An Exploratory Study of Patient and Informal Caregiver Stigma and Empathic Behaviour in Smoking and Non-Smoking Related Illnesses

by

Freya D. Hansen

A Thesis submitted to the Faculty of Graduate Studies of

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in partial fulfilment of the requirements of the degree of

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Of

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Abstract

Patients with smoking-related illnesses (lung cancer, Chronic Obstructive Pulmonary Disease) may face stigma. Empathic Behaviour (EB) is one measure of communication between the patient and Informal Caregiver (IC). This study (n=34) compared patient and IC stigma and EB of dyads with smoking-related illnesses (n=19) to those with colorectal cancer (n=15). EB scales demonstrated reliability; however, stigma scales had poor reliability within smoking-related illness groups. Patient or IC stigma did not differ between groups. Younger patients, patients and ICs without religion reported more stigma. EB was positively correlated with education and income, and negatively correlated with patient and IC smoking. Smoking-related illness patients rated ICs as less empathic and patient stigma was negatively correlated with IC's perception of patient's EB. In the colorectal cancer group, IC stigma was negatively correlated with patient's perception of self and IC's EB. Empathic behavior is potentially modifiable and interventions may improve communication and patient outcomes.

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CHAPTER 1

Statement of the problem

Introduction

In Canada and the United States, efforts at health promotion and disease prevention efforts have often had the unintended consequence of blaming the victim when they become ill especially with regard to illnesses that are seen to be preventable. In particular, the shift regarding attitudes towards cigarette smoking have resulted in "victim blaming" and a social stigma facing smokers and those with smoking related illnesses such as lung cancer and Chronic Obstructive Pulmonary Disease (COPD). Stigma, defined as a spoiled identity, has many detrimental consequences including social isolation, psychological distress, treatment seeking delay, and negative impacts on personal or family relationships. The results of a recent meta-analysis of 165 studies (Chida, Hamer, Wardle & Steptoe, 2008) suggested that psychosocial stress is related to a higher incidence of cancer in healthy populations and poorer survival in those diagnosed with cancer indicating that it is imperative to study psychosocial factors in oncology nursing.

Lung cancer is the leading cause of cancer deaths in both males and females in Canada and the United States (Canadian Cancer Society, 2008a; American Cancer Society, 2008a). Overall, COPD is the fourth leading cause of death in both Canada and the United States (Public Health Agency of Canada, 2008; American Lung Association, 2008). This information depicts that there are a large number of patients, along with their informal caregivers (ICs), who face not only a devastating illness with resultant

physiological and psychological stressors and symptoms, but additional stressors and challenges because their illness is a stigmatized illness.

Stigma is defined as the labelling of a person as tainted or less desirable (Goffman, 1963). Any illness and, in particular, a cancer diagnosis may be associated with stigma (Muzzin, Anderson, Figueredo, & Gudelis, 1994). However, lung cancer and COPD patients may face an increased stigma from family, friends, and health care professionals. It appears that a person's reaction to illness depends, in part, on the degree of perceived personal responsibility afforded to the patient in relation to the cause of the disease (Weiner, Perry & Magnusson, 1988). Thus, as society changes its views about cigarette smoking, along with an increasing onus on individuals for preventing illness, patients with perceived smoking-related illnesses may be viewed as being accountable for causing their own illness and will face increased stigmatization. There is some evidence to suggest that stigma faces those who have smoking-related illnesses. In a qualitative study, Chapple, Ziebland and McPherson (2004) found that lung cancer patients feel particularly stigmatized. As well, stigma affects those who are diagnosed with COPD (O'Neill, 2002). Stigma may have many consequences for the stigmatized individual such as increasing social isolation, an increase in psychological distress manifested as guilt or shame, a delay in treatment seeking, and it may impact on personal or familial relationships, such as relationships between the patient and their IC (Muzzin, Anderson, Figueredo, & Gudelis, 1994; Weiner, 1995; Fife & Wright, 2000; Parker & Aggleton, 2003; Lebel and Devins, 2008; Lobchuk, McClement, McPherson & Cheang, 2008). Additionally, those who are close to the stigmatized person may also be stigmatized, an occurrence known as courtesy stigma (Goffman, 1963).

Increasingly, due to cutbacks that encourage shortened hospital stays, our healthcare system relies extensively on ICs to care for patients in the community, provide for the transition between hospital and home (and vice versa) and act as a patient advocate when the patient is hospitalized. This reliance on ICs is expected to continue to rise as our population ages and more individuals are living with serious diseases. The IC, who is often untrained for the role, must perform a myriad of activities to assist the patient. At times, the IC may become responsible for the patient's symptom management, act as a patient advocate, and become the primary decision maker as the patient's condition deteriorates. Communication with the patient is central to the IC role, and there are numerous cognitive processes and skills essential for optimal communication, such as listening skills and the ability to be able to perspective-take or engage in empathic behaviour. As a result of the increasing significance of the IC role, it is important to study factors that may assist or inhibit effective communication between patients and ICs which in turn, may influence patient symptom management or illness outcomes.

Several studies have examined empathic behaviour as exhibited by perceptual understanding and agreement between patient and IC dyads. For example, Lobchuk, Kristjanson, Degner, Blood, and Sloan (1997) examined the level of agreement between patients with lung cancer and their ICs on patient symptom distress. These authors found that ICs were able to provide reasonably accurate symptom assessments of ten of thirteen symptoms. Additionally, Lobchuk and Vorauer (2003) found that ICs appeared to make a concerted effort to understand the advanced cancer patient's physical symptoms, such as decreased energy, from the patient's perspective, but that psychological symptoms, such as patient worry, appeared to be influenced by their own worry states. In a follow-up

study, Lobchuk, Degner, Chateau, and Hewitt (2006) reported that instructional sets prompting the caregiver to imagine the patient's perspective produced assessments of patient symptoms that were similar to neutral prompts, suggesting that ICs naturally engaged in perspective-taking. Additionally, these authors found that factors such as the length of the patient and IC relationship, the type of care provided, the amount of IC contact, and the proximity may impact perspective-taking.

Recently, Lobchuk, McClement, McPherson and Cheang (2008) reported preliminary study findings involving 100 lung cancer patients along with their ICs in relation to the impact of the IC's illness attribution reactions on his or her helping behaviour. The authors found that IC attributions of patient responsibility for controlling the illness and anger placed the IC at risk for impaired helping behaviour especially if the patient had a cigarette smoking history or continued smoking. This study provided preliminary support for Weiner's (1995) theory on the link between controllable illness attributions and helping behaviour.

Purpose of the Study

The purpose of the present study was to build on Lobchuk, McClement, McPherson and Cheang's (2008) study to expand our knowledge on the relationship between stigma and empathic behaviours by patients with smoking-related illnesses and their ICs. However, instead of examining illness attributions and affective states, stigma and empathic behaviour were measured along with patient and IC demographic data inclusive of cigarette smoking history to determine the association among these variables. Also, a comparison group of patients diagnosed with colorectal cancer along with their ICs was included to test whether linkages among the patient's or IC's perceptions of

stigma, empathic behaviours and demographic variables differed between smoking-related illnesses and a non smoking related illness. This study was guided by an exploratory framework developed by the author based on a review of the empirical literature.

Operational Definitions

Informal Caregiver (IC): a family member or other person identified by the patient who provides unpaid and informal care in response to a patient's illness or functional impairment.

***Informal Caregiver/Patient dyad*:** The pair which consists of the patient and his or her informal caregiver.

Stigma: the labelling of a person as tainted or less desirable (Goffman, 1963).

Courtesy stigma: Stigma that may be experienced by those who are close to the stigmatized individual such as family members or informal caregivers (Goffman, 1963).

Health-related stigma: a "social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group... based on an enduring feature of identity conferred by a health problem" (Weiss et al., 2006, p. 280).

***Patient Stigma*:** the total score of scaled stigma items regarding the patient's illness utilized to capture perceptions of stigma by patients in the dyad.

***Informal Caregiver Stigma*:** the total score of scaled stigma scales regarding the patient's illness utilized to capture perceptions of stigma by ICs in the dyad.

Stigma discrepancy: a calculation of the matched scores of the patient stigma score total minus the IC stigma score total. If the patient's stigma score is higher than the IC's score, the discrepancy score will be positive. If the patient's stigma score is lower than the ICs, the discrepancy score will be negative.

Perspective-taking: "the tendency to adopt the partner's point of view in reacting to a given interdependence situation, attempting to see the situation from the partner's perspective, feeling and thinking as the partner would feel and think" (Arriaga & Rusbult, 1998, p. 930).

***Perspective-taking within the Caregiver/Patient dyad*:** "an underlying process of empathy which impacts on communication competence and cognitive understanding of another's distressing experiences" (Lobchuk, 2006, p. 331-332).

***Patient Empathic Behaviour*:** the total score of scaled perspective-taking items utilized to capture perceptions of empathic communication and behaviours by patients in the dyad.

***Informal Caregiver Empathic Behaviour*:** the total score of scaled perspective-taking items utilized to capture perceptions of empathic communication and behaviours by ICs in the dyad.

Informal caregiver empathic behaviour discrepancy: a calculation of the matched scores of the patient's perspective of the IC empathic behaviour total minus the IC's perception of their own empathic behaviour total. If the patient rates the IC higher in empathic behaviour than the IC rates him/herself, then the discrepancy score will be positive. If the IC rates him/herself as higher in empathic behaviour than the patient does then the discrepancy score will be negative.

Patient empathic behaviour discrepancy: a calculation of the matched scores of the patient's perception of their own empathic behaviour minus the IC's perception of the patient's empathic behaviour. If the patient rates him/herself higher in empathic behaviour then the IC does, then the discrepancy score will be positive. If the IC rates the patient as higher in empathic behaviour than the patient rates him/herself then the discrepancy score will be negative.

Research Questions

The following quantitative research questions were asked in this comparative, descriptive study:

1. What are the relationships between demographic characteristics of patients and ICs (age, gender, income, education, religion, smoking history, length of relationship) and patient and IC responses on stigma and empathic behaviour?
2. What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour?
3. What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?
4. What is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking related illness group and colorectal cancer groups?

Significance of the Study

This study addressed an identified gap in the literature by examining whether stigma is associated with empathic behaviours in a study sample of patients and ICs dealing with smoking-related illnesses or colorectal cancer, as well as whether demographic or relationship characteristics are related to stigma or empathic behaviours. There are a large number of patients and ICs dealing with smoking-related diseases that may ultimately benefit from research on the impact of stigma on empathic behaviours. Empathic behaviour is a potentially modifiable factor in patients and caregivers, and interventions may be developed to ameliorate or prevent any detrimental effects of stigma that may impede optimal communication in the patient / IC relationship.

Summary

There are many people in Canada and the United States who are affected by smoking- related illnesses, including lung cancer and COPD. Health promotion strategies which actively attempt to decrease cigarette smoking have resulted in a shift in thinking about cigarette smoking from that of a socially acceptable behaviour to an increasingly stigmatized behaviour. Stigma has been demonstrated to have a number of detrimental effects such as threatening the individual's self-esteem and contribute toward delays or interruptions of treatment. Stigma may also impact ICs through courtesy stigma. As our healthcare system relies extensively on ICs to care for patients in the community as well as assist in hospitals and transitions between care settings, it is important to examine factors that may impact on the IC's ability to communicate with the patient about his or her illness experiences. Stigma may hazardously affect the IC's ability to comprehend the patient's point of view, or their ability to engage in empathic behaviour and result in

decreased effectiveness of the patient/ IC relationship and decreased quality of care for the patient. As the stigmatization of those individuals dealing with smoking-related illnesses and the occurrence of the IC role are increasing within our health care system, it is essential to examine factors that may impact the IC's ability to engage in empathic behaviour in order to develop patient-oriented interventions that will ultimately improve patient care.

CHAPTER II

Literature Review

Introduction

A literature review was conducted to determine the state of knowledge in the main conceptual areas targeted in this study. There were six main areas relevant to this study: lung cancer, chronic obstructive pulmonary disease (COPD), colorectal cancer, stigma, informal caregiving, and empathic behaviour.

Lung cancer

Definition, incidence, and pathophysiology

Lung cancer refers to a group of malignant diseases that arise from the epithelium of the bronchi within the respiratory tract (Brashers, 2006). Lung cancer is the leading cause of cancer death in both males and females in Canada and the United States (Canadian Cancer Society, 2008a; American Cancer Society, 2008a). In 2008, it was estimated that 23,300 Canadians and 215,020 Americans would develop lung cancer; and 20,200 Canadians and 161,840 Americans would die from the disease (Canadian Cancer Society, 2008a; American Cancer Society, 2008a). While the death rates for some cancers such as breast cancer and skin cancer continue to decline due to improved screening protocols, early detection and treatment, the death rate for lung cancer continues to be dismally high. For example, since 1993 breast cancer rates have stabilized and the death rate has steadily declined (Canadian Cancer Society, 2008a). By contrast, lung cancer occurrence and mortality is actually increasing among Canadian women (Canadian Cancer Society, 2008a).

The most common cause of lung cancer is cigarette smoking which has long been known to be causally related to lung cancer. Since 1950, smoking has been linked to the development of 80- 90% of lung cancers (Peto et al., 2000). Although the risk of developing lung cancer decreases if a person stops smoking, the risk of lung cancer remains higher among former smokers, even those who have quit for up to forty years (Brashers, 2006). Other risk factors to developing lung cancer include exposure to environmental hazards such as second hand smoke, or other inhaled pollutants such as benzopyrene, radon, asbestos fibres, coal and iron mining, and diesel exhaust (Brashers, 2006). Additionally, there is mounting evidence that there is a genetic component to the development of lung cancer as researchers have discovered strong evidence of a lung cancer susceptibility region on a segment of chromosome six. The National Cancer Institute (2006) reported that the Genetic Epidemiology of Lung Cancer Consortium discovered that in those who were not carriers of the familial lung cancer gene, the chance of developing lung cancer was dose specific to the number of cigarettes smoked. However, in carriers of the familial lung cancer gene, any amount of cigarette smoking increased lung cancer risk, suggesting that even a very small amount of smoking may lead to lung cancer for those who have an inherited susceptibility.

Types of Lung Cancer

There are two main types of lung cancer: non-small carcinoma (NSCLC) which accounts for 75% of lung cancers and small cell carcinoma (SCLC) which accounts for 14% of lung cancers. Other rare cancers, such as adenosquamous carcinomas or bronchial gland carcinomas make up the remaining lung cancer cases (Brashers, 2006). These rare cancers will not be addressed in this document as only patients with NSCLC

or SCLC were recruited for this study. In general, the patient's prognosis and treatment of the non-small or small cell lung cancer depends on the type and stage of the lung cancer, as well as the presence of other comorbidities or lung disorders.

