to bodily signs that were cut or burnt into the body to expose something unusual or bad about the moral status of the signifier (Goffman, 1963). These signs advertised that the bearer was a "slave, a criminal, or a traitor – a blemished person ritually polluted, to be avoided, especially in public places" (Goffman, 1963, p. 1).

In modern times, stigma has been applied to a multitude of circumstances. There is a great deal of research on this concept, most of which was inspired by the work of Erving Goffman in 1963. Goffman felt that in modern society, stigma was widely used in a similar manner to the original literal sense, however, now stigma applies more to the disgrace itself than the bodily evidence of it. He defined stigma as "an attribute that is deeply discrediting" and reduces the bearer "from a whole and usual person to a tainted, discounted one" rendering them "not quite human" (1963, p. 3). He further went on to divide stigma into three distinct types: abominations of the body such as physical deformities, blemishes of character such as addiction (cigarette smoking), and tribal stigma of race, nation and religion (Goffman, 1963).

Goffman's now classic work was the catalyst for elaborations, refinements, and demonstrations of the negative impact that stigma has on the lives of the stigmatized

(Link & Phelan, 2001). Professionals from a wide range of disciplines have examined the concept of stigma in many different contexts ranging from medical situations including human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) (Fife & Wright, 2000), mental illness (Corrigan, Watson, Warpinski, & Gracia, 2004), and cancer (Chapple, Ziebland, & McPherson, 2004; Fife & Wright, 2000), to studies of stigma in the workplace (Gilbert, et al., 1998) and concerning the unemployed (Prince & Prince, 2002).

A common thread found in many of the review articles was criticism in relation to the variability that exists in the definition of this concept (Fife & Wright, 2000; Link & Phelan, 2001). For example, variations on Goffman's 1963 definition included membership in a social category that results in a spoiled identity setting the individual apart from others (Fife & Wright, 2000), as well as dictionary-type definitions such as a mark of disgrace (Link & Phelan, 2001). Crocker stated that "a person who is stigmatized is a person whose social identity . . . calls into question his or her full humanity – the person is devalued, spoiled or flawed in the eyes of others" (1999, p. 89). Link and Phelan (2001) speculated that the reason for this variability is that stigma has been applied to an enormous array of situations. Each context is unique, and as such, leads each investigator to conceptualize stigma from a slightly different angle. For the purposes of this study, stigma will be defined as an attribute or undesirable behaviour that results in an individual being disgraced or deeply discredited (Goffman, 1963).

Upon deeper examination of this concept, stigma is found to be a constantly changing social process, conceptualized by society on the basis of what it considers "different or "deviant" (Parker & Aggleton, 2003). It is then applied by society both

subtly and overtly through the use of rules or sanctions (Fife & Wright, 2000; Parker & Aggleton, 2003). Through their work on HIV/AIDS related stigma, Parker and Aggleton (2001) declared that stigma is closely linked to the workings of social inequality. In their view, stigma plays a large role in “producing” and “reproducing” relations of power and control, causing some groups to be devalued while other groups feel superior in some way. As a result, in their opinion, stigma is not an isolated phenomenon, or an expression of individual attitudes or of cultural values, but rather is central to the “constitution of social order” (Parker & Aggleton, 2003, p. 17). Link and Phelan (2001) also stated that stigma is completely dependent on social, economic and political power. These authors stated that a stigma will exist when labelling, stereotyping, separation, status loss and discrimination culminate in a power situation.

It is important to consider how stigma held or perpetuated by the macro environment impacts on the group or individual being stigmatized. Due to the negative affective responses from others, the stigmatized individual internalizes their label as an “outsider” or “deviant”. The individual subsequently constructs a negative self-concept where his or her new “title” becomes a part of their identity and a part of the self that generates behaviour (Fife & Wright, 2000; Parker & Aggleton, 2003). Their acceptance of this negative designation within society often results in self-depreciation and shame, jeopardizing their emotional wellbeing (Fife & Wright, 2000). These individuals often withdraw from social interaction lessening their life chances and opportunities (Fife & Wright, 2000).

Stigma is a highly salient issue in the healthcare arena. The affliction of an illness that is stigmatized, such as cancer, increases the stress accompanying the illness. It can

contribute to secondary psychological and social morbidity consequently affecting quality of life and physical wellbeing. In addition, stigma can have a profound impact on the family of the ailing individual, further compounding the psychological burden. (Fife & Wright, 2000).

Cancer has been cited as the most feared of all illnesses, and has long been stigmatized (Fife & Wright, 2000). Cooper (1984) stated “cancer in the 20th century joins the ranks of such diseases as leprosy and tuberculosis in its tendency not only to strike terror in its victims but also to stigmatize them” (p. 301). Stigmatization likely occurs when individuals, who interact with cancer patients, are reminded of their own vulnerability and mortality, or when the cause of the disease is not always understood, or because it is seen as a “death sentence” (Chapple et al., 2004). Perhaps the most stigmatized of all cancers is lung cancer.

Since the 1960s when the etiology of lung cancer was empirically linked to tobacco use, even non-smoking lung cancer patients have felt the effects of being stigmatized by family, friends, and health care professionals (Kim & Shanahan, 2003). Smoking is now considered a deviant behaviour with smokers being socially isolated and embarrassed in an unfavourable smoking climate (Kim & Shanahan, 2003). In addition, the passing of non-smoking laws by various levels of government and mass media campaigns against smoking highlighting its deleterious effects further fuels the unfavourable public sentiment and reinforces the stigma associated with lung cancer.

To date, the effects of stigma on lung cancer patients and their families have been largely unexplored. Recent qualitative work by Chapple and colleagues (2004) reported that many lung cancer patients have experienced negative reactions, including blame for

the occurrence of the disease, by family, friends, and health care professionals. Lung cancer patients also reported feelings of social isolation. In addition, Chapple and colleagues (2004) found that upon diagnosis, patients themselves often felt the disease occurrence was self-inflicted as a result of their smoking history and as such they “deserved it”, subsequently withdrawing from society. Patients reported experiencing feelings of shame and self-blame, and were less likely to seek support (Chapple et al., 2004). These feelings of self-depreciation might deter the patient from expressing his or her emotions and symptom experiences to their caregiver, straining communication lines, and distancing the relationship. This distance between the patient and informal caregiver may negatively impact the caregiver’s ability to estimate the patient’s symptom experiences, and lead to inadequate symptom management.

Zhang and Siminoff (2003a) found, in their study on the role of family in treatment decision making of lung cancer patients, that smoking was a very “contentious issue”. Families reported feelings of frustration, anger, and hurt regarding the patients’ smoking habits. In another of their studies on communication among Stage III and IV lung cancer patients and their family members, Zhang and Siminoff (2003b) found that 65% of families experienced difficulties in communication, with avoidance of family communication being a common theme in the data. Some of the patients reported feeling stigmatized due to their feelings of guilt about long-term smoking. These patients reportedly did not want to talk about cancer because they did not want others to “feel sorry” for them or “look down” on them (Zhang & Siminoff, 2003b). Other patients “retreated into a state of denial and shut down their thoughts and associated feelings about cancer to prevent emotional upset” (Zhang & Siminoff, 2003b, p. 422).

These intense emotions may make it very difficult for the caregiver to engage in reflective communication and empathic processes such as perspective-taking with the patient, which can potentially cause inadequate symptom assessment and management. Zhang and Siminoff (2003b) stated that “silence prevents family members from accurately assessing patients’ needs and physical conditions, resulting in a lack of appropriate care for patients” (p. 427). The emotions and reactions of both the patient and the caregiver are perhaps more clearly understood within the context of an attributional framework.

Illness attribution or causal attribution is defined as an individual’s perception, inference of cause, or common-sense reason for the occurrence of an event based on a cause-effect analysis (Berckman & Austin, 1993; Faller, Schilling, & Lang, 1995). One of the most popular and widely utilized attribution theories is the Theory of Social Conduct developed by Bernard Weiner (1995).

According to Weiner (1995), people who are stricken by a negative event, such as the diagnosis of a serious illness, generally make an effort to find the causal explanation for its origin. The process of attributing an event to a specific cause(s) allows that person to make sense of what has happened, gain some control over their environment, and to predict and influence future events (Berckman & Austin, 1995; Faller et al., 1995). When the illness is linked to a stigma however, often the stigma itself implies a cause, thus negating the need for further information or introspection (Weiner, 1995). Attributions are not reserved for only those afflicted with the illness but are also ascribed by family, friends, and society in general.

In accordance with Weiner's attributional framework, causal beliefs give rise to inferences of personal responsibility. If the cause of an illness is believed to be due to the individual's own free will (controllable), for example, the individual with lung cancer was a smoker, then that person may be deemed personally responsible for their plight. When a person is judged responsible for the stigma, there are not only affective reactions towards the stigmatized person such as anger and hostility, but also behavioural responses such isolation, withdrawal and an unwillingness to take part in help-intended actions. This framework is applicable to both the perception of others and self-perception, which is appropriate in the context of studying the occurrence of stigma within the lung cancer patient and informal caregiver relationship (Weiner, 1995).

Numerous studies corroborate Weiner's theory where results have shown that the degree of stigmatization of a disease often depends on whether the individual is blamed or held responsible for the occurrence of the disease (Chapple et al., 2004; Fife & Wright, 2000). Research has demonstrated that stigma attributed to controllable factors (i.e. factors under the control of the individual such as tobacco usage) evoke a stronger negative reaction than stigma attributed to uncontrollable factors (factors out of the control of the individual such as exposure to environment toxins) (Chapple et al., 2004; Menec & Perry, 1995; Weiner, 1995).

The concept of illness attribution has generated a wealth of research in the area of health care. A review of the literature found a host of studies examining illness attribution in relation to mental illness (Licht & Hooley, 2004), myocardial infarction (Arefjord et al., 2002), AIDS (Peters et al., 1994), and falls in the elderly (Hinman, 1998). Numerous studies specifically examined causal attributions in relation to cancer

diagnosis and adjustment (Berckman & Austin, 1995; Dirksen, 1995; Faller et al., 1995; Lavery & Clarke, 1996; Linn, Linn, & Stein, 1982; Taylor, Lictman, & Wood, 1984). Most of these studies were conducted over ten years ago and none of them examined the attributions of caregivers. A review of these studies highlighted a number of inconsistencies.

There is some debate concerning how many people actually make causal attributions, with percentages ranging from 70%, 95%, to 100%, with some question as to whether patients and family members make attributions to the same degree (Lavery & Clarke, 1996; Linn et al., 1982; Taylor et al., 1984). All studies reviewed cited self-blame as one of the most common illness attributions made by cancer patients, however, there is great debate over the importance of such an ascription. Some believe that self-blame is adaptive as it re-establishes the patients' belief in a controllable environment thereby enhancing their ability to cope (Faller et al., 1995). Others however, found that those who made an uncontrollable attribution were more likely to use information-seeking behaviour, and become more actively involved in their efforts to battle the disease, than those who made a controllable attribution (Lavery & Clarke, 1996). Berkman and Austin (1993) questioned whether causal attributions had any real bearing on adjustment, suggesting that perhaps not making any attribution is an adaptive process itself.

With respect to lung cancer, a notable gap in attributional research was found in the literature. While some research mentioned lung cancer in passing (Lin et al., 1982; Menec & Perry, 1995; Weiner, 1995), only three studies were found that specifically examined casual attribution and lung cancer (Berckman & Austin, 1993; Chapple et al.,

2004; Faller et al., 1995). While all studies reported smoking as the most frequently mentioned attribution when asked the cause of the cancer, smoking was attributed less often to their disease by patients who had lung cancer than those without lung cancer (Fuller et al., 1995). This led to an interesting discovery that while lung cancer patients would mention smoking as a cause, they would often give a qualifying statement with it. Eighty-one percent of patients gave at least one argument which served to qualify the relevance of smoking. For example, some patients pointed out that non-smokers developed lung cancer or that they had quit smoking and therefore it could not be the cause of their disease (Fuller et al., 1995).

Fuller and colleagues (1995) suggested that self-blame causal attributions trigger some confusion within the individual, leading to an attempt to reduce the confusion by qualifying the significance of smoking as a causative factor. Berckman and Austin (1995) speculated that this may be part of a denial system, shielding the patient from their own anxiety and guilt concerning their lack of health-promoting behaviour. This may also be an attempt to avoid or distance oneself from the stigma associated with their disease.

Perspective-taking requires help-intended, reflective communication within an open relationship. This may be a difficult undertaking when the patient has created a denial system as previously discussed, in addition to the internalized feelings of anger and frustration on the part of the caregiver in relation to the patient's smoking behaviours. Such intense and negative emotions may result in a strain on communication patterns within the patient-caregiver relationship, making empathic processes difficult, subsequently jeopardizing symptom perception, estimation and management. It is

important to note that none of these studies looked at the interplay of attributions in relation to the patient and family caregiver, and the potential impact this has on specific help-intended behaviours, highlighting the need for further, more detailed research in this area.

To review, stigma is a concept that has been in existence since ancient times, however, still lacks a concise, standard definition. Stigma can be perpetuated by social, economic, and political power, which promotes labelling, stereotyping, separation, status loss and discrimination. Stigma is particularly salient within the healthcare arena, especially in relation to lung cancer. Lung cancer is a highly stigmatized disease due to the smoking-lung cancer linkage empirically proven in the 1960s and highly publicized by mass media today.

To date, the effects of stigma on lung cancer patients and their caregivers have been largely unexplored. Scant research reveals that lung cancer patients experience negative reactions such as blame and anger from family, friends, and healthcare professionals. Family members of lung cancer patients have reported feelings of frustration, anger, and hurt toward the patient for their past or present smoking behaviours. In addition, caregivers may also experience feelings of self-blame or guilt in light of their own tobacco consumption and exposing the patient to second hand smoke or perhaps enabling the patient's own smoking habit because they both smoke. Patients have reported feelings of guilt and self-blame believing they "caused" the disease due to their smoking history. Other patients appeared to create a denial system, essentially shutting down from society. The negative emotions from lung cancer patients and their informal caregivers may result in a strain in communication and openness within the

relationship, potentially challenging empathic processes such as perspective-taking, thereby possibly leading to inadequate symptom management. These variables are better understood within an attributional framework, such as Weiner's (1995) Theory of Social Conduct.

A notable gap in the literature exists, with no published studies found examining the relationships among smoking, stigma, illness attribution, caregiver perspective-taking, and levels of agreement between patient and caregiver regarding patient symptom experiences. Due to the staggering number of individuals currently afflicted with this disease, the prediction of an explosion in the number of individuals diagnosed with lung cancer in the coming years, and the high level of symptom distress within this patient population, further knowledge in this area is not a luxury but a necessity in order to improve patient care.

Conceptual Framework

Overall, this study is guided by the concepts of stigma, illness attribution, informal caregiving, informal caregiver perspective-taking and symptom experience within the context of lung cancer. Currently there is no known empirical work that has systematically examined the relationships among patient and informal caregiver perceptions of illness attributions, affective states, caregiver perspective-taking, and perceptual agreement of the informal caregiver on lung cancer patient symptom experiences. However, Weiner's attribution theory provides reasonable grounds to support the belief that a relationship does exist among these concepts and as such Weiner's (1995) Theory of Social Conduct provides the foundation for conceptualization of this study.

Weiner's theory was originally developed in relation to motivation and achievement. However, he has subsequently modified the theory to address the issue of stigmatization which has been tested by him and other researchers in social psychology (Menec & Perry, 1995; Weiner, 1995). As previously discussed, Weiner (1995) theorized that when a negative event or outcome occurs, such as being diagnosed with lung cancer, both the patient and the caregiver search for a causal explanation or a determination of onset responsibility. Onset responsibility refers to whom or what is responsible for the disease occurrence. Weiner classified this as the locus of causality. With respect to stigmatization, however, often the stigma itself and the heavily publicised smoking-lung cancer linkage imply the cause, greatly influencing the patient's feelings upon introspection.

If the patient is deemed to have caused the disease or the caregiver lays self-blame due to smoking behaviours, Weiner stated that this leads to inferences of personal responsibility or controllability, a key dimension in this theory. Weiner (1995) has declared responsibility to be a "linchpin concept, linking antecedent beliefs about causes with consequent affective and behavioural reactions" (p. 83). Being held personally responsible for one's current predicament directly impacts the subsequent helping behaviour of others (which may include caregiver empathy and perspective-taking), with emotions serving as the intervening variables (Weiner, 1995).

Within the context of lung cancer, when an individual is diagnosed with the disease, it is believed both the patient and their caregiver begin an inner-search to determine their beliefs regarding the cause of the disease. If the patient has a history of smoking, Weiner postulated, that the patient and their caregiver will often hold him or her

personally responsible for causing the disease due to the smoking-lung cancer linkage. A determination of personal responsibility for the onset of the disease results in subsequent affective and behavioural responses on the part of both the patient and their caregiver.

Weiner (1995) stated that being responsible for a negative situation results in feelings of anger and blame in others, and guilt and self-reproach within the patient. On the other hand if the patient or the caregiver is not held responsible, then this may elicit feelings of sympathy and pity on the part of others. These positive or negative feelings may then have a direct impact on social behaviours, with anger resulting in others being more likely to withdraw help than give help to the patient. Conversely, if the caregiver feels responsible because of a smoking habit, then he or she may feel pity and as a result feel an increased need to offer help-intended behaviours such as perspective-taking.

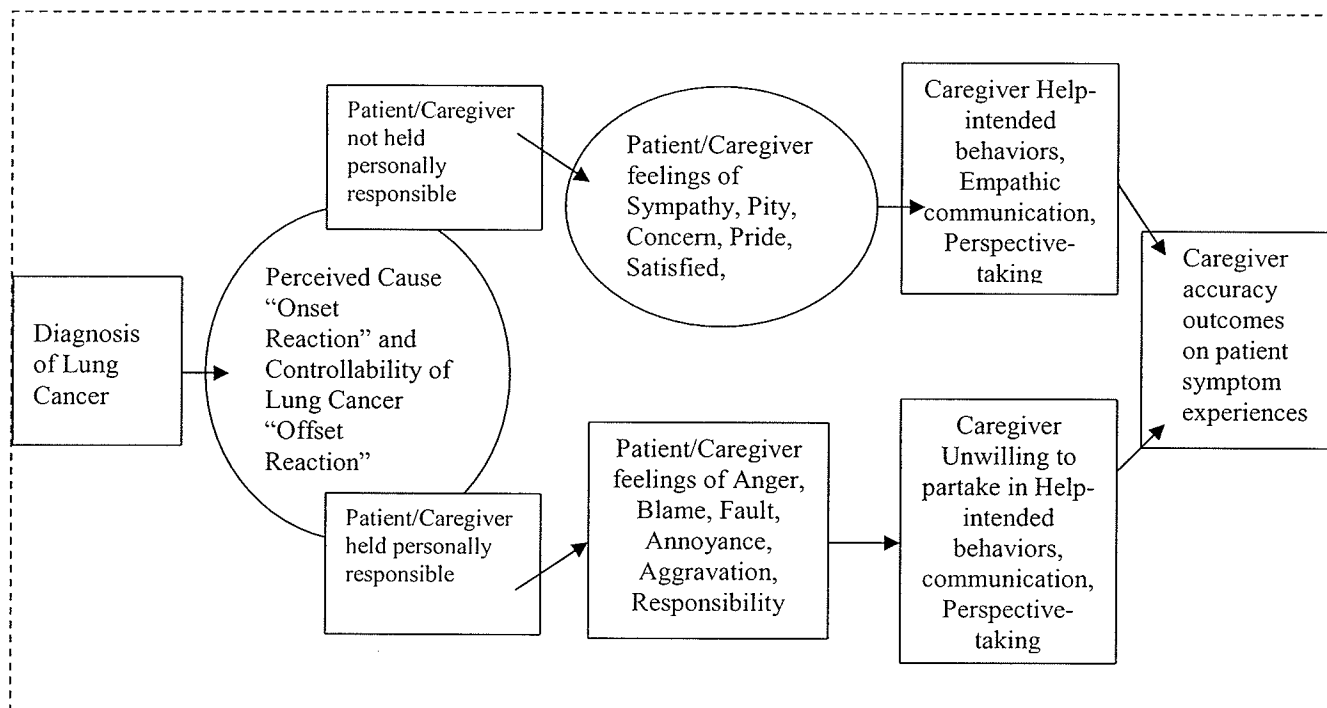
“Reactions to the stigmatized are, in part, based on moral evaluations. Stigmatized persons considered responsible for their marks are construed as moral failures, which generates morality-related negative affects and, in turn, uncooperative behaviours” (Weiner, 1995, p. 65). Also, if the caregiver feels to blame or if the patient blames the caregiver, then the caregiver may be viewed as a moral failure, which can generate more compensatory behaviours on the part of the caregiver to mitigate one’s self-imposed guilt or the patient’s imposition of caregiver guilt.

Within the context of lung cancer, when the patient is deemed by him or herself and possibly their caregiver as being personally responsible for the onset of the disease due to their smoking history, feelings of guilt and self-reproach for this negative life experience may emerge within the patient. In addition, Weiner (1995) postulated that the caregiver can also be plagued with feelings of anger and frustration toward the patient

because of his or her smoking history. According to Weiner (1995) these affective responses have a significant impact on behavioural outcomes. For example, if the patient is held responsible and feelings of anger and blame ensue on the part of the caregiver, they are less likely to behave in a caring, empathetic manner. In turn, reflective communication, help-intended behaviours and empathic processes may be severely limited or absent, making symptom perception, estimation and management much more difficult for the caregiver. In addition, if feelings of guilt and self-reproach plague the patient, it is postulated that they may be less likely to openly communicate and express their feelings to their caregiver. This, in turn, may place undue strain on the communication patterns and openness of the relationship thereby challenging the caregiver's ability to perspective-take on the patient's viewpoint of his or her symptom experiences.

Another possible situation is that if the caregiver has had a history of smoking, they may experience feelings of guilt and shame for potentially causing the lung cancer in their loved-one due to the second-hand smoke-lung cancer linkage. This may also place strain on the communication patterns within the relationship as the caregiver may withdraw or distance themselves from the patient, further challenging empathic processes and help-intended behaviours. However, if the caregiver has self-imposed feelings of guilt, they may try harder by working on their perspective-taking behaviours in an attempt to mitigate their guilty feelings.

Figure 1 represents an adaptation of the theory provided by Weiner (1995).



In order to test the relationships between controllability and responsibility in relation to specific affects and behaviours, Weiner (1995) conducted an investigation where the cause of various stigmas were manipulated to be controllable or uncontrollable through the use of vignettes. Cancer, chosen as one of the stigmas to be examined in this study, was characterized as being caused by smoking (controllable) or by unknowingly living in a toxic area (uncontrollable). The results confirmed Weiner's theorization, those stigmas deemed uncontrollable increased pity and decreased anger whereas controllability increased anger and decreased pity (Weiner, 1995).

Another facet of Weiner's theory that was utilized this study is offset responsibility. "Offset responsibility" is the degree of "perceived control" the patient is deemed to have in relation to disease progression (Weiner, 1995). Taylor and colleagues (1984) postulated that cancer patients and their informal caregivers develop theories

about not only the cause of the cancer (onset responsibility), but also whether or not the patient can control its progression (offset responsibility). Taylor and colleagues (1984) speculated that offset responsibility has more impact on adjustment and coping than perceptions of onset responsibility by the patient and family.

Researchers in related areas have documented the considerable impact family environment can play on offset responsibility over the course of chronic illnesses such as schizophrenia (Harrison, Dadds, & Smith, 1998; Yang, Phillips, Licht, & Hooley, 2004), depression (Hooley & Licht, 1997), and Alzheimer's disease (Tarrier, Barrowclough, Ward, Donaldson, Burns, & Gregg, 2002). Hooley and Licht (1997) revealed that under circumstances where patients were thought to be responsible for their predicament by virtue of their behaviour (and unwillingness to change), for instance when a lung cancer patient continues to smoke after diagnosis, families were found to be highly critical and hostile toward the patient. This behaviour is known as expressed emotion.

Expressed emotion (EE) is defined as "a construct encompassing several key aspects of close interpersonal relationships. It reflects critical, hostile, or emotionally overinvolved attitudes on the part of a family member toward a relative with a disorder or impairment" (Barrowclough & Hooley, 2002, p. 850), and has been the focus of much research in the field of psychology. Researchers have found high levels of EE in families are linked with poorer outcomes, such as relapse. For example, individuals with schizophrenia who lived in a high EE environment were twice as likely to relapse as those living in a low EE environment (Hooley & Licht, 1997). Within the context of lung cancer, patients living in a high EE environment may be more likely to continue using tobacco or begin to smoke again to cope with this additional stressor. Research has

demonstrated that continued smoking after the diagnosis of lung cancer has been linked with numerous risks, including increased risk of recurrence or secondary primary cancer, increased weight loss, increased risk for postoperative surgical morbidity, and increased risk of infection (Sarna, 1995).

Researchers have indicated that the perception of control of disease progression or offset responsibility is significant to both the patient and caregiver. Cooper (1984) and Zhang and Siminoff (2003a) found that when informal caregivers disagreed with how lung cancer patients dealt with their disease, such as by continuing to smoke, there was potential for anger, blame, frustration, and criticism toward the patient. Hooley and Licht (1997) revealed that spouses who were highly critical made more negative attributions than low critical spouses about behaviours which they considered to be more controllable by the patient, such as smoking. Consistent with previous theory and research on the relationship between caregivers' beliefs about illness behaviours and their subsequent EE responses, caregivers may voice criticism and annoyance toward lung cancer patients' continued smoking behaviour that they perceive to be controllable by the patient (Lobchuk, 2005).

Weiner's theory has provided the conceptual framework for a number of studies within the healthcare arena (Berckman & Austin, 1993; Chapple et al., 2004; Fopma-Loy & Kessner Austin, 1997; Hinman, 1998). In one such study, Menec and Perry (1995) examined reactions to stigmas within the context of ageism using very similar methods to Weiner (1995). They constructed vignettes that manipulated the controllability or uncontrollability of ten stigmas (including lung cancer) that were subsequently administered to 249 Canadian university students. The results supported Weiner's theory

in that the controllability of stigmas influenced both anger and pity. Stigmas ascribed to uncontrollable factors evoked less anger but more pity than when the stigma was ascribed to controllable causes (Menec & Perry, 1995). Results also indicated that, in general, uncontrollable stigmas evoked more willingness to help than controllable stigmas (Menec & Perry, 1995). The other studies reviewed (Berckman & Austin, 1993; Chapple et al., 2004; Fopma-Loy & Kessner Austin, 1997; Hinman, 1998) drew conclusions similar to that of Menec and Perry (1995).

To review, Weiner's (1995) Theory of Social Conduct provides the theoretical framework for this study. Within the context of lung cancer, Weiner postulated that when an individual is diagnosed with lung cancer, both the patient and their caregiver perform an inner-search to determine their beliefs regarding the cause of the disease and the degree of controllability over disease progression. If the patient has a smoking history (past, present, or both), often the patient will hold him or herself personally responsible as well as being held responsible by the caregiver for cause of the disease.

Personal responsibility results in feelings of anger and blame on the part of the caregiver toward the patient, and feelings of shame and guilt on the part of the patient. These affective reactions can lead to unwillingness on the part of the caregiver to undertake help-intended behaviours such as open communication and perspective-taking. The patient may also be less willing to openly communicate and express his or her emotions and symptom experiences with the caregiver. Conversely, if the patient is deemed not to be personally responsible for the disease onset, feelings of empathy are evoked on the part of the caregiver, and Weiner theorized they will then be more willing to perform help-intended behaviours, communication and perspective-taking.

This framework has guided numerous studies within the healthcare field with great success. However, to date, no study exploring relationships between smoking histories, onset and offset reactions, caregiver perspective-taking and perceptual congruence between lung cancer patient and informal caregiver on patient symptom experiences exists, underscoring the importance of this work.

Summary

Lung cancer is a devastating disease with many distressing symptoms such as pain, fatigue, and dyspnea. The diagnosis not only impacts on the patient, but the family as well. The caregiver is now assuming a larger role with respect to caring for the patient within the home setting. In order to manage symptoms effectively, the informal caregiver must be able to provide reasonable patient-oriented estimates on patient symptom experiences, requiring a good line of communication between the patient and caregiver, and a motivation on the part of the caregiver to partake in help-intended communication and behaviour. There is speculation however, that these interpersonal dynamics or motivation to provide help-intended communication and behaviour may be jeopardized in relation to the stigma attached to lung cancer and the subsequent illness attributions and emotions of both the patient and the caregiver.

Weiner's Theory of Social Conduct (1995) provides a relevant and well supported theoretical framework that guided the investigator's identification of key interpersonal factors within the caregiving context involving lung cancer patients, such as patient and caregiver thoughts and feelings about the cause and control of the disease, as well as caregiver help-intended or empathic behaviours such as perspective-taking, and patient-caregiver perceptual agreement on patient symptoms. This project tackles a new area of

research in exploring and describing perceptual agreement on attributional variables between lung cancer patients and informal caregivers in accordance with Weiner's theory. The analysis plan of this project is to explore whether perceptual disagreement occurs between patient and caregiver on the attributional factors that might impact on perceptual agreement on patient symptom experiences. The results arising from the larger ongoing study by Dr. Lobchuk, Dr. McClement, and Dr. McPherson will be examined with a view to exploring relationships between these variables in accordance with Weiner's theory.

To date, no known empirical evidence exists that explores and describes perceptual agreement on attributional variables between lung cancer patients and informal caregivers. Such knowledge is needed in order to lay a foundation for further work that can lead to the recognition of patient-caregiver dyads at risk for faulty symptom assessments to target for intervention.

CHAPTER III

Methodology

Given the paucity of research investigating lung cancer patient- and caregiver-held illness attributions and caregiver perspective-taking, and the potential impact they have on perceptual agreement between lung cancer patients and informal caregivers on patient symptom experiences, a descriptive comparative study was judged to be the most appropriate level of investigation to pursue. The main purpose of this study was to explore the relationships and differences between lung cancer patient and caregiver respective responses on their smoking histories, 'onset' and 'offset' reactions, caregiver perspective-taking, and perceptions on patient symptom experiences. The second aim was to test the effect of any existing perceptual discrepancies for onset and offset reactions, and caregiver perspective-taking on patient-caregiver levels of agreement on patient symptom experiences. This analysis was conditional to the occurrence of perceptual discrepancies between the patient and informal caregiver on onset and offset reactions, and caregiver perspective-taking.

A descriptive-comparative design allowed the researcher to explore the relationships and differences among variables. In this study, the dependent variables were: (a) caregiver perspective-taking activities as reported by the patient and caregiver and (b) caregiver discrepancy scores on patient pain, fatigue, and dyspnea including total symptom scores and separate scores for symptom frequency, severity, and distress. The independent variables were patient- and caregiver-held illness attribution responses as represented by the 'onset' (perceived cause of the disease) and 'offset' (perceived controllability over disease progression) reactions.

Population and Sample

The population under scrutiny consisted of lung cancer patients and their primary informal caregivers. A convenience sample of 40 patient-caregiver dyads was determined to be sufficient for analysis of pilot data collected within the larger study. A power analysis was not done as this was a preliminary study, however, one was conducted for the larger, ongoing study by Dr. Lobchuk, Dr. McPherson, and Dr. McClement.

The initial inclusion criteria for patients to be eligible to participate in the study included patients who were (a) medically diagnosed with advanced stage (Stage III and IV non-small cell lung cancer, and limited and extensive stage small cell lung cancer) adult lung cancer patients; (b) receiving active treatment (i.e. chemotherapy or radiotherapy) at the thoracic clinic site at CancerCare Manitoba; (c) experiencing unrelieved pain, fatigue, and shortness of breath experiences, rated as three or greater on the Edmonton Symptom Assessment Survey (ESAS) completed as part of the clinic routine with every patient visit to the cancer agency. Pain has been highlighted as a major symptom implicated in symptom complexes such as dyspnea and fatigue (Miaskowski & Lee, 1999; Wickman, 2002). Pain requires attention with every clinic visit as recommended by the CCHFA as a key component of its revised accreditation evaluation of hospitals and institutes (Canadian Pain Mechanisms, Diagnosis and Management Consortium, 2005); (d) 18 years of age or older (e) able to speak, read, and write the English language; and (f) well enough to participate and gave no evidence of mental confusion by scoring higher than or equal to 24 out of 30 on the Folstein's Mini-Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975).

However, five months of active recruitment produced only eight participant-dyads, a number far from the seven participants per month required to meet the projected sample size of 40 participant dyads for this study, and 84 participant dyads for the larger study. As a result, Dr. Michelle Lobchuk (principal investigator) and Dr. Susan McClement (co-investigator) agreed that a revision to the inclusion criteria to include all lung cancer patients, regardless of type, staging and treatment status was warranted. A change was also made in the recruitment protocol wherein the nursing staff was no longer extending the letters of invitation to participate and as such, the ESAS score could no longer be part of the inclusion criteria. With the support of the Chair, Thoracic Disease Site Group and the Nurse Manager, it was decided that the unit clerk would extend the letters of invitation to all lung cancer patients, regardless of stage and treatment regimen, who present to the clinic. Ethical amendments were submitted and approved for the above changes.

The inclusion criteria for informal caregivers cited they must be: (a) identified by the patient as being primarily involved in the care of the patient in the home setting (biological, legal or functional relationships); (b) 18 years of age or older; (c) able to speak, read, and write the English language; and (d) score higher than or equal to 24 out of 30 on the MMSE (Folstein et al., 1975). Similar cut-off scores on the MMSE were used in previous studies involving participants capable of responding reliably on self-reports of pain severity (Bruera, et al., 1992; Grossman, Sheidler, Swedeen, Mucenski, & Piantadosi, 1991).

Procedures for Data Collection

As part of the larger study being conducted by Lobchuk, McPherson, and McClement, written approval to conduct this study was obtained from the Education/Nursing Research Ethics Board (ENREB), University of Manitoba. Written approval to access subjects and medical records was obtained from CancerCare Manitoba. In addition, the Chair of CancerCare Manitoba Thoracic Disease Site Group provided verbal and written agreement to serve as this investigator's external committee member and a collaborator on Lobchuk and colleagues larger study to assist them in obtaining permission to access lung cancer patients and their informal caregivers in the clinic setting (see Appendix A).

Recruitment of Subjects

Initially, the principal investigator of the larger study, Dr. Michelle Lobchuk, obtained verbal support from the Chair of the Thoracic Clinic and the Nurse Manager of the Thoracic Clinic as well as written approval of the cancer agency's Resource Impact Committee as to the role of the clinic staff in facilitating access to the patient-family caregiver study population. It was agreed that the clinic nurse role would be to assist the investigation by approaching eligible lung cancer patients, based on the initial inclusion criteria discussed above, to speak to the Research Nurse and this investigator about the study. However, it became apparent that the nursing staff did not have adequate time to undertake this request due to the high volume of patients seen in the thoracic clinic. As such, an ethical amendment was obtained wherein the unit clerk in the thoracic clinic agreed to distribute the letter of invitation to patients and family caregivers (Appendix B) to all patients attending thoracic clinic at the time of patient check-in. The patients read

and completed the letters of invitation indicating whether or not they were interested in participating and returned the invitation to the unit clerk, who securely stored them until they were collected each week by the Research Nurse who was hired for the larger study.

In addition, alternate recruitment sites were obtained including the radiation department at CancerCare Manitoba. The radiotherapy technicians agreed to distribute the letter of invitation to lung cancer patients seen for radiation treatment. Once the letters of invitation were returned to the radiation technicians, they were securely stored until pick by the Research Nurse on a weekly basis. In addition, the Victoria General Hospital outpatient chemotherapy oncology department agreed to assist in the recruitment of patients into the study by distributing the letter of invitation to eligible lung cancer patients seen for chemotherapy. Ethical approval was granted for these alternative sites and site access was granted by the Victoria General Hospital.

Upon receipt of the letters of invitation completed by patients indicating whether or not they were interested in participating in the study, the Research Nurse and this investigator proceeded to contact those patients who indicated an interest in the study by phone. At that time, the Research Nurse or the investigator confirmed the patients' eligibility and their desire to participate. Once the patient and informal caregiver were deemed eligible and agreed to participate, a home visit was scheduled at a convenient time for all parties. Home visits were conducted by both the Research Nurse and this investigator either together or separately to ensure that all willing participants were visited with fewer scheduling conflicts.

Data Collection Protocol

In the home setting, the Research Nurse and this investigator obtained the informed consent of the patient (Appendix C) and family caregiver (Appendix D) by providing the written consent to the participants, making sure both the patient and caregiver read and understood the consent prior to signing, and that each participant scored higher than or equal to 24 out of 30 on the MMSE (Folstein et al., 1975). If one or both of the subjects scored lower than or equal to 24 out of 30 on the MMSE, the Research Nurse and this investigator thanked the patient and the caregiver for their time. These dyads were not enrolled in the study.

If both participants were found to be cognitively intact, the Research Nurse and this investigator proceeded to answer any remaining questions that the participant or caregiver may have had concerning the study. The patient and the caregiver were then separated into different interview rooms to read the questionnaire instructions, and once each participant verbalized an understanding of the procedure, they were instructed to complete the questionnaires. Both the Research Nurse and this investigator remained available to participants to answer any questions about the questionnaires or the study, and to provide assistance in completing the questionnaires if needed. The Research Nurse and this investigator also ensured that the participants did not discuss their responses to survey items until after they had completed the questionnaires, and returned them to the interviewers to avoid any outside influence.

Instruments

Five types of measures were used in this study. The first instrument was a formal mental status examination of the patient and the family caregiver. The second instrument

was a measure of patient and caregiver socio-demographic information, caregiving relationship information, and information on their respective smoking histories as developed by the principal investigator of the larger study, Dr. Michelle Lobchuk. The third instrument was an abbreviated version of the Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994) used to capture the patient and caregiver perceptions of the patient's pain, fatigue and dyspnea multidimensional experiences. The fourth measurement consisted of a series of Likert-type questions designed to measure onset and offset reactions to the control over the cause of the disease and disease progression. The fifth instrument captured the informal caregiver perspective-taking activities as reported by patients and caregivers.

The Folstein Mini-Mental Status Examination

The MMSE was administered to assure that data was collected from patients and caregivers capable of responding reliably (Folstein et al., 1975). The examination was administered by the Research Nurse and this investigator to the patients and the caregivers prior to administering the study questionnaires (Appendix E). Participants with MMSE scores greater than 24 out of 30 were eligible to participate in this study. Similar cut-off scores were used for the MMSE involving patients capable of responding reliably on self-reports of symptom experiences (Lobchuk, 1995; Lobchuk & Degner, 2002; Lobchuk & Vorauer, 2003). The administration of the MMSE took approximately five to seven minutes for each dyadic participant.

Demographic Data Forms

Demographic data was obtained to describe the sample in terms of socio-demographic information, caregiving relationship, and smoking history of the patient and

family caregiver (Appendices F & G). Demographic data forms required approximately eight minutes to complete.

The patient demographic data form.

The patient demographic data form was used to collect information concerning: patient age, gender, marital status, language, ethnicity, religion, education, occupational status, current (or previous) employment, annual family income, type of cancer (NSCLC, SCLC), stage of cancer (the TNM staging system, as previously discussed, was employed in this study), actual date of diagnosis, current treatment, previous treatment, and nursing care in home setting.

In all instances demographic data was elicited from the patient. The Research Nurse and this investigator also obtained permission to access patients' charts in the patient consent form. In instances of lack of clarity of demographic data (stage of illness, date of diagnosis, treatment), the patient's chart was reviewed for clarification and accuracy of demographic data. All information obtained from patients' medical records was kept confidential and was handled in accordance with the Personal Health Information Act (PHIA) guidelines. If the patient did not wish to have his or her medical records accessed, they were still eligible to participate in the study and data that was not collected was recorded as "missing".

In addition to the above noted demographic questions, patients were also asked two questions pertaining to their smoking history (Appendix F questions 21 & 22) and five, 5-point Likert-type about the caregiving relationship (Appendix F questions 23-27) previously used by the principal investigator (Dr. Michelle Lobchuk) in recent work with lung cancer patients. These questions included: length of time the caregiver has cared for

the patient, the relationship of the caregiver to the patient, the extent of assistance the caregiver provides to the patient, the degree of communication between the patient and caregiver about the patient's symptom experiences, how well the caregiver knows how the patient thinks and feels about his/her pain, and the amount of contact the caregiver has with the patient.

The informal caregiver demographic form.

The informal caregiver demographic form was used to collect data from the primary family caregiver concerning: age, gender, marital status, language, ethnicity, religion, education, occupational status, and current (or previous) employment status. The informal caregivers were also asked two questions concerning their smoking history (Appendix G, questions 10 & 11). In addition, the caregivers were asked six, 5-point Likert-type questions concerning the caregiving relationship (Appendix G, questions 12-17) that were similar to the questions posed to the patient.

The Memorial Symptom Assessment Scale

The Memorial Symptom Assessment Scale (MSAS) was developed by Portenoy and colleagues (1994) in a heterogeneous population of cancer patients who were primarily diagnosed with metastatic disease. Portenoy and colleagues (1994) addressed the need for an assessment tool that measured the multidimensional aspect of cancer symptoms by capturing symptom frequency, severity, and distress (Lobchuk & Degner, 2002). In its original form the MSAS is comprised of 32, four- and five- point Likert-type scales assessing symptoms in three categories: physical, psychological and global symptom experiences with a Cronbach's alpha reliability level of 0.88 in the high-

prevalence physical symptom, 0.58 in the low prevalence physical symptom, and 0.83 in the psychological symptom subscale groups (Portenoy et al., 1994).

The MSAS has been widely used in studies examining symptom experiences in cancer patients (Hwag, Chang, Monste, & Kasimis, 2003; Lobchuk & Degner, 2002; Lobchuk & Vorauer, 2003; Tranmer, Heyland, Dudgeon, Groll, Squires-Graham, & Coulson, 2003; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). However, the effectiveness of this tool in relation to family caregiver use was unknown until Lobchuk (2003) conducted a study to determine whether the MSAS could serve as a feasible, reliable and valid tool for use in assessing the reports by informal caregivers on the symptom experiences of advanced cancer patients, including those diagnosed with lung cancer.

Lobchuk (2003) modified the MSAS through a minor change in wording so as to allow the caregiver to respond on the patient's symptom experience over the preceding week, and proceeded to test it in its modified form with 98 advanced stage cancer patients and their informal caregivers. Lobchuk's results indicated the adapted MSAS had good reliability, based on high internal reliability consistency coefficients with an overall α reliability coefficient of 0.82 for the PSYCH scale, 0.84 for the PHYS scale, and 0.84 for the MSAS-GDI scale; moderately correlated items with an average inter-item correlation $r = 0.45$ on the PSYCH scale, $r = 0.30$ on the PHYS scale, and $r = 0.35$ on the MSAS-GDI scale; and moderate to strong item-to-scale correlations of $r = .60$ for the PSYCH scale, $r = .50$ for the PHYS scale, and $r = .54$ for the MSAS-GDI subscales (Lobchuk, 2003).

The Kappa values between patient and caregiver responses on the presence of symptoms for the modified MSAS ranged between 0.22 to 0.70 on the PHYS symptoms and 0.16 to 0.48 on PSYCH symptoms. The ICC on the PHYS scale was 0.68 and the ICC on the PSYCH subscale was 0.32. On the MSAS-GDI (a short version of the tool designed to target on certain symptoms and symptom dimensions), the ICC value for the total MSAS-GDI was 0.82 (Lobchuk, 2003). The researcher concluded the MSAS to be a “concise, multidimensional tool fit for use within a population of caregivers to report on physical symptoms and global symptom distress experienced by advanced stage cancer patients in the home care setting” (Lobchuk, 2003, p. 653) with minimal burden to patients and their informal caregivers.

With respect to this study, the MSAS was administered in an abbreviated form to both patient (Appendix H) and family caregiver (Appendix I) to capture their perceptions of the patient’s pain, fatigue and dyspnea experiences.

Measurement of Onset and Offset Reactions

To capture the patient and caregiver attributional onset and offset reactions, participants were administered a series of 5-point Likert-type questions employed in previous health research to measure onset and offset reactions related to the control over that cause of the disease and disease progression (Taylor et al., 1984) (Appendices J and K for Onset tools and Appendices L and M for the Offset tools). More specific onset and offset reactions (related to emotions) were captured by a series of three 5-point Likert-type questions previously employed by attributional researchers in health and social psychology as respective indicators of perceived responsibility, anger, sympathy, and pride (Reisenzein, 1986; Weiner, 1995). To date, no known tool exists or has been

published that tests stigma with lung cancer patients. Annette Street, a researcher from Australia, is currently developing a stigma tool that has not yet been published (Latrobe, 2005).

Caregiver Perspective-Taking Tool

Long's (1987) Other Dyadic Perspective-Taking Scale (ODPT) initially consisted of 20 items in a 5-point Likert-type tool designed to capture a partner's perception of the other's perspective-taking activities in the relationship. When employed by Long and Andrews (1990), the Cronbach's alpha coefficient was 0.93 for husbands and 0.95 for wives. In this study, the ODPT was re-named the Caregiver Perspective-Taking Tool and reworded slightly for caregivers to report on their own perspective-taking tendencies within the caregiving situation. This measurement tool was administered to both patients (Appendix N) and caregivers (Appendix O) independently. The ODPT tool was previously employed by Lobchuk (2001) and was found to be acceptable to complete with minimal burden by patients and their informal caregivers. Cronbach's α coefficient calculated for this modified Caregiver Perspective-Taking Tool was 0.88 for caregivers and 0.92 for patients.

Protection of Human Subjects

As part of the larger study being conducted by Lobchuk, McPherson, and McClement, written approval to conduct this study was obtained from the Ethical Review Committee, Nursing and Education, University of Manitoba. Written approval to access subjects and medical records was obtained from CancerCare Manitoba.

Only those subjects who voluntarily agreed to participate in the study were included. A verbal and written explanation of the purpose of the study and its risk and

benefits were given to each participant. The investigator stressed that the patients and primary informal caregivers could withdraw at any time during the study with no effect on their care or treatment. The consent forms also contained a written explanation that there are no risks or direct benefits associated with their participation in the study. However, findings from this study might be helpful to health care professionals in providing information about how to improve the care they provide to patients and informal caregivers.

All information was gathered from the patients and informal caregivers themselves. Permission to access patients' charts was sought in the patient consent form for instances where a lack of clarity in demographic data existed. Demographic data was obtained to describe the representativeness of the sample.

The confidentiality of information obtained in questionnaires was guaranteed by the investigator. No names or other personal data appeared on any of the data collection forms. All participants were assigned a dyad code number. Participants were instructed not to write their names on forms and were assured that no names would appear in reports of the study or in any future publications. The patient and caregiver consents and their corresponding code numbers were kept separate from collected data under lock and key. Drs. Lobchuk, McClement, McPherson, the Research Nurse, and this investigator were the only individuals with access to the raw data. Data was reported in aggregate form so that individual identities were protected. The consent forms explained that the questionnaires will be securely locked up, and kept for seven to ten years upon which time it will be destroyed and treated as confidential waste.

Data Analysis

In order to describe the overall sample characteristics in terms of socio-demographic, illness-, and treatment-related variables, analyses were employed, including statistics such as frequency distributions, means, standard deviations, percentages, and confidence intervals.

Research Question 1: What are the relationships and differences between lung cancer patient and caregiver respective responses on their smoking histories, 'onset' and 'offset' reactions, caregiver perspective-taking, and perceptions on patient pain, fatigue and dyspnea experiences (symptom experiences)?

In order to address the first study question namely to describe the relationship between caregiver and patient reports on their respective smoking histories, onset and offset reactions, caregiver perspective-taking, and perceptions of patient symptom experiences, non-parametric testes of differences using the Wilcoxon matched-pairs signed rank test and correlations using Kendall's *tau b* for ordinal data were performed.

Research Question 2: If discrepancies are identified during the analysis of question one, what is the effect of these discrepancy scores for patient and caregiver 'onset reactions', 'offset reactions', and caregiver perspective-taking on caregiver accuracy outcomes for patient symptom experiences?

To answer the second study question to determine the effect of discrepancy scores for patient and caregiver onset reactions, offset reactions, and caregiver perspective-taking on levels of perceptual agreement between patient and caregiver reports on patient symptom experiences, a correlational analysis was using Kendall's *tau_b* test was performed.

Summary

This chapter has outlined the methods that were used to carry out a descriptive-comparative study aimed at exploring the relationships and differences between lung cancer patient and family caregiver respective responses on their smoking histories, onset and offset reactions, caregiver perspective-taking, and perceptions of patient symptom experiences. The second aim was to explore the potential effect of discrepancy scores for patient and caregiver onset and offset reactions on levels of perceptual agreement between patient and caregiver responses on patient fatigue, pain, and dyspnea.

A formal mental status examination, a socio-demographic tool capturing caregiving relationship and smoking history items, an abbreviated MSAS questionnaire, onset and offset reaction questions, and the Caregiver Perspective-Taking Tool were used to collect data from patients and their informal caregivers. The results of reliability and validity assessments for the Caregiver Perspective-Taking Tool were discussed indicating that psychometric criteria were met. The inclusion criteria for patients and informal caregivers, and the data collection protocol were discussed. The data analysis plan was described to address two study questions, (1) What are the relationships among lung cancer patient and family caregiver respective responses on their smoking histories, onset and offset reactions, caregiver perspective-taking, and perceptions of patient symptom experiences? and (2) What is the effect of discrepancy scores for patient and caregiver onset and offset reactions and caregiver perspective-taking on patient and caregiver perceptual agreement on patient symptom experiences? The procedure for assuring ethical treatment and subject protection was also described.

CHAPTER IV

Results of Data Analysis

The purpose of this study was to explore the relationships and differences between patient and caregiver smoking history, illness attributions (through 'onset' and 'offset' reactions), perceptions of caregiver perspective-taking, and assessments of patient pain, dyspnea, and fatigue experiences. To date, some of these relationships have remained unexplored by researchers, in particular, the association between patient and caregiver attributional responses, and their impact on levels of patient-caregiver agreement on patient symptom experiences. This chapter will describe the characteristics of both the patient and the family caregiver samples and report on the reliability of the instruments used within each group. Statistical analysis of the research questions will be presented in conjunction with a report of the major findings.

The specific research questions posed were:

1. What are the relationships and differences between lung cancer patient and caregiver respective responses on their smoking histories, 'onset' and 'offset' reactions, caregiver perspective-taking, and perceptions on patient pain, fatigue and dyspnea experiences (symptom experiences)?
2. If discrepancies are identified during the analysis of question one, what is the effect of these discrepancy scores for patient and caregiver 'onset reactions', 'offset reactions', and caregiver perspective-taking on levels of patient and caregiver perceptual agreement on patient symptom experiences?

Data for this study was collected over a six month period between October 2005 and March 2006. Subjects were recruited from the Thoracic Clinic at CancerCare Manitoba,

McDermot site in Winnipeg, Manitoba. Data collected from each of the participants included demographic data and their responses on an abbreviated version of the Memorial Symptom Assessment Scale (MSAS), 'onset' and 'offset' questionnaires, and caregiver perspective-taking questionnaires. The computer package SPSS 14.0 for Windows was utilized to analyze the results.

Description of the patient and caregiver samples

A total of 152 patients were approached for participation in the study. Of the 152 patients approached, 33 were deemed not eligible due to numerous reasons provided in Table 1. Of the 119 dyads eligible to participate, the refusal rate was 71% (85 of 119 patients). Thirty-four patient and family caregiver dyads agreed to participate in the study.

Demographic Characteristics of Patients

A convenience sample of 20 (58.8%) women and 14 (41.2%) men comprised the patient population for this study (Table 2). The mean age of the patients was sixty-four years of age. Twenty-nine percent (n=10) described their ethnic origin as English. Seventy-three percent (n=25) of patients were married. Sixty-four percent (n=27) of patients reported having completed high school or less than high school education. Seventy-three percent (n=25) of patients were retired. Sixty-seven percent (n=23) of patients reported an annual family income of less than or equal to \$40,000. With respect to cigarette smoking behaviour, thirty-eight percent (n=13) of patients reported actively smoking at the time of interview, followed by fifty-three percent (n=18) of patients who indicated being a former smoker. Nine percent (n=3) of patients indicated they had never smoked.

Table 1. Reasons for non-participation of patients/caregivers (n=118)

Reason	Number of Dyads
A. Recruitment difficulty	
- Patient too ill – admitted to hospital	8
- Wrong diagnosis for study	11
- Language Barrier	3
- Cognitive inability	2
- No symptoms	3
- No caregiver	6
B. Refusals	85
TOTAL	118

Seventy-six percent (n=26) of patients in the sample had non-small cell lung cancer with fifty-eight percent (n=20) reporting an advanced stage of the disease (Stage III or Stage IV). Eight patients (24 percent) had small cell lung cancer, with nine percent (n=3) reporting their stage of disease to be limited and nine percent (n=3) reported it to be extensive. Two patients (six percent) indicated they did know the stage of their small cell lung cancer. An examination of their medical records did not contain a medical diagnosis that indicated the stage of their disease, therefore it was reported as unknown.

Seventy percent (n=24) of patients had lived with the diagnosis for nine months or less, 21% (n=7) had lived with the diagnosis between ten months and thirty-six months; and 9% (n=3) had lived with the lung cancer diagnosis for greater than thirty-six months. Table 2 provides a complete reporting of demographic data as well as current and past treatment. At the time of interview of those twenty-one patients who were receiving current treatment, thirty-eight percent (n=13) of patients reported receiving chemotherapy and 21% (n=7) receiving radiotherapy. In relation to past treatment, forty-one percent (n=14) of patients reported having had radiotherapy and thirty-five percent (n=12) reporting having undergone previous chemotherapy treatment.

With regards to the characteristics of the patient/caregiver relationship (Table 3), fifty-three percent (n=18) of patients reported receiving care from their family caregiver for eighteen months or less. Seventy-six percent (n=26) of patients reported living with their caregiver. With regard to the amount of caregiver assistance the patients received, sixty-four percent (n=22) reported always receiving assistance from their caregiver. Fifty-three percent (n=18) of patients reported usually communicating with their caregivers regarding their symptoms while sixty-two percent (n=21) of patients reported

that they perceived their caregiver to know their thoughts and feelings very well concerning their symptoms.

The mean Folstein Mini-Mental Status Examination (MMSE) score for the entire patient group was 28.68 (SD 1.34) out of a possible score of 30, which is considered to be in the unimpaired range (Folstein et al., 1975). Patients with scores greater than or equal to 24 out of 30 on the MMSE were eligible to participate. Similar cut-off scores on the MMSE were used in previous studies involving participants capable of responding reliably on self-reports and inferences of patient symptom experiences (Lobchuk, 2001). None of the sample patient population scored lower than 24 out of 30, and as such, no patient participants were excused from the study.

Demographic Characteristics of Family Caregivers

A convenience sample of 20 (59%) women and 14 (41%) men comprised the caregiver population in this study (Table 2). The mean Folstein Mini-Mental Status Examination (MMSE) score for the entire caregiver group was 28.85 (SD 1.23) out of a possible score of 30, which is considered to be in the unimpaired range (Folstein et al., 1975). None of the sample caregiver population scored lower than 24 out of 30, and as such, no caregiver participants were excused from the study.

The mean age of the caregivers was sixty-one years of age. Twenty percent (n=7) described their ethnic origin as English. Eighty-eight percent (n=30) of caregivers were married. Fifty-eight (n=20) of caregivers reported having completed or less than high school education. Sixty-two percent (n=21) of caregivers were retired. With respect to cigarette smoking behaviour, twenty-seven percent (n=9) of caregivers reported being an active smoker at the time of interview. Fifty-three percent (n=18) of caregivers reported

they quit smoking, of which six (2%) caregivers stated they quit smoking at time of patient diagnosis. Seventeen percent (n=6) of caregivers indicated they had never smoked, and one caregiver refused to answer.

With respect to the characteristics of the caregiving relationship (Table 3), fifty percent (n=17) of caregivers indicated they had been providing care to the patients for less than or equal to 18 months. The majority of caregivers, seventy-nine percent (n=27) indicated they lived with the patients. Concerning the amount of caregiver assistance provided, sixty-eight percent (n=23) of caregivers indicated they frequently or always provided the patients with care. Seventy-three percent (n=25) of caregivers stated they frequently or usually communicated with the patients regarding the patients' symptoms. With regards to the amount of perceived knowledge of the patients' thoughts and feelings about symptoms, fifty percent (n=17) of caregivers indicated they perceived the patients' feelings very well. Seventy percent (n=24) of caregivers indicated they were the patients' spouses.