Non-small cell lung cancer. NSCLC is classified according to the International System for Staging Lung Cancer which utilizes the TMN classification (T refers to the size or growth of the tumour, M refers to the presence or absence of metastasis and N refers to lymph nodal involvement) and provides for staging from I to IV lung cancer based on the patient's TMN classification (Mountain, 1997). There are three types of NCLC: adenocarcinoma, squamous cell carcinoma, and large cell or oat cell carcinoma (Brashers, 2006).

Squamous cell carcinomas account for approximately 30% of NSCLC and are typically located near the hilus. These tumours may remain fairly localized and if diagnosed prior to metastasis, surgical resection may be the only treatment required. Because of the location of the tumour, patients may present with symptoms such as a non-productive cough or hemoptysis. This type of tumour has been strongly associated with cigarette smoking (Brashers, 2006).

Adenocarcinoma accounts for approximately 35%-45% of NSCLC. Tumours of this type have a moderate rate of growth and patients are most often asymptomatic. The tumour may be discovered incidentally early in the course of the disease or patients present with shortness of breath or chest pain due to a pleural effusion late in the course of the disease. Treatment often consists of surgery and adjuvant chemotherapy (i.e., post-surgical chemotherapy) or radiation. This type of lung carcinoma is the least strongly associated with cigarette smoking (Brashers, 2006).

Large cell carcinoma is also known as undifferentiated large cell anaplastic cancer because the cell has lost all evidence of differentiation. This type of lung cancer accounts for approximately 10%-15% of NSCLC. Patients are often symptomatic and have early and wide spread metastasis prior to diagnosis. Treatment may consist of palliative surgery. This type of carcinoma has also been associated with cigarette smoking (Brashers, 2006).

Small-cell lung cancer. SCLC is staged as either limited or extensive. This staging system was developed by the Veterans Administration Lung Cancer Study Group (Simon & Wagner, 2003). Although accounting for only 14% of lung cancers, small cell carcinoma has the highest rate of mortality. These tumours are aggressive and rapidly growing and have a tendency to metastasize early. Approximately 70% - 80% of patients with SCLC present with extensive disease. The survival time for untreated SCLC is approximately only one to three months. If treated with chemotherapy, 10% of patients are alive after two years. This type of tumour is most strongly associated with cigarette smoking (Brashers, 2006).

SCLC is not often treated surgically because of the nature of the tumours as small and scattered in healthy lung tissue. As well, metastasis has often occurred prior to diagnosis (Brashers, 2006). One large longitudinal study of survivorship for SCLC patients treated surgically conducted in the 1970s showed no benefit for surgery and the role of surgery for SCLC was largely abandoned at that time (Simon & Wagner, 2003). Subsequent studies have replicated this finding, however, there is some evidence that the rare patient with limited SCLC may benefit from surgery (Simon & Wagner, 2003). The main treatment is concurrent chemotherapy and radiation for patients with limited SCLC

and chemotherapy for patients with extensive disease. Treatment may be curative for up to 20% of patients with limited SCLC (Simon & Wagner, 2003).

In general, if caught early, NSCLC may be removed surgically with either a wedge resection or lobectomy, and often adjuvant chemotherapy or radiation is offered to patients. SCLC is treated with chemotherapy and radiation or chemotherapy alone. Any type of lung cancer may invade local chest wall tissue or metastasize via the lymph system to distant sites, such as the brain, liver or bones (Brashers, 2006). Although there is variability in the survival rate depending on lung cancer histology, overall, the five year survival rate for lung cancer patients approximates only 15% (National Cancer Institute, 2006).

Many factors contribute to the high mortality rate among lung cancer patients. For example, lung cancer does not have many early recognizable symptoms. Furthermore, symptoms of lung cancer are often attributed to other causes (e.g. fatigue due to overwork or cough due to a viral infection or cigarette smoking). Like most other cancers, the lung cancer patient's prognosis can be improved by early treatment. However, only approximately twenty percent of patients with non small carcinoma (i.e., the type of lung cancer with the best surgical outcomes) are diagnosed in an early disease stage (Traynor & Schiller, 2002). Thus, by the time patients seek medical treatment for symptoms there may already be the presence of widespread metastases (Haas, 2003). Interestingly, patients with the best prognosis are those who received their lung cancer diagnosis through "dumb luck", such as when a patient is in a car accident and an x-ray reveals a tumour. Sometimes these patients are candidates to receive surgery when the

cancer is still in early disease stages (Unrah, personal communication, November 15, 2006).

Physical symptom distress

Lung cancer patients face many distressing symptoms such as fatigue, breathlessness, cough, pain, and insomnia throughout their illness trajectory. Degner and Sloan (1995) found that among ambulatory cancer patients, symptom distress was the highest in lung cancer patients in comparison to patients with other types of cancers. Furthermore, they found that higher symptom distress scores were associated with increased mortality, and all lung cancer patients with high symptom distress had shortened survival times. Cooley (2000) conducted a review of the literature on lung cancer symptoms and found that the symptoms lung cancer patients experienced changed over the illness trajectory, as well as throughout treatment phases. Cooley's review found that the most common symptoms among newly diagnosed lung cancer patients were fatigue, pain, loss of appetite, coughing and insomnia, while among patients with advanced lung cancer, there was a high prevalence of uncontrolled symptoms such as pain, dyspnea, and anorexia, The most common symptoms in patients receiving chemotherapy were nausea, vomiting, and hair loss, and in patients receiving radiation were dysphagia and sore throat.

Empirical research (Cooley, Short, & Moriarty, 2003) with lung cancer patients confirmed that patients who are diagnosed with lung cancer experienced a change in symptom distress over time and in response to treatment. However, across treatment groups, the authors found that lung cancer patients experienced moderate to high symptom distress at diagnosis, and that although many symptoms improve over time,

fatigue and pain frequency continued to be the most distressing symptoms among adults receiving treatment for lung cancer. Tishelman et al. (2005) found that among non-operable lung cancer patients symptom intensity did not always predict the amount of symptom distress experienced, suggesting that there are psychological variables that may mediate reports of distress arising from symptoms. The authors found that breathlessness, pain and fatigue were the most distressing symptom for patients, even if they were not judged to be the most intense. The authors concluded that distress was related to the patient's fears of future and past symptom experiences and proposed that this knowledge may provide a basis for preventative interventions.

Psychological symptom distress

Distressing physical symptoms of illness do not exist in isolation from psychologically distressing symptoms and lung cancer patients may also have symptoms of psychological distress. For example, Zabora, BrintzenhofeSzoc, Curbow, Hooker and Piantadosi (2001) found that lung cancer patients reported greater psychological distress than patients with other cancer types. The authors speculated that the lung cancer patient's poor prognosis, self-attribution for the cause of their illness, and difficulties that confront their families play a role in the increased psychological distress in this patient group. The authors concluded that, "Lung cancer patients possessed higher levels of distress than other cancer diagnoses, and this finding indicates that special attention must be paid to patients who enter their cancer experience with a much higher level of risk" (p. 27). Fox and Lyon (2006) found that symptoms among lung cancer patients appeared in a cluster of depression and fatigue which negatively impacted the patient's quality of life. Sarna et al. (2005) found that among women with NSCLC, psychological and social

aspects of quality of life were disrupted including depressed mood and negative meaning of illness. In particular, patients reported distress with diagnosis, fear of metastasis, impact on sexual functioning, and distress with family. The authors found that young women who have a depressed mood, negative meaning of illness, and comorbid conditions were at particular risk for disruptions in their quality of life. Downe-Wamboldt, Butler and Coulter (2006) found that among lung cancer patients and their families, quality of life was predicted most by the meaning ascribed to the illness, especially whether or not the illness was perceived as being manageable.

Social relations

Lung cancer patients may also face stigmatization of their disease due to the widely known link between lung cancer and smoking history. In their qualitative study, Chapple, Ziebland, and McPherson (2004) found that lung cancer patients feel particularly stigmatized. These authors explained that the "experience of stigma in lung cancer is shaped by the association between the disease and smoking, the perception of the disease as a self inflicted injury, its high death rate, and the type of death" (p. 2). This perceived stigma may lead to further complications among lung cancer patients such as an increase in psychological distress manifested as guilt or shame, or decreasing social support. Additionally, Tod, Craven, and Almark (2007) found that symptom ambiguity, lack of knowledge, fear, blame and stigma contributed to a delay in seeking treatment among lung cancer patients. LoConte, Else-Quest, Eickhoff, Hyde and Schiller (2007) compared guilt and shame in patients with NSCLC to breast cancer and prostate cancer patients and found that patients with NSCLC had higher levels of perceived cancer-related stigma, but not higher levels of shame and guilt. These researchers also found that

cigarette smoking was correlated with higher levels of guilt and shame regardless of cancer type, and a belief that one caused one's diagnosis of cancer was correlated to higher levels of guilt, shame, anxiety and depression.

Carmack Taylor et al. (2008) studied lung cancer patients and their spouses (n=167) and found that 34.6% of patients and 36.4% of spouses reported psychological distress. Although only 10.9% of patients and 14.1% of spouses reported distressed spousal relationships, distress predictors emerged for patients as less positive social support, more behavioural disengagement and self-distraction coping. Predictors of relationship distress for spouses were more behavioural disengagement, more blaming the patient for causing the cancer and more use of mood altering substances to cope. Other researchers have examined social relations between lung cancer patient and IC dyads (Lobchuk, Kristjanson, Degner, Blood & Sloan, 1997; Lobchuk, Degner, Chateau & Hewitt, 2006; Lobchuk, Murdoch, McClement & McPherson, 2008; Lobchuk, McClement, McPherson, & Cheang, 2008). The results of their research will be discussed in later sections.

Chronic Obstructive Pulmonary Disease (COPD)

Definition, incidence, and pathophysiology

Chronic Obstructive Pulmonary Disease (COPD) is an umbrella term which describes chronic lung diseases that cause limitations in lung airflow. This diagnosis encompasses the more familiar terms 'chronic bronchitis' and 'emphysema' that are no longer used (World Health Organization, 2007). The syndrome involves airflow limitation that is not completely reversible in response to pharmacological agents, and involves progressive changes associated with inflammatory responses within the bronchi

to noxious particles or gasses (Brashers, 2006). In Canada and the United States, COPD is the fourth leading cause of death and approximately 754,700 Canadians and 12.1 million Americans are estimated to have COPD (Public Health Agency of Canada, 2008; American Lung Association, 2008). It was estimated that COPD claimed the lives of 127,049 Americans in 2005 and the number of women who die from the disease has exceeded that of men (American Lung Association, 2008). In Canada, the Public Health Agency of Canada (2008) reports that the most recent estimates available are for 2004 and that in this year COPD was the cause of 5,152 deaths among men and 4,455 deaths among women. COPD deaths in Canada account for approximately 4% of all deaths but the actual mortality rate may be higher because COPD patients may die of one of two COPD complications (pneumonia or congestive heart failure) and these complications may be listed as the cause of death for those with COPD. The trend in Canada for female deaths is increasing, and is estimated that female deaths will outnumber males by the year 2008 (Public Health Agency of Canada, 2008). In addition, COPD is an underdiagnosed illness, and in 2008, it was estimated that of the three million Canadians that currently have COPD, 1.6 million of those patients remain undiagnosed (Canadian Lung Association, 2008).

Chronic bronchitis involves a hypersecretion of mucus and is characterized by a productive cough for at least three months of the year for a period of two consecutive years. The development of chronic bronchitis is initiated by inhaled irritants (such as tobacco smoke or pollution) that increase the mucus production within the epithelium of the respiratory tract as well as the number of goblet cells which produce mucus. This mucus is stickier than the mucus normally produced and thus more likely to provide a

hospitable environment for bacteria such as Haemophilus *influenzae* and Streptococcus *pneumoniae*. The resultant infection reduces ciliary function within the lungs, and also causes further mucus production which causes the bronchial walls to become inflamed and edematous. This persistent inflammation and recurrent infections lead to bronchospasm, poor airway clearance and eventually causes permanent narrowing of all of the airways. This leads to premature closure of the airways and results in air trapping in the distal portion of the lung during expiration. The obstruction eventually leads to decreased oxygenation and increased carbon dioxide retention (Brashers, 2006). Symptoms of chronic bronchitis include recurrent lung infections, decreased exercise tolerance, cough and shortness of breath. If not reversed, hypoxemia may lead to cor pulmonale (right sided heart failure) or pulmonary hypertension which may lead to severe disability or death. Although the pathologic changes are not reversible, symptom progression may be halted by stopping smoking. Bronchodilators, expectorants, chest physiotherapy and supplemental oxygen may be used to control symptoms, but there is no cure for chronic bronchitis and the disease often runs its course with acute exacerbations precipitated by recurrent infections (Brashers, 2006).

Unlike chronic bronchitis, emphysema is characterized by bronchial obstruction resulting from loss of elastic recoil in the lung tissues rather than from mucus production and inflammation. Although many older people have this loss of elastic recoil in their lung tissue as a result of aging, when this occurs in younger people, it is almost always secondary to cigarette smoking. Primary emphysema, which is very rare and accounts for only 1 -2% of emphysema is linked to an inherited deficiency of an enzyme, alpha antitrypsin, which causes increased proteolysis in lung tissue. People who smoke and

have this inherited deficiency are more likely to develop emphysema. Secondary emphysema results from exposure to cigarette smoke or air pollution and is also caused by an inability to inhibit proteolytic enzymes in the lung. Approximately 20% of those who smoke are susceptible to developing emphysema (Brashers, 2006).

Emphysema is characterized by destruction of the alveoli within the lung and destruction of elastin in the alveolar septa. The enzyme responsible for inhibition of proteolysis of lung tissue (alpha antitrypsin) is inhibited by toxins such as cigarette smoke. This results in breakdown of elastin and results in the elimination of portions of the capillary bed and results in air trapping in the acinus. Along with the destruction of the elastic recoil of the airways, expiration becomes difficult. This results in hyperinflation of the alveolas (bullae) and air pockets adjacent to the pluera (blebs). The result is that the patient is unable to exhale fully as part of every exhalation is trapped in the acinus. In addition, an inflammatory response from bronchospasms may further constrict the airways. There are two types of emphysema that include centriacinar emphysema that tends to occur in smokers with chronic bronchitis and panacinar emphysema that tends to occur in elderly people or those with primary emphysema (Brashers, 2006).