Table 2. Demographic and Medical Characteristics of Patients and Family Caregivers

Characteristic	Patients (N=34)		Caregivers (N=34)	
Age (years)				
Mean	64.6		61.00	
SD	8.17		11.49	
Range	50-86		36-83	
Marital Status				
Married or common-law	25	73	30	88
Never Married	1	3	-	-
Widowed	3	9	1	3
Divorced or separated	5	15	3	9
Total	34	100	34	100
Gender				
Female	20	59	20	59
Male	14	41	14	41
Total	34	100	34	100
Education				
Less than High School	13	38	10	29
High School Graduate	9	26	10	29
Partial College (at least 1 year)	6	18	4	12
College or University	1	3	6	18
Graduate/Professional Training	5	15	4	12
Total	34	100	34	100
Cultural/Ethnic Background				
English	10	29	7	20
German	2	6	3	8
French	4	12	4	12
Ukrainian	5	14	4	12
Scottish	4	12	2	6
Canadian	4	12	4	12
Belgian	1	3	1	3
Jewish	1	3	1	3
Native Canadian	1	3	2	6
Metis	1	3	1	3
Polish	1	3	1	3
Mennonite	-	-	2	6
Romanian	-	-	1	3
Irish	-	-	1	3
Total	34	100	34	100

Characteristic	Patients (N=34)		Caregivers (N=34)	
	n	%	n	%
Religion				
Anglican	7	21	4	12
Baptist	1	3	-	-
Lutheran	1	3	1	3
Roman Catholic	8	23	8	23
United Church	8	23	8	23
Mennonite	1	3	3	9
Greek Orthodox	-	-	1	3
Jewish	-	-	1	3
No preference	5	15	4	12
Other	3	9	4	12
Total	34	100	34	100
Occupational Status				
Full-time	3	9	9	26
Part-time	1	3	2	6
Medical leave	4	12	2	6
Unemployed	1	3	-	-
Retired	25	73	21	62
Total	34	100	34	100
Current or Previous Employment				
Clerical	3	9	3	9
Labourer	6	18	4	12
Homemaker	3	9	1	3
Professional	8	23	7	21
Management	6	18	8	23
Other	8	23	11	32
Total	34	100	34	100
Annual Family Income				
Below \$10,000	1	3	-	-
\$10,000 - \$20,000	6	18	-	-
\$21,000 - \$30,000	8	23	-	-
\$31,000 - \$40,000	8	23	-	-
\$41,000 - \$50,000	-	-	-	-
\$51,000 - \$60,000	3	9	-	-
\$61,000 - \$70,000	3	9	-	-
Over \$71,000/year	3	9	-	-
Missing	2	6	-	-
Total	34	100		
Cigarette Smoking Behavior				
-I smoke regularly now, about the same amount as before diagnosis	1	3	5	15
- I smoke regularly now, but have but have cut down since diagnosis	10	29	2	6
- I smoke every once in awhile	2	6	2	6

- I have quit smoking since diagnosis	5	15	2	6
- I am a former smoker and was not smoking around the time of diagnosis	13	38	16	47
- I never smoked	3	9	6	17
- Refused to answer	-	-	1	3
Total	34	100	34	100
Tumor Type				
Small cell lung cancer	8	24	-	-
Non-small cell	26	76	-	-
Total	34	100		
Stage of diagnosis				
Small cell lung cancer				
Limited	3	9	-	-
Extensive	3	9	-	-
Unknown	2	6	-	-
Total	8	24		
Non small cell lung cancer				
Stage I	2	6	-	-
Stage II	3	9	-	-
Stage III	10	29	-	-
Stage IV	10	29	-	-
Unknown	1	3	-	-
Total	26	76		
Months since diagnosis				
0-9	24	70	-	-
10-36	7	21	-	-
> 36	3	9	-	-
Total	34	100		
Current Treatment				
Chemotherapy	13	38	-	-
Radiotherapy	7	21	-	-
Other	1	3	-	-
Total	28	62		
Past Treatment				
Surgery	10	29	-	-
Chemotherapy	12	35	-	-
Radiotherapy	14	41	-	-
Other	1	3	-	-
Total	37			

Table 3. Caregiving Relationship Characteristics of Patients and Family Caregivers

Characteristic	Patients (N=34)		Caregivers (N=34)	
	n	%	n	%
Receiving nursing care at home				
Yes	1	3	-	-
No	33	97	-	-
Total	34	100		
Months of family caregiving				
0 to 9 months	14	41	15	44
10 to 18 months	4	12	2	6
19 to 36 months	3	9	5	15
> 36 months	13	38	12	35
Total	34	100	34	100
Amount of caregiver assistance				
Never	1	3	-	-
Sometimes	4	12	11	32
Frequent	7	21	8	24
Always	22	64	15	44
Total	34	100	34	100
Amount of communication about symptoms				
Rare	3	9	1	3
Sometimes	2	6	8	24
Frequent	11	32	14	41
Usual	18	53	11	32
Total	34	100	34	100
Amount of perceived knowledge of patient thoughts and feelings about symptoms				
Not very well	1	3	5	15
Has some knowledge	3	9	5	15
Adequate	9	26	7	20
Very well	21	62	17	50
Total	34	100	34	100
Amount of contact with patient				
Daily, I live with the patient.	26	76	27	79
Daily, I do not live with the patient.	4	12	3	9
Weekly, I don't live with the patient	-	-	1	3
More than weekly, I don't live with the patient	4	12	3	9
Total	34	100	34	100

Characteristic	Patients (N=34)		Caregivers (N=34)	
	n	%	n	%
Relationship to patient				
Wife	-	-	12	35
Husband	-	-	12	35
Daughter	-	-	3	9
Son	-	-	2	6
Sister	-	-	3	9
Friend	-	-	1	3
Other	-	-	1	3
Total			34	100

Overall, in comparing the patient and caregiver groups on demographic characteristics, many similarities were found. The age of patients and caregivers was similar (patient mean age 64 years old and caregiver mean age 61 years old), although there was a greater range of age for caregivers (36-83 years old) when compared to that of patients (50-86 years old). Caregivers had slightly higher levels of education with ten caregivers reported having less than high school education and thirteen patients reported having less than high school education. English was the most common ethnic background for both respondent groups. More caregivers were employed full-time than patients, with twenty-five (85%) patients being retired and twenty-one (68%) caregivers being retired at time of interview.

A cursory comparison of perceptions of the caregiving relationship found many differences between dyad member responses. While both dyad members reported similar perceptions in the length of the caregiving relationship, patients perceived themselves as requiring more care than what the caregivers perceived the patients to need. Patients perceived higher levels of communication with their caregivers regarding symptoms compared to levels reported by caregivers. Patients also perceived caregivers to have greater knowledge of their thoughts and feelings about their symptoms. The majority of caregivers (70%, n=24) reported being the patients' spouse, followed by son or daughter, sister, friend, and 'other'.

Instrument Reliability

Internal consistency reliability of the Caregiver Perspective-taking Scale was estimated for both patient and the caregiver groups using Cronbach's coefficient alpha. The criterion for adequate reliability is often established at 0.80 (Nunnally, 1978). In this

study, the Cronbach's alpha score for the caregiver version of the dyadic perspective-taking scale was 0.88 and 0.92 for the patient version. The reliability coefficients in this study were similar to those reported by Long and Andrews (1990) for the Other Dyadic Perspective-taking Scale, which was 0.93 for husbands and 0.95 for wives.

Analysis of the Research Questions

In order to rigorously answer the research questions posed in this project, nonparametric techniques were employed. Nonparametric tests are commonly used to analyze nominal or ordinal data answering research questions exploring possible relationships between two variables or whether groups differ on an outcome measure (Hazard Munro, 2001). Nonparametric tests contain no assumptions about the distribution of the variables in the population (Hazard Munro, 2001). In order to examine possible relationships and differences between respondent groups in relation to onset and offset reactions, the nonparametric tests Kendall's *tau_b* and Wilcoxon matched-pairs signed rank tests were carried out. Kendall's *tau-b* is a common correlational test that measures the rank order association between two scale or ordinal variables (Hazard Munro, 2001). The Wilcoxon matched-pairs signed rank test was also employed to test for differences between patient and caregiver responses on the onset reaction, offset reaction, caregiver perspective-taking and symptom experience questionnaires. It is a common nonparametric test that tests whether the distribution of two paired variables in two related samples is the same. This test takes into account the degree of difference between two paired variables (Hazard Munro, 2001).

Research Question #1

What are the relationships and differences between lung cancer patient and caregiver respective responses on their smoking histories, 'onset' and 'offset' reactions, caregiver perspective-taking, and perceptions on patient pain, fatigue and dyspnea experiences (symptom experiences)?

To answer research question one several steps were taken. First, a comparison of rank order of mean responses was conducted to evaluate any similarities or differences in participant group responses with regard to locus of causality for the disease. To test for possible relationships among patient and caregiver responses on onset and offset reactions, caregiver perspective-taking, and symptom experiences, Kendall's *tau b* was employed. Significant differences between the responses of the groups were then detected using the non-parametric Wilcoxon matched-pairs test (Hazard Munro, 2001). Each step is described in further detail below with a reporting of all significant findings ($p \leq 0.05$). In addition, discrepancy scores between responses of the patient and caregiver respondent groups were calculated for locus of causality, 'onset reactions', and 'offset reactions', as well as caregiver perspective-taking and symptom experiences to allow for further analysis of levels of dyadic agreement. Discrepancies were based on calculating the absolute difference scores (i.e., the patient score minus the caregiver score) for each response item in the study questionnaires. The theoretical range of absolute differences ranged from zero to four on individual scale questions.

Smoking histories.

To capture the smoking history of the patients and caregivers respectively, each participant was asked to indicate their smoking status according to several Likert-type

response options. Table 2 provides a summary of the response options. A cursory examination of frequency responses occurred in the comparison of patient and caregiver group responses on smoking history. Results indicated that ninety-one percent (n=31) of patients and 79% (n=27) of caregivers had a history of tobacco usage (Table 4). In relation to smoking history within dyads, 15 dyads (n=44%) indicated at least one member continued to smoke regularly since diagnosis. Of the fifteen dyads, six (40%) dyads were comprised of only patients who continued to smoke, two dyads (13%) were comprised of only caregivers who continued to smoke, and seven dyads (46%) were comprised of both patients and caregivers who continued to smoke. Eighteen dyads (53%) indicated both the patient and caregiver were former smokers. Seven (39%) of those eighteen dyads indicated that at least one member had quit since the diagnosis; in five dyads this was the 'patient'. Eight dyads (23%) indicated that at least one member of the dyad had never smoked. Of those eight dyads, five dyads were comprised of caregivers who had never smoked, two were comprised of patients who had never smoked, and one dyad was comprised of a patient and caregiver who never smoked. Of the 34 dyads, one dyad consisted of a caregiver who refused to answer any questions regarding smoking history. The patient member of that dyad indicated that the caregiver did indeed continue to smoke cigarettes at the time of the interview.

In summary, the largest portion of the sample population was comprised of dyads who were former smokers (n=18). A majority (n = 11) of these 18 dyads of former smokers were comprised of members who had quit smoking prior to the patients' diagnosis. At the time of interview, fifteen dyads indicated that at least one dyadic member continued to smoke since the diagnosis.

Patients were also asked to indicate their caregivers' preference regarding patient smoking behaviour. Sixty-two percent (n=21) of patients indicated this was not applicable to their situation because they were not smoking at the time of interview. Thirty-two percent (n=11) indicated the caregiver preferred that the patient stop smoking, with one patient (3%) indicating the carer preferred the patient to smoke, and one patient (3%) indicating they did not know caregiver preference.

Caregivers were also asked about patient preference on caregiver smoking behaviour. Similar to patient perceptions of caregiver preferences regarding patient smoking behaviours, seventy percent (n=24) of the 34 caregivers indicated this was not applicable to their current situation as they were not smoking at the time of interview. The remaining caregiver responses however were much more variable. Six percent (n=2) of caregivers indicated their belief that the patients' preferred the caregivers to smoke. Both of these dyads consisted of patients and caregivers who were actively smoking at the time of interview. Nine percent (n=3) of the 34 caregivers responded that patients preferred they quit smoking. Of these three dyads, two were comprised of patients who had quit smoking and one dyad was comprised of a patient who continued to smoke. An additional 12% (n=4) indicated they did not know the patients' preference. Interestingly, one dyad consisted of a caregiver who indicated the patients' preference regarding caregiver smoking behaviour was not applicable. However, both the patient and caregiver in that dyad smoked regularly. One caregiver (3%) refused to answer this question and no reason for this refusal was provided by the caregiver

Table 4. Smoking Histories

Smoking Behaviors	Patient % (N=34)	Caregiver % (N=34)
Continue to Smoke since Diagnosis	38 (n=13)	27 (n=9)
Former Smoker	53 (n=18)	53 (n=18)
Never Smoked	9 (n=3)	17 (n=6)
Refused to Answer	0	3 (n=1)
Total	100 (n=34)	100 (n=34)

Onset Reactions

Locus of Causality. When analyzing responses to onset reactions, the rank order of mean scores were examined with respect to patient and caregiver perceptions on the locus of causality for the lung cancer diagnosis as captured on the respective onset reaction questions (Appendices J and K) (Table 5). In rank order of mean scores, patients rated themselves (mean= 2.18, SD 1.60), 'hereditary or genetics' (mean = 1.79, SD 1.45), and 'environment' (mean = 1.32, SD 1.32) with the highest locus of causality of the disease. The items of 'someone else', 'Divine will', and the 'caregiver' were ranked least for locus of causality by patients.

Analysis of rank order of mean scores rated by the caregivers found the 'patient' (mean= 2.32, SD 1.66), the 'environment' (mean = 1.65, SD 1.53), and 'hereditary or genetics' (mean = 1.62, SD 1.48) with the highest locus of causality for the disease. The items with the lowest ranking were the 'caregiver', 'someone else', and 'Divine will'. The rank orders of mean items for locus of causality were similar between patients and the caregivers. A complete listing of the results in rank order is summarized in Table 5.

For locus of causality, the theoretical range of mean scores was 0 to 4. No significant differences were detected between patient and caregiver mean responses on the response items of 'patient', 'caregiver', 'someone else', 'environment', 'chance', 'fate or destiny', 'Divine will', and 'heredity or genetics'. However, a trend was detected ($p \geq 0.05-0.10$) where the patient mean score of 0.23 (SD 0.74) was significantly lower than the caregiver mean score of 0.56 (SD 1.08) on 'caregiver' control over the cause of the patient's disease (Table 5). It is possible that in a larger sample, significant differences might have been detected in mean scores for locus of causality items.

Table 5. Rank order of mean scores related to cause of cancer

Locus of causality	Patient rank	Patient mean (SD)	Caregiver rank	Caregiver mean (SD)	Kendall's Tau b	Absolute Difference Mean (SD)
Patient	1	2.18 (1.60)	1	2.32 (1.66)	0.06	1.61 (1.50)
Caregiver	8	0.23 (0.74)	6	0.56 (1.08)**	0.22	0.56 (0.86)
Someone else	6	0.35 (0.77)	7	0.53 (1.21)	0.18	0.59 (0.92)
Environment	3	1.32 (1.32)	2	1.65 (1.53)	0.10	1.32 (1.36)
Chance	4	1.11 (1.45)	4	1.11 (1.30)	-0.07	1.41 (1.48)
Fate or destiny	5	0.97 (1.34)	5	0.85 (1.23)	-0.13	1.41 (1.37)
Divine will	7	0.26 (0.79)	8	0.47 (1.12)	-0.20	0.73 (1.26)
Hereditry or genetics	2	1.79 (1.45)	3	1.62 (1.48)	0.24	1.35 (1.01)

* $p \leq 0.05$ indicating either a significant association between variables or a significant difference in Wilcoxon matched-pairs signed-rank test; Absolute difference mean scores were calculated by subtracting the patient response from the informal caregiver response

** trend in data ($p \geq 0.05$ -0.10)

The Kendall's tau-b coefficient analysis revealed non-significant ($p < 0.05$), low correlations ranging between ± 0.06 to 0.22.

With respect to the absolute differences between patient and caregiver reports of locus of causality (including 'the patient', 'the caregiver', 'someone else', 'environment', 'chance', 'fate or destiny', 'Divine will', and 'heredity or genetics') a range of 0.56 (SD 0.86) to 1.61 (SD 1.50) out of a theoretical range of 0-4 was found. The largest discrepancy was found between patient and caregiver reports related to 'the patient' locus of causality with a discrepancy score of 1.61 (SD 1.50). The least discrepancy between scores occurred in relation to patient and caregiver reports of 'the caregiver' locus of causality with a discrepancy score of 0.56 (SD 0.86). The remaining discrepancy scores for locus of causality response options included a score of 0.59 (SD 0.92) for 'someone else', 1.32 (SD 1.36) for 'environment', 1.41 (SD 1.48) for 'chance', 1.41 (SD 1.37) for 'fate or destiny', 0.73 (SD 1.26) for 'divine will', and 1.35 (SD 1.01) for heredity or genetics (Table 5).

Attributional Responses. Associations between patient and caregiver responses to the onset reaction questions for responsibility, anger, and sympathy items were tested (Table 6). The results revealed mainly non-significant ($p \leq 0.05$) correlations ranging between -0.39 to 0.72. Only one correlation using Kendall's *tau_b* was found to be significant, that being pity toward 'the caregiver' for the patient getting cancer with a correlation of -0.39. This means that as the patients' feelings of pity toward the caregivers increased, the caregivers' feelings of pity for themselves decreased. A complete listing of significant and non-significant findings is provided in Table 6. Further analysis of attribution responses between the respective groups for onset

reactions revealed several significant differences according to the Wilcoxon matched-pairs signed rank test. Each will be described below.

Degree of responsibility for causing patients' lung cancer.

With respect to the attributional responses between patient and caregiver groups related to responsibility, four significant differences ($p \leq 0.05$) were detected (Table 6). First, a significant difference was found in relation to the attribution of blame toward 'the caregiver' for the patient getting cancer. In this case, the caregivers placed greater blame on themselves (mean = 0.29, SD 0.58) compared to the level of blame the patients placed on the caregivers (mean = 0.06, SD 0.24).

A highly significant difference was also found in relation to the degree of fault placed on 'the patient' for getting cancer ($p = 0.00$). Patients placed significantly more fault on themselves (mean = 1.24, SD 1.52) for causing their cancer compared to the degree of fault the caregivers placed on the patients (mean = 0.94, SD 1.39). With respect to responsibility for causing the disease, a significant difference ($p = 0.02$) in mean scores was found between the patient mean score of 2.20 (SD 1.59) and the caregiver mean score of 1.32 (SD 1.45), indicating that the patients held themselves significantly more responsible for getting the disease than did the caregivers. Conversely, a significant difference ($p = 0.04$) was found in the level of responsibility placed on 'the caregiver' for the patients getting cancer where caregivers placed more responsibility on themselves (mean = 0.32, SD 0.64) compared to the responsibility the patients' placed on the caregivers (mean = 0.06, SD 0.24).

Further examination of attributions of blame revealed a trend that may have been significant if a larger sample had been obtained (that is, p values that ranged between

0.05 and .10). In this case, the attribution of blame toward 'the patient' revealed a trend in the Wilcoxon matched-pairs sign rank test with a p value of 0.07. A comparison of mean scores suggested the patients may have placed significantly more blame on themselves for the cause of the lung cancer (mean = 1.97, SD 1.55) than the caregivers placed on 'the patient' (mean = 1.35, SD 1.57). Trends have been reported throughout this chapter as they may provide additional insight and further the understanding of the relationships among the variables.

With respect to the discrepancy scores for illness attributions/emotional responses for onset reactions related to dimensions of responsibility, the greatest discrepancy was found between scores related to holding 'the patient' responsible for getting cancer with an absolute difference score of 1.76 (SD 1.39), perceptions of holding 'the caregiver' responsible for the cause of the disease had a discrepancy score of 0.38 (SD 0.65). One of the smallest absolute mean differences was found related to faulting 'the caregiver' for the patient getting cancer 0.35 (SD 0.60). The discrepancy score for faulting 'the patient' was much higher at 1.70 (SD 1.36). The absolute mean difference related to blaming 'the caregiver' for the patient getting cancer was 0.35 (SD 0.60) whereas the discrepancy score related to blaming 'the patient' for getting cancer was 1.67 (SD 1.25). The theoretical range of absolute difference scores was from 0 to 4 (Table 6).

Degree of anger for causing patients' lung cancer.

With respect to attributional responses related to anger, four significant differences were detected between the respondent groups (Table 6). First, patients felt significantly ($p = 0.00$) more anger toward themselves for their cancer diagnosis (mean =

1.09, SD 1.33) when compared to the degree of anger felt towards patients by the caregivers (mean = 0.20, SD 0.54).

Second, a highly significant difference ($p = 0.00$) was also found in the level of annoyance felt toward 'the patient' for getting cancer. In this case, the patients reported more feelings of annoyance with themselves (mean = 1.65, SD 1.30) than the caregivers (mean = 0.32, SD 0.73) reported feeling toward the patients. On the other hand, the results on the level of annoyance felt toward 'the caregiver' for the patients getting cancer indicated that caregivers were significantly more annoyed with themselves (mean = 0.26, SD 0.66) compared to what the patients reported feeling toward the caregivers (mean = 0.00, SD 0.00). In addition, the patients reported significantly more feelings of aggravation with themselves for getting cancer (mean = 1.70, SD 1.51) than the caregivers reported feeling toward the patients (mean = 0.32, SD 0.68).

A trend in data was found (p values between 0.05 and .10) relating to attributions of anger toward 'the caregiver' for the patients getting cancer ($p=0.07$). Results suggested that the caregivers felt significantly more anger toward themselves (mean = 0.23, SD 0.70) for 'the patient' getting cancer than the patients felt toward the caregivers (mean = 0.00, SD 0.00). An additional trend was detected relating to feelings of aggravation toward 'the caregiver' for the patient getting cancer ($p=0.07$). With the patients' mean score of 0.00 (SD 0.00) and the caregivers' mean score of 0.20 (SD 0.64), results suggested the caregivers felt significantly more aggravation towards themselves than what the patients reported feeling towards them.

Discrepancy scores for the dimensions of anger related to onset reactions found the greatest discrepancy between patient and caregiver scores related to aggravation

toward 'the patient' for getting cancer 1.56 (SD 1.35), with the absolute difference related to aggravation toward 'the caregiver' being the least discrepant among the dimensions of anger with a score of 0.20 (SD 0.64). Feelings of annoyance toward 'the patient' had an absolute difference score of 1.56 (SD 1.23), where as feelings of annoyance toward 'the caregiver' had a discrepancy score of 0.26 (SD 0.66). Attributions of anger toward 'the patient' had a discrepancy score of 1.00 (SD 1.23) with attributions of anger toward 'the caregiver' with a discrepancy score of 0.23 (SD 0.70) (Table 6). The theoretical range of absolute difference scores was from 0 to 4.

Degree of sympathy for causing patients' lung cancer.

Several significant differences were detected in relation to attributions of sympathy for the cause of the patient's cancer (Table 6). A highly significant difference was found in the level of sympathy felt for 'the patient' for getting cancer ($p=0.00$). A large difference in mean scores revealed that caregivers were significantly more sympathetic toward patients (mean = 3.61, SD 0.97) than what patients were feeling toward themselves (mean = 1.03, SD 1.24). Similar results were found in relation to the differences in attributions of pity ($p=0.02$), where caregivers reported more feelings of pity toward the patients (mean = 1.73, SD 1.66) than patients (mean = 0.76, SD 1.13) reported feeling toward themselves for getting cancer.

Significant differences were also found in the amount of concern felt by and for dyad members. First, feelings of concern toward 'the patient' for getting cancer were significantly different ($p = 0.00$) where caregivers reported more concern for the patients (mean = 3.76, SD 0.79) than patients reported for themselves (mean = 2.23, SD 1.39). Conversely, a significant difference ($p= 0.02$) was detected in relation to the levels of

concern reported for 'the caregiver'. In this case, patients indicated more concern for the caregivers (mean = 2.56, SD 1.69) than caregivers reported feeling for themselves (mean= 1.63, SD 1.60). See Table 6 for significant and non-significant results.

Discrepancy scores for the dimensions of sympathy related to onset reactions found the greatest discrepancy between patient and caregiver scores related to feelings of sympathy toward 'the patient' with an absolute difference score of 2.54 (SD 1.52). Feelings of sympathy toward 'the caregiver' were also highly discrepant with a score of 2.21 (SD 1.61). Feelings of pity toward 'the caregiver' had a discrepancy score of 2.06 (SD 1.52), whereas feelings of pity toward 'the patient' had a discrepancy score of 1.73 (SD 1.48). Feelings of concern toward 'the patient' had an absolute difference score of 1.73 (SD 1.42) whereas feelings of concern toward 'the caregiver' had the least amount of discrepancy with an absolute difference score of 1.54 (SD 1.54) (Table 6). The theoretical range of absolute difference scores was from 0 to 4.

Table 6. Onset Reactions

	Patient Mean Score (SD)	Caregiver Mean Score (SD)	Kendall's tau_b score	Absolute Difference Mean (SD)
<i>Degree of responsibility for causing patients' lung cancer</i>				
Blame patient for getting cancer	1.97 (1.55)	1.35 (1.57)**	0.14	1.67 (1.25)
Blame caregiver for patient getting cancer	0.06 (0.24)	0.29 (0.58)*	-0.13	0.35 (0.60)
Fault patient for getting cancer	1.24 (1.52)	0.94 (1.39)*	0.72	1.70 (1.36)
Fault caregiver for patient getting cancer	0.18 (0.72)	0.29 (0.58)	0.12	0.35 (0.60)
Hold patient responsible for getting cancer	2.20 (1.59)	1.32 (1.45)*	0.06	1.76 (1.39)
Hold caregiver responsible for patient getting cancer	0.06 (0.24)	0.32 (0.64)*	-0.13	0.38 (0.65)
<i>Degree of anger for causing patients' lung cancer</i>				
Anger toward patient for getting cancer	1.09 (1.33)	0.20 (0.54)*	0.18	1.00 (1.23)
Anger toward caregiver for patient getting cancer	0.00 (0.00)	0.23 (0.70)**	Unable to compute	0.23 (0.70)
Annoyance toward patient for getting cancer	1.65 (1.30)	0.32 (0.73)*	0.10	1.56 (1.23)
Annoyance toward caregiver for patient getting cancer	0.00 (0.00)	0.26 (0.66)*	Unable to compute	0.26 (0.66)
Aggravation toward patient for getting cancer	1.70 (1.51)	0.32 (0.68)*	0.29	1.56 (1.35)
Aggravation toward caregiver for patient getting cancer	0.00 (0.00)	0.20 (0.64)**	Unable to compute	0.20 (0.64)
<i>Degree of sympathy for causing patients' lung cancer</i>				
Sympathy toward patient for getting cancer	1.03 (1.24)	3.61 (0.97)*	-0.06	2.54 (1.52)
Sympathy toward caregiver for patient getting cancer	1.97 (1.78)	1.27 (1.57)	-0.15	2.21 (1.61)
Pity toward patient for getting cancer	0.76 (1.13)	1.73 (1.66)*	-0.11	1.73 (1.48)
Pity toward caregiver for patient getting cancer	1.35 (1.67)	0.79 (1.27)	-0.39*	2.06 (1.52)
Concern toward patient for getting cancer	2.23 (1.39)	3.76 (0.79)*	0.01	1.73 (1.42)
Concern toward caregiver for patient getting cancer	2.56 (1.69)	1.63 (1.60)*	0.20	1.54 (1.54)

* $p \leq 0.05$ indicating either a significant association between variables or a significant difference in Wilcoxon matched-pairs signed-rank test (Informal caregiver score – Patient score)

** trend in data ($p \geq 0.05$ -0.10)

Footnote: Correlations for anger, annoyance, and aggravation towards the caregivers for the patients getting cancer were incomputable as the mean scores for the patients' responses for each of these questions was zero.

Supplemental within-group analysis for onset reactions

The investigator conducted supplemental within-group analysis in relation to onset reactions. This analysis provided additional insight into the respective patient and caregiver attributional reactions. A within-group analysis compares mean scores within the same participant group related to a specific measure or question(s). For example caregiver responses to blame toward the patient, blame toward the caregiver, and fault toward the patient, fault toward the caregiver were compared. A between-group analysis compares mean score between different participant groups related to a specific measure or question(s). For example, patient and caregiver responses to blame toward the patient, fault toward the patient, and responsibility toward the patient were compared.

Between group analysis – blame, fault, and responsibility. As previously discussed, analysis of between-group mean scores for the attributions of blame, fault, and responsibility for the cause of the lung cancer were reported strongest towards ‘the patient’ by the patients themselves when compared to caregivers’ mean scores (patient mean score blame toward the patient was 1.97 (SD 1.55), caregiver mean score blame toward the patient was 1.35 (SD 1.57); patient mean score fault toward the patient was 1.24 (SD 1.52), caregiver mean score fault toward the patient was 0.94 (SD 1.39); patient mean score responsibility toward the patient was 2.20 (SD 1.59), caregiver mean score responsibility toward the patient was 1.32 (SD 1.45). Conversely, attributions of blame, fault, and responsibility toward ‘the caregiver’ for the cause of the patients’ disease were consistently reported higher by the caregivers themselves when compared to the patients’ mean scores (caregiver mean score blame toward caregiver was 0.29 (SD 0.58), patient mean score blame toward the caregiver was 0.06 (SD 0.24); caregiver mean score fault

toward caregiver was 0.29 (SD 0.58), patient mean score fault toward the caregiver was 0.18 (SD 0.72); caregiver mean score responsibility toward the caregiver was 0.32 (SD 0.64), patient mean score responsibility toward the caregiver was 0.06 (SD 0.24).

Within-group analysis – blame, fault, and responsibility. In contrast to between-group responses, within-group analyses of mean scores reported by the caregivers revealed the caregivers consistently reported higher attributions of blame, fault, and responsibility toward ‘the patient’ than they did toward themselves (caregiver mean score blame toward the patient was 1.35 (SD 1.57), caregiver mean score blame toward the caregiver was 0.29 (SD 0.58); caregiver mean score fault toward the patient was 0.94 (SD 1.39), caregiver mean score fault toward the caregiver was 0.29 (SD 0.58); caregiver mean score responsibility toward the patient was 1.32 (SD 1.45), caregiver mean score responsibility toward the caregiver was 0.32 (SD 0.64). The within group analysis of caregiver responses clearly indicated that caregivers appear to hold ‘the patient’ more to blame, more at fault and more responsible for the cause of the lung cancer than they do themselves. These findings were not readily apparent when examining only between-group responses.

A review of within-group mean scores for the patient respondent group consistently demonstrated that the patients hold themselves more to blame, more at fault and more responsible for the cause of their disease than they do toward the caregivers (patient mean score blame toward the patient was 1.97 (SD 1.55), patient mean score blame toward the caregiver was 0.06 (SD 0.24); patient mean score fault toward the patient was 1.24 (SD 1.52), patient mean score fault toward the caregiver was 0.18 (SD 0.72); patient mean score responsibility toward the patient was 2.20 (SD 1.59), patient

mean score responsibility toward the caregiver was 0.06 (SD 0.24). Whether the comparison of blame, fault, or responsibility responses by patients occurred between or within groups, the consistency in patient responses in blaming, faulting, or attributing more responsibility toward themselves than their caregivers was apparent.

Between group analysis – anger, annoyance, and aggravation. Between-group analysis of the attributions of anger, annoyance, and aggravation for the cause of the patients' disease by 'the patient' once again were reported highest by patients themselves when compared to the mean scores reported by the caregivers (patient mean score anger toward the patient was 1.09 (SD 1.33), caregiver mean score anger toward the patient was 0.20 (SD 0.54); patient mean score annoyance toward the patient was 1.65 (SD 1.30), caregiver mean score annoyance toward the patient was 0.32 (SD 0.73); patient mean score aggravation toward the patient was 1.70 (SD 1.51), caregiver mean score annoyance toward the patient was 0.32 (SD 0.73). Conversely, the attributions of anger, annoyance, and aggravation for the cause of the lung cancer were reported highest toward 'the caregiver' by the caregivers themselves when compared to the mean scores of the patients (caregiver mean score anger toward the caregiver was 0.23 (SD 0.70), patient mean score anger toward the caregiver was 0.00 (SD 0.00); caregiver mean score annoyance toward the caregiver was 0.26 (SD 0.66), patient mean score annoyance toward the caregiver was 0.00 (SD 0.00); caregiver mean score aggravation toward the caregiver was 0.20 (SD 0.64), patient mean score aggravation the toward caregiver was 0.00, (SD 0.00).

Within-group analysis – anger, annoyance, and aggravation. A within-group analysis of caregivers' mean scores for the attributions of annoyance and aggravation

revealed the caregivers reported feeling higher levels of these emotions toward 'the patient' than they did toward themselves (caregiver mean score annoyance toward the patient was 0.32 (SD 0.73), caregiver mean score annoyance toward the caregiver was 0.26 (SD 0.66); caregiver mean score aggravation toward the patient was 0.32 (SD 0.68), caregiver mean score aggravation toward the caregiver was 0.20 (SD 0.64). With respect to feelings of anger, the caregivers reported a slightly higher level of anger toward themselves (mean score 0.23, SD 0.70) relating to the cause of the patients' disease than they reported feeling toward 'the patient' (mean score 0.20, SD 0.54). The findings related to annoyance and aggravation were not readily apparent when examining the between-group analysis, evidencing that the caregivers' appeared to feel more annoyed and aggravated with 'the patient'. With respect to feelings of anger, the caregivers, while feeling angry with 'the patient' also felt anger toward themselves with respect to their perceived role in the cause of the patients' disease.

A within-group analysis of the patients' mean scores revealed that patients were attributing more feelings of anger, annoyance and aggravation toward themselves than toward the caregivers as the mean scores of patient responses to attributions of anger, annoyance, and aggravation toward 'the caregiver' were all zero. This finding is consistent with the between-group analysis results.

Between-group analysis – sympathy, pity and concern. As previously discussed, a between-group analysis of mean scores for the attributions of sympathy, pity, and concern revealed they were reported highest for 'the patient' by the caregiver respondent group (caregiver mean score sympathy toward patient was 3.61, SD 0.97 and patient mean score sympathy toward patient was 1.03, SD 1.24; caregiver mean score pity

toward patient 1.73, SD 1.66 and patient mean score pity toward the patient was 0.76, SD 1.13; caregiver mean score concern toward the patient was 3.76, SD 0.79 and patient mean score concern toward the patient was 2.23, SD 1.39) and highest toward 'the caregiver' by the patients (patient mean score sympathy toward the caregiver was 1.97, SD 1.78 and caregiver mean score sympathy toward the caregiver was 1.27, SD 1.57; patient mean score pity toward the caregiver was 1.35, SD 1.67 and caregiver mean score pity toward the caregiver was 0.79, SD 1.27; patient mean score concern toward the caregiver was 2.56, SD 1.69 and caregiver mean score concern toward the caregiver was 1.63, SD 1.60).

Within group analysis – sympathy, pity, and concern. A within-group analysis for caregiver mean scores on the attributions of sympathy, pity, and concern revealed that caregivers reported these feelings more toward the patients than themselves (caregiver mean score sympathy toward the patient was 3.61, SD 0.97; caregiver mean score sympathy toward the caregiver was 1.27, SD 1.57; caregiver mean score pity toward the patient was 1.73, SD 1.66; caregiver mean score pity toward the caregiver was 0.79, SD 1.27; caregiver mean score concern toward the patient was 3.76, SD 0.79; caregiver mean score concern toward the caregiver was 1.63, SD 1.60) a finding consistent with the between-group analysis.

A within-group analysis for patient mean scores for attributions of sympathy, pity, and concern supported between-group analysis results where patients tended to report more sympathy, pity, and concern toward the caregivers than toward themselves (patient mean score sympathy toward the caregiver was 1.97, SD 1.78; patient mean score sympathy toward the patient was 1.03, SD 1.24; patient mean score pity toward the

caregiver was 1.35, SD 1.67; patient mean score pity toward the patient was 0.76, SD 1.13; patient mean score concern toward the caregiver was 2.56, SD 1.69; patient mean score concern toward the patient was 2.23, SD 1.39). These findings were consistent with the between-group analysis.

In summary, a within-group analysis for attributional responses related to onset reactions revealed many interesting findings. First, caregivers appeared to attribute more blame, fault and responsibility to 'the patient' than toward themselves related to the cause of the disease. On the other hand, patients appeared to attribute more blame, more fault, and more responsibility toward themselves than their caregivers regardless of whether between- or within-group analyses was conducted. Second, caregivers also reported higher levels of annoyance and aggravation toward 'the patient' than themselves with only slightly higher levels of anger toward themselves. Regardless of within- or between-group analysis, patients reported much higher levels of anger, annoyance and aggravation toward themselves as opposed to the caregivers.

Offset Reactions

Locus of Control over disease progression. When analyzing responses to offset reactions, the rank order of mean scores were examined with respect to patient and caregiver perceptions on the locus of controllability over the progression of lung cancer captured on the respective offset reaction questions (Appendices L and M) (Table 7). In rank order of mean scores, patients rated themselves (mean = 2.35, SD 1.37), 'someone else' (mean = 2.03, SD 1.75), and 'heredity or genetics' (mean = 1.47, SD 1.50) with the highest locus of controllability over disease progression. The items of the 'caregiver', 'chance', and 'fate or destiny' were ranked least for locus of controllability by patients.

For rank order of mean scores, the caregivers rated the 'patient' (mean= 2.44, SD 1.44), 'someone else' (mean = 2.29, SD 1.40), and 'hereditary or genetics' (mean = 1.59, SD 1.46) with the highest locus of controllability for disease progression. The items with the lowest ranking were the 'Divine will', 'chance', and 'fate or destiny'. A complete listing of the results in rank order is summarized in Table 7.

Table 7. Rank order of mean scores related to control over course of cancer

Locus of control	Patient rank	Patient mean (SD)	Caregiver rank	Caregiver mean (SD)	Kendall's Tau b	Absolute Difference Mean (SD)
Patient	1	2.35 (1.37)	1	2.44 (1.44)	0.12	1.32 (1.25)
Caregiver	5	1.12 (1.32)	4	1.32 (1.34)	0.26	1.09 (1.00)
Someone else	2	2.03 (1.75)	2	2.29 (1.40)	-0.04	1.79 (1.51)
Environment	5	1.12 (1.49)	5	1.20 (1.45)	0.15	1.32 (1.34)
Chance	6	0.91 (1.26)	7	0.73 (1.08)	-0.10	1.23 (1.23)
Fate or destiny	7	0.82 (1.17)	7	0.73 (1.08)	0.02	1.03 (1.24)
Divine will	4	1.18 (1.57)	6	0.88 (1.36)	0.16	1.23 (1.39)
Heredity or genetics	3	1.47 (1.50)	3	1.59 (1.46)	0.32*	1.32 (1.04)

* $p \leq 0.05$ indicating either a significant association between variables or a significant difference in Wilcoxon matched-pairs signed-rank test (Informal caregiver score – Patient score)

Overall, the rank order of locus of control items by caregivers was consistent with patient ratings. Both dyadic members perceived 'someone else' and 'heredity or genetic' factors to have a similar degree of locus of control in relation to the course of the cancer. The remaining items of 'fate' or 'destiny', 'environment', 'chance', 'divine will', and 'the caregiver' received similar low rankings by patients and caregivers. Of note, the degree of control assigned to 'the caregiver' in relation to disease progression was higher for both respondent groups (patients' mean score 1.12, SD 1.32; caregivers' mean score 1.32, SD 1.34), than the degree of control assigned to 'the caregiver' in relation to cause of the disease (patients' mean score 0.23, SD 0.74; caregivers' mean score 0.56, SD 1.08). Such findings indicated that both groups afforded the caregivers more control over the patients' disease progression (offset reaction) than over the cause of the patients' disease (onset reaction).

A further comparison of findings between onset and offset reactions showed 'Divine will' to play a more prominent role in the perception of control over disease progression, particularly within the patient respondent group whose mean score in relation to offset reactions was 1.18 (SD 1.57) compared to the mean score given in the measurement of onset reactions of 0.26 (SD 0.79). The 'environment' was perceived to have less of an impact on disease progression by both patients and caregivers than it did in relation to disease occurrence. For instance, patient mean score for environmental control over disease progression was 1.12 (SD 1.49) in comparison to the mean score of 1.32 (SD 1.32) on control over cause of disease. Caregiver mean score for environmental control over disease progression was 1.20 (SD 1.45), in comparison to the mean score of

1.65 (SD 1.53) on environmental control over cause of disease. Although differences may be slight, due to the small sample size, even small differences can be worth noting.

An examination of discrepancy scores related to locus of controllability (which included 'patient', 'caregiver', 'someone else', 'environment', 'chance', 'fate/destiny', 'divine will', and 'heredity or genetic factors'), with a theoretical range of absolute differences of 0-4, found the largest discrepancy related to 'someone else' locus of controllability with a discrepancy score of 1.79 (SD 1.51). The least discrepancy between scores occurred in relation to patient and caregiver reports of 'fate or destiny' locus of controllability with a discrepancy score of 1.03 (SD 1.24). The remaining discrepancy scores for locus of controllability response options included a score of 1.32 (SD 1.25) for 'the patient', 1.09 (SD 1.00) for 'the caregiver', 1.32 (SD 1.34) for 'environment', 1.23 (SD 1.23) for 'chance', 1.23 (SD 1.39) for 'divine will', and 1.32 (SD 1.04) for heredity or genetics (Table 7).

In order to examine further any possible relationships and differences between respondent groups in relation to locus of controllability responses (including 'the patient', 'the caregiver', 'someone else', 'environment', 'chance', 'fate or destiny', 'Divine will', and 'heredity or genetics'), the nonparametric tests Kendall's τ_b and Wilcoxon matched-pairs signed rank tests were carried out. In this study, the results revealed mainly non-significant ($p \leq 0.05$) low correlations around the 0.1 level. A significant, low positive correlation was detected between patient and caregiver responses in relation to 'heredity or genetics' control over the course of the disease ($\tau_b = 0.32$). This means that as caregiver ratings of 'hereditary or genetics' control over disease progression increased, patients' ratings of same also increased. The Wilcoxon matched-pairs signed rank test revealed no significant differences between patient and caregiver mean scores on locus of controllability responses.

Attributional Responses

Associations between patient and caregiver responses to the offset reaction questions for responsibility, anger, and pride items were tested. The results revealed mainly non-significant ($p \leq 0.05$) low to moderate correlations ranging between 0.01 to 0.44. Only one correlation between patient and caregiver responses was found to be significant. The degree of fault placed on 'the patient' in relation to control over the disease was highly significant ($p \leq 0.00$) with a correlation of 0.44. Therefore, as patients' feelings of fault increased, so to did the feelings of fault the caregivers felt toward 'the patient' in his or her efforts to control the course of the disease. A complete listing of significant and non-significant findings is provided in Table 8.

Table 8. Offset Reactions

	Patient Mean Score (SD)	Caregiver Mean Score (SD)	Kendall's tau_b score	Absolute Difference Mean (SD)
<i>Degree of responsibility for controlling patients' lung cancer</i>				
Blame patient for efforts to control aspects of the disease	1.24 (1.56)	0.94 (1.32)	0.29	1.06 (1.37)
Blame caregiver for efforts to control aspects of the patients' disease	0.06 (0.24)	0.53 (1.02)*	-0.15	0.61 (1.03)
Fault patient in efforts to control aspects of the disease	1.24 (1.52)	0.88 (1.27)	0.44**	1.00 (1.20)
Fault caregiver for efforts to control aspects of the patients' disease	0.15 (0.51)	0.47 (0.86)***	-0.18	0.64(0.93)
Hold patient responsible in efforts to control aspects of the disease	2.91 (1.35)	1.97 (1.60)*	-0.13	1.94 (1.39)
Hold caregiver responsible for efforts to control aspects of the patients' disease	0.79 (1.41)	1.09 (1.31)	0.10	1.21 (1.34)
<i>Degree of anger for controlling patients' lung cancer</i>				
Anger toward patient for efforts to control aspects of the disease	1.00 (1.32)	0.50 (1.05)***	0.18	0.97 (1.16)
Anger toward caregiver for efforts to control aspects of the patients' disease	0.00 (0.00)	0.38 (0.78)***	Unable to compute	0.39 (0.79)
Annoyance toward patient for efforts to control aspects of the disease	1.45 (1.54)	0.65 (1.10)*	0.25	1.09 (1.44)
Annoyance toward caregiver for efforts to control aspects of the patients' disease	0.06 (0.35)	0.53 (0.93)*	-0.11	0.61 (0.97)
Aggravation toward patient for efforts to control aspects of the disease	1.54 (1.46)	0.53 (0.99)*	0.21	1.18 (1.31)
Aggravation toward caregiver for efforts to control aspects of the patients' disease	0.06 (0.24)	0.50 (0.96)*	0.09	0.48 (0.97)
<i>Degree of pride for controlling patients' lung cancer</i>				
Pride in patient for attempts to control aspects of the disease	2.76 (1.15)	2.76 (1.46)	0.23	1.12 (1.02)
Pride in caregiver for efforts to control aspects of the patients' disease	3.06 (1.30)	1.79 (1.45)*	0.16	1.76 (1.22)
Satisfied with patient for attempts to control aspects of the disease	2.70 (0.92)	2.76 (1.33)	0.09	1.18 (0.95)

Satisfied with caregiver for attempts to control aspects of the patients' disease	3.24 (1.06)	2.23 (1.48)*	0.08	1.61 (1.25)
Hopeful in patient for attempts to control aspects of the disease	3.06 (1.00)	3.00 (1.20)	-0.03	1.12 (0.99)
Hopeful in caregiver for attempts to control aspects of the patients' disease	3.15 (1.23)	2.94 (1.23)	-0.01	1.24 (1.27)

* $p \leq 0.05$ indicating either a significant association between variables or a significant difference in Wilcoxon matched-pairs signed-rank test (Informal caregiver score – Patient score)

** $p \leq 0.01$

*** trend in data ($p \geq 0.05-0.10$)

Footnote: Correlation for anger related to the caregivers' efforts to control the cancer was incomputable as the mean score for the patients' response for this question was zero.

Further analysis of attribution responses between patients and caregivers on offset reactions, including judgments of responsibility and emotions, revealed several significant differences according to the Wilcoxon matched-pairs sign rank test. Each will be described below.

Degree of responsibility for controlling patients' lung cancer.

Two significant differences were detected by the Wilcoxon matched-pairs sign rank test in relation to attributions of responsibility for controlling the patients' lung cancer, the first being the attribution of blame toward 'the caregiver' ($p = 0.02$). Examination of mean scores revealed the caregivers felt significantly more to blame in their efforts to control the patients' disease (mean = 0.53, SD 1.02) when compared to reported feelings of blame the patients' felt toward the caregivers for same (mean = 0.06, SD 0.24).

Another significant difference was found between patient and caregiver responses related to holding 'the patient' responsible in relation to their efforts to control disease progression ($p = 0.03$). In this case, mean scores revealed that patients held themselves more responsible in their efforts to control the disease (mean = 2.91, SD 1.35) in comparison to the levels of responsibility caregivers placed on patients (mean = 1.97, SD 1.60).

A trend in the data (p values between 0.05 and .10) was detected in relation to attributions of fault in 'the caregiver' for efforts to control the course of the patients' lung cancer. The results suggested that caregivers placed significantly more fault on themselves for their efforts (mean = 0.47, SD 0.86) than the patients placed in the

caregivers (mean = 0.15, SD 0.51) for controlling the progression of lung cancer ($p = .10$).

Discrepancy scores for the remaining illness attributions/emotional responses for offset reactions related to dimensions of responsibility found the greatest discrepancy between scores related to holding 'the patient' responsible for controllability over the cancer with an absolute difference score of 1.94 (SD 1.39), with holding 'the caregiver' responsible for controllability over the cancer being the next most discrepant score of 1.21 (SD 1.34). Feelings of blame toward 'the patient' had an absolute mean difference score of 1.06 (SD 1.37) whereas feelings of blame toward 'the caregiver' had the smallest discrepancy score of 0.61 (SD 1.03). Faulting 'the patient' had an absolute difference score of 1.00 (SD 1.20) and faulting 'the caregiver' had a discrepancy score of 0.64 (SD 0.93) (Table 8). The theoretical range of absolute difference scores was from 0 to 4.

Degree of anger for controlling patient's lung cancer

In relation to feelings of annoyance toward 'the patient', an examination of mean scores revealed that patient were significantly more annoyed with their own efforts to control the disease (mean = 1.45, SD 1.54) than what the caregivers reported feeling toward the patients (mean = 0.65, SD 1.10) ($p = 0.01$). Conversely, caregivers reported feeling significantly more annoyed with their efforts to control patient disease (mean = 0.53, SD 0.93) than what patients reported feeling toward caregivers for controlling the disease progression (mean = 0.06, SD 0.35) ($p = 0.02$).

Feelings of aggravation were also found to be significantly different between patient and caregiver groups. First, patients were significantly more aggravated with themselves in their efforts to control the disease (mean = 1.54, SD 1.46) when compared

with the level of aggravation they felt toward 'the patient' to control the disease (mean = 0.53, SD 0.99) ($p = 0.00$). In addition, caregivers reported greater feelings of aggravation in their attempts to control patient disease (mean = 0.50, SD 0.96) than what the patients reported feeling toward the caregiver for their efforts to control patient disease (mean = 0.06, SD 0.24) ($p = 0.02$).

Significant trends were found relating to attributions of anger for controlling the course of lung cancer. First, attributions of anger toward 'the caregiver' in their efforts at controlling disease progression were reported to be higher on the part of caregivers (mean = 0.38, SD 0.78) than on the part of patients (mean = 0.00, SD 0.00) ($p = 0.07$). A trend in the data was also found in that patients reported greater feelings of anger toward themselves in relation to their attempts to control the disease (mean = 1.0, SD 1.32) compared to what the caregivers reported feeling toward the patients for same (mean = 0.50, SD 1.05) ($p = 0.08$).

Discrepancy scores for the dimensions of anger related to offset reactions found the greatest discrepancy between patient and caregiver scores related to aggravation toward 'the patient' for controllability over the cancer with a score of 1.18 (SD 1.31), the discrepancy score for aggravation toward 'the caregiver' for controllability over the cancer was 0.48 (SD 0.97). Feelings of annoyance toward 'the patient' was the next most discrepant with an absolute difference score of 1.09 (SD 1.44). Feelings of annoyance toward 'the caregiver' had a discrepancy score of 0.61 (SD 0.97). The discrepancy score related to attributions of anger toward 'the patient' related to controllability over the cancer was 0.97 (SD 1.16), with the absolute difference between patient and caregiver

reports of anger toward 'the caregiver' being the least discrepant at 0.39 (SD 0.79). The theoretical range of absolute difference scores was from 0 to 4.

Degree of pride for controlling patient's lung cancer.

Two significant differences were detected in relation to attributions of pride for controlling the progression of lung cancer. First, an examination of mean scores revealed that patients reported feeling significantly more pride in the caregivers' attempts (mean = 3.06, SD 1.30) to control the disease than caregivers reported feeling in their efforts to control the disease (mean = 1.79, SD 1.45) ($p = 0.00$). Second, feelings of satisfaction in the attempts of 'the caregiver' to control aspects of the disease differed significantly between patients and caregivers, with patients reporting higher levels of satisfaction with the caregivers (mean = 3.24, SD 1.06) than the caregivers reported feeling with themselves (mean = 2.23, SD 1.48) ($p = 0.01$). Table 8 contains a list of all significant and non-significant findings.

Discrepancy scores for the dimensions of pride related to offset reactions found the greatest discrepancy between patient and caregiver scores related to feelings of pride in caregiver attempts at controlling the cancer with an absolute difference score of 1.76 (SD 1.22). Feelings of pride in patient attempts had an absolute difference score of 1.12 (SD 1.02). The absolute difference score related to feelings of satisfaction in attempts of 'the caregiver' to control the disease was 1.61 (SD 1.25), whereas feelings of satisfaction in the attempts of 'the patient' had a discrepancy score of 1.18 (SD 0.95). The discrepancy score for feelings of hopefulness in patient attempts at controlling the disease was the least discrepant at 1.12 (SD 0.99) whereas feelings of hopefulness in caregiver

attempts had an absolute difference score of 1.24 (SD 1.27) (Table 8). The theoretical range of absolute difference scores was from 0 to 4.

Comparison of between-group attribution responses to onset and offset reactions

When analyzing between-group responses to offset reactions, it is important to consider how the mean scores of the patient and caregiver groups compared to their onset reactions in the onset condition. A cursory examination of the attributional reactions and emotions held by patients and caregivers was conducted. Both significant and non-significant attributions were considered.

Attributions of Blame.

Both patient and caregiver groups provided higher mean ratings of blame toward 'the patient' than toward 'the caregiver' in relation to control over the cause of the lung cancer (patient mean score was 1.97, SD 1.55; caregiver mean score was 1.35, SD 1.57) in comparison to control over disease progression (patient mean score was 1.24, SD 1.56; caregiver was mean score 0.94, SD 1.32).

Attributions of Fault.

Although patient and caregiver groups provided higher mean ratings of fault toward 'the patient' than 'the caregiver' in relation to control over the cause of the lung cancer (patient mean score was 1.24, SD 1.52; caregiver mean score was 0.94, SD 1.39) and control over disease progression (patient mean score was 1.24, SD 1.52; caregiver mean score was 0.88, SD 1.27), the respective mean scores were similar for both onset and offset conditions.

Attributions of Responsibility.

Feelings of responsibility were reported more strongly by both respondent groups toward 'the patient' rather than 'the caregiver' in relation to efforts to control the course of the lung cancer (patients' mean score 2.91, SD 1.35; caregivers' mean score 1.97, SD 1.60) as opposed to feelings of responsibility over control over the cause of the disease (patients' mean score 2.20, SD 1.59; caregivers' mean score 1.32, SD 1.45).

Emotion of Anger.

The ratings on anger in relation to the cause and control of the patients' lung cancer varied slightly between patient and caregiver groups. Anger was felt more strongly toward 'the patient' than 'the caregiver' in both onset and offset reaction conditions. However, patients reported slightly higher feelings of anger toward themselves in the onset reaction condition (patients' mean score onset 1.09, SD 1.33; caregivers' mean score 0.20, SD 0.54), whereas caregivers reported higher levels of anger toward 'the patient' in the offset reaction condition (patients' mean score 1.00, SD 1.32; caregivers' mean score 0.50, SD 1.05).

Emotion of Annoyance.

Feelings of annoyance were reported strongest toward 'the patient' as opposed to the 'caregiver' in relation to both the cause of the cancer (onset reaction condition) and control over the progression of the cancer (offset reaction condition) by both patients and caregivers. However patients reported higher levels of annoyance toward themselves than caregivers in relation to onset condition (patient mean score was 1.65, SD 1.30; caregiver mean score was 0.32, SD 0.73), whereas caregivers reported higher levels of

annoyance toward 'the patient' in the offset reaction condition, (patient mean score 1.45, SD 1.54; caregiver mean score was 0.65, SD 1.10).

Emotion of Aggravation.

Feelings of aggravation were reported strongest toward 'the patient' as opposed to the 'caregiver' in relation to both the cause of the cancer (onset reaction condition) and control over the progression of the cancer (offset reaction condition) by both patients and caregivers. However patients reported higher levels of aggravation toward themselves than caregivers in relation to onset condition (patient mean score was 1.70, SD 1.51; caregiver mean score was 0.32, SD 0.68), whereas caregivers reported higher levels of aggravation toward 'the patient' in the offset reaction condition, (patient mean score 1.54, SD 1.46; caregiver mean score was 0.53, SD 0.96).

Supplemental within-group analysis for offset reactions

As done with the onset reaction responses, supplemental within-group analyses was conducted with offset reactions to provide additional insight into the respective patient and caregiver attributional reactions.

Between-group analysis – blame, fault, and responsibility. As previously reported, the mean scores indicated that more blame, fault, and responsibility toward the 'the patient' were reported by patients in comparison to reports by the caregivers (patient mean score blame toward patient was 1.24, SD 1.56; caregiver mean score blame toward patient was 0.94, SD 1.32; patient mean score fault toward patient was 1.24, SD 1.52; caregiver mean score fault toward patient was 0.88, SD 1.27; patient mean score responsibility toward patient was 2.91, SD 1.35; caregiver mean score fault toward patient was 1.97, SD 1.60). Conversely, attributions of blame, fault, and responsibility toward 'the caregiver' for

control over the course of patient disease were consistently higher as reported by caregivers in comparison to patient mean scores (caregiver mean score blame toward caregiver was 0.53, SD 1.02; patients' mean score blame toward caregiver was 0.06, SD 0.24; caregiver mean score fault toward caregiver was 0.47, SD 0.86; patient mean score fault toward caregiver was 0.15, SD 0.51; caregiver mean score responsibility toward caregiver was 1.09, SD 1.31; patient mean score responsibility toward caregiver was 0.79, SD 1.41).

Within-group analysis – blame, fault, and responsibility. A within-group analysis of mean scores reported by caregivers revealed that caregivers consistently reported higher attributions of blame, fault, and responsibility toward 'the patient' than they did toward themselves regarding control over disease progression (caregiver mean score blame toward patient was 0.94, SD 1.32; caregiver mean score blame toward caregiver was 0.53, SD 1.02; caregiver mean score fault toward patient was 0.88, SD 1.27; caregiver mean score fault toward caregiver was 0.47, SD 0.86; caregiver mean score responsibility toward patient was 1.97, SD 1.60; caregiver mean score responsibility toward caregiver was 1.09, SD 1.31). The results suggested that caregivers tended to hold patients more to blame, more at fault, and more responsible for their efforts to control the course of the lung cancer than they did toward themselves. These findings were not apparent when examining solely between-group responses.

A review of within-group mean scores for the patient respondent group consistently demonstrated that patients tended to hold themselves more to blame, more at fault, and more responsible for their efforts to control the course of their disease than they did for caregivers (patient mean score blame toward patient was 1.24, SD 1.56; patient

mean score blame toward caregiver was 0.06, SD 0.24; patient mean score fault toward patient was 1.24, SD 1.52; patient mean score fault toward caregiver was 0.15, SD 0.51; patient mean score responsibility toward patient was 2.91, SD 1.35; patient mean score responsibility toward caregiver was 0.79, SD 1.41). These findings are consistent with between-group analyses results.

Between-group analysis – anger, annoyance, and aggravation. Between-group analysis of emotions of anger, annoyance, and aggravation for efforts to control the course of patient disease received the highest ratings for ‘the patient’ by patients in comparison to the mean scores reported by caregivers (patient mean score anger toward patient was 1.0, SD 1.32; caregiver mean score anger toward patient was 0.50, SD 1.05; patient mean score annoyance toward patient was 1.45, SD 1.54; caregiver mean score annoyance toward patient was 0.65, SD 1.10; patient mean score aggravation toward patient was 1.54, SD 1.46; caregiver mean score aggravation toward patient was 0.53, SD 0.99). Emotions of anger, annoyance, and aggravation toward ‘the caregiver’ received the highest ratings by caregivers in comparison to the mean scores of patients (caregiver mean score anger toward caregiver was 0.38, SD 0.78; patient mean score anger toward caregiver was 0.00, SD 0.00; caregiver mean score annoyance toward caregiver was 0.53, SD 0.93; patient mean score annoyance toward caregiver was 0.06, SD 0.35; caregiver mean score aggravation toward caregiver was 0.50, SD 0.96; patient mean score aggravation toward caregiver was 0.06, SD 0.24).