Diagnosis of COPD is suspected when a patient presents with dyspnea, cough, or sputum production and a history of risk factors for the disease (exposure to cigarettes and/or environmental or occupational pollutants). The Canadian Thoracic Society (2008) screening guidelines for COPD recommends spirometry for patients who are 40 years of age or older, are current or ex-smokers, and have *one* of the following symptoms: regular cough, cough with phlegm, shortness of breath with activities, wheezing at night or on

exertion, or frequent persistent colds. Diagnosis is confirmed when the patient's spirometry results on post-bronchodilator reveal a Forced Expiration Volume in one second (FEV1) and Forced Vital Capacity (FVC) <0.7 which confirms that airflow limitation is not fully reversible (American Thoracic Society, 2007). Depending on the airflow limitation, COPD may be classified from mild to very severe (American Thoracic Society, 2007). Treatment of COPD may include smoking cessation assistance, bronchodilators, inhaled corticosteroids, supplemental low-dose oxygen, chest physiotherapy or lung reduction surgery. Although the condition may not be reversed, multi-disciplinary pulmonary rehabilitation results in significant improvement in multiple outcome areas including dyspnea, exercise tolerance, improved quality-of-life and health status and decreased healthcare utilization (American Thoracic Society, 2007).

Physical symptom distress

The most common symptom of COPD is breathing difficulty characterized by intermittent cough and sputum production that initially occurs in the morning but becomes persistent throughout the day, and dyspnea upon exertion that later progresses to shortness of breath at rest (American Thoracic Society, 2007). These symptoms may be partially managed with the use of bronchodilators, inhaled corticosteroids and low dose oxygen. Fatigue results from oxygen deprivation. The course of the disease is often long and prolonged with exacerbations of increasing dyspnea and infection that result in cor pulmonale and death (Brashers, 2006). Gysels and Higginson (2008) conducted a qualitative study of patients with COPD (n=18) and discovered that breathlessness itself may result in low access to services by COPD patients due to its insidious onset, stigma regarding breathlessness and invisibility of the symptom that may result in discrediting of

patient experiences by health care institutions. In particular, these authors found that patients often adapted, compensated and accepted breathlessness as it progressed, and might not have mentioned it to their care providers as the symptom may not have been present while in the doctor's office unless the patient was having an acute exacerbation. Breathlessness was an invisible symptom that made it difficult because not only was the symptom not evident to care providers but it was not evident to others who may have ascribed the patient's inactivity to laziness. Fatigue has generally been ranked as the second most important symptom for COPD patients (Kapell, Larson, Patel, Covey & Berry, 2007). Kapella et al. conducted a study of fatigue among patients diagnosed with moderate to severe COPD (n=130) and found that fatigue is an important problem among COPD patients that interfered with the performance of activities of daily life. Fatigue was brought on by physical exertion and was partially relieved by rest, sleep or cooler temperatures. The authors also found that there was a complex relationship between dyspnea, fatigue, anxiety, depression and sleep.

Psychological distress

As well as distressing physical symptoms, such as breathlessness and fatigue, patients with COPD also experience psychological symptoms, such as anxiety and depression (Felker, Katon, Hedrick, Rasmussen, McKnight & McDonall, 2001) and a decrease in their health related quality of life (McCathie, Spence & Tate, 2002). Individuals with COPD have difficulty performing activities of daily living (e.g. bathing, dressing and eating) and also report poorer emotional and psychological functioning as compared to patients with other chronic conditions (Gore, Brophy, & Greenstone, 2000). Laurin et al. (2007) found in one sample of COPD patients (n=116) an overall prevalence

of psychiatric disorders of 49% with anxiety disorders most prevalent, followed by mood disorders (depression). The authors also found that women had a higher prevalence of psychiatric disorders than men. Surprisingly, in a recent study Kunik et al. (2005) found an 80% prevalence rate of anxiety and depression among veteran male patients with chronic breathing problems including COPD (n=1067). Patients with an underlying mental illnesses have a higher risk of development of COPD due to the increased rates of cigarette smoking within this population. Himelhoch, Lehman, Kreyenbuhl, Daumit, Brown, and Dixon (2004) conducted a survey of a random sample of 200 adults with a serious mental illness and these authors found a significantly higher prevalence of COPD within this population (22.6%) than the general population (5%).

Social relations

Keele-Card, Foxall, and Barron (1993) conducted a study with COPD patients and their spouses (n=30) and found that spouses and patients experienced similar psychosocial symptoms of loneliness and depression. However, spouses reported more loneliness than patients, and patients reported more depression than spouses. In addition, the authors found that spouses were less satisfied with their social support network than were patients, and satisfaction with social support was linked to loneliness and depression for patients but not for spouses. Research on stigma experiences has suggested that, similar to lung cancer patients, COPD patients experienced negative affect such as guilt and shame about their illness, which also affected their quality of life (Hu & Meek, 2005). Toms and Harrison (2002) found that COPD patients reported perceived stigma in relation to their illness as a self-inflicted illness. As a result, these patients experienced isolation and diminishing social support as well as a loss of self-

esteem, role and identity. Similarly, O'Neill (2002) reported that women with COPD experienced not only physical symptoms such as dyspnea and fatigue, but also a sense of stigma and social isolation. Johnson, Campbell, Bowers and Nichol (2007) reviewed the COPD literature and concluded that COPD is a physical illness with many psychological consequences. The stigma associated with COPD arises because patients are held accountable for their illness as a result of having participated in a stigmatized behaviour (cigarette smoking). Often patients with COPD are marked with a physical reminder of the illness (oxygen tank or medication inhalers), and frequently have disruptions in their social interactions.

Interestingly, Guell et al. (2006) found that pulmonary rehabilitation has a beneficial effect on not only physical symptoms but also psychosocial symptoms of patients with advanced COPD. The authors noted that although their sample of COPD patients did not receive a psychological intervention, there was a significant improvement in many psychological symptoms among this group of patients. It is unclear whether this improvement resulted from the patient's physical symptom improvement, an increased ability to cope or other processes such as the beneficial effects of socialization.

Colorectal cancer

Definition, incidence, and pathophysiology

Colorectal cancer includes cancers of the lower intestinal tract that develop in the colon or the rectum (Huether, 2006). Colorectal cancer is the second most common cause of cancer deaths for both men and women in Canada (Canadian Cancer Society, 2008b). In 2008, an estimated 21,500 Canadians will be diagnosed with colorectal cancer and 8,790 will die from the disease (Canadian Cancer Society, 2008b). In the

United States, colorectal cancer is also the second most common cause of cancer death and there were an estimated 148,810 new cases of colon and rectal cancer in 2008 and 49, 960 deaths (American Cancer Society, 2008a).

Colorectal cancers most often develop slowly over a period of several years. Colorectal cancer may develop from a non-cancerous polyp on the lining of the colon or rectum and more than 95% of colorectal cancers are adenocarcinomas (American Cancer Society, 2008b). There are a number of risk factors for developing colorectal cancer including increasing age (over 90% occur in people over age 50), a personal history of colorectal cancer, colorectal polyps or inflammatory bowel disease, genetic susceptibility to the disease, family history of colorectal cancer, familial polyp disease, a diet that is high in fat, especially fats from animal sources, and tobacco smoking (American Cancer Society, 2008b). A younger age of onset and more distal location of colorectal cancer are associated with factors such as alcohol use and smoking (Zisman, Nickolov, Brand, Gorchow, Roy, 2006). Although there is some evidence that is suggestive of a causal rather than correlational association between cigarette smoking and the development of colorectal cancer (Chao, Thun, Jacobs, Henley, Rodriguez & Calle, 2000), cigarette smoking is not widely known in the general population to be a cause of colorectal cancer. Cancer of the colon tends to occur more commonly worldwide in populations of higher socioeconomic standards, possibly because of lifestyle and dietary habits. Both genetic and environmental factors impact the risk of developing colorectal cancer (Huether, 2006).

Treatment consists of surgery, radiation therapy, chemotherapy, and targeted therapies such as monoclonal antibodies (American Cancer Society, 2008b). Surgical

intervention is the primary curative treatment for colorectal cancer and approximately 75% of colorectal patients have surgery, most often involving removal and anastamosis of the colon and possibly a temporary or permanent colostomy (Sargent & Murphy, 2003). In general, if caught early, patients with colorectal cancer have a good prognosis for survival, and the 5 year survival rate is 65% in the United States (Bazensky, Shoobridge-Moran & Yoder, 2007). However, the survival rate varies greatly by cancer stage and if treatment occurs early, the five-year survival rate can be more than 90%, but if metastases are present prior to diagnosis, the five-year survival rate drops to less than 9% (Berg, 2003).

Physical symptom distress

Patients with colorectal cancer face distressing symptoms such as blood in stools, abdominal or back pain, gas or bloating, weight loss, fatigue, anaemia and vomiting (Bazesnsky, Shoobridge-Moran, & Yoder, 2007). Although patients may experience a surgical cure and relief of some of these symptoms, many patients experience persistent symptoms post operatively such as sleep disturbance, fatigue, pain and disruptions in physical mobility (Whynes & Nelson, 1997). Many patients also have to deal with permanent disfigurement and the reality of life with a colostomy or illeostomy appliance, along with the threat of recurrence of their cancer (Berg, 2003).

Psychological symptom distress

Colorectal patients may also face distressing psychological symptoms. For example, Wasio (2004) found that 43% of post-surgical colorectal cancer patients experienced psychological distress with anxiety rates (57%) being higher than depressive symptomology (37%). Additionally, this researcher found that the most prevalent

physical symptoms were lack of energy, pain, dry mouth, and difficulty concentrating. In their review of the literature, Lynch, Steginga, Hawkes, Pakenham and Dunn (2008) found that the prevalence and trajectory of psychological distress among patients with colorectal cancer were not well defined in the literature. These authors utilized a prospective survey of colorectal cancer patients (n=1,822) to assess psychological symptom distress, along with potentially predictive measures of distress such as optimism, threat of cancer appraisal, social support and physical activity. Although they found that global psychological distress was relatively low in this cohort (8.3% at 6 months and 6.7% at 12 months), they recommended distress screening at regular intervals as psychological distress in cancer survivors may be detrimental to treatment outcomes.

Social relations

There have been studies to examine colorectal cancer within the context of marital relationships. For example, Goldzweig et al. (2008) contended that recently completed cancer treatment involved ongoing adjustment of the patient's family members as well as ongoing concerns for the cancer patient's survival. Family members or other caregivers who participated in patient activities remained attuned to the patient's needs once treatment was completed. These authors surveyed patients diagnosed with colorectal cancer (n=231) and their spouses to measure psychological distress, social support, and medical symptoms. These authors found that male patients (whether healthy or sick) were more distressed than their wives, and also that males (healthy or sick) received more support from their wives. The authors proposed that this main effect for gender may mean that men do not use social support as efficiently as women.

There have been few studies to examine stigma among colorectal cancer patients. One study conducted by Macdonald and Anderson (1984) examined perceptions of stigma and quality of life in patients with rectal cancer (n=420) and found that approximately half the patients felt stigmatized with a higher proportion of younger patients and patients with a colostomy appliance reporting stigma. The authors also found that feelings of stigma were associated with poor health, emotional problems, other medical problems and disability. Furthermore, factors such as employment status, higher income, social and housing class were not protective against stigma. Although most patients enjoyed close relationships with intimate others, those who were stigmatized were more likely to withdraw from participation in social activities. Similarly, Desnoo and Faithfull (2006), found in their qualitative study that patients with rectal cancer (n = 7) who had undergone resection surgery reported that they avoided going out because they feared what others may think if they needed to toilet frequently or had embarrassing accidents with their bowel movements. The researchers also found that patients had difficulty with the decision to disclose their cancer to others because of the difficult and embarrassing aspect of discussing bowels. Additionally, they found that the patient's bowel patterns had an effect on their social life. Social activities were impeded until patients were able to develop mental and physical strategies to cope with the disease and its effects.

Disease Summary

Both lung cancer and COPD are considered to be cigarette smoking-related illnesses. Lung cancer is usually an asymptomatic illness that often results in a late diagnosis and shortened life expectancy, and may have a more abrupt onset of symptoms

once the disease is in an advanced stage or has metastasized. Patients with COPD often have progressive symptoms that result in many years of increasing symptom experiences and decreasing ability to engage in activities of daily living. Both lung cancer and COPD are largely incurable, although there is a chance of surgical intervention with early stage lung cancer. On the other hand, although surgery is not often a treatment modality for COPD patients, symptom progression in this disease may be slowed with pulmonary rehabilitation, medication and smoking cessation. Both illnesses involve distressing physical symptoms such as dyspnea, cough and fatigue, and psychological symptoms such as anxiety, depression, and a decrease in the patient's quality of life. Because lung cancer and COPD are associated with cigarette smoking, both illnesses are often perceived by family, friends, and health care professionals as self-inflicted illnesses and patients may face stigmatization of their illness.

On the other hand, colorectal cancer is not usually considered a smoking-related illness. Colorectal cancer includes cancers of the lower intestinal tract that develop in the colon or the rectum and most often develop slowly over a period of several years. There are a number of risk factors for developing colorectal cancer including increasing age, personal or familial history of colorectal cancer, certain colorectal illnesses, genetic susceptibility, familial polyp disease, a diet that is high in animal fat, and tobacco smoking. Surgical intervention is the primary curative treatment for colorectal cancer. In general, if caught early, patients with colorectal cancer have a good prognosis for survival. Patients with colorectal cancer face distressing physical symptoms such as blood in stools, abdominal or back pain, gas or bloating, weight loss, fatigue, anaemia and vomiting. These patients may have to deal with permanent disfigurement and the

reality of life with a colostomy or illeostomy appliance. Colorectal patients may also face distressing psychological symptoms such as the threat of recurrence of their cancer; however, the prevalence of psychological distress among patients with colorectal cancer is not well defined in the literature. Although there have been only a few studies that examined stigma among colorectal cancer patients, the literature is suggestive that colorectal cancer patients may also face stigmatization of their illness.

Stigma

Stigma Definition

The term stigma originated from the Greek word *stizein* which means to tattoo, and referred to a bodily mark which was branded or cut onto slaves or traitors to indicate that there was something wrong with the person (Meriam Webster, 2007). In recent times, stigma has been defined in the seminal writings of Ervine Goffman who defined stigma as the labeling of a person as tainted or less desirable (Goffman, 1963). Informal caregivers, including family members or other people who are close to the stigmatized person, may also experience stigma that is known as "courtesy stigma" (Goffman, 1963).

Theoretical background

The concept of stigma has been researched in both sociological and psychological frameworks, and Jones et al. (1984) refined the conceptualization of stigma as a relationship between the attributes of the stigmatized person and the stereotypes of those undesirable characteristics of that person. A social psychological approach would define stigma as a mark (whether visible or implied) which links a person to a set of undesirable characteristics or stereotypes. The stigmatized person's

opportunities are diminished because they are isolated from others and are considered to be inferior to others. The person's stigma becomes a focal point in their self perception.