Within group analyses – anger, annoyance, and aggravation. A within-group analyses of mean scores reported by caregivers revealed that caregivers consistently provided higher ratings of anger, annoyance, and aggravation toward ‘the patient’ than

toward themselves (caregiver mean score anger toward patient was 0.50, SD 1.05; caregiver mean score anger toward caregiver was 0.38, SD 0.78; caregiver mean score annoyance toward patient was 0.65, SD 1.10; caregiver mean score annoyance toward caregiver was 0.53, SD 0.93; caregiver mean score aggravation toward patient was 0.53, SD 0.99; caregiver mean score aggravation toward caregiver was 0.50, SD 0.96).

Within-group mean scores of the patient respondent group revealed however that they reported more anger, annoyance, and aggravation toward themselves in their efforts to control aspects of their disease than they did toward 'the caregiver' (patient mean score anger toward patient was 1.0, SD 1.32; patient mean score anger toward caregiver was 0.00, SD 0.00; patient mean score annoyance toward patient was 1.45, SD 1.54; patient mean score annoyance toward caregiver was 0.06, SD 0.35; patient mean score aggravation toward patient was 1.54, SD 1.46; patient mean score aggravation toward caregiver was 0.06, SD 0.24). These findings are consistent with findings derived from the between-group analyses.

Between-group analyses – pride, satisfaction, and hopefulness. As previously noted, between-group analyses of mean scores for emotions of pride, satisfaction, and hopefulness revealed that mean ratings of pride in the patient's attempt at controlling aspects of the disease were similar between patient and caregiver groups (patient mean score was 2.76, SD 1.15; caregiver mean score was 2.76, SD 1.46). Reports on satisfaction in the patient's efforts to control aspects of the disease were more highly rated by caregivers than by patients (caregiver mean score was 2.76, SD 1.33; patient mean score was 2.70, SD 0.92). However reports on hopefulness in patient attempts to control the course of the disease were more highly rated for 'the patient' by patients

themselves (patient mean score was 3.06, SD 1.00; caregiver mean score was 3.00, SD 1.20). Reports on feelings of pride, satisfaction, and hopefulness in attempts by 'the caregiver' were rated more highly by patients when compared to the mean scores of caregivers (patient mean score pride toward caregiver was 3.06, SD 1.30; caregiver mean score pride toward caregiver was 1.79, SD 1.45; patient mean score satisfaction toward caregiver was 3.24, SD 1.06; caregiver mean score satisfaction toward caregiver was 2.23, SD 1.48; patient mean score hopeful toward caregiver was 3.15, SD 1.23; caregiver mean score hopeful toward caregiver was 2.94, SD 1.23).

Within-group analyses – pride, satisfaction, and hopefulness. A within-group analyses of caregiver mean scores for pride, satisfaction, and hopefulness revealed that caregivers consistently reported higher levels of these feelings toward 'the patient' than for themselves (caregiver mean score pride toward patient was 2.76, SD 1.46; caregiver mean score pride toward caregiver was 1.79, SD 1.45; caregiver mean score satisfaction toward patient was 2.76, SD 1.33; caregiver mean score satisfaction toward caregiver was 2.23, SD 1.48; caregiver mean score hopefulness toward patient was 3.00, SD 1.20; caregiver mean score hopefulness toward caregiver was 2.94, SD 1.23).

Conversely, a review of mean scores for the patient respondent group revealed that they felt more pride, satisfaction and hopeful toward 'the caregiver' than toward themselves in efforts to control the course of the disease (patient mean score pride toward caregiver was 3.06, SD 1.30; patient mean score pride toward patient was 2.76, SD 1.15; patient mean score satisfaction toward caregiver was 3.24, SD 1.06; patient mean score satisfaction toward patient was 2.70, SD 0.92; patient mean score hopeful toward

caregiver was 3.15, SD 1.23; patient mean score hopeful toward patient was 3.06, SD 1.00).

In summary, a within-group analysis for attributional responses related to offset reactions revealed many interesting findings. First, caregivers appeared to attribute more blame, fault, and responsibility to 'the patient' than toward themselves in relation to control over the course of the disease. Patients also attributed more blame, more fault, and more responsibility toward themselves than toward their caregivers. Second, caregivers also consistently reported more anger, annoyance, and aggravation toward 'the patient' than toward themselves. Patients also reported higher levels of anger, annoyance, and aggravation toward themselves as opposed to their caregivers. While caregivers provided more high ratings on the dimensions of responsibility and anger toward the patient than toward themselves, they also reported more highly on pride, satisfaction, and hopefulness toward 'the patient' than toward themselves. The patients reported the feelings of pride, satisfaction, and hopefulness more-so toward the caregivers than themselves.

Caregiver Perspective-Taking

The mean responses to the 20 items and a total score on the Caregiver Perspective-Taking Scale were calculated for both patient and caregiver groups (Table 9). First, the total mean scores for both groups were similar (the patient group total mean score was 58.82, SD 13.33) and the caregiver group total mean score was 57.06, SD 11.81) with less than one unit difference, indicating similar perceptions between the groups regarding the perspective-taking ability of the caregivers. The Wilcoxon matched pair sign rank test confirmed that there was no significant difference in the total mean

Table 9. Caregiver Perspective-taking

	Patient Mean Score (SD)	Caregiver Mean Score (SD)	Kendall's tau_b score	Absolute Difference Mean Score (SD)
CPT Question 1: "When involved in an argument with me, my caregiver is the type of person who will consider and take into account my point of view and compare that with his/her own"	3.03 (0.87)	2.79 (1.07)	0.23	0.88 (0.73)
#CPT Question 2: "My caregiver is not good at understanding my problems"	3.00 (1.35)	2.88 (1.15)	0.12	1.23 (1.16)
CPT Question 3: My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from.	3.29 (0.97)	2.76 (1.10)*	0.25	1.00 (0.70)
#CPT Question 4: My caregiver does not seem to know how I feel.	3.26 (1.08)	2.82 (1.11)***	0.01	1.15 (0.99)
CPT Question 5: My caregiver is able to accurately compare his/her point of view with mine.	2.94 (0.92)	2.58 (1.10)***	0.13	1.06 (0.65)
CPT Question 6: "My caregiver evaluates my motivation for doing something before he/she makes a judgment about a situation"	3.06 (0.78)	2.85 (1.05)	0.15	0.91 (0.83)
#CPT Question 7: "My caregiver easily becomes impatient with me"	2.85 (1.30)	2.91 (1.21)	-0.07	1.35 (1.25)
#CPT Question 8: My caregiver is not able to put him/herself into my shoes.	2.79 (1.27)	2.17 (1.31)***	0.07	1.44 (1.18)
CPT Question 9: "My caregiver nearly always knows exactly what I mean"	2.88 (0.91)	2.70 (1.00)	0.08	0.82 (0.80)
#CPT Question 10: "My caregiver does not sense or realize what I am feeling"	1.15 (1.39)	1.12 (1.12)	0.24	1.15 (1.05)
CPT Question 11: "My caregiver realizes what I mean even when I have difficulty saying it"	3.09 (0.90)	2.94 (0.95)	0.14	0.79 (0.88)
#CPT Question 12: "My caregiver does not usually understand the whole meaning of what I am saying to them"	1.06 (1.04)	1.15 (1.05)	0.05	1.09 (0.93)

CPT Question 13: "My caregiver appreciates how things I experience feel to me"	3.29 (0.83)	3.20 (0.95)	0.29	0.67 (0.84)
CPT Question 14: Before criticizing me, my caregiver tries to imagine how I feel.	3.06 (1.15)	3.15 (0.92)	0.44**	0.67 (0.91)
#CPT Question 15: "If my caregiver thinks I am right about something he/she does not waste much time listening to my arguments"	1.65 (1.30)	1.44 (1.37)	0.04	1.38 (1.25)
CPT Question 16: My caregiver tries to understand me better by imagining how things look from my perspective.	2.85 (1.05)	3.09 (0.86)	0.31*	0.76 (0.89)
CPT Question 17: "My caregiver believes there are two sides to every argument and he/she tries to look at both sides"	3.15 (0.86)	3.23 (0.85)	0.05	0.79 (0.81)
#CPT Question 18: "My caregiver sometimes finds it difficult to see things from my perspective"	1.50 (1.21)	1.59 (1.10)	0.11	1.15 (1.02)
CPT Question 19: "My caregiver tries to look at my perspective before making a decision"	3.12 (0.81)	3.20 (0.77)	-0.04	0.79 (0.88)
CPT Question 20: When my caregiver is upset with me he/she tries to put him/herself in my shoes for awhile.	2.50 (0.96)	3.03 (0.80)*	0.09	0.94 (0.92)
Total Caregiver Perspective-taking (CPT) Score	58.82 (13.33)	57.06 (11.81)	0.32	

* $p \leq 0.05$ indicating either a significant association between variables or a significant difference in Wilcoxon matched-pairs signed-rank test (Informal caregiver score – Patient score)

** $p \leq 0.01$

*** trend in data ($p \geq 0.05$ -0.10)

indicates reversed score questions as per instructions of Long & Andrew (1990). When "0" is chosen indicating the question "does not describe my partner very well" a score of 4 points is given. When "4" is chosen indicating the question "does describe my partner very well" a score of zero points are given.

responses between the patient and caregiver groups ($p = 0.33$). Also, Kendall's τ_b did not reveal a statistically significant correlation between total perspective-taking scores between patients and caregivers ($r = 0.32$, $p = 0.20$).

Kendall's τ_b and Wilcoxon matched pairs tests were also performed on the individual questions from the Caregiver Perspective-taking Scale to detect any statistically significant correlations and mean differences between patient and caregiver responses. Two significant correlations were revealed. The first significant correlation was related to caregiver ability to imagine patient feelings, or as stated in Question 14, "Before criticizing me, my caregiver tries to imagine how I feel". This item had a moderately strong, positive association between patient and caregiver responses (Kendall's $\tau_b = 0.44$; $p \leq 0.01$). As such, the caregiver's perception of his or her ability to imagine how the patient feels varied similarly to that of the patient's perception of the caregivers' ability to imagine the patient's feelings.

The second significant correlation was in relation to the caregiver's ability to understand the patient through perspective-taking, or as stated in Question 16, "My caregiver tries to understand me better by imagining how things look from my perspective." This item had a weak positive association between patient and caregiver responses (Kendall's $\tau_b = 0.31$, $p \leq 0.05$). In other words, the caregiver's perception of his or her ability to understand the patient through perspective-taking varied similarly with the patient's perception of the caregiver's ability to perspective-take.

Two significant differences were found between patient and caregiver perceptions of caregiver perspective-taking in their relationship. First, patients and caregivers differed in their perceptions regarding Question 3 ($p = 0.01$), or as stated, "My caregiver

not only listens to what I am saying but really understands and seems to know where I am coming from.” The patients were more likely to perceive the caregivers to be more successful at understanding them than caregivers themselves did (the patient mean score was 3.29, SD 0.97; the caregiver mean score was 2.76, SD 1.10). The second significant difference was found in relation to Question 20 ($p = 0.02$) that was stated as follows, “When my caregiver is upset with me he/she tries to put him/herself in my shoes for awhile.” In relation to this finding, caregivers were more likely to agree with this statement than patients (patient mean score 2.50, SD 0.96; caregiver mean score 3.03, SD 0.80).

Three trends (i.e. p values greater than 0.05 and less than .10) in the data were observed. The first trend occurred in relation to Question 4 that was stated as, “My caregiver does not seem to know how I feel.” Caregivers were more likely than the patients to be in agreement with this statement (patient mean score 3.26, SD 1.08; caregiver mean score 2.82, SD 1.11). The next trend was found in Question 5 which stated “My caregiver is able to accurately compare his/her point of view with mine.” In this case, patients were more likely to be in agreement with this statement than were caregivers (patient mean score 2.94, SD 0.92; caregiver mean score 2.58, SD 1.10). The last trend related to Question 8 that was stated as follows: “My caregiver is not able to put him/herself into my shoes” or in other words, caregivers are not able to put themselves in patients’ situations in order to gain a better understanding of those situations. The caregivers agreed with this statement more than patients (patient mean score 2.79, SD 1.17; caregiver mean score 2.17, SD 1.31. Mean scores for this question were based on reverse scoring as instructed by Long & Andrew (1990) wherein a lower

score indicates a higher level of agreement with the statement and a higher score indicates a lower level of agreement with the statement. Table 9 provides a listing of all significant and non-significant findings.

The discrepancy score on the individual questions from Caregiver Perspective-Taking Scale ranged from 0.67 - 1.44 out of a theoretical range of 0-4. Overall, the range of discrepancy scores was small, indicating similar perceptual congruence between patients and caregivers on caregiver perspective-taking skill. The largest discrepancy was found for Caregiver Perspective-taking Question #8 "My caregiver is not able to put him/herself into my shoes" with an absolute difference score of 1.44 (SD 1.18). The least discrepancy was found for Caregiver Perspective-taking Question # 13 "My caregiver appreciates how things I experience feel to me" with an absolute difference score of 0.67 (SD 0.84). A complete listing of discrepancy scores for the Caregiver Perspective-taking Scale can be found in Table 9.

Symptom Experiences

The symptom experiences (presence, frequency, severity, and distress) of patients were measured in relation to pain, shortness of breath, and fatigue from the perspectives of both patients and caregivers on an abbreviated version of the MSAS (Appendices H and I). Descriptive statistics were used to analyze the results. Table 10 provides a summary of findings regarding symptom presence. Patients and caregivers were asked to reply to the response option "did not have" for each of the three symptoms during the preceding week if the patients were deemed not to have experienced the symptom. Frequency data was recorded for the presence of each symptom. Percentages were calculated to allow for comparison between patient and caregiver responses for each of

the three symptoms. The paired Chi squared test was used to test for differences between categorical data surrounding symptom presence. No statistically significant p values were detected, indicating that there were no significant differences between how patients and caregivers perceived symptom presence in patients over the preceding week.

A review of percentages between respondent groups in relation to the presence of patient symptom experiences revealed several findings. With regard to the presence of pain, the caregivers tended to underestimate the occurrence of pain in patients over the preceding week with fifty-three percent (n=18) of caregivers indicating 'the patient' had pain compared to sixty-five percent (n=22) of patients who indicated that they experienced pain in the previous week. In relation to the experience of shortness of breath in the preceding week, the caregivers underestimated its occurrence in patients with sixty-eight percent (n=23) of caregivers indicating 'the patient' experienced some shortness of breath in the previous week compared to the seventy-three percent (n=25) of patients who indicated experiencing shortness of breath. Reports of fatigue in patients over the preceding week were overestimated by the caregivers with eighty-five percent (n=29) indicating that patients experienced fatigue compared to the seventy-three percent (n=25) reported by patients.

Table 10. Symptom Presence

Symptom Presence	Patient %, (n of 34)	Caregiver %, (n of 34)	Paired Chi squared test (p)
Pain	Yes: 65, (22) No: 35, (12)	Yes: 53, (18) No: 47, (16)	0.42
Shortness of Breath	Yes: 73, (25) No: 27, (9)	Yes: 68, (23) No: 32, (11)	0.73
Fatigue	Yes: 73, (25) No: 27, (9)	Yes: 85, (29) No: 15, (5)	0.22

In order to further compare perceptual agreement between patients and caregivers on underlying symptom experiences, each symptom was explored in relation to its frequency, severity, and distress. The theoretical range of scores for each of the symptom dimension ranged from zero to four. If a symptom was not perceived by the patient or the caregiver to be experienced by the patient over the preceding week, each dimension was scored as a zero. The values for frequency and severity dimensions were based on Likert-type scales ranging from one to four, where one indicated 'rarely' on the frequency scale and 'slight' on the severity scale, and four was 'almost constantly' on the frequency scale and 'very severe' on the severity scale. A zero on the distress scale represented 'not at all' and four represented 'very much' distress arising from the symptom. Total symptom scores were also calculated for each respondent group and consisted of the average of the scores on the frequency, severity, and distress subscales (Portenoy et al., 1994).

Pain

A comparison of respondent group mean scores for frequency, severity and distress for pain was conducted (Table 11). The mean scores for pain frequency and severity were slightly higher for patients (frequency 1.65, SD 1.41; severity 1.35, SD 1.20) than caregivers (frequency 1.47, SD 1.50; severity 1.23, SD 1.18). Patients' pain distress on the other hand was rated slightly higher by the caregivers (caregivers' mean score 1.32, SD 1.47; patients' mean score 1.03, SD 1.22). Correlations between patients' and caregivers' responses were performed for the three symptom dimensions using Kendall's tau_b revealing significant moderate correlations. The respondent group scores for pain frequency had a significant positive correlation ($\tau_b = 0.30, p \leq 0.05$),

Table 11 Symptom dimensions and total symptom scores

Symptom dimensions	Patient n; range	Patient Mean (SD)	Caregiver n; range	Caregiver Mean (SD)	Kendall's tau_b	Absolute Difference Mean Score (SD)
Pain						
Frequency	34; 0-4	1.65 (1.41)	34; 0-4	1.47 (1.50)	0.30*	1.12 (1.22)
Severity	34; 0-4	1.35 (1.20)	34; 0-4	1.23 (1.18)	0.35*	0.83 (1.0)
Distress	34; 0-4	1.03 (1.22)	34; 0-4	1.32 (1.47)	0.45**	0.88 (1.01)
Total Score	34; 0-4	1.34 (1.20)	34; 0-4	1.34 (1.34)	0.41**	
Shortness of Breath						
Frequency	34; 0-4	1.76 (1.39)	34; 0-4	1.82 (1.40)	0.55**	0.82 (0.87)
Severity	34; 0-4	1.44 (1.16)	34; 0-4	1.50 (1.19)	0.46**	0.76 (0.78)
Distress	34; 0-4	1.17 (1.40)	34; 0-4	1.35 (1.18)	0.46**	0.82 (0.94)
Total Score	34; 0-4	1.46 (1.21)	34; 0-4	1.56 (1.19)	0.51**	
Fatigue						
Frequency	34; 0-4	1.97 (1.38)	34; 0-4	2.50 (1.28)*	0.36*	1.06 (1.15)
Severity	34; 0-4	1.56 (1.56)	34; 0-4	1.88 (1.01)	0.42**	0.85 (0.78)
Distress	34; 0-4	1.47 (1.50)	34; 0-4	1.79 (1.32)	0.59**	0.79 (0.81)
Total Score	34; 0-4	1.67 (1.26)	34; 0-4	2.06 (1.08)*	0.50**	

* $p \leq 0.05$ indicating either a significant association between variables or a significant difference in Wilcoxon matched-pairs signed-rank test (Informal caregiver score – Patient score)

** $p \leq 0.01$

pain severity had a significant positive correlation ($\tau b = 0.35$, $p \leq 0.05$), and pain distress had a significant positive correlation ($\tau b = 0.45$, $p \leq 0.01$) (see Table 11). The Wilcoxon matched-pairs test did not reveal any significant differences between the scores of the respondents.

The total score for pain had a significant positive correlation ($\tau b = 0.41$, $p \leq 0.01$) between patients' and caregivers' responses (patients' total score 1.34, SD 1.20; caregivers' total score 1.34, SD 1.34). The Wilcoxon matched-pairs test on the total scores between the groups revealed no significant differences between group means. Table 11 summarizes the findings.

Shortness of Breath

Patient and caregiver mean responses to frequency, severity, and distress for shortness of breath are reported in Table 11. The caregiver mean scores for frequency, severity, and distress were slightly higher than patient mean scores (caregiver mean score frequency was 1.82, SD 1.40; patient mean score frequency was 1.76, SD 1.39; caregiver mean score severity was 1.50, SD 1.19; patient mean score severity was 1.44, SD 1.16; caregiver mean score distress was 1.35, SD 1.18; patient mean score distress was 1.17, SD 1.40). Kendall's τ_b correlations revealed moderate to strong correlations for each of the three dimensions. Significant associations between patient and caregiver responses were found on shortness of breath frequency ($\tau b = 0.55$, $p \leq 0.01$), shortness of breath severity ($\tau b = 0.46$, $p \leq 0.01$), and shortness of breath distress ($\tau b = 0.46$, $p \leq 0.01$). No significant differences between patient and caregiver mean scores for shortness of breath frequency, severity, and distress were detected.

The total mean scores for shortness of breath (patient mean score was 1.46, SD 1.21; caregiver mean score was 1.56, SD 1.19) were significantly correlated ($\tau_b = 0.51, p \leq 0.01$). There was no significant difference between total scores for patients and caregivers.

Fatigue

The mean scores for all three dimensions of fatigue were reported higher by caregivers compared to patient reports (caregiver mean fatigue frequency score 2.50, SD 1.28; patient mean score for fatigue frequency 1.97, SD 1.38; caregiver mean score severity was 1.88, SD 1.01; patient mean score severity was 1.56, SD 1.56; caregiver mean score distress was 1.79, SD 1.32; patient mean score distress was 1.47, SD 1.50). Kendall's τ_b correlations revealed moderate to strong correlations for each of the three dimensions. Significant associations between patient and caregiver responses were found on fatigue frequency ($\tau_b = 0.36, p \leq 0.05$), severity ($\tau_b = 0.42, p \leq 0.01$), and distress ($\tau_b = 0.59, p \leq 0.01$).

The total mean scores for fatigue (patient mean 1.67, SD 1.26; caregiver mean 2.06, SD 1.08) were significantly correlated ($\tau_b = 0.50, p \leq 0.01$). The total mean scores for patients and caregivers were also found to be significantly different according to the Wilcoxon matched-pairs test ($p = 0.04$) where the caregiver was more likely to report significantly higher levels of fatigue (caregiver mean 2.06, SD 1.08) than the patient (mean score 1.67, SD 1.26).

Discrepancy scores found for the symptom dimensions had a theoretical range of 0-4. A review of the absolute difference scores (Table 11) calculated for each of the symptom dimensions (frequency, severity, and distress) for pain, shortness of breath, and

fatigue revealed small discrepancies between patient and caregiver reports. The absolute difference between pain frequency was 1.12 (SD 1.22), pain severity 0.83 (SD 1.00), and pain distress 0.88 (SD 1.01). With respect to shortness of breath frequency, the discrepancy score was 0.82 (SD 0.87), for shortness of breath severity the absolute difference score was 0.76 (SD 0.78) and for shortness of breath distress, the absolute difference score was 0.82 (SD 0.94). The absolute difference score for fatigue frequency was calculated as 1.06 (SD 1.15), for fatigue severity 0.85 (SD 0.78), and for fatigue distress 0.79 (SD 0.81).

Research Question #2

If discrepancies are identified during the analysis of question one, what is the effect of these discrepancy scores for patient and caregiver ‘onset reactions’, ‘offset reactions’, and caregiver perspective-taking on levels of patient and caregiver perceptual agreement on patient symptom experiences?

To address research question two, the means of absolute differences between patient and caregiver perceptions on each attributional reaction (judgments of responsibility, negative emotions, and positive emotions) were correlated with the means of absolute differences calculated for each of three symptom dimensions, frequency, severity and distress for pain, shortness of breath, and fatigue. In addition, the means of absolute differences between patient and caregiver perceptions on caregiver perspective-taking were also correlated with the means of absolute differences on patient symptom experience dimensions. Only the significant correlations are reported in Tables 12-14.

Onset reactions (see Table 12).

Pain - severity. There were no significant correlations found between discrepancy scores for onset attributional responses (including 'blame', 'fault', responsibility', 'anger', 'annoyance', 'aggravation', 'sympathy', pity', and 'concern') and pain frequency or pain distress. However, there was a significant correlation between pain severity and 'faulting the patient for getting lung cancer' ($\tau b = 0.31$; $p \leq 0.05$) (see Table 12). In other words, the greater the discrepancy between patient and caregiver perceptions on patient fault for getting lung cancer, the greater the discrepancy in patient and caregiver perceptions of patient pain severity.

Shortness of breath -frequency. Significant correlations were also found between the discrepancy scores for onset attributional responses and shortness of breath frequency. First, there was a significant correlation between discrepancy scores for caregiver control over the cause of patient disease and shortness of breath frequency ($\tau b = 0.45$, $p \leq 0.01$). In other words, as differences between patient and caregiver perceptions relating to the caregiver degree of control over the cause of patient disease increased, the differences also increased between dyadic perceptions on frequency of shortness of breath. Second, a significant correlation was found related to the discrepancy score for blame toward 'the caregiver' for the cause of the disease and the discrepancy score for shortness of breath frequency ($\tau b = 0.36$, $p \leq 0.05$). As differences in perceptions between dyad members increased regarding the degree of blame placed on 'the caregiver' for the cause of the disease, so to did the differences in their respective perceptions of shortness of breath frequency. Third, the discrepancy score regarding feelings of fault placed on 'the caregiver' for the cause of patients'

Table 12. Correlations between discrepancy scores on onset attributional responses and patients' symptom experiences

	Patient-Caregiver Correlation Kendall's tau_b
<i>Discrepancy Pain Severity</i>	
Discrepancy fault patient for getting the disease	0.31*
<i>Discrepancy Shortness of Breath Frequency</i>	
Discrepancy control over cause of disease Caregiver	0.45**
Discrepancy caregiver blame for cause of disease	0.36*
Discrepancy fault caregiver for patient getting the disease	0.36*
Discrepancy caregiver held responsible for patient getting the disease	0.38*
Discrepancy annoyance toward caregiver for patient getting the disease	0.39*
<i>Discrepancy Shortness of Breath Distress</i>	
Discrepancy, sympathy toward Patient for cause of disease	0.37*
<i>Discrepancy Fatigue Frequency</i>	
Discrepancy anger toward Patient re: cause of disease.	-0.39**
Discrepancy annoyance toward patient re: cause of disease.	-0.32*
Discrepancy sympathy toward Patient re: cause of disease.	0.34*

* $p \leq 0.05$ ** $p \leq 0.01$

disease was also significantly correlated with the discrepancy score for shortness of breath frequency ($\tau_{b} = 0.36, p \leq 0.05$). In other words, as differences in perceptions of patients and caregivers increased on perceptions of fault toward 'the caregiver' for the cause of the disease, so to did differences in their perceptions regarding the frequency of shortness of breath in patients.

Fourth, a significant correlation was found between the discrepancy score for 'the caregiver' being held responsible for the cause of the disease and the discrepancy score for shortness of breath frequency ($\tau_{b} = 0.38; p \leq 0.05$). In other words, as differences in patient and caregiver perceptions increased regarding caregiver responsibility for disease occurrence, so did differences between patient and caregiver perceptions on the frequency of patient shortness of breath. Fifth, the discrepancy score on feelings of annoyance toward 'the caregiver' for causing patient disease was significantly correlated with the discrepancy score for shortness of breath frequency ($\tau_{b} = 0.39, p \leq 0.05$). In other words, as the difference in feelings of annoyance toward 'the caregiver' increased between patients and caregivers, the difference in their respective perceptions also increased on the frequency of patient shortness of breath.

Shortness of breath – distress. One significant correlation was found on shortness of breath distress. The discrepancy score for sympathy toward 'the patient' for getting cancer was found to correlate significantly with the discrepancy score for shortness of breath distress ($\tau_{b} = 0.37, p \leq 0.05$). In other words, as the difference increased in feelings of sympathy towards 'the patient' for getting cancer between patients and caregivers, the degree of difference increased in their respective perceptions on patient distress related to shortness of breath by patients.

Fatigue – frequency. In relation to the discrepancy score for fatigue frequency, several correlations were found. First, a negative correlation existed between the discrepancy score for anger toward the patient regarding the cause of the disease and the discrepancy score for fatigue frequency ($\tau b = -0.39$; $p \leq 0.01$). In other words, as patient and caregiver discrepancies in their respective feelings of anger toward ‘the patient’ decreased, there was greater discrepancy between patients and caregivers on frequency of fatigue frequency experienced by patients.

Second, a negative correlation was also detected between the discrepancy score for annoyance toward ‘the patient’ for the cause of the disease and the discrepancy score for fatigue frequency ($\tau b = -0.32$; $p \leq 0.05$). In other words, as patient and caregiver discrepancies on feelings of annoyance toward ‘the patient’ decreased, the discrepancy score related to the perceptions of fatigue frequency increased. Third, as the discrepancy score increased on feelings of sympathy toward ‘the patient’ regarding the cause of the disease, so did the discrepancy score on fatigue frequency ($\tau b = 0.34$, $p \leq 0.05$). In other words, as differences in feelings of sympathy toward ‘the patient’ increased between patients and caregivers, differences also increased in their perceptions of the frequency of patient fatigue.

Offset Reactions (see Table 13).

Pain – severity. Several significant correlations were found between attributional reactions and pain severity. First, as differences in perceptions of patients and caregivers increased regarding caregiver control over the course of the disease, differences also increased in patient and caregiver respective perceptions of patient pain severity ($\tau b = 0.30, p \leq 0.05$). Second, a significant negative correlation was also detected between discrepancies for fault toward ‘the caregiver’ regarding control over disease progression and discrepancies on pain severity ($\tau b = -0.39, p \leq 0.05$). In other words, as differences increased between patient and caregiver perceptions on fault regarding caregiver control over disease progression, differences decreased between their respective perceptions on patient pain severity.

Third, as differences increased between patient and caregiver feelings of annoyance toward ‘patient’ efforts in controlling the disease, differences also increased in their respective perceptions on patient pain severity ($\tau b = 0.34, p \leq 0.05$). Fourth, a significant negative correlation was also found between the discrepancy scores for pain severity and satisfaction in caregiver efforts to control disease progression. In other words, as discrepancy scores on satisfaction in caregiver efforts to control the disease increased, discrepancy scores decreased on patient and caregiver perceptions of pain severity ($\tau b = -0.34, p \leq 0.05$).