Link and Phelan (2001) expanded on the sociological conceptualization of stigma by defining it as not just as a label that others affix onto a person, but also a process which begins when dominant social groups notice a difference about the individual(s) and whether the observed difference connotes unfavourable information about these 'target' individuals. The targeted individuals are then set apart in a distinct category and stereotyped that lead to various forms of disapproval, rejection, exclusion and discrimination. This process is entirely dependent on the dominant group's access to economic, political, and social power that allows the stereotypes, labelling, and exclusion of stigmatized persons to perpetuate. Link and Phelan (2006) expanded on this definition to define stigma as a process of five interrelated components that included: identifying and labelling of salient human differences in the individual, linking the individual to undesirable characteristics, separating the individual (the "us" from the "them") from the dominant group, discriminating and loss of status of the individual, and finally, supporting access to and exercise of power by the dominant group.

Corrigan and Watson (2002) described the concept of self-stigma as a process that occurs when members of a stigmatized group are aware of the negative judgments and stereotypes. Members of the stigmatized groups may internalize beliefs, feelings, and behaviours such as shame, guilt, and unworthiness, and attempt to conceal their stigmatized condition. The authors recognized that stigmatized individuals often react by developing lowered self-esteem or, conversely, with righteous anger and feel energized by the injustice. The authors also noted there appears to be a third group who seems to be

neither harmed nor helped by the stigma. They proposed a model of stigma which takes into account the person's attributions of the perceived legitimacy of the stigmatization, as well as how strongly the person identifies with their stigmatized group. According to this model, those who perceive the stigma or negative belief as legitimate will respond with lower self–esteem. Those who perceive the stigma as not legitimate will have their self-esteem remain intact. Further, if the person has a high identification with the stigmatized group, they will react with righteous anger, and low group identification will result in indifference to the stigma.

Stigmatization of cigarette smokers

The way in which society views cigarette smoking, and thus smoking related illnesses, has changed dramatically in western society over the last sixty years. In particular, the public image of cigarette smoking has changed from being a socially acceptable and perhaps even desirable choice to an undesirable or 'sinful' behaviour. For example, a 1946 cigarette advertisement for Camel cigarettes proclaimed that, "More doctors smoke Camels!" (Reynolds, 1946). Until 1953, American tobacco companies were allowed to make claims of health benefits for cigarette smoking (Borio, 2001). However, Street's (2004) critical examination of recent tobacco advertisements revealed that there has been a "shift or rupture in the positioning of smoking portrayed as a glamorous and healthy recreation, to that of a morally reprehensible habit that harms all parts of the body" (Street, 2004, p. 233). The shift in the media's portrayal of smokers, along with efforts to inspire health promotion and disease prevention through restrictions on the sale of tobacco and smoking bans, combine to assign responsibility to the smoker.

Cigarette smokers are currently portrayed as, "culpable subjects responsible for their individual health" (Street, 2004, p. 227).

Bayer and Stuber (2006) presented a compelling case that the stigmatization of smokers parallels that of other health related stigmas such as HIV/ AIDS stigma, which has detrimental consequences for individuals who face stigmatized illnesses as well as their family members. They raised interesting questions as to whether or not stigmatizing smokers will result in effective health benefits by reducing the number of people who smoke by preventing people from starting or encouraging them to quit smoking, and whether or not stigmatization of smokers is justified. The authors claimed that, "stigmatization of those who are already vulnerable provides the context within which disease spreads, exacerbating morbidity and mortality by erecting barriers between caregivers and those who are sick" (p. 47).

Stigma and illness

Stigma is a socially defined concept, and any disease including a cancer diagnosis may be associated with stigma (Muzzin, Anderson, Figueredo, & Gudelis, 1994). The stigma facing cancer patient may stem mainly from cancer's status as being the most feared of all illnesses, and interactions with cancer patients may be avoided because this interaction reminds others of their own vulnerability (Fife & Wright, 2000). As well, persons with cancer often fear disclosing their cancer status to others because of the stigmatization, which also increases the isolation and alienation facing cancer survivors (Fife & Wright, 2000). Cancer-related stigma may result from people believing that the cancer patient somehow deserved to get cancer, and the individual is blamed for the illness, thereby decreasing one's fear of the perceived vulnerability to develop cancer.

This view is supported by Lebel and Devins (2008) who recently conducted a review of the stigma literature to determine if the degree of stigma is affected by the perception that cancer patients' behaviours may have contributed to their illness. By exploring 38 studies that empirically examined cancer-related stigma, these authors concluded that there was increased negative attitudes and more severe stigma towards patients who have cancers that are perceived to be causally related to the patients' behaviour (e. g. lung cancer and cervical cancer) than cancers that are not perceived as causally related to patients' behaviour (e. g. breast cancer or prostate cancer).

Stigma and lung cancer /COPD

Lung cancer and COPD patients appear to be at risk for increased and/or more overt stigmatization because of the association of these diseases with cigarette smoking and the perception by others that they are the causal agents of their own illness. Empirical literature suggests that the process behind the development of stigma depends, in part, on the degree of personal responsibility for the cause of the disease. For example, Weiner's attribution theory (1986) proposed that when a negative achievement outcome occurs such as failure at a task, a search is undergone to determine the cause of the outcome. These causes will be judged along the lines of locus of causality (internal or external), stability (stable or unstable), and controllability (controllable or uncontrollable). This attributional analysis will, in turn, result in perceptions of high or low ability and expectations of future success or failure to attain positive achievement outcomes. In another study by Weiner, Perry and Magnusson (1988) stigma of various illnesses was conceptualized as an outcome that would undergo attributional reactions by observers of another's affliction. These researchers found support for the notion that disease or

illness-related stigmas undergo an attributional analysis, similar to the analysis of achievement outcomes. They found that illnesses perceived as onset uncontrollable (i.e., the person had little or no responsibility for causing the stigmatized condition) such as physically based stigmas (Alzheimer's disease, blindness or cancer) elicited more sympathy, no anger and more willingness to help. Conversely, mental-behavioural stigmas (such as child abuse, drug abuse and obesity) which were perceived as onset controllable (i.e., the person was held responsible for causing the stigmatized condition) elicited little sympathy, much anger and neglect.

Weiner's (1995) theory may partially explain the historical shift in societal attitudes toward cigarette smoking and smoking-related illnesses. That is, Weiner's postulations about the linkages among attributional reactions may explain the stigma that patients with lung cancer and COPD face as both diseases are linked to cigarette smoking. In other words, both lung cancer and COPD are viewed as smoking-related illnesses that are behaviourally induced (i.e., both diseases are attributed with an internal locus of causality in relation to patients 'choice' to engage in smoking behaviours). Thus, reactions to lung cancer and COPD patients are based on judgements of controllability for the cause of the disease and those with controllable stigmas are considered responsible for their illness and are judged to be moral failures (Weiner, 1995). Lobchuk, Murdoch, McClement, and McPherson (2008) compared the attributional reactions (i.e., judgments of responsibility, anger, sympathy, and pride) of 100 patients diagnosed with lung cancer and their ICs in illness onset and offset conditions. The results of their ongoing study provided preliminary support for Weiner's theory in that both lung cancer patients and ICs attributed greater responsibility to the patient for causing and controlling

the lung cancer which in turn perpetuated greater anger toward patients who had either smoked or continued to smoke cigarettes. The authors concluded that judgments of responsibility for causing the illness created a risk for dysfunctional helping behaviours by ICs especially if patients had a history of tobacco use.

Psychological effects of stigma.

Most studies that examined the effects of stigma on the stigmatized individual have consistently demonstrated that stigma has undesirable psychosocial effects on the people who are affected by it (Parker & Aggleton, 2003). For example, there have been numerous studies conducted in different countries and with different disease states, including HIV/AIDS (Human Immunodeficiency Virus/Acquired Immunosuppressant Disease; see Crawford, 1996 for a meta-analysis), leprosy (Opala & Boillot, 1996), mental illness (Corrigan & Penn, 1999; Phelan, Link, Steuve & Pescosolido, 2001; Link, Struening, Neese-Todd, Asmussen, Phelan, 2001), cancer (Fife and Wright, 2000), and lung cancer (Chapple, Ziebland & McPherson, 2004; Lobchuk, McClement, McPherson & Cheang, 2008, and Lobchuk, Murdoch, McClement & McPherson,2008).

Stigma may increase social isolation and therefore decrease some of the potential social supports available that can help alleviate the impact of psychosocial stressors encountered by stigmatized individuals. The idea that social supports may act to buffer the effects of stress and enhance coping has been well supported in research conducted over the last thirty years (Delongis & Holtzman, 2005). People with a stigmatized condition are more likely to have a smaller or less diverse social network, as well as a decrease in resources to assist with psychosocial coping.

Stigma to delay treatment seeking

Stigma may also have consequences for those who have a stigmatized illness by causing a delay in treatment seeking or disruptions in treatment. For example, studies of other stigmatized illnesses, such as Sexually Transmitted Diseases or AIDS (Chesney & Smith, 1999; Fortenberry, McFarlane & Bleaky, 2002), depression (Halter, 2004), and lung cancer (Tod, Craven & Almark, 2007) have shown that patients with a perceived stigmatized disease may delay seeking treatment. Of course this delay may contribute to higher patient morbidity and mortality. Stigma has been known to cause a barrier to seeking treatment among patients with mental illness. The United States Department of Health and Human Services (1999) has cited the public's stigmatization of mental illness as a leading cause of underdiagnosis and undertreatment. They estimated that nearly half of Americans who have a severe mental illness do not seek treatment. The leading barrier to treatment seeking is stigmatization of mental illnesses.

Weiss, Ramakrishna, and Somma (2006) proposed that this is one consequence of health related stigma. These authors contended that many chronic health problems have a stigma which contributes to patient suffering and also interferes with the appropriate use of health care services by patients. They also stated that stigma is a "social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group... based on an enduring feature of identity conferred by a health problem" (Weiss et al., 2006, p. 280). It is also noted that health related stigma has many similarities across diverse illnesses and cultures. For

example, Van Brakel (2006) conducted a review on the measurement of stigma and discrimination in diverse illnesses such as HIV/AIDS, leprosy, tuberculosis, mental health, epilepsy, and other health conditions. The author found that the consequences of stigma were remarkably similar across different health conditions and different countries, despite enormous cultural diversity. The author found that stigma may affect marriage and other interpersonal relationships, employment, access to treatment and care, education, and leisure activities, and attendance at social and religious functions. This author also revealed that behaviours in the community, media, health and social services, educational system, and legislation are important contributing factors toward promoting stigma of individuals.

Measurement of stigma

Health research is concerned with the concept of stigma for several reasons as stigma adds to the disease burden in various ways and also may cause treatment seeking delay or termination (Weiss & Ramakrishna, 2001). Weiss and Ramakrishna (2001) suggested that there are three main areas in which stigma should be examined. Firstly, the effects and perceptions of various stigmatized conditions from the perceptions of the stigmatized individual as well as others within the community may be studied. Secondly, the stigmatizing attitudes of health care professionals or other community leaders such as teachers or policy makers should be examined. Thirdly, family members of those who have a stigmatized condition make up a unique group for assessment of stigma, as they may face courtesy stigma. Interestingly, family members or others who are close to the person may also engage in stigmatizing behaviours and contribute to the stress of the stigma. Other people who may be affected by courtesy stigma are those who are close to

the stigmatized individual such as friends, loved ones, health staff and volunteers that work with the stigmatized individual.

There have been various methods utilized to measure health-related stigma. In the HIV/AIDS area, surveys have been used to research the general population and the attitudes of the perpetrators of stigma (Weiss & Ramakrishna, 2001). As well, research has been conducted on those with HIV/AIDS to determine the effects of stigma. For example, Berger, Ferrans, and Lashley (2001) developed the HIV stigma scale to measure the stigma perceived by those with HIV. The scale is a 93 item Likert-type questionnaire with four subscales. The HIV stigma scale showed good reliability and the overall scale reliability co-efficient Alpha was .96. The subscale's measures of reliability are: personalized stigma subscale (co-efficient Alpha = .93), disclosure subscale (co-efficient Alpha = .90), negative self-image subscale (co-efficient Alpha = .91), and public attitudes subscale (co-efficient Alpha = .93). The test-retest reliability measures on all subscales all had correlations in excess of .87.

The recent scale devised by Swendeman, Rotheram-Borus, Comulad, Weiss and Ramos (2006) measured HIV-related stigma but also distinguished between perceived and enacted stigma. Perceived stigma is defined by Scambler (1998) as fear of stigmatization or the internalized shame of stigma, while enacted stigma includes actual experiences of stigma and discrimination. The scale consisted of 11 yes/no items for occurrences of enacted stigma (one scale for lifetime occurrence and another for the past three months). Perceived stigma was assessed by a four point Likert-type scale on seven items which asked how often the respondents felt blamed or shamed by their HIV status.

Much of health research on stigma has focused on the mental health population of patients. For example, research with mental illness often consisted of the use of vignettes which portrayed a protagonist with or without a mental illness who were judged on a variety of attributes (Weiss & Ramakrishna, 2001). Weiner, Perry and Magnusson (1988) utilized this methodology to determine how stigma was perceived by other individuals. Research in the mental health area has also focused on the effects of stigma on the person who has been stigmatized. For example, Wahl (1999) developed a survey instrument that included a nine-item stigma scale and a twelve-item discrimination scale to examine the experiences of consumers of mental health services. Link, Mirotznik, and Cullen (1991) examined the effects of styles of coping on experiences of stigma among people who have been labelled mentally ill. The authors developed a Likert-type stigma scale with separate subscales for devaluation-discrimination (12 items- Alpha = .84) and ways of coping with stigma including: secrecy (5 items – Alpha =.71), education (5 items – Alpha =.67), and avoidance-withdrawal (7 items– Alpha =.71). The authors found that none of the ways of coping were effective in diminishing the negative effects of labelling on employment or psychological distress. The authors concluded that these results suggest that stigma is a powerfully reinforced social construct and its effects are not easily overcome by the individual.

Boyd Ritsher, Otillingam and Grajales (2003) developed the Internalized Stigma of Mental Illness scale to evaluate the subjective experiences of stigmatization. This measure used 29 Likert-type items, with subscales measuring alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance. The scale had an internal consistency reliability coefficient alpha of .90. The test-retest

reliability coefficient was 0.92. The subscale alpha-coefficients were all above .70 with the exception of the stigma resistance scale.