Pain – distress. A significant positive correlation ($\tau b = 0.30; p \leq 0.05$) was found to exist between the discrepancy score for locus of control over course of disease, ‘someone else’, and the discrepancy score for pain distress. In other words, increased differences between patient and caregiver perceptions regarding the control someone else

Table 13. Correlations between discrepancy scores on offset attributional responses and patients' symptom experiences

Patient-Caregiver Correlation Kendall's tau_b*Discrepancy Pain Severity*

Discrepancy control over course of disease caregiver 0.30*

Discrepancy fault caregiver re: control over course of patient's disease - 0.39*

Discrepancy annoyance toward patient re: control over course of disease 0.34*

Discrepancy satisfied in caregiver re: control over course of patient's disease -0.34*

Discrepancy Pain Distress

Discrepancy control over course of disease someone else 0.30*

Discrepancy Shortness of Breath Frequency

Discrepancy control over course of disease environment 0.31*

Discrepancy Shortness of Breath Severity

Discrepancy control over course of disease Patient 0.38*

Discrepancy Shortness of Breath Distress

Discrepancy, blame Patient re: control over disease progression -0.34*

Discrepancy pride for Patient re: control over disease progression 0.32*

Discrepancy Fatigue Severity

Discrepancy control over course of disease progression Patient 0.42**

Discrepancy Fatigue Distress

Discrepancy anger toward Patient re: control over course of disease 0.45**

* $p \leq 0.05$ ** $p \leq 0.01$

had over patient disease progression appeared to be associated with increased perceptual differences between patients and caregivers on patient pain distress. There were no significant correlations between attributional reactions and pain distress.

Shortness of breath – frequency. The discrepancy score on environmental control over the course of disease progression was found to have a positive correlation ($\tau b = 0.31$; $p \leq 0.05$) with the discrepancy score on shortness of breath frequency. In other words, as patient and caregiver differences in perceptions of environmental control over the course of patient disease progression increased, differences increased in their perceptions on shortness of breath frequency experienced by patients.

Shortness of breath – severity. On shortness of breath severity, one significant correlation was detected. As the discrepancy score increased on patient control over the course of the disease, so did the discrepancy score on patient shortness of breath severity ($\tau b = 0.38$, $p \leq 0.05$). In other words, as differences in perceptions by patients and caregivers increased on patient control over the course of the disease, differences increased between their respective perceptions on the severity of patient shortness of breath.

Shortness of breath – distress. Two significant correlations were found related to the discrepancy score for shortness of breath distress. First, a negative correlation was found between the discrepancy score on blame toward ‘the patient’ for efforts to control aspects of the disease and the discrepancy score for shortness of breath distress ($\tau b = -0.34$; $p \leq 0.05$). In other words, as the discrepancy score increased in relation to blame toward ‘the patient’ regarding control over disease progression, the discrepancy score on patient shortness of breath distress decreased. As well, discrepancy scores on feelings of

pride toward 'the patient' in his or her efforts to control disease progression was positively correlated with discrepancy scores on patient shortness of breath distress ($\tau_{b} = 0.32, p \leq 0.05$). In other words, as differences in feelings of pride toward 'the patient' for efforts to control the course of the disease increased, differences increased between patient and caregiver perceptions on shortness of breath distress experienced by patients.

Fatigue – severity. One finding was that discrepancy scores between patient and caregiver perceptions of patient control over disease progression and fatigue severity were significantly correlated ($\tau_{b} = 0.42; p \leq 0.01$). In other words, as differences in perceptions of patients and caregivers increased on patient control over disease progression, differences also increased in their respective perceptions on fatigue severity experienced by the patient.

Fatigue – distress. A significant positive correlation was detected between discrepancy scores on anger toward 'the patient' in relation to control over disease progression and fatigue distress ($\tau_{b} = 0.45; p \leq 0.01$). In other words, as differences in perceptions between patients and caregivers increased on feelings of anger toward 'the patient' related to patient control over disease progression, differences also increased between patient and caregiver perceptions of fatigue distress experienced by the patient.

Caregiver Perspective-taking

Pain Severity. The discrepancy scores for caregiver-perspective taking responses by patients and caregivers were correlated with discrepancy scores calculated for pain frequency, however no significant correlations were detected. Of note, only significant correlations were reported in Table 14. A significant correlation was found between discrepancies on pain severity and on Caregiver Perspective-Taking Question 10, “My caregiver does not sense or realize what I am feeling” ($\tau b = 0.39$; $p \leq 0.01$). In other words, as differences in perceptions of patients and caregivers increased on the caregivers’ ability to ‘sense’ what the patient is feeling, differences also increased in their respective perceptions on patient pain severity.

Shortness of breath – frequency. First, there was a significant correlation between discrepancy scores on shortness of breath frequency and Caregiver Perspective-Taking Question 10, “My caregiver does not sense or realize what I am feeling” ($\tau b = 0.32$; $p \leq 0.05$). In other words, as differences increased in perceptions of patients and caregivers on the caregiver’s ability to sense or realize what the patients’ feeling, differences also increased on their respective perceptions on shortness of breath frequency.

Second, there was a significant correlation between discrepancy scores on shortness of breath frequency and the Caregiver Perspective-Taking Question 16, “My caregiver tries to understand me better by imagining how things look from my perspective” ($\tau b = 0.38$, $p \leq 0.05$). In other words, as differences in perceptions of patients and caregivers increased on the ability of ‘the caregiver’ to understand ‘the patient’ by imagining his or her perspective, differences also increased in their respective perceptions on shortness of breath frequency experienced by patients.

Table 14 Correlations between discrepancy scores on caregiver perspective-taking responses and patients' symptom experiences

Patient-Caregiver Correlation
Kendall's tau_b

<i>Discrepancy Pain Severity</i>	
Discrepancy CPT Q10: My caregiver does not sense or realize what I am feeling.	0.39**
<i>Discrepancy Shortness of Breath Frequency</i>	
Discrepancy CPT Q10: My caregiver does not sense or realize what I am feeling.	0.32*
Discrepancy CPT Q16: My caregiver tries to understand me better by imagining how things look from my perspective.	0.38*
<i>Discrepancy Shortness of Breath Severity</i>	
Discrepancy CPT 16: My caregiver tries to understand me better by imagining how things look from my perspective	0.34*
<i>Discrepancy Shortness of Breath Distress</i>	
Discrepancy CPT Q16: My caregiver tries to understand me better by imagining how things look from my perspective.	0.50**
<i>Discrepancy Fatigue Frequency</i>	
Discrepancy Total Perspective-Taking Score	0.34*
Discrepancy CPT Q16: My caregiver tries to understand me better by imagining how things look from my perspective.	0.35*
Discrepancy CPT Q 3: My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from.	0.28***
Discrepancy CPT Q 5: My caregiver is able to accurately compare his/her point of view with mine.	0.31***
<i>Discrepancy Fatigue Severity</i>	
Discrepancy Total Perspective-Taking Score	0.23***
Discrepancy CPT Q 3: My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from.	0.29***
Discrepancy CPT 5: My caregiver is able to accurately compare his/her point of view with mine.	0.28***
Discrepancy CPT 6: My caregiver evaluates my motivation for doing something before he/she makes judgments about a situation.	0.35*
Discrepancy CPT 10: My caregiver does not sense or realize what I am feeling.	0.28***

Discrepancy CPT 14: Before criticizing me, my caregiver tries to imagine how I feel.	-0.38*
Discrepancy CPT 16: My caregiver tries to understand me better by imagining how things look from my perspective.	0.44**
Discrepancy CPT 20: When my caregiver is upset with me he/she tries to put him/herself in my shoes for awhile.	0.26***
<i>Discrepancy Fatigue Distress</i>	
Discrepancy Total Perspective-Taking Score	0.22***
Discrepancy CPT 12: My caregiver does not usually understand the whole meaning of what I am saying to them.	0.30*
* $p \leq 0.05$	
** $p \leq 0.01$	
*** trend in data ($p \geq 0.05-0.10$)	

Shortness of breath – severity. One significant correlation was found related to shortness of breath severity. As the discrepancy score increased on Caregiver Perspective-Taking Question 16, “My caregiver tries to understand me better by imagining how things look from my perspective”, the discrepancy score also increased on patient shortness of breath severity ($\tau b = 0.34, p \leq 0.05$). In other words, as differences in patient and caregiver perceptions on the ability of ‘the caregiver’ to understand ‘the patient’ by imagining things from the patient’s perspective increased, differences also increased in their respective perceptions on severity of patient shortness of breath experienced by patients.

Shortness of breath – distress. One significant correlation was found related to shortness of breath distress. As the discrepancy score increased regarding Caregiver Perspective-Taking Question 16, “My caregiver tries to understand me better by imagining how things look from my perspective”, the discrepancy score also increased on patient shortness of breath distress ($\tau b = 0.50, p \leq 0.05$). In other words, as differences in patient and caregiver perceptions on the ability of ‘the caregiver’ to understand ‘the patient’ by imagining things from ‘the patient’ perspective increased, differences also increased in their respective perceptions on patient distress caused by shortness of breath.

Fatigue – frequency. Two significant correlations were found related to the discrepancy score for fatigue frequency. First, as differences in the total score for caregiver perspective-taking increased, differences also increased in patient and caregiver perceptions of patient fatigue frequency ($\tau b = 0.34; p \leq 0.05$). Second, as dyadic differences increased on Caregiver Perspective-Taking Question 16, “My caregiver tries to understand me better by imagining how things look from my perspective”, differences

also increased in their respective perceptions on frequency of fatigue experienced by patients ($\tau b = 0.35, p \leq 0.05$). In other words, as differences increased on patient and caregiver perceptions on the ability of 'the caregiver' to understand 'the patient' by imagining things from 'the patient' perspective, differences also increased on their respective perceptions on frequency of fatigue experienced by the patient.

Two trends in the data were also detected ($p \geq 0.05-.10$) related to fatigue frequency. The first trend related to fatigue frequency and Caregiver Perspective-Taking Question 3: "My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from" ($\tau b = 0.28$). In other words, as differences increased on patient and caregiver perceptions of the ability of the caregiver to "listen" and "understand" the patient, differences also increased on their respective perceptions on the frequency of fatigue experienced by the patient. As well, a trend was detected with Caregiver Perspective-Taking Question 5: "My caregiver is able to accurately compare his/her point of view with mine" ($\tau b = 0.31$). In this case, as differences increased on patient and caregiver perceptions on the ability of 'the caregiver' to accurately compare points of view, differences also increased on their respective perceptions on the frequency of fatigue experienced by the patient.

Fatigue – severity. Three correlations were found in relation to the discrepancy score for fatigue severity. First, as discrepancy scores on fatigue severity increased, discrepancy scores also increased on Caregiver Perspective-Taking Question 6, "My caregiver evaluates my motivation for doing something before he or she makes judgments about a situation" ($\tau b = 0.35, p \leq 0.05$). In other words, as differences in perceptions of patients and caregivers increased on the ability of 'the caregiver' to

evaluate the motivation of 'the patient' before passing judgment on a situation, differences also increased between perceptions of patients and caregivers on the severity of patient fatigue.

The discrepancy score on Caregiver Perspective-Taking Question 14, "Before criticizing me, my caregiver tries to imagine how I feel" was negatively correlated with the discrepancy score on fatigue severity ($\tau b = -0.38, p \leq 0.01$). In other words, as differences between patient and caregiver perceptions decreased on the ability of 'the caregiver' to consider the feelings of 'the patient' before criticizing, differences increased between their respective perceptions on fatigue severity.

In addition, the discrepancy score for fatigue severity was significantly correlated with the discrepancy score related to Caregiver Perspective-Taking Question 16, "My caregiver tries to understand me better by imagining how things look from my perspective" ($\tau b = 0.44, p \leq 0.01$). This finding means that as differences in perceptions between patients and caregivers increased on the ability of 'the caregiver' to understand 'the patient' by imaging the patients' perspective, differences also increased between their respective perceptions on the severity of patient fatigue.

Several trends were also found in the data related to the discrepancy score for fatigue severity. The first trend was found for the discrepancy score calculated for the total perspective-taking scale with a correlation value $\tau b = .23$. Next a trend was found related to the discrepancy score calculated for Caregiver Perspective-Taking Question 3: "My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from" with a correlation of $\tau b = 0.29$. In this case, as differences increased on patient and caregiver perceptions of the ability of the caregiver

to “listen” and “understand” the patient, differences also increased on their respective perceptions of the severity of fatigue experienced by the patient. Another trend was detected related to Caregiver Perspective-Taking Question 5: “My caregiver is able to accurately compare his/her point of view with mine with a correlation value of $\tau b = 0.28$. As discrepancy scores on fatigue severity increased, discrepancy scores also increased in patient and caregiver perceptions on the ability of ‘the caregiver’ to accurately compare points of view.

Another trend was found in relation to fatigue severity related to Caregiver Perspective-Taking Question 10, “My caregiver does not sense of realize what I am feeling” ($\tau b = 0.28$). In other words, as differences in perceptions of patients and caregivers increased on the caregivers’ ability to ‘sense’ what the patient is feeling, differences also increased in their respective perceptions on patient fatigue severity. In addition, a trend between discrepancy scores on fatigue severity and Caregiver Perspective-Taking Question 20 was found ($\tau b = 0.26$). Question 20 states: “When my caregiver is upset with me he/she tries to put him/herself in my shoes for awhile” In other words, as discrepancies between patients and caregivers increased regarding caregiver ability to put him/herself in the patient’s shoes, discrepancy scores also increased on fatigue severity.

Fatigue – distress. An examination of findings revealed one significant correlation between discrepancy scores on fatigue distress and Caregiver Perspective-Taking Question 12, “My caregiver does not usually understand the whole meaning of what I am saying to them” ($\tau b = 0.30, p \leq 0.05$). In other words, as differences in perceptions of patients and caregivers increased on ‘the caregiver not understanding the

meaning of what the patient was communicating', differences also increased in their respective perceptions on fatigue distress experienced by the patient. One trend was found regarding the correlation between discrepancy scores on fatigue distress and the total score for caregiver perspective-taking ($\tau b = 0.22$).

Summary

The analyses and interpretation of data collected from 34 lung cancer patient and caregiver dyads was the focus of this chapter. The demographic characteristics of the patient and caregiver groups were described. An acceptable internal consistency reliability estimate was established for the patient and the caregiver versions of the Caregiver Perspective-taking Scale.

Research Question #1:

What are the relationships and differences between lung cancer patient and caregiver respective responses on their smoking histories, 'onset' and 'offset' reactions, caregiver perspective-taking, and perceptions on patient pain, fatigue and dyspnea experiences (symptom experiences)?

The patient and caregiver responses to smoking history, onset and offset reactions, patient symptom experiences and caregiver perspective-taking were analysed using descriptive statistics. A number of non-parametric statistical techniques were used to examine relationships and differences between patient and caregiver responses by conducting a correlational analysis with Kendall's τ_b , and testing for group differences in ordinal data with the Wilcoxon matched-pairs test.

With regard to patient and caregiver respective responses on their smoking histories, fifteen dyads (n=44%) indicated that, at time of interview, at least one member

continued to smoke regularly since diagnosis. Eighteen dyads (53%) indicated they were former smokers. Seven (39%) of those eighteen dyads indicated that at least one member had quit since the diagnosis; in five dyads this was the 'patient'. Eight dyads (23%) indicated at least one member never smoked cigarettes.

The correlational analyses of onset and offset reactions by patients and caregivers revealed mainly weak correlations (ranging from 0.01 to 0.72). Several significant differences were detected between dyadic responses on onset and offset reactions. An examination of mean scores between respondent groups revealed attributions of blame, fault, anger and responsibility were directed more to 'the patient' than to 'the caregiver' by lung cancer patients and their caregivers.

The analyses of patient and caregiver responses on the Caregiver Perspective-Taking Scale revealed similar total mean scores between respondent groups that suggested patients and caregivers tended to agree on the level of perspective-taking engaged in by their caregivers. The correlational analyses between dyadic responses on caregiver perspective-taking revealed low to moderate correlations, with few statistically significant results. A number of significant differences between dyadic responses on individual Caregiver Perspective-Taking Scale items were found.

Based on a comparison of patient and caregiver reports on patient symptom experiences, findings revealed that caregivers tended to under-report the presence of pain and shortness of breath experienced by patients in the preceding week. With respect to the 'presence' of fatigue in the preceding week, caregivers tended to over-report the experiences of the patient. The correlational analyses of patient and caregiver responses

on symptom frequency, severity, and distress for pain, shortness of breath, and fatigue revealed statistically significant moderate to strong correlations.

Research Question #2:

If discrepancies are identified during the analysis of question one, what is the effect of these discrepancy scores for patient and caregiver 'onset reactions', 'offset reactions', and caregiver perspective-taking on levels of patient and caregiver perceptual agreement on patient symptom experiences?

The absolute differences between patient and caregiver scores were calculated for onset and offset reactions and caregiver perspective taking questionnaires. The discrepancy scores for onset and offset reactions, and caregiver perspective-taking were then correlated with discrepancy scores on three symptom experiences and the underlying dimensions of pain, fatigue, and shortness of breath. A number of significant correlations were reported on all symptom dimensions, except for pain frequency. The results revealed that patient and caregiver discrepancies on certain onset and offset reactions, and caregiver perspective-taking had a significant impact on patient and caregiver discrepancy scores for three symptom experiences. However, for some significant negative correlations, it was difficult to interpret the pattern of association between discrepancy scores for onset and offset reactions, and symptom experiences. A number of trends (p values between 0.05 and 1.0) were discussed that likely would have resulted in significant results in a larger study sample.

CHAPTER V

Discussion

This pilot study was designed to conduct a descriptive, comparative examination of relationships and differences between lung cancer patient and caregiver smoking histories, illness attributions, perceptions of caregiver perspective-taking, and assessments of patient pain, dyspnea, and fatigue experiences. Overall, this study was guided by the concepts of stigma, illness attribution, empathic communication (perspective-taking), and symptom experiences. Weiner's (1995) Theory of Social Conduct provided the foundation for conceptualization of this study.

Although numerous study findings were revealed, this chapter focuses on three important findings that were interpreted in accordance with the premises of Weiner's (1995) attributional model and/or related study findings, and subsequent conclusions were presented in this chapter. A statement of this study's limitations, nursing practice implications, and recommendations for further research are also provided.

Discussion of the Findings

The first study finding was in relation to the comparison of patient and caregiver perceptions on the 'locus of causality' for the lung cancer diagnosis. Based on the positive receptivity of participants, it appears appropriate to have prompted patients and caregivers to respond to questions about their beliefs regarding causality (or onset) and controllability (or offset) about the diagnosis of lung cancer. In this study, a consistent theme was detected where out of eight possible response options related to locus of causality (which included 'patient', 'caregiver', 'someone else', 'environment', 'chance', 'fate/destiny', 'divine will', and 'heredity or genetic factors'), 'the patient' was ranked as

having the highest degree of control for causing their diagnosis of lung cancer by both patients and caregivers. No significant differences in mean locus of causality toward the patient was detected between the perceptions of patients and caregivers. Although not systematically tested, we can infer that these perceptions were related to the patient's volitional act of having engaged in cigarette smoking. Ninety-one percent ($n=31$) of the patients reported that they had either smoked or continued to smoke cigarettes at the time of interview.

In accordance with Weiner's (1995) model, when individuals attempt to understand the cause of negative events, like being diagnosed with lung cancer, they may view the act of cigarette smoking as an internal and controllable act by the patient. In this study, both patients and caregivers ascribed the patient with personal causality in relation to cigarette smoking that resulted in the negative outcome of being diagnosed with lung cancer. It is very likely that the patient was implicated for causing his or her lung cancer in relation to having a current or past history of cigarette smoking. In today's society, the public is exposed to widespread health promotion messages on the 'evils' of cigarette smoking, and that cigarette smoking is widely viewed as a wilful act that makes the patient accountable for being the cause of receiving a dire diagnosis, such as lung cancer (Chapple et al., 2004). In accordance with Weiner's theory, cigarette smoking can be viewed as an internal, controllable act by a patient that has subsequent implications for attributions of responsibility and emotions held by patients and their caregivers.

In regard to 'onset' reactions related to illness attributions and subsequent emotions, the results consistently revealed that patients assigned more personal responsibility (including attributions of blame and fault), and more anger (including

feelings of annoyance and aggravation) toward themselves for the cause of their disease compared to what was assigned toward them by their caregivers. In addition, patients reported more feelings of sympathy, concern, and pity toward the caregiver when compared to caregiver reports about sympathy, concern, and pity toward themselves.

An examination of offset reactions for 'locus of controllability' on disease progression revealed similar findings. Of eight possible response options (which included 'patient', 'caregiver', 'someone else', 'environment', 'chance', 'fate/destiny', 'divine will', and 'heredity or genetic factors'), 'the patient' was assigned the most control over the course of their disease progression by both patients and caregivers. Further examination of illness attribution and subsequent emotional responses in the offset condition revealed a consistent pattern where patients assigned more blame and responsibility toward themselves, than caregivers assigned toward patients. Patients also reported more anger, annoyance and aggravation toward themselves in relation to their efforts to control their disease compared to reports by caregivers toward 'the patient'. Interestingly, however, patients displayed more pride, satisfaction, and hopefulness in the attempts of 'the caregiver' toward controlling the progression of the disease than was reported by caregivers toward themselves.

These findings suggested that lung cancer patients in this study held strong beliefs in relation to personal causality for the disease and personal control over the progression of their lung cancer. They also appeared to be dealing with anger and blame that was directed at themselves for causing their diagnosis. Despite dealing with strong negative emotions directed at themselves for causing the diagnosis, lung cancer patients also reported feelings of sympathy, pity, and concern in relation to the impact of their lung

cancer diagnosis on their caregivers. In the offset condition, patients also reported positive feelings of pride and satisfaction in their caregivers' efforts to control the progression of their lung cancer. Based on these findings, the impression one receives is that lung cancer patients in this study were riding an emotional "see-saw" of negative attributions and emotions directed at themselves, while yet experiencing positive sentiments for their caregivers. The findings suggested that such emotional 'teetering' experienced by lung cancer patients might hazardously create a vulnerable psychological and emotional state in patients that warrants further discussion.

A review of related literature on stigma was helpful in comprehending the psychological and emotional impact on individuals who are held to blame for causing and controlling their disease or illness. Fife and Wright (2000), in their study on the dimensionality of stigma in relation to HIV and AIDS, found that an individual's acceptance of a stigma often results in self-depreciation and shame, jeopardizing their emotional wellbeing. Chapple and colleagues (2004) discussed both 'felt' and 'enacted' stigma. Felt stigma referred to feelings of shame associated with having a disease and to the feelings of fear of being discriminated against on the grounds of social inferiority. 'Enacted' stigma described the actual act of discrimination on the above noted grounds. The findings from this study suggested that lung cancer patients might have been experiencing 'felt' stigma in association with their feelings of anger and aggravation toward themselves in the context of reactions they received from family, friends, and health care professionals. However, as this study did not capture feelings of shame and fear of being discriminated against by their caregivers or others, it is difficult to determine if 'felt' or 'enacted' stigma was indeed experienced by this study sample of

lung cancer patients in their relationship with family caregivers. The experiences of shame and fear by patients therefore warrant further exploration in relation to their impact on the caregiving relationship, and perceptual accuracy between lung cancer patients and their caregivers on patient illness experiences such as symptoms.

Nonetheless, the undertone of self-blame was observed by the investigator during data collection with lung cancer patients who agreed to participate in this study. The patients consistently verbalized to the investigator their feelings of anger toward themselves for putting not only themselves, but also their loved ones in such a dire situation through their history of tobacco usage. As most dyad members were at or around retirement age, the patients expressed strong feelings of guilt and sadness for, “robbing” themselves and their loved ones of the retirement life they had planned to share together for so many years. A palpable sense of resignation and sadness was felt within this group by the investigator.

Chapple and colleagues (2004) reported similar findings in their qualitative work where often lung cancer patients described finding themselves in the position of feeling they caused the disease and as such, deserved to be in the unpleasant predicament of being diagnosed with lung cancer. Patients were also often quick to verbalize to the investigator their great appreciation for their caregiver and the caregiver’s efforts to care for and assist the patient to cope, both physically and emotionally. It appeared to the investigator that when patients expressed strong sentiments of gratitude and pride toward their caregivers in managing the disease, these feelings further deepened their feelings of guilt and shame toward themselves. Some lung cancer patients verbalized their feelings of amazement at the selfless and caring efforts of their caregivers, wondering aloud how

their caregivers could be this way considering, from the patient's point of view, that the patient was responsible for the illness.

An examination of the responses provided by caregivers in the 'onset' and 'offset' conditions provided an important dimension to this study's findings. As reported in the previous chapter, a between group analyses of onset and offset reactions revealed results that suggested caregivers tended to ascribe less responsibility, and anger toward the patient than did patients toward themselves. On the other hand, caregivers felt more responsibility and anger toward themselves in relation to their involvement in the cause and control over the disease compared to patient reports of responsibility and anger toward the caregiver. This analysis suggested that patients and caregivers assumed their own respective degrees of responsibility for the diagnosis, while either 'no' or 'limited' responsibility was directed toward them from the other dyadic member.

However, an examination of within-group results revealed important findings that demonstrated a different interpretation of what caregivers were experiencing in terms of the degree of responsibility and anger they felt toward the patient. While the results of the within-group analyses of patient responses were consistent with previous between-group analysis, that is, patients tended to ascribe more responsibility or fault, and feelings of anger toward themselves and not toward their caregivers, the results for caregivers varied from the between-group analyses. In the within-group analysis, the findings revealed that caregivers tended to attribute a greater degree of responsibility (including attributions of blame and fault) and reported greater feelings of annoyance and aggravation toward the patient than toward themselves in relation to the cause of the disease (or onset reactions). With respect to attributions on offset reactions (i.e., degree of control over disease

progression), caregivers attributed more responsibility toward the patient (including higher levels of blame and fault), as well as greater feelings of anger, annoyance, and aggravation toward the patient than toward themselves. A within-group analysis compares mean scores within the same participant group related to a specific measure or question(s). For example caregiver responses to blame toward the patient, blame toward the caregiver, and fault toward the patient, fault toward the caregiver were compared. A between-group analysis compares mean score between different participant groups related to a specific measure or question(s). For example, patient and caregiver responses to blame toward the patient, fault toward the patient, and responsibility toward the patient were compared.

Although not directly tested, it is reasonable to infer that caregiver ascriptions of responsibility and anger toward the patient in the onset and offset conditions were related to this study's sample of 91% of lung cancer patients who reported either current or past tobacco usage. These findings on caregiver responses are supported by the work of Zhang and Siminoff (2003b) who examined levels of communication between family members and lung cancer patients regarding treatment decision-making. In the Zhang and Siminoff study, family members also reported feelings of frustration, anger, and hurt toward patients while referencing patient history of tobacco usage.

The within-group analyses of illness attributions and feelings held toward the patient by the caregiver adds an important dimension in our understanding of relational dynamics in this disease population. This study's evidence supports findings by other researchers (e.g., Chapple et al., 2004; Kim & Shanahan, 2003; Zhang and Siminoff, 2003b) that lung cancer patients encounter negative feelings and attributions not only

from health care professionals and the public-at-large, but also from their informal or family caregivers, exposing patients to 'enacted' stigma as previously discussed by Chapple and colleagues (2004). This study's findings prompted further speculation by this investigator as to whether the patient detected negative attributions of blame and feelings of anger from the caregiver. If so, how did this impact on his or her own casual attributions, feelings, and subsequent empathic behaviour with and by the caregiver? The investigator suspected that results from the larger, ongoing study by Dr. Lobchuk and colleagues, which involves more rigorous structural equation model testing, will provide answers to some of these questions.

The next set of findings will be discussed in relation to the effects of patient and caregiver conflicts in illness attributions, and perceptions of caregiver perspective-taking on dyadic discrepancies on their respective perceptions of patient symptom experiences. The investigator viewed both illness attributions and caregiver perspective-taking skills to be modifiable factors, and by identifying areas of conflict (i.e. communication, understanding) through the examination of discrepancy scores between patient and caregiver responses on these variables, interventions (i.e. education, counselling) can be developed and administered by health professionals as they care for lung cancer patients and their family caregivers.

The second finding that warranted further discussion was in relation to the effects of discrepancy scores for patient and caregiver responses on 'locus of causality' and 'locus of controllability', and illness-related attributional cognitions and emotions on the degree of dyadic discrepancy for symptoms and symptom dimensions. As reported in Chapter Four, Kendall's *tau_b* test was performed to detect significant correlations

between the absolute difference scores for 'onset' and 'offset' illness attributions and the absolute difference scores for symptom experiences. Significant correlations between discrepancy scores highlighted problematic illness attributions or emotions held by patients and family caregivers that are potentially modifiable, and when addressed by health care professionals in the care of lung cancer patients and their families, may lessen the amount of discrepancy in the assessment of patient symptom experiences. Any conflicts that exist within the context of comprehending the 'cause' of the disease and 'control' over disease progression, as well as subsequent illness attribution reactions may have deleterious effects on the assessment and management of patient symptoms by family caregivers.