Raguram, Raghu, Vounatsou and Weiss (2004) developed a scale designed to measure the patterns of distress, the perceived causes and help seeking behaviour among schizophrenia patients. The measure included thirteen items to assess stigma, including disclosure of illness, experiences of inclusion or rejection, blame and devaluation, self-esteem, impact on family, and effects on marriage or ability to marry. This Likert-type scale had an internal consistency of .81.

Wight, Aneshensel, Murphy, Miller-Martinez and Beals (2006) developed a stigma scale to examine stigma among patients with AIDS and their caregivers. The authors utilized a nine-item Likert type scale to assess both personal stigma among AIDS patients and courtesy stigma among their caregivers. The scale demonstrated excellent reliability based on alpha coefficients of .81 to .86, respectively for patients and caregivers. This HIV stigma scale emerged as a tool that could be easily adapted to measure perceived stigma among lung cancer, COPD, and colorectal cancer patients as well as their ICs.

Summary

Efforts to decrease lung cancer and COPD have focused almost exclusively on cigarette smoking prevention and cessation. Along with these efforts, the attitudes towards cigarette smoking have undergone a shift from a socially acceptable to a highly stigmatized behaviour. As a result of this stigma label, affected individuals can experience lowered self esteem, deteriorated self image, decreased quality-of-life and decreased social support. Stigma may actually act to impede seeking assistance for

cessation of smoking, or delay treatment seeking for smoking-related or other stigmatized illnesses. Recommendations for research on stigma have been made by experts in the field and numerous scales have been developed to assess stigma within the general population as well with stigmatized individuals or family members.

Informal caregiving

Definition and prevalence

As the Canadian population ages and our health care system faces increasing cutbacks that encourage shortened lengths of hospital stays, many patients, including those diagnosed with COPD, lung cancer, and colorectal cancer are being cared for in the home by family or other informal caregivers, or have frequent transitions between home and hospital care. This trend is increasing and according to Pollara (2006), 26% of Canadians had reported caring for a family member or a friend with a serious illness within the past year. The term *family caregiving*, "refers to care that is provided in response to illness or functional impairment that exceeds the 'normal' care or help provided with families" (Shumacher, Beck & Marren, 2006, p. 42). Most often, this care is provided by members of the patient's family. However, at times, this care may be provided by others such as a friend or neighbour. Therefore to be inclusive, the term *informal caregiver (IC)* will be employed in this study to capture family members or other persons (i.e., friends or significant others) who provide unpaid care and support in response to a patient's illness or functional impairment. ICs conduct many diverse tasks within the context of caring for patients that include assistance with the patient's activities of daily living such as eating and bathing; engagement in clinical judgment and problem solving with symptom management and treatment regimens; organizational and

communication activities such as advocating for the patient and organizing appointments with health care professionals and prevention of injury or supervisory activities (Shumacher, Beck & Marren, 2006).

As the patient becomes increasingly ill, ICs are often relied upon by health care professionals to monitor and manage the patient's troublesome symptoms. Often ICs are expected to take on complex tasks of symptom management based on the untested assumption by health care professionals that ICs possess the skill and knowledge required to manage symptoms (Lobchuk, Degner, Chateau, & Hewitt, 2006).

Impact of caregiving

Because caregiving involves a complex set of skills, tasks, and demands on the IC, the required demands may be stressful and negatively impact the IC's coping skills. Caregiver burden is defined as the strain or load borne by a person who provides care for an elderly, ill, or otherwise disabled family member or other person. The burden is described as a multidimensional response to the physical, psychological, emotional, social, and financial stressors associated with the provision of care (Stuckey, Neundorfer, & Smyth, 1996). Caregiver burden may lead to caregiver burnout which is "the progression of caregiver burden to the point where the experience is no longer a viable or healthy option for either the caregiver or the person receiving care" (Kasuya, Polgar-Bailey, & Takeuchi, 2000, p. 119). Often in families, the illness experience is confined not only to the ill person, but the illness frequently has a ripple effect and the health effects become apparent across the entire family group, affecting the health of the family and the quality of care that the caregiver can provide (Kasuya, Polgar-Bailey, & Takeuchi, 2000). There is an extensive body of evidence that has identified many

negative impacts of informal caregiving, including deleterious effects on the social, interpersonal, financial, and physical state of the caregiver. In particular, caregivers have an increased risk of depression and anxiety, diminished immune responses, and a greater risk of hospitalization and mortality (Lantz, 2004).

Caregiving and communication

Effective communication between the patient and IC is a crucial caregiver skill that underlies the myriad of caregiver activities as described in the above. ICs often play important roles in the processes of negotiating decisions about care, advocating for the patient, and engaging in surrogate decision-making when the patient's condition deteriorates (Siminoff, Rose, Zhang, & Zyzanski, 2006). The ability of ICs to fulfill the important roles of advocate and primary caregiver may depend on the level of communication between the patient and IC on aspects of care such as symptom experiences and management. There are a number of factors which may influence decision-making and cause disagreement among family members in treatment decisions, such as patient and IC stress, disruption of family cohesion and relations, and patient and IC differences regarding the perception of patient stress and symptoms (Siminoff, Rose, Zhang, & Zyzanski, 2006). These factors have potential to influence effective communication between patients and ICs, and empathic behaviour. One concept that has emerged as being vital in examining patient and IC communication and perceptual understanding of the other's experiences is the empathic process of perspective-taking. The ability to communicate empathically is essential to the IC/patient relationship as it can help to ameliorate conflicts that may occur within caregiving relationships (Lobchuk, 2006). Effective communication involves a number of factors, including empathy and

empathy promoting attitudes and behaviours such as self-awareness, nonjudgmental regard for others, good listening skills, and self-confidence (Davis, 1996). According to Davis's empathy model, empathic processes such as perspective-taking may occur when a person is exposed to a weak or distressed person. Perspective-taking is defined as the imaginative ability to step inside another's shoes to understand this person's distressing situation (Davis, 1996).

Perspective-taking is an empathic processes that is akin to the term, social decentering. Redmond (1995) referred to *social decentering* as a process by which a person attempts to understand and respond to the thoughts, feelings and perspectives of another. Redmond contended that the ability to accurately understand another person will be affected by a number of factors that affect the quality of experience-based social decentering. These factors include the amount of information perceived, the information's accuracy, the previous experiences in memory, the accuracy of the recalled experiences, the relevancy of the recalled information, the weighting given to the perceived and the recalled information, and the recognition of the similarities and differences between the perceived and recalled information (Redmond, 1995). Furthermore, Redmond identified three methods utilized to social decenter: use-of-self (imagining what it would be like to be in that situation); use-of-specific other (based on relevant information that the person recalls or perceives about the other); and use-of-generalized others (use of personal theories of how people generally think in the situation).

Empathic Behaviour

For the purpose of this thesis, *empathic behaviour* is defined as the total score of perspective-taking items utilized to capture empathic communication between the patient and informal caregiver dyad. *Perspective taking* is defined by Arriaga and Rusbult (1998) as, "the tendency to adopt the partner's point of view in reacting to a given interdependence situation, attempting to see the situation from the partner's perspective, feeling and thinking as the partner would feel and think" (p. 930). Lobchuk (2006) examined *perspective taking among informal caregivers* and provided a definition specific to the patient caregiver relationship: "an interpersonal empathic process involving a conscious effort in differentiating one's view from the view of another that can bring the caregivers' viewpoints in closer alignment with patients' viewpoints" (p. 330).

Competent and accurate communication is enhanced by the person's ability to engage in perspective-taking. That is, drawing on Davis' (1996) theory, increased perspective-taking by the caregiver will result in a more accurate interpretation of the patient's perspective, and allow the IC to gain a better understanding of the patient's experience. Although perspective-taking may be desirable within the patient / IC relationship, there are a number of factors which may affect perspective-taking. These factors include confrontational style, inferences of behaviours that invoke positive, neutral or negative emotions, degree of exposure to the 'target' individual, gender of dyadic members, degree of intimacy in the relationship, corrective feedback on the other's thoughts and feelings, physical attractiveness of the one being observed, and higher intellect of the perceivers (Simpson, Ickes, & Blackstone, 1995).

Empathic behaviour by informal caregivers.

There have been a number of studies in the nursing literature that have examined empathic behaviour and factors that impact empathic processes such as perspective-taking by ICs. There are many factors which may impact on a person's ability to perspective-take. For example, Lobchuk, Degner, Chateau, and Hewitt (2006) reported that the length of the patient and IC relationship, type of care provided, amount of caregiver contact, and proximity of patients to their ICs may impact perspective-taking. The authors pointed out that, "within the social context of the family, unique relationship dimensions of empathic support, cohesion, and affiliation exist that have beneficial influences on patient-caregiver interaction and the reliability of family surrogate responses regarding patients' quality-of-life experiences (e. g., symptoms)" (p. 274).

Recent literature has focused on how perspective taking may be induced in patient-IC dyads. Lobchuk and Vorauer's (2003) study of 98 advanced cancer patient and caregiver dyads found that ICs appeared to make a concerted effort to understand the patient's decreased energy from the patient's perspective, but their understanding of patient worry appeared to be influenced by their own worry. In other words, ICs tended to project their own experiences with worrying onto their inferences of the patients' worrying experiences. However, on the patient's physical symptom 'lack of energy', ICs naturally inferred patient's symptom experiences in ways similar to patients' self-reports of lack of energy. In addition, their 'naturally' inferred responses were similar to their reports of patient lack of energy in the imagine-patient perspective-taking condition.

This study's findings were further supported by those derived from a more rigorous, counterbalanced study conducted by Lobchuk, Degner, Chateau and Hewitt (2006). These authors found that ICs of patients who were in close, long-term relationships with lung cancer patients (e.g., spouses) appeared to naturally engage in perspective-taking in order to understand patient's symptom experiences. These authors found that instructional sets that prompted the IC to imagine the patient's perspective were similar to 'neutral' prompts (i.e., prompts that neither encouraged or discouraged perspective-taking) in terms of their respective effects on the IC's ability to reliably estimate patient's fatigue level and worrying. The authors concluded that both the imagine-patient and the neutral prompts invoked similar perceptions by ICs that were concordant to those reported by patients on fatigue and worrying.

Most recently, Lobchuk, McClement, McPherson and Cheang (2008) conducted preliminary work to uncover the potential mediating effects of illness attributions and emotional states by ICs on their helping behaviours with lung cancer patients. Preliminary results with 100 dyads of lung cancer patients and ICs indicated that IC judgments of responsibility, anger, and pride in the lung cancer patients' efforts to control the disease progression impacted the caregiver's ability to engage in empathic support and communication. Drawing on Weiner's (1995) attributional theory, these authors had hypothesized that judgments of responsibility or blame, anger, and pride held by caregivers underlie feelings of stigma towards the lung cancer patient and would influence the ability of the IC to engage in perspective taking and influence helping behaviour. To date, there are no known studies that directly measured stigma responses,

or captured the relationship between stigma and empathic behaviours like perspective-taking by patients and ICs dealing with smoking-related diseases.

Measurement of empathic behaviour

Empathic behaviour is commonly measured via perspective-taking and the type of perspective-taking which most closely parallels the IC / patient relationship is specifically called *dyadic perspective taking.* Dyadic perspective-taking "indicates whether or not one individual seeks to understand the point of view of the other person in the dyad" (Long, 1990, p. 93). Long devised two scales to measure dyadic perspective-taking. The Self Dyadic Perspective-Taking Scale (SDPT) was developed to measure one's self report of perspective-taking, and the Other Dyadic Perspective-Taking Scale (ODPT) was designed to assess the perceptions of the partner's ability to perspective take. Long (1990) conducted a series of three experiments to assess the psychometric properties of the scales. On the 16 item SDPT scale, alpha coefficients were found to be .89 for all three experiments. On the 20 item ODPT, alpha coefficients were found to be .95, .93, and .94.

Perspective-taking has been measured in the nursing literature by using comparisons of reports of symptoms between patients and their caregivers. To determine whether or not differing perspective-taking instructional sets had an effect on perspective-taking by caregivers, in her dissertation study, Lobchuk (2001) systematically tested the accuracy of 98 IC perceptions of patient symptom experiences captured in different instructional set conditions (i.e., neutral prompt, imagine-self and imagine patient conditions) (Lobchuk & Vorauer, 2003). Although ICs appeared to make a real effort to perspective-take, they had a bias to overestimate the patient's symptoms.

To account for any potential order effects, a subsequent study was conducted by Lobchuk, Degner, Chateau, and Hewitt (2006) where they employed a counterbalanced design with randomization to control for any order effects. The authors found no order effects of the instructional sets and that ICs in long term and openly communicative relationships likely employed a patient oriented perspective to assist them in understanding the patient's illness experiences.

O'Brien and Delongis (1990) developed three scales to examine coping: a problem-focused coping scale, emotion-focused coping scale, and relationship or empathy-focused coping scale. The authors found that the relationship-focused coping scale had excellent reliability with a Cronbach's alpha of 0.93. To capture perspective-taking, Bokari (2006) adapted the relationship-focused coping scale to create the Patient Perception of Caregiver Empathic Behaviour scale (Appendix G) to capture ovarian cancer patient's perception of their IC's empathic behaviour. This scale proved excellent reliability with a Cronbach's alpha coefficient of 0.934. This scale has been further modified by the Investigator with permission from Dr. Anita Delongis to develop three additional perspective-taking scales to capture empathic behaviour of ICs and patients diagnosed with smoking-related illnesses (i.e., lung cancer and COPD) and non-smoking related illness (i.e., colorectal cancer) for the purposes of this study.

Summary

The prevalence of family members and friends providing care for chronic illness patients, such as individuals diagnosed with lung cancer, COPD, or colorectal cancer who are living in the community or transitioning between home and hospital is a common and growing phenomenon in our cost restrained health care system. There are

many types of tasks that ICs engage in as they care for their loved one. Empathic communication and understanding, however, is a salient concept that undergirds many caregiving tasks. To further comprehend empathic communication competence by ICs who care for lung cancer, COPD and colorectal cancer patients, it is important to explore the underlying empathic process of perspective-taking as a measure of empathic behaviour. To date, we know little about factors that may impact empathic behaviours like perspective-taking as a process of communication competence by ICs in the context of chronic illness. However, the literature thus far suggests that empathic behaviour is impacted by a number of factors, and there has been no research to examine whether stigma associated with smoking-related diseases impact empathic behaviour of patients and ICs. Based on the literature review, stigma may be a concept that impacts the ability of the IC or patient to engage in empathic behaviour, and therefore interfere with patient and family communication and ultimately result in suboptimal patient care.