A review of significant correlations between discrepancy scores on 'onset' attributional responses and the discrepancy scores for patient and caregiver perceptions of symptom experiences reported in Table 12 revealed several patterns. For instance, the discrepancy found in the perceptions of shortness of breath frequency experienced by the patient was significantly correlated with the discrepancy scores for several attributions related to caregiver involvement in the 'cause' of the disease. The greater the discrepancy between patient and caregiver attributions of caregiver 'locus of causality' for the disease (Kendall's τb 0.45), caregiver 'responsibility' for the cause of the disease (Kendall's τb 0.38), as well as feelings of 'blame' (Kendall's τb 0.36), 'fault' (Kendall's τb 0.36), and 'annoyance' (Kendall's τb 0.39) toward the caregiver, the more discrepant the reports of shortness of breath frequency experienced by the patient.

To comprehend the above associations that appear to implicate the caregiver's role in 'causing' the disease, the investigator compared the mean responses between patients and caregivers. It was found that caregivers reported higher levels of control, blame, fault, responsibility, and annoyance toward themselves than the patient reported toward the caregiver. These findings indicated that modification of caregiver negative attributions toward oneself might assist in enhancing their ability to perceive patient symptom experiences in ways similar to the way patients view their symptoms. In other words, feelings of blame and anger toward oneself in relation to one's own tobacco usage may serve as inhibitors of open communication and unbiased viewpoints by the caregiver on the patient's illness experiences. For instance, if the caregiver is feeling responsible, at fault or to blame for the patient's diagnosis due to their own history of tobacco usage (79% or $n = 27$ caregivers reported a history of tobacco usage), perhaps education of the caregiver as to the addictive nature of nicotine can mediate or 'soften' attributions of 'blame', 'fault', and 'annoyance' by the caregiver as they gain an enhanced understanding of why it is difficult to quit smoking. Depending on the patient's exposure to risk factors, another strategy might be to educate the caregiver as to other possible causes of lung cancer, including exposure to asbestos, radon, occupational agents, indoor air pollution, dietary factors, and family history (Ingle, 2000). These strategies might help to ameliorate negative attributions and emotions felt by the caregiver toward oneself, and serve to foster more open communication between the dyads on various symptom experiences, such as the frequency of shortness of breath experienced by the patient.

Similar analysis involving the patient's role in causing the disease also found that the discrepancy in feelings of 'fault' toward the patient for getting lung cancer was

significantly correlated with the discrepancy in the perceptions of pain severity (Kendall's $\tau b = 0.31$). Again, based on a comparison of mean scores, the patient reported greater feelings of 'fault' for the diagnosis than the caregiver reported toward the patient which, in turn, appeared to impact the level of perceptual concordance between patients and caregivers on the patient's pain severity experiences. Just as it appears important to target interventions to educate the caregiver, it seems equally important to include patients in educational programs that address the addictive effects of nicotine. Again, this strategy may help to ameliorate attributions of 'fault' felt by the patient for their diagnosis as they gain a better understanding of why it is difficult to quit smoking. Also, as previously mentioned, education as to other possible causes of the disease may be beneficial for the patient in reducing feelings of fault. This in turn may serve to foster more open communication between the patient and family caregiver in relation to various illness-related matters and lessen the discrepancy in the perceptions of pain severity.

The dyadic discrepancy score on 'sympathy' toward the patient for the 'onset' of the disease was significantly correlated with respective discrepancy scores on shortness of breath distress (Kendall's $\tau b = 0.37$) and fatigue frequency (Kendall's $\tau b = 0.34$), with caregivers reporting higher levels of sympathy toward patients than patients did toward themselves. However, if steps are taken to assist the patient in gaining a better appreciation of the potential impact of extraneous variables (such as the nature of addiction to nicotine, and other causes of lung cancer) as discussed above, they may feel more positive or at least more accepting of their situation. Positive feelings and greater understanding of risk factors in their disease may help in moderating negative attributions and feelings, and improve patient willingness to communicate with their caregiver. In

turn, a greater willingness to communicate with the caregiver by the patient would assist the caregiver in gaining an enhanced understanding of patient distress associated with shortness of breath, and frequency in experiencing fatigue. The overall aim would be develop and test strategies that reduce negative attributions and feelings in order to enhance dyadic communication. This requires an understanding of barriers that prohibit open relational dynamics between patients and caregivers, which are vital to optimal symptom management in the home setting. This study's findings suggested that illness attributions and associated feelings held by both patients and caregivers are important factors to target in future intervention studies that test strategies to enhance communication and understanding of patient symptoms by family caregivers.

The impact of dyadic discrepancy scores on 'offset' attributional responses on discrepancies for patient symptoms were also explored. The results revealed several associations between discrepancy scores on locus of controllability responses (including 'patient', 'caregiver', 'environment', and 'someone else') and dyadic perceptions on patient symptom experiences. In particular it was found that as discrepancies increased on perceptions of pain distress and shortness of breath frequency, caregivers attributed greater control of disease progression toward 'someone else' and 'the environment' than did patients. Although it is difficult to decipher these associations, it appeared that as the caregiver attributed greater control over disease progression to external factors (i.e. environment or someone), it was more difficult for them to accurately assess patient symptom experiences. These results suggested that perhaps caregivers are uncertain related to what they can do to aid in controlling the progression of the disease. In perceiving that the controllability of the patient's lung disease to 'be in the hands of'

external factors, such as health care professionals, it is possible that family caregivers felt somewhat powerless and uncertain in their role regarding the assessment and management of the patient's illness experiences like symptoms.

The testing and development of strategies to modify the causal attributions of the caregiver and perhaps provide the caregiver with a greater sense of control and power over the situation are requested. Informational and educational support of both patients and caregivers on the role of family caregivers in symptom management might be empowering. Depending on the status of the caregiver's tobacco usage, education or assistance with a tobacco cessation program may help empower family caregivers who continue, but desire the cessation of their tobacco consumption, and may aid patients who also want to quit. Referrals of interested patients and caregivers to local support groups may provide the dyad with an outlet to share their experiences and gain support from others in their desire to gain control in the management of their disease. In addition, advising patients and caregivers of various mind-body connection techniques such as yoga, meditation, prayer, and positive attitude may serve to reduce stress and give the patient and caregiver an increased sense of control over the situation. All of these strategies might work in enhancing a sense of internal control over the disease progression by patients and caregivers that might contribute toward more open and shared communication within the dyad, thus reducing discrepancies and improving symptom perceptions.

The third major finding was in relation to the effects of differences in perceptions of patients and caregivers on the level of empathic communication engaged in by caregivers on perceptual concordance on patient symptom experiences. Perspective-

taking is an underlying process of empathic communication in the caregiving relationship (Lee et al., 2001; Long & Andrews, 1990). Perspective-taking is defined as “the imaginative tendency to put oneself in another person’s place” (Long & Andrews, 1990, p. 126). Previous research, albeit limited, has revealed that perspective-taking on the part of the caregiver can potentially enhance patient and caregiver perceptual agreement on patient symptom experiences (Lobchuk & Vorauer, 2003; Lobchuk, Degner, Chateau, & Hewitt, 2006). Perspective-taking was viewed by the investigator to be a potentially modifiable factor in caregivers that can serve to enhance perceptual understanding and concordance between patients and caregivers on patient symptom experiences (Stephenson & Wicklund, 1983).

Lobchuk’s (2001) dissertation study and subsequent studies (Lobchuk, Degner, Chateau, & Hewitt, 2006; Lobchuk, McClement, Daeninck, & Shay, 2007) provided preliminary evidence related to how perspective-taking prompts employed by health care professionals might enhance caregiver perceptions on patient symptom experiences. However, one major limitation of Lobchuk and colleagues’ studies to date have been that they were comprised of convenient samples of voluntary dyads comprised of cancer patients and informal caregivers in long-term relationships who appeared to ‘naturally’ engage in perspective-taking activities that resulted in low discrepancies on patient symptom experiences. Further research is required to test the impact of perspective-taking training by patients and caregivers in samples of patients and caregivers where conflicts exist in their relationships. Results from the larger ongoing study by Lobchuk and colleagues might serve to enhance our understanding of dyads at high risk for poor

symptom management that is potentially influenced by conflicted illness attribution reactions and empathic communication by lung cancer patients and their caregivers.

In this study, the mean individual item scores on the Caregiver Perspective-Taking Scale ranged between 0.67 and 1.44, out of a theoretical mean range of 0-4. Overall, the range of mean discrepancy scores appeared small, indicating similar perceptions between patients and caregivers on caregiver perspective-taking behaviours. A test of association, Kendall's *tau b*, was performed on dyadic discrepancy scores for the item responses on the Caregiver Perspective-taking Scale and individual symptom dimensions. A review of results found in Table 14 suggested several problematic areas in caregiver perspective-taking behaviours that, with modification strategies, may be ameliorated leading to improved communication and symptom assessment by caregivers. The investigator's discussion below will focus on some of these associations related to caregiver perspective-taking.

First, the discrepancy between patient and caregiver perceptions of Caregiver Perspective-taking Question #16: "My caregiver tries to understand me better by imagining how things look from my perspective" was found to be positively correlated with discrepancy scores for pain severity (Kendall's *tau b* 0.38), shortness of breath severity (Kendall's *tau b* 0.34), shortness of breath distress (Kendall's *tau b* 0.50), fatigue frequency (Kendall's *tau_b* 0.35), and fatigue severity (Kendall's *tau_b* 0.44). Second, the discrepancy reported for Caregiver Perspective-taking Question #20 which states: "When my caregiver is upset with me he/she tries to put him/herself in my shoes for awhile" was significantly correlated with the discrepancy score for fatigue severity (Kendall's *tau b* 0.26). Third, there was an association between the discrepancy scores

for Question #5 that states: "My caregiver is able to accurately compare his/her point of view with mine" and fatigue severity (Kendall's τb 0.28) and fatigue frequency (Kendall's τb 0.31).

Overall, the three findings suggested that the more discrepant patients and caregivers were in their respective perspectives on the caregiver's ability to either accurately view things from the patient's viewpoint or put oneself in the patient's shoes, the greater their discrepancy was on several symptom dimensions. From the perspective of the health care professional, providing caregivers with a description of the different ways they can view the patient's illness events (e.g., either taking a self- versus patient-oriented perspective), may provide important insights to them, and subsequently encourage them to engage in a more patient-oriented approach in understanding the patient's experiences with illness events, like symptoms. Early research by Stephenson and Wicklund (1983) suggested that instruction or training on self-reflection by observers (or family caregivers) on the difference between a 'self' versus 'other' orientation in viewing another's experience(s) may guide caregivers to orient to patients' perspectives.

In addition, facilitating an open dialogue between patients and caregivers on their respective perspectives regarding symptoms events may help to improve caregivers' understanding of patients' perceptions. Once an open dialogue between patients and caregivers is established, the health care professional can facilitate discussions regarding the thoughts and feelings of patients and caregivers on various issues, including areas of difficulty in coping with the illness and managing the disease. When each member of the dyad has a greater appreciation for the thoughts and feelings of the other, a better line of

ongoing communication may evolve thus easing the challenge of reliable symptom assessment and accurate estimation on the part of the caregiver.

Strategies for enhancing caregiver perspective-taking also have implications for caregiver understanding of patient rationale behind their medical decisions made in relation to the management of their symptoms. For instance, an increased understanding of patient motivation may lessen the discrepancy found on Caregiver Perspective-taking Question #6 which states: "My caregiver evaluates my motivation for doing something before he/she makes judgments about a situation." This perspective-taking item was significantly correlated with the discrepancy score for fatigue severity (Kendall's τb 0.35). As each member of the dyad feels more understood in their motives, they are less likely to feel judged and may be more likely to communicate with one another on management of the patient's symptom experiences, thereby increasing dyadic perceptual congruence on symptom experiences, such as fatigue severity.

Limitations of the Study

The investigator identified several limitations in this study. First, due to the small study sample of 34 patient and caregiver dyads, there is limited generalizability of study findings. Although a homogenous sample of patients with primary lung cancer was obtained for this preliminary analysis of findings from a larger ongoing study, the investigator was challenged in being able to determine whether this study sample of lung cancer patients was representative of the larger lung cancer population. In addition, small sample sizes tend to increase the chances of sampling error and produce less accurate estimates than larger samples (Polit & Tatano Beck, 2004).

Another limitation to this study was the use of convenience sampling. The use of this sampling technique is subject to bias as the participants volunteer to participate (Polit & Tatano Beck, 2004). This point raises the issue of the representativeness of this study's sample of patients and caregivers. For example, Lobchuk and colleagues (2003; 2007) have found that their convenient samples were comprised of long-term patient-caregiver dyads who had lower levels of discord on perceptions related to patient symptom experiences and they appeared to 'naturally' engage in perspective-taking behaviours with one another. It is apparent that there are challenges associated with the recruitment of dyads of cancer patients and informal caregivers who are struggling with symptom assessment and communication issues in the context of caregiving in the home setting. This is unfortunate, as those dyads who refuse to participate are potentially most in need of being studied in order to develop interventions to assist them with psychological coping and management of illness effects, such as symptom experiences.

As previously mentioned, this study was mainly comprised of older patients and caregivers who were married to, and in long term relationships with lung cancer patients (that is, 70% of dyads were comprised of individuals who were married to each other). Of the sample population, 85% of the patients and 73% of the caregivers indicated they "frequently" or "usually" communicated about symptoms. As such, it may make it difficult to generalize findings to non-married, younger caregivers (e.g., children of the patient, siblings, or friends), and to younger patients diagnosed with lung cancer. Previous research by Menec and Perry (1995) indicated that the age of caregivers and patients can have an impact on attributional reactions. Importantly, Menec and Perry's (1995) work on the impact of caregiver and patient age on illness attributions needs to be

considered in light of predictive statistics that suggest the average age at time of lung cancer diagnosis will steadily drop from the current age of seventy-five years to middle-age (ages 35-69) over the next ten to fifteen years (Sarna, 1999).

Implications for Practice

The investigator proposed three implications for practice that can be developed from the results of this study and for future studies that will build upon this work. First, poor symptom perception and estimation on the part of the caregiver may potentially lead to inappropriate and ineffective treatment. As lung cancer is the second most commonly diagnosed cancer, with numbers predicted to rise over the coming years (Cooley, 2002; Silvestri, Sherman, Williams, Swan-Swan, Flume, & Turrisi, 2002), it is imperative that lung cancer patients and caregivers at risk for poor empathic communication, ineffective perspective-taking abilities, and subsequent poor symptom estimation are identified by healthcare providers. A tool that can identify dyads at-risk through the monitoring of dyadic differences on illness attributions and communication dynamics should be developed for clinical use in the provision of holistic care of lung cancer patients and their families.

Second, it is important for clinicians to be aware that negative illness attributions toward the lung cancer patient regarding the diagnosis and the control over the course of cancer are made not only by lung cancer patients, but also by their family caregivers. This study found several significant linkages such as those between "fault" held by the patient and caregiver toward the patient, and discrepancies on symptom experiences such as pain severity, and those between "anger" held by the patient and caregiver toward the patient, and discrepancies on symptom experiences of fatigue frequency and fatigue distress.

However, attributional reactions involving blame and anger are potentially modifiable and might be mediated when health care providers offer educational efforts designed to enhance patient and caregiver awareness of the addictive effects of nicotine, other possible causes of lung cancer, or the availability of smoking cessation programs. The modification of negative illness attributions can potentially impact dyadic members' emotions about themselves and each other, work to improve help-intended communication, and enhance congruence of patient and caregiver perceptions on illness events, such as patient symptom experiences. Health care professionals, such as nurses, must remain cognizant that negative illness attributions or decreased caregiver perspective-taking ability can be modified, and take steps to develop supportive interventions or modification strategies, such as those suggested in the above. Lobchuk and colleagues (2003, 2007) suggested perspective-taking behaviours are modifiable and can be taught to family caregivers to enhance their information gathering abilities and communication with cancer patients.

A final clinical implication is for health care professionals who perform assessments and provide direct care to cancer patients and their families. Front-line health care providers need ongoing education or awareness about their own behaviours and attitudes that have potential to promote stigma perceived by lung cancer patients and their family caregivers. It is important for clinical staff to understand that due to casual attributions, and subsequent feelings of blame and likely shame, patients and caregivers are hesitant to seek help when they are experiencing difficulties with communication, support, and understanding in the caregiving unit at home (Zhang & Siminoff, 2003b). Health care professionals, like nurses, can be key players in the identification of those

patients and caregivers at risk for ineffective communication and inaccurate symptom assessment, and also in the provision of timely and effective interventions.

Recommendations for Future Research

The writer proposed three recommendations for future research based on this pilot study. The first recommendation is that there is a need for continued investigation that examines the linkages among illness attributions, caregiver perspective-taking, and symptom assessment with a larger study sample. Lobchuk and colleagues aim to accrue a sample size of 200 dyads and conduct a more sophisticated data analysis to provide more convincing evidence for the investigator's inference of relationships that exist in this preliminary investigation of study results.

Next, further research is required to determine whether the linkage between empathic communication or perspective-taking by caregivers and perceptual accuracy on symptoms is influenced by specific caregiver groups (i.e. spouses, siblings, children, and friends). Higgins (1981) suggested that perspective-taking may be reliant on relationship qualities, characteristics, and the roles played by each party. As such, it is possible that individual differences in perspective-taking skill may exist between individual caregiver groups. Such evidence would broaden the knowledge base on caregiver perspective-taking and foster the development of a more tailored assessment tool on patient-caregiver communication, and subsequent interventions.

Lastly, a qualitative component should be incorporated in future quantitative studies on this clinical topic. While qualitative studies in this area have been conducted in the recent past (Chapple et al., 2004, Zhang & Siminoff, 2003a, Zhang & Siminoff, 2003b), it was clear to the investigator that a large number of study participants wanted to

share their experiences through discussion at the time of interview in the patient's home. Combining a qualitative reporting of experiences, attributions, and feelings with quantitative analyses of study findings would provide richness and depth to the evidence. The themes detected in future qualitative work on the experiences of lung cancer patients and family caregivers may assist researchers in developing a more sensitive risk assessment tool for dyads at risk for poor communication, as well as supportive interventions that are meaningful to patients and their family caregivers.

Conclusion

Overall, this preliminary analysis of findings from a larger, ongoing study provided several interesting findings for the consideration of clinicians and researchers who work with dyads of lung cancer patients and their family caregivers. Major study findings are supported by previous evidence that suggests patients and caregivers attribute the cause and controllability of the disease to the patient, thereby resulting in feelings of anger, shame, aggravation, and annoyance toward 'the patient' by both patients and caregivers (Chapple et al., 2004, Zhang & Siminoff, 2003a, Zhang & Siminoff, 2003b, Weiner, 1995). This study's findings indicated that not only do negative illness attributions and negative emotions held by patients and caregivers toward the patient exist, but they also impact dimensions of caregiver perspective-taking and perceptual concordance between patients and their caregivers. Several significant differences and non-significant patterns in responses between patients and caregivers indicated there is an ongoing need to develop an evidence base that can help clinicians identify dyads at risk for sub-optimal empathic communication and concordant symptom reporting. Several factors that may put them at risk for sub-optimal communication and

perceptual agreement on illness events include conflicts in their attributional reactions that are significant to the stigmatized disease of lung cancer. Both illness attributions and perspective-taking behaviours by patients or caregivers consist of modifiable cognitions and behaviours that can be altered by interventions. Further investigation needs to be conducted in this unexplored area of clinical care.

Several limitations to this study were addressed including the small sample size that made it difficult to detect significant results and extend generalizability of study findings. Implications for clinical practice were discussed that included the development of a clinical tool to identify patient-caregiver dyads at risk for difficulty with communication and empathic processes. Supportive interventions must also be developed for dyads deemed to be “at risk” to promote enhanced perspective-taking and foster open communication between patients and family caregivers. Steps also need to be taken to enhance the awareness and knowledge of front-line healthcare providers on the potential impact of attributional reactions of ‘blame’ and ‘anger’ on symptom assessment by patients and family caregivers.

Future studies with larger sample sizes are required for the ongoing testing of attributional reactions toward lung cancer patients. Research designs should also control for patient and caregiver characteristics (e.g., age, patient-caregiver relationships) that may impact perceptions of illness attributions and empathic communication in caregiving relationships. More sophisticated statistical analysis that explores the causal relationships among illness attributions, emotions, help intended communication, and perceptual accuracy on illness events between patients and caregivers is also recommended. Also, the inclusion of a qualitative component in future quantitative studies will add a greater

dimension to the interpretation of study findings and may, through increasing our understanding of the area, enhance the future development of a sensitive and specific assessment tool for high-risk dyads. Effective interventions might then be designed and tested in high risk patient-family caregiver populations to help them cope with symptom assessment and management in the home.

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APPENDIX A



CancerCare
MANITOBA

Action Cancer Manitoba

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August 24, 2004

Michelle Lobchuk, RN, PhD
Assistant Professor, University of Manitoba
Faculty of Nursing
Room 315, Helen Glass Centre for Nursing
Winnipeg, Manitoba R3T 2N2

Dear Dr. Lobchuk:

RE: Research Proposal

Pursuant to our discussion of your research proposal, "Lung Cancer Stigma: Attribution effects on informal caregiver perspective-taking and accuracy outcomes on symptom experiences", I am pleased to inform you that I am supportive of the project.

As we have discussed earlier, I believe that the Thoracic Cancer Clinic at CancerCare Manitoba will certainly provide the required numbers of patients to be enrolled in this study. On average, we see 15 advanced stage lung cancer patients per month.

I would be pleased to assist you in recruiting 84 dyads of advanced stage lung cancer patients and informal caregivers by providing you access to them in the thoracic tumor clinic.

Sincerely,

Sri Navaratnam, MBBS, FRCPC, PhD
Chair, Thoracic Disease Site Group

SN/le

APPENDIX B

Invitation to Patients and Family Caregivers

(A study by Michelle Lobchuk, Principal Investigator, Faculty of Nursing, University of Manitoba, Winnipeg, Canada)

Michelle Lobchuk is a registered nurse and an Assistant Professor at the Faculty of Nursing, University of Manitoba, Winnipeg, Canada. Dr. Christine McPherson is a registered nurse and a Research Scientist in the Department of Palliative Care, Elisabeth Bruyere Research Institute, Ottawa. Dr. Susan McClement is also a registered nurse and an Assistant Professor at the Faculty of Nursing, University of Manitoba. They are doing research here about lung cancer patients' pain, fatigue, and shortness of breath, and the ways family members view the patient's illness and symptom experiences. They are also interested in understanding how patients and family members understand the cause and control of lung cancer in the patient that can help health care professionals to improve symptom management by family caregivers of lung cancer patients.

The information that you and your family member give will be kept strictly confidential. Whether or not you decide to participate will in no way influence the care that you receive.

A research nurse would like to talk to you about the study. Please print and sign your name below and indicate if you would be willing to speak to them so that they can explain the study to you.

Print Name: _____ Date: _____

Signature: _____

_____ Yes, I agree to speak with the research staff

Home Phone #: _____ Other _____

Best time to Call: _____

_____ No, I do not agree to speak to the research staff

(MY REASON) _____

**PLEASE RETURN THIS PAGE TO THE NURSE, CLERK or
RADIATION THERAPIST**

APPENDIX C

Patient Consent Form

Research Project Title: Lung cancer stigma: Attributional effects on family caregiver perspective-taking and accuracy outcomes on symptom experiences

Researchers: Dr. Michelle Lobchuk, University of Manitoba, Faculty of Nursing; Dr. Christine McPherson, Department of Palliative Care, Elisabeth Bruyere Research Institute, Ottawa; Dr. Susan McClement, Faculty of Nursing University of Manitoba.

Sponsor: (This study is supported by the Canadian Cancer Society).

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Nature and Purpose of the Study

You are invited to take part in a study about patients' and family caregivers' beliefs about the cause of the patient's lung cancer (e.g, stress, environmental toxins, smoking) and in being able to control the disease and its symptoms. We are interested also in exploring how patients' and family caregivers' emotions influence how they view patients' symptom experience of pain, shortness of breath, and fatigue.

What am I being asked to Consent to? What is the Nature of my Participation in the Study?

If you consent to take part in the study, you are agreeing to answer the questions that the Research Nurse or the nursing student will ask you, and fill out the questionnaires that he or she will give you in the home setting on a one-time basis.

The Research Nurse, Chris Shay (474-6221), or Master's nursing student, Tammy Murdoch, will first ask you eleven short questions that relate to your thinking, memory, and concentration abilities. He or she will ask you questions like, "Can you tell me what day it is today?", and "Can you tell me what season we are in?" The Research Nurse or nursing student will also ask you to complete five questionnaires in a room where your verbal responses to questions cannot be heard by your caregiver. He or she will first ask

you questions as to your age, marital status, occupation, caregiving relationship, and smoking such as “Which of the following statements best describes your cigarette smoking?” and “Does your carer prefer that you smoke or not smoke?” You will also complete a questionnaire about how you have been feeling in regard to pain, shortness of breath, and fatigue you may be having and another two questionnaires about how you view the cause and control of your disease. The final questionnaire will ask you about how your carer behaves and acts towards you to help him or her understand how you are feeling. It is expected that answering the Research Nurse’s or nursing student’s questions and filling in the forms will take about 30 minutes of your time. If you require assistance in reading or filling out any of the forms, the Research Nurse or nursing student will be pleased to assist you.

If you consent to take part in this study, you are also giving the Research Nurse and nursing student permission to access your chart at CancerCare Manitoba (formerly known as the Manitoba Treatment and Research Foundation) for medical information. The medical information that will be sought includes: the type of cancer you have; the stage of your disease; the actual date of your diagnosis, the type of cancer treatment you may be receiving, and the types of cancer treatment you may have received in the past. The Research Nurse or nursing student will access this information under the direction of the nurse who runs the clinic that you usually attend at CancerCare Manitoba. All information obtained from your medical record will be kept confidential, and will be handled in accordance with the Personal Health Information Act (PHIA) guidelines. If you do not want your chart accessed by the Research Nurse or nursing student, but would still like to participate in the rest of the study that is fine. The information you do agree to provide will be collected for the purposes of the study, but your request to not access your chart will be respected.

Once the Research Nurse or nursing student has finished collecting information from you, she or he will conduct a similar process with your caregiver. When both you and your caregiver have completed the questionnaires, the Research Nurse or nursing student will be willing to spend additional time with you and your caregiver to answer any questions that you and your caregiver might have about your responses to your questionnaires.

Handling of Information During & After the Study

Any information that you provide to the Research Nurse and nursing student will be kept confidential. The only exception would be if the Research Nurse or nursing student discovered abuse in the course of the study, in which case he or she is legally bound to report this to the appropriate authorities. No personal identifying information will be recorded on any of the data collection forms used in this study. Your physician(s) will not know how you responded to this study’s questions or that you participated in this study. To protect your identity, you will be assigned a code number that is known only to the Principal Investigator, Dr. Lobchuk. Only Dr. Lobchuk, the Research Nurse, and the nursing student for the study will know the names of those who have agreed to take part in the study. The Research Nurse, the nursing student, Dr. Lobchuk, and the data analyst will have access to the questionnaires that you and your caregiver completed. During and

after the study, all consents and questionnaires will be securely locked up in Dr. Lobchuk's office in the Faculty of Nursing at the University of Manitoba. Study data will be kept for seven to ten years, and destroyed, and treated as confidential waste. The results from this study may be published, and presented at scientific meetings. However, under no circumstances would your identity be revealed. Information will be reported in aggregate or group form as opposed to individual responses.

Benefits and Burdens Associated with Participating in the Study

There are no immediate benefits to you for taking part in the study. However, the results of the study may be helpful to health professionals (like nurses and doctors) who want to know how to improve the care they give patients and their caregivers. There are no known risks involved with participating in the study. However, the Research Nurse or nursing student will provide you with information or resources at Cancer Care Manitoba, such as the Psychosocial Oncology Department, that you can contact to help you deal with issues or answer questions that may arise as a result of participating in this study.

Can I Get a Copy of the Results of the Study?

A summary of the results of the study will be made available to you if you would like to receive them once the study is completed. To indicate your interest in receiving a summary of the study, please fill out the detachable form at the end of the consent.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. You may obtain information and clarification from the Principal Investigator of the study, Dr. Michelle Lobchuk. Michelle can be reached by telephone at (204) 474-7135.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB) of the University of Manitoba, and the Research Access Board of CancerCare Manitoba. If you have any concerns or complaints about this project, you may contact Dr. Lobchuk at 474-7135, or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Prior to signing this consent form, please put a check mark in the box below that reflects your level of participation in this study.

☐ I agree to participate in this study as outlined in this consent, and also give my permission for the Research Nurse or nursing student to access my medical record at CancerCare Manitoba to collect information for the study as outlined in this consent.

☐ I agree to participate in this study, however, I do not want my medical record at CancerCare Manitoba accessed by the Research Nurse or nursing student to collect information for the study as outlined in this consent.

Participant's Signature

Date

Researcher and/or Delegate's Signature

Date

APPENDIX D

Caregiver Consent Form

Research Project Title: Lung cancer stigma: Attributional effects on family caregiver perspective-taking and accuracy outcomes on symptom experiences

Researchers: Dr. Michelle Lobchuk, University of Manitoba Faculty of Nursing; Dr. Christine McPherson, Department of Palliative Care, Elisabeth Bruyere Research Institute, Ottawa; Dr. Susan McClement, Faculty of Nursing, University of Manitoba.