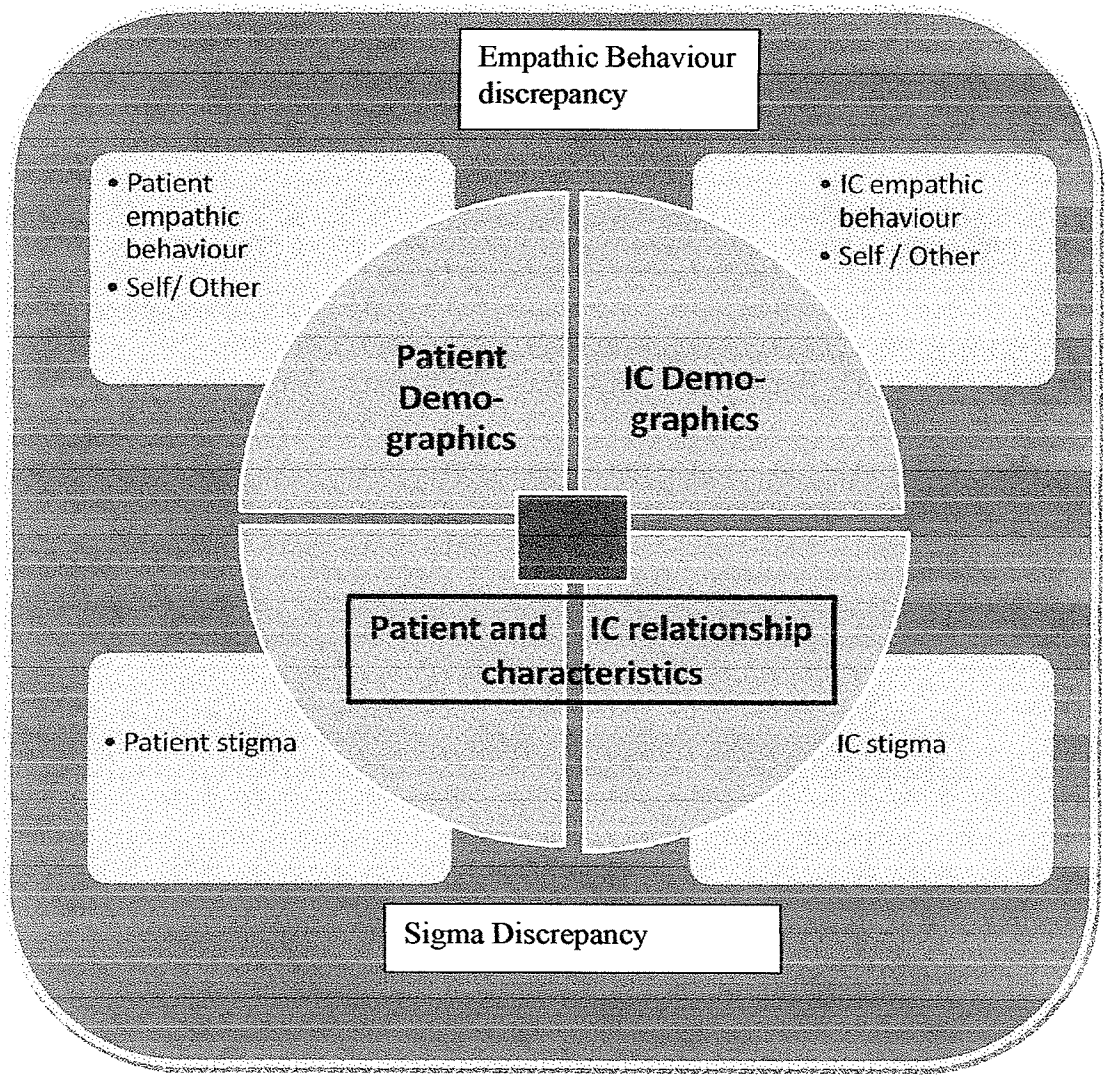
Conceptual Framework

An exploratory framework (see Figure 1) was developed by the author to examine the relationships between patients and IC demographic characteristics including age, gender, income, religion, smoking history, inclusion in diagnostic group, and IC/patient relationship characteristics such as length of relationship, type of relationship, and amount of contact. The relationship between those independent variables and patient and IC stigma measures including discrepancy scores was examined. As well, the relationship between IC and patient demographic characteristics and patient and IC empathic behaviour (by self and other) and discrepancy scores were explored. Additionally, the

relationships between patient and IC stigma were examined between the measures of empathic behaviour (for self and other).

Figure 1

Conceptual Framework



Summary

It is important for nursing to implement interventions that include health promotion and illness prevention strategies, especially for diseases that are highly preventable such as lung cancer and COPD. However, placing the onus on the individual for disease prevention may have unintended consequences including stigmatization of those who develop illness. This stigmatization may be counterproductive to health outcomes due to undesirable psychological consequences, or causing those with stigmatized illnesses to delay or avoid seeking medical assistance or treatment due to fear of being stigmatized. Additionally, stigma might pose as a hazard to the patient and IC relationship as it may interfere with the IC's ability to engage in empathic behaviour, a salient component of IC and patient communication competence that optimizes patient-centred care. Given our health care system's increasing reliance on ICs to provide care for patients with lung cancer, COPD, and colorectal cancer in the community or hospital settings it is important to examine factors that may interfere with optimal patient / IC communication. In this study, an exploratory conceptual framework was developed to examine perceived stigma by patients and their ICs as a potential factor that impedes the ability of ICs and patients to engage in empathic behaviour to understand one another. Previous studies have demonstrated that empathic behaviour is a modifiable and crucial component in communication competence that undergirds many tasks engaged in by ICs including symptom management, patient advocacy and decision making.

Chapter III

Methodology

Introduction

The following chapter describes the study design and research methodology utilized in this pilot study that examined the relationship between stigma and empathic behaviour within smoking-related and non-smoking related illnesses. Information regarding the study sample, inclusion criteria, setting and recruitment procedure, data collection protocol, instruments utilized, protection of human subjects, and data analysis is presented.

Design

This pilot study employed a descriptive comparative design based on an exploratory conceptual framework (see figure 1) with a major correlational component to examine the following research questions:

1. What are the relationships between demographic characteristics of patients and ICs (age, gender, education, income, ethnic background, length of relationship, religion, smoking history, and diagnostic group inclusion) and patient and caregiver responses on stigma and empathic behaviour?
2. What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour?

3. What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?

4. What is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking related illness group and colorectal cancer groups?

The dependent variables were perceptions of patient and IC empathic behaviour and perceived stigma by patient / IC dyads of patients diagnosed with either lung cancer, COPD, or colorectal cancer. The independent variables were two major categories of smoking-related illness (patients diagnosed with lung cancer or COPD) and non-smoking related illness (patients diagnosed with colorectal cancer), as well as patient and IC age, gender, gross annual income, religion, ethnic background, and smoking history, and patient / IC relationship characteristics such as length of relationship and amount of contact. The feasibility of conducting research with the target population, as well as the appropriateness of the measurement tools selected with this population was determined.

Participants and inclusion criteria

A purposive sample of medically diagnosed adult patients with lung cancer, COPD, or colorectal cancer was recruited to participate in the study. Inclusion criteria were patients who were cognitively intact (as determined by the Mini-Mental Status Examination [MMSE]; Folstein, Folstein, & McHugh, 1975), able to speak, read, and write English, and able to identify an adult informal caregiver (IC) who assisted them with their illness and/or symptom management. Inclusion criteria for ICs included adults who were cognitively intact (as determined by the MMSE), and able to speak, read, and

write English. In consultation with the statistician, the recruitment aim for sample size was determined by a power analysis for the stigma and empathic behaviour scales. Based on standard deviations from published empathic behaviour results, it was determined that a moderate effect size with two-tailed *t*-test alpha=0.05 and 80% power would be possible with 35 pairs in each group. Therefore, the recruitment aim was 35 patient / IC dyads per group over a six month time period (M. Cheang, Biostatician, personal communication, November 8, 2007).

Setting and recruitment procedure

Patients were recruited from CancerCare Manitoba (*MacCharles Unit* and *St. Boniface Unit),* Riverview Health Centre, and the Respiratory Clinic at Health Sciences Centre in Winnipeg, Manitoba. The Investigator first met with medical and nursing staff at all sites in order to request assistance to identify patients who met the inclusion criteria to participate in the study, as well as to identify one primary clinic contact person within each clinic setting. The designated primary contact person was a full time health professional who was willing to assist the researcher with patient recruitment, able to identify eligible participants, and agreeable to keeping a list of all patients who had already been asked to participate in the study. Due to the variability in obtaining access approval at the three recruitment sites, recruitment commenced at different times across the sites. Recruitment at Riverview Health Centre began in April, 2008; at Health Sciences Centre in May, 2008 and at the two CancerCare Manitoba sites in June, 2008. In addition to the three recruitment sites, a thoracic surgeon gave permission for the Investigator to commence recruitment of lung cancer patients in September, 2008 at the Health Sciences Centre.

At each clinic the primary clinic contact person was provided with a list of inclusion criteria as well as an orientation to the study, along with a supply of invitation letters and envelopes. Patients who met the inclusion criteria were identified by the primary clinic contact person who would consult with their list of patients who had already ready been given an invitation to participate. If the patient had not been asked to participate, the primary clinic contact person would proceed to provide the patient with a letter of invitation to participate in the study (Appendix A). The patient was asked to read the invitation letter and then indicate on the second page of the invitation whether or not they would like to speak to the Investigator about the study by placing their response in a sealed envelope that was provided to them by the primary clinic contact person. The sealed envelope provided additional assurance to the patient that his or her physician(s) or nurse(s) would remain unaware of the patient's interest and possible participation or non-participation in the study. Due to workload constraints, primary clinic contact persons across recruitment sites did not keep a record of the number of patients who refused to read the invitation letter.

It was expected that interested patients would be able to identify an IC to ask if he or she was also interested in speaking with the Investigator about the study. If the patient wished to first take the letter home to discuss the study with their IC that was acceptable and the patient would then be encouraged to return the invitation letter with their decision regarding participation (in the sealed envelope) to the primary clinic contact person during their next visit. The Investigator's phone number was provided in the invitation letter so that if the patient or IC had any questions about participation they could contact the Investigator directly. At least once per week, the Investigator attended

the recruitment sites to retrieve completed invitation response forms from the primary clinic contact person.

Data Collection Protocol

In general, within a week of receiving a positive response to the invitation to speak to the Investigator about participating in the study, the Investigator contacted the patient by telephone to inquire whether they were still interested in participating and provide additional information if requested. If the patient and the IC were agreeable an appointment was set at a mutually agreed upon date, time, and place to facilitate completion of informed consent and the questionnaires. Most often, the Investigator met with the patient and IC in the patient's home. However, for the patient's convenience, there were some occasions that the Investigator met with the patient at a Chemotherapy Clinic at CancerCare Manitoba or in a local restaurant in Winnipeg. Usually data were collected from the patient and IC simultaneously but if there was a schedule conflict, the Investigator met with the IC later at a separate appointment or completed the questionnaires over the telephone within a two week time period.

The Investigator provided written consents to the patient (Appendix B) and to the IC (Appendix C). Once the consents were read and understood, the Investigator administered the MMSE (Appendix D). Permission to employ the MMSE was obtained from Psychological Assessment Resources. If both dyad members were found to be cognitively intact (i.e., a score of 23/30 or greater on the MMSE), the Investigator proceeded with the questionnaires. A cut-off score of 23/30 was used as it is the most widely accepted cut-off score for the MMSE and scores lower than 23 indicate the presence of cognitive impairment (Psychological Assessment Resources, 2001). None of

the patients or ICs scored below 23/30 on the MMSE therefore, no participants were found to be ineligible to participate due to cognitive reasons.

In order to maintain the privacy and confidentiality of responses, the patient and IC were asked to proceed to separate rooms in their home (or another table if in a public place) to read and respond to the questionnaires. The Investigator first attended to the patient and then the IC to ensure that they understood the questionnaire instructions, and had responded to all items. For three dyads, the Investigator met with patients and caregivers in separate sessions because the IC and the patient were unable to meet at the same time due to a schedule conflict. In two instances, the patient completed the interview at home and the IC later completed the questionnaire over the telephone. In those instances, the IC consent form along with an addressed and stamped envelope was left with the patient to give to the IC, and once the IC had read and signed the informed consent it was mailed in to the Investigator. When a telephone appointment was conducted, in order to provide confidentiality of responses the Investigator instructed the IC to ensure their responses would not be overheard by the patient. The Investigator read the questionnaire instructions to the IC over the telephone and then read the questionnaire items and response choices. Regardless of where the interview took place (i.e., in the patient's home, in the clinic setting, or over the telephone) completion of the questionnaires took approximately 15 to 25 minutes per participant. Once all questionnaires were completed, the patient and IC were asked if they had any additional questions or comments regarding the study. The Investigator then thanked the patient and IC for their time and provided each of them with a $5.00 gift card to be used at a local quick service coffee restaurant chain.

Instruments

The patient and IC were given four separate but similar questionnaires in this study. The first instrument was a demographic questionnaire that captured the socio-demographic characteristics of patients and ICs. The second tool captured the participant's perception of their own empathic behaviour and the third tool captured their perceptions of the other's empathic behaviour. The fourth tool was employed to capture the patient's or IC's perceptions of stigma.

Demographic Data Forms

The Investigator collected demographic data in order to describe the general characteristics of the sample and to determine if relationships exist between demographic variables and the dependent variables of perceptions of patient and IC empathic behaviour and perceived stigma by patients and ICs.

The Patient Demographic Data Form. The patient completed the Patient Demographic Questionnaire that was adapted with permission from Dr. Michelle Lobchuk (Appendix E). This tool included response items about gender, age, marital status, education, occupational status and type of occupation, gross annual income, ethnic background, religion, smoking history, medical diagnosis type, date of diagnosis, treatment and medication, and questions about the length, type, and amount of contact within the patient / IC relationship. In all instances medical data were obtained from patients (at times with assistance from their IC) and although permission had been solicited from the patients to access their medical information in instances of lack of clarity of any medical information, no chart review for accuracy or clarification of data was deemed necessary by the Investigator.

The Caregiver Demographic Data Form. The caregiver completed the Caregiver Demographic Questionnaire that was adapted with permission from Dr. Michelle Lobchuk (Appendix F). This tool included response items on gender, age, marital status, education, occupational status and type, ethnic background, religion, smoking history, and questions about the length, type, and amount of contact within the patient / IC relationship.