Sponsor: (This study is supported by the Canadian Cancer Society).

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Nature and Purpose of the Study

You are invited to take part in a study about patients' and family caregivers' beliefs about the cause of the patient's lung cancer (e.g., stress, environmental toxins, smoking) and in being able to control the disease and its symptoms. We are interested in exploring how patients' and family caregivers' emotions influence how they view patients' symptom experience of pain, shortness of breath, and fatigue.

What am I being asked to Consent to? What is the Nature of my Participation in the Study?

If you consent to take part in the study, you are agreeing to fill out the questionnaires that the Research Nurse or the nursing student will give you in the home setting on a one-time basis.

The Research Nurse, Chris Shay (474-6221), or the Master's nursing student, Tammy Murdoch, will first ask the person you provide care for, some questions that relate to his/her thinking, memory, and concentration abilities. The Research Nurse or the nursing student will ask him/her questions like, "Can you tell me what day it is today?", and "Can you tell me what season we are in?". He or she will then ask the person to complete five questionnaires in a room where their verbal responses to questions cannot be heard by you. The Research Nurse or the nursing student will first ask the person some simple questions as to age, marital status, occupation, caregiver relationship, and smoking such

as “Which of the following statements best describes your cigarette smoking?” and “Does your carer prefer that you smoke or not smoke?”. The patient will also complete a questionnaire about how he or she have been feeling in regard to pain, shortness of breathe, and fatigue, and another two questionnaires about how he or she views the cause and control of his or her disease. The final questionnaire will ask the person about how you behave and act towards him or her to help you to understand how the person is feeling. It is expected that this will take about 30 minutes of their time. If they require assistance in reading or filling out the any of the questionnaires, the Research Nurse or the nursing student will be pleased to assist them.

While the person you provide care for is completing his/her questionnaire, the Research Nurse or the nursing student will ask you to complete five brief questionnaires. The Research Nurse or the nursing student will first ask you questions that relate to your thinking, memory, and concentration abilities. He or she will ask you questions like, “Can you tell me what day it is today?”, and “Can you tell me what season we are in?”. The next form will ask you simple questions as to your age, marital status, occupation, caregiving relationship, and smoking such as “Which of the following statements best describes your cigarette smoking?” and “Does the patient prefer that smoke or not smoke?”. You will also complete a questionnaire about how the person has been feeling in regard to pain, shortness of breath, and fatigue. The next two questionnaires will ask you about how you view the cause and control of the person’s disease. The final questionnaire will ask you about how you behave and act toward the person to help you understand how the person is feeling. It will take approximately 20 minutes of your time to complete all questionnaires. The Research Nurse or nursing student will also be willing to spend additional time with you to answer any questions that you might have about your responses to your questionnaires.

Handling of Information During & After the Study

Any information that you provide to the Research Nurse or nursing student will be kept confidential. The only exception would be if the Research Nurse or the nursing student discovered abuse in the course of the study, in which case she is legally bound to report this to the appropriate authorities. No personal identifying information will be recorded on any of the data collection forms used in this study. The patient’s physician(s) will not know how you and the patient responded to this study’s questions or that you and the patient participated in the study. To protect your identity, you will be assigned a code number that is known only to the Principal Investigator, Dr. Lobchuk. This code number will be used instead of your name on all the data collection forms for the study. The Research Nurse, the nursing student, Dr. Lobchuk and the data analyst will have access to the questionnaires that you and the patient completed. During and the after the study, all consents and questionnaires will be securely locked up in Dr. Lobchuk’s office in the Faculty of Nursing at the University of Manitoba. Study data will be kept for seven to ten years, and destroyed, and treated as confidential waste.

The results from this study may be published, and presented at scientific meetings. However, under no circumstances would your identity be revealed. Information will be reported in aggregate or group form as opposed to individual responses.

Benefits and Burdens Associated with Participating in the Study

There are no immediate benefits to you for taking part in the study. However, the results of the study may be helpful to health professionals (like nurses and doctors) who want to know how to improve the care they give patients and their caregivers. There are no known risks involved with participating in the study. However, the Research Nurse or nursing student will provide you with information or resources at CancerCare Manitoba, such as the Psychosocial Oncology Department, that you can contact to help you deal with issues or answer questions that may arise as a result of participating in this study.

Can I Get a Copy of the Results of the Study?

A summary of the results of the study will be made available to you if you would like to receive them once the study is completed. To indicate your interest in receiving a summary of the study, please fill out the detachable form at the end of the consent.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. You may obtain information and clarification from the Principal Investigator of the study, Dr. Michelle Lobchuk. Michelle can be reached by telephone at (204) 474-7135.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB) of the University of Manitoba, and the Research Access Board of CancerCare Manitoba. If you have any concerns or complaints about this project, you may contact Dr. Lobchuk at the number listed above, or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature

Date

Researcher and/or Delegate's Signature

Date

If you would like to receive a summary of the results of this study, please fill out the form below:

Name of person to whom study results should be sent: _____

Mailing
address: _____

Postal
Code: _____

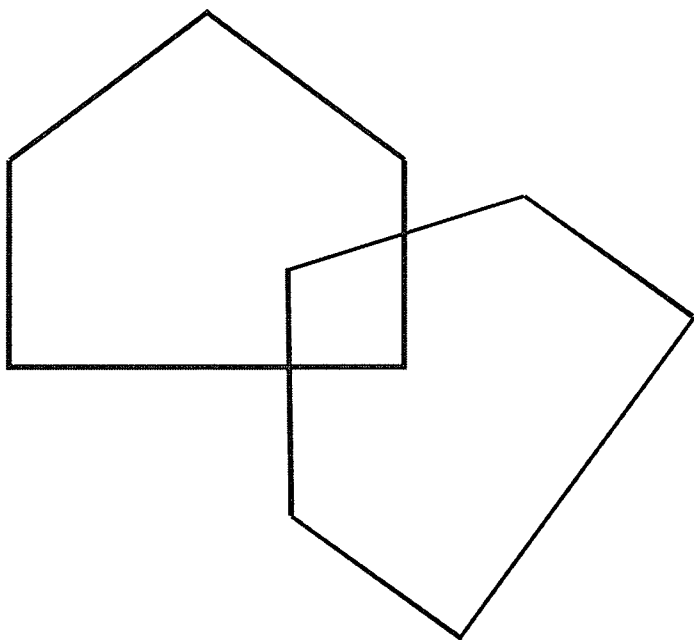
APPENDIX E

MINI-MENTAL STATUS EXAMINATION

PATIENTS AND INFORMAL CAREGIVERS

Max	Score	Orientation
5	()	What is the (year) (season) (date) (day) (month)?
5	()	Where are we? (country) (province) (city) (street) (street number)
Registration		
3	()	Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record.
		<div style="display: flex; justify-content: space-between; padding: 0 10px;"> Car Horse Plant Trials: _____ </div>
Attention		
5	()	Serial 7's. 1 point for each correct. Stop after 5 answers. Alternatively spell "world" backwards.
Recall		
3	()	Ask for the 3 objects repeated above. Give 1 point for each correct.
Language		
9	()	Name a pencil, and watch (2 points) Repeat the following "No ifs, ands or buts." (1 point) Follow a 3-stage command: "Take a paper in your right hand, fold it in half, and put it on the floor" (3 points)
		Read and obey the following: CLOSE YOUR EYES (1 point) Write a sentence (1 point) Copy design (1 point)
<div style="display: flex; justify-content: space-between;"> <div style="width: 30%;"> <hr style="border: 0; border-top: 1px solid black; margin-bottom: 5px;"/> TOTAL SCORE </div> <div style="width: 65%; text-align: center;"> ASSESS level of consciousness along a continuum. <div style="display: flex; justify-content: space-around; margin-top: 10px;"> Alert Drowsy Stupor Coma </div> </div> </div>		

**Close
your
eyes**



APPENDIX F

Lung Cancer Patient – Demographic Survey

To begin our survey, I would like to ask you a few questions about your background. We ask these questions so that we can describe the overall characteristics of the group of people who took part in the survey.

1.	What language do you speak most of the time at home? (What is your main, or first language?)	1. English 2. French 3. Other (Specify) _____
2.	What is your cultural or ethnic background? For example, what part of the world do your ancestors come from? (How would you describe your ethnic or cultural heritage?)	Specify:
3.	What is your religion, if any?	1. No preference 2. Anglican 3. Baptist 4. Greek Orthodox 5. Jehovah's Witness 6. Jewish 7. Lutheran 8. Mennonite 9. Pentecostal 10. Presbyterian 11. Roman Catholic 12. United Church 13. Other (Specify) _____
4.	How far did you go in school?	1. Less than High school 2. High School Graduate 3. Partial College (at least one year) 4. College or University Graduate 5. Graduate/Professional Training
5.	What is your marital status? (Have you ever been married?)	1. Married 2. Common-law 3. Never Married 4. Widowed

		5. Separated 6. Divorced
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6.	What is your age?	_____
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7.	What is your gender?	1. Female 2. Male
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8.	What is your occupational status?	1. Full-time 2. Part-time 3. Medical leave 4. Unemployed 5. Retired
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9.	What is your current (or previous) employment?	1. Clerical 2. Labourer 3. Homemaker 4. Professional 5. Management 6. Other (Specify) _____
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10	What is your annual family income?	1. Below \$10,000 2. \$10,000-\$20,000 3. \$21,000 - \$30,000 4. \$31,000 - \$40,000 5. \$41,000 - \$50,000 6. \$51,000 - \$60,000 7. \$61,000 - \$70,000 8. Over \$71,000/year
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11.	What type of lung cancer do you have?	1. Small cell lung cancer 2. Non-small cell lung cancer
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12.	If you have non-small cell lung cancer, what stage is your cancer?	1. Stage I 2. Stage II 3. Stage III 4. Stage IV
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		5. Unknown
13.	If you have small cell lung cancer, what stage is your cancer?	1. Limited 2. Extensive 3. Unknown
14.	What is the actual date of your diagnosis?	_____
15.	Are you receiving current treatment for lung cancer?	1. Yes 2. No
16.	If you are receiving current treatment for your lung cancer, what kind are you receiving? Check off all treatments that apply to you.	1. Chemotherapy 2. Radiotherapy 3. Surgery 4. Other (Specify) _____
17.	Did you receive treatment for lung cancer in the past?	1. Yes 2. No
18.	If you did receive treatment in the past, what kind of treatment did you receive? Check off all treatments that apply to you.	1. Chemotherapy 2. Radiotherapy 3. Surgery 4. Other _____
19.	Are you currently receiving nursing care in your home?	1. Yes 2. No
20.	If you are currently receiving nursing care in your home, how long have you been receiving nursing care? (in months)	_____

Questions about smoking behavior

21.	Which of the following statements best describes your cigarette smoking?	<ol style="list-style-type: none"> 1. I smoke regularly now – about the same amount as before finding out I have lung cancer 2. I smoke regularly now – but I've cut down since I found out I have lung cancer 3. I smoke every once in a while 4. I have quit smoking since finding out I have lung cancer 5. I am a former smoker, however I wasn't smoking around the time I found out I have lung cancer, and I don't currently smoke 6. I never smoked
22.	Does your carer . . .	<ol style="list-style-type: none"> 1. Prefer that you smoke 2. Prefer that you stop smoking 3. I don't know 4. Not applicable

Questions about the caregiving relationship

23.	How long has your carer been caring for you? (Months)	<ol style="list-style-type: none"> 1. 0 to 9 2. 10 to 18 3. 19 to 36 4. More than 36
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24.	What is the extent to which your carer assists you in coping with your medical condition and symptoms?	1. Never assists me 2. Rarely 3. Sometimes 4. Frequently 5. Always
25.	Do you and your carer talk openly about what your thoughts and feelings are in regard to your symptoms?	1. Never 2. Rarely 3. Sometimes 4. Frequently 5. Usually
26.	How well do you think your carer knows 'how you think and feel' about your symptoms?	1. Totally not at all 2. Not very well 3. Has some knowledge 4. Adequate 5. Very well
27.	How much contact does carer have with you?	1. Daily, my carers lives with me 2. Daily, but my carer doesn't live with me 3. More than weekly, I don't live with my carer 4. Weekly, I don't live with my carer 5. Less than weekly, I don't live with my carer

APPENDIX G

Informal Carer – Demographic Survey

To begin our survey, I would like to ask you a few questions about your background. We ask these questions so that we can describe the overall characteristics of the group of people who took part in the survey.

1.	What language do you speak most of the time at home? (What is your main, or first language?)	1. English 2. French 3. Other (Specify) <hr style="border: 0; border-top: 1px solid black; margin-top: 5px;"/>
2.	What is your cultural or ethnic background? For example, what part of the world do your ancestors come from? (How would you describe your ethnic or cultural heritage?)	Specify:
3.	What is your religion, if any?	1. No preference 2. Anglican 3. Baptist 4. Greek Orthodox 5. Jehovah's Witness 6. Jewish 7. Lutheran 8. Mennonite 9. Pentecostal 10. Presbyterian 11. Roman Catholic 12. United Church 13. Other (Specify) <hr style="border: 0; border-top: 1px solid black; margin-top: 5px;"/>
4.	How far did you go in school?	1. Less than High school 2. High School Graduate 3. Partial College (at least one year) 4. College or University Graduate 5. Graduate/Professional Training
5.	What is your marital status? (Have you ever been married?)	1. Married 2. Common-law 3. Never Married 4. Widowed

		5. Separated 6. Divorced
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6.	What is your age?	_____
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7.	What is your gender?	1. Female 2. Male
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8.	What is your occupational status?	1. Full-time 2. Part-time 3. Medical leave 4. Unemployed 5. Retired
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9.	What is your current (or previous) employment?	1. Clerical 2. Labourer 3. Homemaker 4. Professional 5. Management 6. Other (Specify) _____
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Questions about smoking behavior

10.	Which of the following statements best describes your cigarette smoking?	1. I smoke regularly now – about the same amount as before finding out the patient has lung cancer 2. I smoke regularly now – but I've cut down since I found out the patient has lung cancer 3. I smoke every once in a while 4. I have quit smoking since finding out that the patient has lung cancer. 5. I am a former smoker, however I wasn't smoking around the time I found out the patient has lung cancer, and I don't currently smoke 6. I never smoked
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11.	Does the patient . . .	<ol style="list-style-type: none"> 1. Prefer that you smoke 2. Prefer that you stop smoking 3. I don't know 4. Not applicable
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Questions about the caregiving relationship

12.	How long have you been caring for the patient? (Months)	<ol style="list-style-type: none"> 1. 0 to 9 2. 10 to 18 3. 19 to 36 4. More than 36
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13.	What is your relationship to the patient?	<ol style="list-style-type: none"> 1. Wife 2. Husband 3. Parent 4. Daughter 5. Son 6. Sister 7. Brother 8. Friend 9. Other (Specify) _____
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14.	What is the extent to which you assist the patient in coping with his or her medical condition and symptoms?	<ol style="list-style-type: none"> 1. Never assist patient 2. Rarely 3. Sometimes 4. Frequently 5. Always
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15.	Do you and the patient talk openly about what the patient's thoughts and feelings are in regard to the patient's symptoms?	<ol style="list-style-type: none"> 1. Never 2. Rarely 3. Sometimes 4. Frequently 5. Usually
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16.	How well do you think you know 'how the patient thinks and feels' about his or her symptoms?	<ol style="list-style-type: none">1. Totally not at all2. Not very well3. Have some knowledge4. Adequate5. Very well
17.	How much contact do you have with the patient?	<ol style="list-style-type: none">1. Daily, I live with the patient2. Daily, but I do not live with the patient3. More than weekly, I don't live with the patient4. Weekly, I don't live with the patient5. Less than weekly, I don't live with the patient

Memorial Symptom Assessment Scale—Patient Self-Report

INSTRUCTIONS:

We have listed several symptoms below. Read each question carefully. If you had any of these symptoms during this past week, please let us know how **OFTEN** you had them, how **SEVERE** they were usually, and how much they **DISTRESSED OR BOTHERED** you by circling the appropriate number. If you **DID NOT HAVE** the symptom, make an "X" in the box marked "DO NOT HAVE".

DURING THE PAST WEEK Did you have any of the following symptoms?	DO NOT HAVE	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
	HAVE	Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Fatigue		1	2	3	4	1	2	3	4	0	1	2	3	4

Memorial Symptom Assessment Scale - Informal Caregiver

INSTRUCTIONS:

We have listed several symptoms below. Read each question carefully. If you believe the patient had any of these symptoms during this past week, please let us know how **OFTEN** the patient had them, how **SEVERE** they were usually, and how much they **DISTRESSED OR BOTHERED** the patient by circling the appropriate number. If the patient **DID NOT HAVE** the symptom, make an "X" in the box marked "DO NOT HAVE".

DURING THE PAST WEEK Did the patient have any of the following symptoms?	DO NOT HAVE	IF YES, How OFTEN did the patient have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER the patient?				
	HAVE	Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Somewhat	Quite A Bit	Very Much
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of Breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Fatigue		1	2	3	4	1	2	3	4	0	1	2	3	4

APPENDIX J

Onset reactions - Patient

Degree of control for causing your lung cancer

1. You are to indicate the degree of “control” for the cause of your lung cancer on the following 5 point scales ranging from 4 (a great deal of responsibility) to 0 (no responsibility)

	Not at all				Entirely
Myself	0	1	2	3	4
My caregiver	0	1	2	3	4
Someone else	0	1	2	3	4
The environment	0	1	2	3	4
Chance	0	1	2	3	4
Fate or destiny	0	1	2	3	4
Divine will	0	1	2	3	4
Heredity or genetics	0	1	2	3	4

Degree of responsibility for causing your lung cancer

1. How much do you blame yourself for getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

2. How much do you blame your caregiver for you getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

3. How much do you fault yourself for you getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

4. How much do you fault your caregiver for you getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

5. How much do you hold yourself responsible for you getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

6. How much do you hold your caregiver responsible for you getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

Degree of anger for causing your lung cancer

1. How much anger do you feel toward yourself for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

2. How much anger do you feel toward your caregiver for you getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

3. How much annoyance do you feel toward yourself for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

4. How much annoyance do you feel toward your caregiver for you getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

5. How much aggravation do you feel toward yourself for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

6. How much aggravation do you feel toward your caregiver for you getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

Degree of sympathy for causing your lung cancer

1. How much sympathy do you feel toward yourself for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

2. How much sympathy do you feel toward your caregiver for you getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

3. How much pity do you feel toward yourself for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

4. How much pity do you feel toward your caregiver for you getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

5. How much concern do you feel toward yourself for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

6. How much concern do you feel toward your caregiver for you getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

APPENDIX K
Onset reactions – Informal Caregiver

Degree of control for the cause of the patient's lung cancer

1. You are to indicate the degree of "control" for the cause of the patient's lung cancer on the following 5 point scales ranging from 4 (a great deal of responsibility) to 0 (no responsibility)

	Not at all				Entirely
Myself	0	1	2	3	4
The patient	0	1	2	3	4
Someone else	0	1	2	3	4
The environment	0	1	2	3	4
Chance	0	1	2	3	4
Fate or destiny	0	1	2	3	4
Divine will	0	1	2	3	4
Heredity or genetic factors	0	1	2	3	4

Degree of responsibility for causing the patient's lung cancer

1. How much do you blame the patient for getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

2. How much do you blame yourself for the patient getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

3. How much do you fault the patient for getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

4. How much do you fault yourself for the patient getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

5. How much do you hold the patient responsible for getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

6. How much do you hold yourself responsible for the patient getting lung cancer?

(Not at all) 0 1 2 3 4 (Entirely)

Degree of anger for causing the patient's lung cancer

1. How much anger do you feel towards the patient for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

2. How much anger do you feel towards yourself for the patient getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

3. How much annoyance do you feel toward the patient for getting cancer?

(None) 0 1 2 3 4 (A great deal)

4. How much annoyance do you feel toward yourself for the patient getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

5. How much aggravation do you feel toward the patient for getting cancer?

(None) 0 1 2 3 4 (A great deal)

6. How much aggravation do you feel toward yourself for the patient getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

Degree of sympathy for causing the patient's lung cancer

1. How much sympathy do you feel toward the patient for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

2. How much sympathy do you feel toward yourself for the patient getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

3. How much pity do you feel toward the patient for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

4. How much pity do you feel toward yourself for the patient getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

5. How much concern do you feel toward the patient for getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

6. How much concern do you feel toward yourself for the patient getting lung cancer?

(None) 0 1 2 3 4 (A great deal)

APPENDIX L

Offset reactions - Patient

Degree of control for the course of the disease

You indicated what you believe to be the cause or causes of your lung cancer. Now you are to indicate the extent of being able to control aspects or the progression of your disease on the following 5 point scales ranging from 4 (a great deal of responsibility) to 0 (no responsibility)

	Not at all			Entirely	
	0	1	2	3	4
Myself	0	1	2	3	4
My caregiver	0	1	2	3	4
Someone else	0	1	2	3	4
The Environment	0	1	2	3	4
Chance	0	1	2	3	4
Fate or destiny	0	1	2	3	4
Divine will	0	1	2	3	4
Heredity or genetic factors	0	1	2	3	4

Degree of responsibility for controlling the patient's lung cancer

1. How much do you blame yourself in your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

2. How much do you blame your caregiver in your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

3. How much do you fault yourself in your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

4. How much do you fault your caregiver in your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

5. How much do you hold yourself responsible for your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

6. How much do you hold your caregiver responsible for your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

Degree of anger for controlling the patient's lung cancer

1. How much anger do you feel toward yourself in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

2. How much anger do you feel toward your caregiver in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

3. How much annoyance do you feel toward yourself in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

4. How much annoyance do you feel toward your caregiver in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

5. How much aggravation do you feel toward yourself in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

6. How much aggravation do you feel toward your caregiver in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

Degree of pride for controlling the patient's lung cancer

1. How much pride do you feel in your attempts to control aspects of your disease?

(None) 0 1 2 3 4 (A great deal)

2. How much pride do you feel in your caregiver's attempts to control aspects of your disease?

(None) 0 1 2 3 4 (A great deal)

3. How satisfied do you feel about your attempts to control aspects of your disease?

(Not at all) 0 1 2 3 4 (Entirely)

4. How satisfied do you feel about your caregiver's attempts to control aspects of your disease?

(Not at all) 0 1 2 3 4 (Entirely)

5. How hopeful do you feel in your attempts to control aspects of your disease?

(Not at all) 0 1 2 3 4 (Entirely)

6. How hopeful do you feel in your caregiver's attempts to control aspects of your disease?

(Not at all) 0 1 2 3 4 (Entirely)

APPENDIX M

Offset reactions – Informal Caregiver

Degree of control for the course of the disease

You indicated what you believe to be the cause or causes of the patient's lung cancer. Now you are to indicate the extent of being able to control aspects or the progression of the patient's disease on the following 5 point scales ranging from 4 (a great deal of responsibility) to 0 (no responsibility)

	Not at all			Entirely	
	0	1	2	3	4
Myself	0	1	2	3	4
The patient	0	1	2	3	4
Someone else	0	1	2	3	4
The Environment	0	1	2	3	4
Chance	0	1	2	3	4
Fate or destiny	0	1	2	3	4
Divine will	0	1	2	3	4
Heredity or genetic factors	0	1	2	3	4

Degree of responsibility for controlling the patient's lung cancer

1. How much do you blame yourself in your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

2. How much do you blame the patient in his or her efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

3. How much do you fault yourself in your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

4. How much do you fault the patient in his or her efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

5. How much do you hold yourself responsible for your efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

6. How much do you hold the patient responsible for his or her efforts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

Degree of anger for controlling the patient's lung cancer

1. How much anger do you feel toward yourself in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

2. How much anger do you feel toward the patient in his or her efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

3. How much annoyance do you feel toward yourself in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

4. How much annoyance do you feel toward the patient in his or her efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

5. How much aggravation do you feel toward yourself in your efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

6. How much aggravation do you feel toward the patient in his or her efforts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

Degree of pride for controlling the patient's lung cancer

1. How much pride do you feel in your attempts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

2. How much pride do you feel in the patient's attempts to control aspects of the disease?

(None) 0 1 2 3 4 (A great deal)

3. How satisfied do you feel about your attempts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

4. How satisfied do you feel about the patient's to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

5. How hopeful do you feel in your attempts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

6. How hopeful do you feel in the patient's attempts to control aspects of the disease?

(Not at all) 0 1 2 3 4 (Entirely)

APPENDIX N
Caregiver Perspective-Taking Scale (Patient version)

How well do the following questions describe your caregiver's behaviour and actions with you on a scale from 0 to 4, where 0 does not describe your caregiver very well, and 4 describes your caregiver very well. For each question circle the number that is the best description of your caregiver's actions towards you.

	0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL					
DOES DESCRIBE MY PARTNER VERY WELL					
<hr/>					
1. When involved in an argument with me, my caregiver is the type of person who will consider and take into account my point of view and compare that with their own.	0	1	2	3	4
2. My caregiver is not good at understanding my problems.	0	1	2	3	4
3. My caregiver not only listens to what I am saying but really understands and seems to know where I am coming from.	0	1	2	3	4
4. My caregiver does not seem to know how I feel.	0	1	2	3	4
5. My caregiver is able to accurately compare his/her point of view with mine.	0	1	2	3	4
6. My caregiver evaluates my motivation for doing something before he/she makes judgments about a situation.	0	1	2	3	4
7. My caregiver easily becomes impatient with me.	0	1	2	3	4

	0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL					DOES DESCRIBE MY PARTNER VERY WELL
8. My caregiver is not able to put him/herself into my shoes.	0	1	2	3	4
9. My caregiver nearly always knows exactly what I mean.	0	1	2	3	4
10. My caregiver does not sense or realize what I am feeling.	0	1	2	3	4
11. My caregiver realizes what I mean even when I have difficulty saying it.	0	1	2	3	4
12. My caregiver does not usually understand the whole meaning of what I say to him/her.	0	1	2	3	4
13. My caregiver appreciates how the things I experience feel to me.	0	1	2	3	4
14. Before criticizing me, my caregiver tries to imagine how I feel.	0	1	2	3	4
15. If my caregiver thinks he/she is right about something he/she doesn't waste much time in listening to my arguments.	0	1	2	3	4
16. My caregiver tries to understand me better by imagining how things look from my perspective.	0	1	2	3	4
17. My caregiver believes that there are two sides to every argument and tries to look at both sides.	0	1	2	3	4
18. My caregiver sometimes finds it difficult to see things from my perspective.	0	1	2	3	4

0	1	2	3	4
DOES NOT DESCRIBE MY PARTNER VERY WELL			DOES DESCRIBE MY PARTNER VERY WELL	

19. My caregiver tries to look at my perspective before making a decision. 0 1 2 3 4

20. When my caregiver is upset with me he/she tries to put him/herself in my shoes for a while. 0 1 2 3 4

APPENDIX O

Caregiver Perspective-Taking Scale – (Caregiver version)

How well do the following questions describe your behaviour and actions with the patient on a scale from 0 to 4, where 0 does not describe you very well, and 4 describes you very well. For each question circle the number that is the best description of your actions towards the patient.

	0	1	2	3	4
DOES NOT DESCRIBE ME VERY WELL					DOES DESCRIBE ME VERY WELL
1. When involved in an argument with the patient, I am the type of person who will consider and take into account the patient's point of view and compare that with my own.	0	1	2	3	4
2. I am not good at understanding the patient's problems.	0	1	2	3	4
3. I not only listen to what the patient is saying but really understand and seem to know where the patient is coming from.	0	1	2	3	4
4. I do not seem to know how the patient feels.	0	1	2	3	4
5. I am able to accurately compare the patient's point of view with mine.	0	1	2	3	4
6. I evaluate the patient's motivation for doing something before I make judgments about a situation.	0	1	2	3	4
7. I easily become impatient with the patient.	0	1	2	3	4

	0	1	2	3	4
DOES NOT DESCRIBE ME VERY WELL					DOES DESCRIBE ME VERY WELL
8. I am not able to put myself into the patient's shoes.	0	1	2	3	4
9. I nearly always know exactly what the patient means.	0	1	2	3	4
10. I do not sense or realize what the patient is feeling.	0	1	2	3	4
11. I realize what the patient means even when the patient has difficulty saying it.	0	1	2	3	4
12. I do not usually understand the whole meaning of what the patient is saying to me.	0	1	2	3	4
13. I appreciate how the things the patient experiences, feel to him or her.	0	1	2	3	4
14. Before criticizing the patient, I try to imagine how the patient feels.	0	1	2	3	4
15. If I think that I am right about something I don't waste much time in listening to the patient's arguments.	0	1	2	3	4
16. I try to understand the patient better by imagining how things look from the patient's perspective.	0	1	2	3	4
17. I believe that there are two sides to every argument and I try to look at both sides.	0	1	2	3	4
18. I sometimes find it difficult to see things from the patient's perspective.	0	1	2	3	4

- 3 -

0	1	2	3	4
DOES NOT DESCRIBE ME VERY WELL				DOES DESCRIBE ME VERY WELL

19. I try to look at the patient's perspective before making a decision. 0 1 2 3 4

20. When I am upset with the patient I try to put myself in the patient's shoes for a while. 0 1 2 3 4