The Empathic Behaviour Scales

The Empathic Behaviour tools were completed by patients and their ICs. Bokari (2006) first adapted the Empathic Responding Scale designed by O'Brien and Delongis (1990) to design a short form to capture ovarian cancer patient's perception of their caregiver's empathic behaviour (Patient Perception of Caregiver Empathic Behaviour, PPCEB, Appendix G). This scale had good reliability with Cronbach's alpha coefficient of 0.934. This scale has been modified by the Investigator with permission from Dr. Anita Delongis (personal communication, November 22, 2007) for this study to create three additional empathic behaviour scales: Patient Perception of Self Empathic Behaviour (PPSEB, Appendix H), Caregiver's Perception of Patient's Empathic Behaviour (CPPEB, Appendix I), and Caregivers Perception of Self Empathic Behaviour (CPSEB, Appendix J).

The Stigma Scales

The Patient Stigma Scale was completed by the patients and the ICs completed the Informal Caregiver Stigma Scale. Wight, Aneshensel, Murphy, Miller-Martinez and Beals (2006) developed the stigma scale to examine stigma among patients with HIV/AIDS and their mother, wife or female partner caregivers. The Stigma Scale is a

nine-item, Likert-type scale developed to assess both personal stigma among HIV/AIDS patients and courtesy stigma among their caregivers. The scale demonstrated excellent reliability based on alpha coefficients of .81 to .86, respectively for HIV/AIDS patients and caregivers (Wight, et al., 2006). This stigma scale was adapted with permission from Dr. Richard Wight (personal communication, October 12, 2007) to measure perceived stigma by patients (Appendix K) and their ICs (Appendix L) within the context of lung cancer, COPD, and colorectal cancer. An additional open-ended question was added to determine the source of perceived stigma reported by patients ("If you experience stigma associated with your disease, can you identify the source of the stigma?") and ICs ("If you experience stigma associated with the patient's disease, can you identify the source of the stigma?).

Protection of Human Subjects

Prior to conducting the study, ethical approval was obtained from the Education / Nursing Research Ethics Board, University of Manitoba. Written access approval was obtained from Riverview Health Centre, CancerCare Manitoba, and the Health Sciences Centre in Winnipeg, Manitoba. All personal and medical information were obtained from the patient and IC and handled by the Investigator in accordance with Manitoba's Personal Health Information Act guidelines. Although permission to obtain medical records was sought by the Investigator in the Informed Consent form for patients, in all cases, the patient was able to provide the requested medical information during the interview so no patient records were obtained from the medical clinic.

Before participating in the study, the patient and IC were provided with an Informed Consent form to read and sign. Patients were assured by the Investigator and in

the informed consent forms that their participation or non-participation in the study would not compromise the care that they were receiving as their health care providers were not informed whether or not they participated in the study. A dyad number was assigned to patient and IC data and this dyad number was written on the questionnaires so that the patients' and ICs' names could not be identified. The participants were instructed by the Investigator not to write their names on the questionnaires, and reassured their names would not appear in written reports or publications of the study. The list that linked participant names with code numbers was kept separately from the data under lock and key in the Investigator's home. The Investigator's advisor and thesis committee were the only other persons to have access to the raw data; however, they did not have access to the participant's names.

There were no risks for patients and their ICs who participated in the study. However, some of the questions regarding empathic behaviour or stigma may have been perceived as sensitive in nature, and it was planned that patients would be directed to one of the Psychosocial Oncology Department at CancerCare Manitoba, or the social worker at Riverview Hospital or Health Sciences Centre to assist them with any potential issues that may have arisen from their participation in this study if requested by the patient or deemed necessary by the Investigator. There were no requests made to access these services by the patient or IC, and, in addition the Investigator attempted to assess potential need for these services by asking all participants if they had any comments about the study or anything further to add once the questionnaires were completed.

Data analysis

The Investigator employed quantitative statistical tests to address this study's research questions as assisted by Mary Cheang, Biostatistician at the Manitoba Centre for Nursing and Health Research at the University of Manitoba. Descriptive statistics, such as frequency distributions, mean and standard deviation when applicable were used to describe the overall sample characteristics in terms of demographic and disease variables, empathic behaviours, and perceptions of stigma by patients and ICs To determine differences between diagnostic groups on sociodemographic variables, T-tests for independent samples, the Mann-Whitney U test, and the McNemar's Chi-square were utilized. Internal consistency reliability of the empathic behaviour scales and stigma scales was estimated for both patient and IC groups using Cronbach's coefficient alpha reliability estimates.

The research questions analyses involved the use of Pearson's *r* correlations, Mann Whitney U tests and / or Analysis of Variance (ANOVA). Relationships between two variables (whether ordinal, interval or ratio) are usually described through correlation analyses (Polit & Beck, 2004). The most common correlation index is Pearson's *r* (also known as the product-moment correlation coefficient) computed by using variables on either an interval or ratio scale. The *r* refers to Spearman's rho and for most psychological variables an *r* of .70 is high with correlations between those types of variables typically in the .10 to .40 range (Polit & Beck, 2004). The Mann Whitney U test (a non-parametric test for assessing whether ordinal or continuous variables were distributed equally between two groups; Polit & Beck, 2004) was utilized for some demographic variables. Additionally, ANOVA was used to determine if variability of

group means within or between groups were likely to be attributable to an independent variable or other variables such as individual differences or error (Polit & Beck, 2004).

In particular, to answer research question number one, "What are the relationships between demographic characteristics of patients and caregivers (age, gender, income, education, religion, smoking history, length of relationship) and patient and IC responses on stigma and empathic behaviour?" a series of Pearson's *r* Correlations were conducted. As well, Mann Whitney U tests were conducted on the categorical variables of religion and gender. To answer research question number two, "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour?" a series of Pearson *r* Corrleations were conducted as well as an ANOVA. To answer research question number three, "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?" statistical analysis involved a series of Pearson's *r* Correlations as well as an ANOVA. As well, the responses to an open ended question asking about the source of stigma were treated as qualitative data and the results were coded and categorized to describe themes. Finally, to answer the fourth research question, "what is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking related illness group and colorectal cancer groups?" a series of Pearson *r* correlation analyses were conducted.

Summary

This chapter has outlined the methods the Investigator employed to carry out a descriptive comparative study aimed at examining the relationships between patient and IC stigma and empathic behaviour in smoking related and non-smoking related illnesses. The independent and dependent variables were described. The study's participants and inclusion criteria, setting and recruitment procedure, instruments utilized, and considerations for protection of human subjects were outlined. As well, the data analysis plan to describe the general characteristics of the sample as well as to answer all four research questions was presented.

CHAPTER IV

RESULTS

Introduction

The purpose of this descriptive comparative study was to examine the following research questions among patient and IC dyads diagnosed with smoking related or non-smoking related illnesses:

1. What are the relationships between demographic characteristics of patients and IC (age, gender, education, income, ethnic background, religion, length of relationship, smoking history, and diagnostic group inclusion) and patient and IC responses on stigma and empathic behaviour?
2. What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour?
3. What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?
4. What is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking related illness group and colorectal cancer groups?

This chapter describes the general characteristics of patient and caregiver samples, and reports on the reliability of instruments used with each group. Statistical analysis of the research questions is presented in conjunction with a report of major findings.

Data for this study was collected over a six month period between April 2008 and October 2008. Sites for recruitment of the participants included: CancerCare Manitoba (*MacCharles Unit* and *St. Boniface Unit),* Riverview Health Centre, and the Respiratory Clinic at Health Sciences Centre in Winnipeg, Manitoba, Canada. Data collected from patients and ICs included demographic data, measures of patient and IC's empathic behaviour, and perceptions of stigma. The computer software package SPSS (version 16) for Windows was utilized to analyze the results of all quantitative data. The open ended question regarding the source of stigma was analyzed by the Investigator as qualitative data and content analysis was conducted to classify, summarize and tabulate the data into categories and identify major themes.

Description of the patient and caregiver samples

Patients were recruited from Riverview Health Centre, Health Sciences Centre, Cancercare Manitoba (*MacCharles* and *St. Boniface units*). Across all recruitment sites, of the 49 completed invitations returned to the Investigator, nine indicated refusals to speak to the Investigator about the study. Of the 40 patients who indicated a willingness to speak to the Investigator about the study, an additional six patients did not participate because they had lost interest in participating (n = 1), they were too ill (n = 2), the caregiver was not willing to participate (n = 1) or it was not a good time for the patient to participate (n = 2). The final purposive sample consisted of a total of 33 patient / caregiver dyads where patients were diagnosed with one of COPD, lung cancer or colorectal cancer and one patient / IC dyad that reported two medical diagnoses of lung cancer and COPD. The patients and ICs were relied upon to provide this medical

information and these diagnoses were not verified by checking the patient's medical record.

The patient / IC dyads were divided into two groups: a smoking related illness group (n= 19/34) which included patients diagnosed with COPD or lung cancer, and one patient who had COPD and lung cancer, and a non-smoking related illness group (n=15/34) that included patients diagnosed with colorectal cancer. The smoking related and non-smoking related illness groups served the basis of comparison in the ensuing statistical analyses of research questions. The data regarding the patient's diagnosis are presented in Table 4.1.

Table 4.1

Patient Diagnosis

Patient Diagnosis	Frequency	Percent
Lung Cancer	4	11.8%
COPD	14	41.2%
Lung Cancer and COPD	1	2.9%
Total Smoking Related Illness (lung cancer and COPD combined)	**19**	**55.9%**
Colorectal Cancer	**15**	**44.1%**
Total	**34**	**100%**

Smoking History

Data were gathered about the smoking history of the patients as well as their ICs (Table 4.2).

Table 4.2

Smoking History

Smoking History	Colorectal cancer patient group (n=15)	Smoking related illness group (n=19)	Total Sample (n=34)
Pt Smoking History			
Same as before dx	-	-	-
Cut down since dx	1 (6.7%)	1 (5.3%)	2 (5.9%)
Quit since dx	1 (6.7%)	8 (42.1%)	9 (26.4%)
Former smoker	6 (40%)	10 (52.6%)	16 (47.1%)
Never smoked	7 (46.7%)	-	7 (20.6%)
Total	15 (100%)	19 (100%)	34 (100%)
IC Smoking History			
Same as before dx	1 (6.7%)	1 (5.3%)	2 (5.9%)
Cut down since dx	1 (6.7%)	4 (21.1%)	5 (14.7%)
Quit since dx	1 (6.7%)	3 (15.8%)	4 (11.8%)
Former smoker	5 (33.3%)	9 (47.4%)	14 (41.2%)
Never smoked	7 (46.7%)	2 (10.5%)	9 (26.4%)
Total	15 (100%)	19 (100%)	34 (100%)

Note 1. IC= Informal Caregiver Pt=Patient Dx= Diagnosis

The response items for smoking history ranged from 1 (never smoked) to 5 (smoke about the same now as prior to my diagnosis). The colorectal cancer patient group reported a higher number of 'never' smokers than the smoking related illness group ('7' versus '0'smokers). In order to ensure that the two groups differed with regards to their smoking history, the Mann-Whitney test of differences was conducted and revealed a highly significant difference in smoking history between the smoking illness-related group (mean rank 21.71) and colorectal cancer group (mean rank 12.77) (U=62.5, z = -2.976, p=.003) with patients in the smoking-related illness group reporting

more former or continued cigarette smoking. There was a similar significant difference in IC smoking behaviours between the smoking-related illness group (mean rank 20.45) and colorectal group of caregivers (mean rank 13.77) (U=86.5, z= -2.039, p=.041) with ICs in the smoking-related illness group reporting more cigarette smoking.

Demographic Information

Data regarding demographic information was collected from the patients and the ICs. In this convenience sample of patients in both smoking-related and colorectal cancer groups, the typical characteristics for patients were married or living common-law, of European or Canadian ethnic descent, mean age 63.61 years and there was an equal representation of female and male genders. In this convenience sample of ICs in both smoking-related and colorectal cancer groups, the typical characteristics for caregivers were married or living common-law, of European or Canadian in ethnic descent, mean age 58 years old, and there were more females than male ICs. Table 4.3 outlines the demographic profile of patients and Table 4.4 outlines the demographic profile of caregivers.

Table 4.3

Demographic Profile of Patients

Patient Characteristics	Colorectal cancer group (n=15)	Smoking related illness group (n=19)	Total Sample (n=34)
Gender			
Female	7 (46.7%)	10 (52.6%)	17 (50%)
Male	8 (53.3%)	9 (47.4%)	17 (50%)
Age range			
50 years of age or under	5 (33.3%)	-	5 (14.7%)
51-60 years of age	-	2 (10.6%)	2 (5.9%)
61-70 years of age	9 (60%)	9 (47.4%)	18 (52.9%)
Over 71 years of age	1 (6.7%)	8 (42.1%)	9 (26.4%)
Mean	57.20 (SD 10.61)	68.68 (SD 7.32)	63.61 (SD 10.5)
Marital Status			
Married	12 (80%)	12 (63.2%)	24 (70.6%)
Common-law	2 (13.3%)	1 (5.3%)	3 (8.8%)
Never married	-	-	-
Widowed	-	3 (15.8%)	3 (8.8%)
Divorced	1 (6.7%)	3 (15.8%)	4 (11.8%)
Education			
Less than high school	3 (20%)	8 (42.1%)	11(32.4%)
High School Graduate	3 (20%)	2 (10.5%)	5 (14.7%)
Partial college or university	2 (13.3%)	3 (15.8%)	5 (14.7%)
College / University Graduate	6 (40%)	6 (31.6%)	12 (35.3%)
Grad / Professional training	1 (6.7%)	-	1 (2.9%)
Occupational Status			
Unemployed	-	-	-
Employed Fulltime	2 (13.3%)	-	2 (5.9%)
Employed Part time	2 (13.3%)	-	2 (5.9%)
Medical leave	6 (40.0%)	2 (10.5%)	8 (23.5%)
Retired	4 (26.7%)	17 (89.5%)	21 (61.8%)

Occupation type			
Clerical	3 (20%)	2 (10.5%)	5 (14.7%)
Labourer	-	1 (5.3%)	1 (2.9%)
Homemaker	-	-	-
Professional	9 (60%)	7 (36.8%)	16 (47.1%)
Management	1 (6.7%)	3 (15.8%)	4 (11.8%)
Skilled Trades	2 (13.3%)	5 (26.3%)	7 (20.6%)
Other	-	1(5.3%)	1 (2.9%)
Gross Annual Income			
Below $20,000	-	2 (10.5%)	2 (5.9%)
$20,000-$39,999	1 (6.7%)	7 (36.8%)	8 (23.5%)
$40,000-$59,999	3 (20.0%)	4 (21.1%)	7 (20.6%)
$60,000-$79,999	3 (20.0%)	3 (15.8%)	6 (17.6%)
$80,000-$99,999	3 (20.0%)	2 (10.5%)	5 (14.7%)
Over $100,000	5 (33.3%)	-	5 (14.7%)
Missing / Refused	-	1 (5.3%)	1 (2.9%)
Ethnic Background			
Canadian	4 (26.7%)	5 (26.3%)	9 (26.4%)
European	10 (66.7%)	11 (57.9%)	21 (61.8%)
Native Canadian / Metis	-	3 (15.8%)	3 (8.8%)
Other	1 (6.7%)	-	1 (2.9%)
Patient Religion			
No preference	6 (40%)	4 (21.1%)	10 (29.4%)
Jehovah's Witness	1 (6.7%)	-	1 (2.9%)
Lutheran	2 (13.3%)	-	2 (5.9%)
Anglican	-	-	-
Mennonite	-	1 (5.3%)	1 (2.9%)
Roman Catholic	3 (20%)	8 (42.1%)	11 (32.4%)
United Church	1 (6.7%)	5 (26.3%)	6 (17.6%)
Other	2 (13.3%)	1 (5.3%)	3 (8.8%)
Home nursing care?			
Yes	1 (6.7%)	7 (36.8%)	8 (23.5%)
No	14 (93.3%)	12 (63.2%)	26 (76.5%)
Length of Nursing care			
0 to 9 months	1 (6.7%)	3 (15.8%)	4 (11.8%)
19 to 36 months	-	2 (10.5%)	2 (5.9%)
More than 36 months	-	2 (10.5%)	2 (5.9%)
Not applicable	14 (93.3%)	12 (63.2%)	26 (76.5%)

Demographic data for entire sample

In this convenience sample of patients, there was an equal representation of female and male gender (50% male and 50% female). The mean age of the sample was 63.61 years (SD 10.5). Most patients were either married (70.6%) or living common-law (8.8%). Almost as many patients (32.4%) had less than high school graduation as were graduates of college or university (35.3%). Almost half (47.1%) were currently or formerly professionally employed. Most (61.8%) were retired, 21.5% were on medical leave and the rest of the patients were working full or part time. The entire sample was divided equally among income groups. Most patients reported being of European descent (61.8%) or Canadian (26.4%). Most patients reported a preference for some type of religion (70.5%). The majority of patients had no home nursing care (76.5%).

Demographic data for patients in the colorectal cancer group

In this convenience sample of patients in the colorectal cancer group, the average age was 57.2 years (SD 10.61) and most patients were either married or living common-law (93.3%). Many colorectal patients were college or university graduates or higher (46.7%), while only 20% had less than high school education. Within this group 40% were on medical leave while 26.7% were retired. The majority of patients (60%) were employed professionally. Most colorectal patients reported being of European background (66.7%) or Canadian (26.7%). There was a variety of patient religions reported and 40% of the colorectal cancer patients had no preference for religion. The majority of patients had no home nursing care (93.3%).

Demographic data for patients in the smoking-related illness group

In this convenience sample of patients in the smoking-related illness group, the average age was 68.68 (SD 7.32). Most were married or living common-law (68.5%). In this group, 42.1% had less than high school education while 31.6% had college or university. Almost all (89.5%) of the smoking related illness group were retired and 10.5% were on medical leave, meaning that no patients were working. Most patients were European in origin (57.9%) or Canadian (26.3%). There was a variety of patient religions reported and 42.1% of the smoking related illness group claimed to be Roman Catholic. Over a third (36.8%) had home nursing care.

Differences in characteristics of patients between illness groups

In order to determine if the demographic characteristics were similar between the two groups of patients, a series of tests were conducted. In conducting the t- test for Equality of Means, it was determined that patients in the colorectal cancer patient group were significantly younger than the smoking-related illness group. In the total sample, roughly half of all the patients were between 61 and 70 years of age, however, the mean age of the colorectal cancer patients was younger than the mean age of the smoking related illness group ($t(32)=3.733$, $p=.001$). Additionally, the Mann Whitney test compared the ranks of income levels between the two groups and revealed that the colorectal cancer patients (mean rank 22.87) had significantly higher incomes than the smoking related illness groups (mean rank =12.11) ($U=47$, $z = -3.241$, $p=.001$). The smoking-related illness group appeared to be less educated than the colorectal cancer group. Forty per cent of the smoking related illness group possessed less than a high school education, while 40% of the colorectal cancer patients had graduated from college

or university. However, 31.6% of the smoking related illness group had also graduated from college or university. Although it appeared that there was a difference in education between the two groups, the Mann-Whitney test revealed no significant differences in education between the colorectal cancer patient group (mean rank 19.80) and the smoking-related illness group (mean rank 15.68) (U=108, z = - 1.250, p=.211).

Chi-square analyses were conducted to determine if there were differences between the colorectal cancer group and the smoking-related illness group on some categorical variables. The proportion of participants in each group did not differ by gender, $\chi^2(1, N = 34) = 0.119, p = .5$. Additionally, the number of patients who reported having no preference for religion did not differ between diagnostic groups $\chi^2(1, N = 34) = 1.45, p = .276$. Cursory analysis revealed homogeneity of the samples on the other categorical variables, including marital status, ethnic background, occupational type and occupational status so analyses of difference were not conducted on those variables.

In sum, it was determined that patients in the colorectal cancer patient group were significantly younger and reported significantly higher incomes than the smoking related illness group.

Table 4.4

Demographic Profile of Informal Caregivers

Caregiver Characteristics	Colorectal cancer patient group (n=15)	Smoking related illness group (n=19)	Total Sample (n=34)
Age range			
50 years of age or under	4 (26.7%)	3 (15.8%)	7 (20.6%)
51-60 years of age	6 (40%)	6 (31.6%)	12 (35.3%)
61-70 years of age	5 (33.3%)	7 (36.8%)	13 (38.2%)
Over 71 years of age	-	3 (15.8%)	3 (8.8%)
Mean	55.13 (SD 9.69)	60.26 (SD 11.04)	58 (SD 10.63)
Gender			
Female	8 (53.3%)	14 (73.7)	22 (64.7%)
Male	7 (46.7%)	5 (26.3%)	12 (35.3%)
Marital Status			
Married	12 (80.0%)	16 (84.2%)	28 (82.4%)
Common-law	2 (13.3%)	1 (5.3%)	3 (8.8%)
Never married	1 (5.3%)	1 (5.3%)	2 (5.9%)
Widowed	-	1 (5.3%)	1 (2.9%)
Divorced	-	1 (5.3%)	1 (2.9%)
Education			
Less than high school	2 (13.3%)	8 (42.1%)	10 (29.4%)
High School Graduate	4 (26.7%)	3 (15.8%)	7 (20.6%)
Partial college or university	2 (13.3%)	4 (21.1%)	6 (17.6%)
College / University Graduate	6 (40.0%)	3 (15.8)	9 (26.4%)
Grad / Professional training	1 (6.7%)	1 (5.3%)	2 (5.9%)
Occupational Status			
Unemployed	-	1 (5.3%)	1 (2.9%)
Employed Fulltime	8 (53.3%)	6 (31.6%)	14 (41.2%)
Employed Part time	1 (6.7%)	1 (5.3%)	2 (5.9%)
Medical leave	1 (6.7%)	2 (10.5%)	3 (8.8%)
Retired	5 (33.3%)	9 (47.4%)	14 (41.2%)

Occupation type			
Clerical	1 (6.7%)	7 (36.8%)	8 (23.5%)
Labourer	1 (6.7%)	3 (15.8%)	4 (11.8%)
Homemaker	-	1 (5.3%)	1 (2.9%)
Professional	7 (46.7%)	4 (21.1%)	11 (32.4%)
Management	4 (26.7%)	3 (15.8%)	7 (20.6%)
Skilled Trades	2 (13.3%)	1 (5.3%)	3 (8.8%)
Other	-	-	-
Ethnic Background			
Canadian	6 (40%)	7 (36.8%)	13 (38.2%)
European	9 (60.0%)	10 (52.6%)	19 (55.9%)
Aboriginal / Metis	-	1 (5.3%)	1 (2.9%)
Other	-	-	-
Caregiver Religion			
No preference	7 (46.7%)	5 (26.3%)	12 (35.3%)
Jehovah's Witness	-	-	-
Lutheran	1 (6.7%)	-	1 (2.9%)
Anglican	1 (6.7%)	1 (5.3%)	2 (5.9%)
Mennonite	-	1 (5.3%)	1 (2.9%)
Roman Catholic	2 (13.3%)	7 (36.8%)	9 (26.4%)
United Church	2 (13.3%)	5 (26.3%)	7 (20.6%)
Other	2 (13.3%)	-	2 (5.9%)

Demographic data for the entire informal caregiver sample

In this convenience sample of ICs in both smoking-related and colorectal disease groups, the typical characteristics for caregivers were female (64.7%) and married (82.4%). The mean age was 58 years old (SD 10.63). Education level attained was distributed almost equally between less than high school (29.4%), high school graduate (20.6%), partial college or university (17.6%) or college/university graduate (26.4%). Most ICs were either retired (41.2%) or working fulltime (41.2%). Almost a third (32.4%) were currently or formerly employed professionally and a further 20.6% were currently or formerly employed in management. Most ICs reported to be either European

in origin (55.9%) or Canadian (38.2%). Over a third reported having no preference for religion (35.3%), with the most common religions reported being Roman Catholic (26.4%) or United Church (20.6%).

Demographic data for informal caregivers in the colorectal cancer group

In this convenience sample of ICs in the colorectal cancer group, the genders were split nearly equally and they were mainly married or living common-law (93.3%). The IC mean age was 55.13 (SD 9.69). There was a variety of occupation types reported, with most of the ICs in the colorectal cancer patient group reporting that they were employed professionally (46.7%) or in management (26.7%) and over half reporting that they worked full time (53.3%). There was a variety of IC religions reported and nearly half (46.7%) of the colorectal cancer ICs reported no preference for religion.

Demographic data for informal caregivers in the smoking-related illness group

In this convenience sample of ICs in the smoking-related illness group they were mainly female (73.7%) and married or living common-law (89.5%). The mean age was 60.26 years (SD 11.04). Most ICs (42.1%) had less than a high school education. Nearly half (47.4%) were retired, while nearly a third (31.6%) were employed fulltime. Over a third (36.8%) reported that they were currently or formerly employed in the clerical area. Most caregivers reported to be of either European (52.6%) or Canadian (36.8%) descent. There was a variety of IC religions reported and 36.8% of ICs in the smoking related illness group claimed to be Roman Catholic, 26.3% reported to be United Church members and 26.3% had no preference for religion.

Differences in characteristics of informal caregivers between illness groups

In order to determine if the demographic characteristics were similar between the two groups of ICs, a series of analyses were conducted. In conducting the t- test for Equality of Means, it was determined that the IC's age was similar in both groups (colorectal cancer caregiver mean age was 55.13; smoking related illness caregiver mean age was 60.26) and this difference was not statistically significant between the two groups ($t(32)=1.418$, $p=.166$). Even though caregiver gender was predominantly female in the smoking related illness group (73.7%) and close to half in the colorectal patient group (53.3%), a Chi-square analyses determined that the percentage of participants in each group did not differ by gender, $\chi^2(1, N = 34) = 1.520, p = .29$. Informal caregivers in the smoking related illness group appeared to be less educated and 42.1% of this group possessed less than a high school education, while 40% of the colorectal cancer patients had graduated from college or university. However, a Mann-Whitney analysis revealed that the difference in education was not statistically significant between the ICs in the colorectal cancer group (mean rank 20.63) and the smoking-related illness group (mean rank 15.03) ($U=95.547$, $z = -1.679$, $p=.104$). Additionally, a Chi-square analysis revealed that the number of ICs who reported having no preference for religion did not differ between diagnostic groups $\chi^2(1, N = 34) = 1.52, p = .288$. Because cursory analyses revealed homogeneity of the samples on the other categorical such as marital status, ethnic background, occupational type and occupation status, analyses of difference were not conducted on those variables. In sum, there were no significant differences regarding demographic characteristics between ICs in the smoking-related illness group and ICs in the colorectal cancer group.

Patient / Informal Caregiver Relationship

Data regarding the patient / caregiver relationship was collected separately from both the patient and the caregiver. Information regarding the patient / IC relationship is presented in Table 4.5 for data reported by the patient and Table 4.6 for data reported by the IC.

Table 4.5

Informal Caregiver / Patient Relationship (reported by patient)

IC / Pt Relationship	Colorectal cancer patient group (n=15)	Smoking related illness group (n=19)	Total Sample (n=34)
Pt Relationship to IC			
Wife	6 (40%)	5 (26.3%)	11 (32.4%)
Husband	6 (40%)	7 (36.8%)	13 (38.2%)
Partner	2 (13.3%)	2 (10.5%)	4 (11.8%)
Parent	-	4 (21.1%)	4 (11.8%)
Daughter	-	-	-
Son	-	-	-
Sister	-	1 (5.3%)	1 (2.9%)
Brother	-	-	-
Friend	1 (6.7%)	-	1 (2.9%)
Length of Caregiving Relationship			
0 to 9 months	6 (40%)	4 (21.1%)	10 (29.4%)
10 to 18 months	4 (26.7%)	3 (15.8%)	7 (20.6%)
19 to 36 months	3 (20%)	1 (5.3%)	4 (11.8%)
Over 36 months	2 (13.3%)	11 (57.9%)	13 (38.2%)
IC knowledge of Illness			
A little	-	2 (10.5%)	2 (5.9%)
Somewhat	-	1 (5.3%)	1 (2.9%)
Quite a bit	4 (26.7%)	4 (21.1%)	8 (23.5%)
Very well	11 (73.3%)	12 (63.2%)	23 (67.6%)
IC contact with patient			
Daily, live with caregiver	14 (93.3%)	16 (84.2%)	30 (88.2%)
Daily, but do not live with caregiver	1 (6.7%)	1 (5.3%)	2 (5.9%)
More than weekly	-	1 (5.3%)	1 (2.9%)
Less than weekly	-	1 (5.3%)	1 (2.9%)

IC assistance with illness			
Rarely	-	4 (21.1%)	4 (11.8%)
Seldom	-	-	-
Frequently	2 (13.3%)	3 (15.8%)	5 (14.7%)
Most of the time	4 (26.7%)	2 (10.5%)	6 (17.6%)
Always	9 (60%)	10 (52.6%)	19 (55.9%)
IC / Pt talk openly about illness experience			
Rarely	1 (6.7%)	4 (21.1%)	5 (14.7%)
Seldom	1 (6.7%)	4 (21.1%)	5 (14.7%)
Frequently	4 (26.7%)	1 (5.3%)	5 (14.7%)
Most of the time	3 (20.0%)	3 (15.8%)	6 (17.6%)
Always	6 (40%)	7 (36.8%)	13 (38.2%)

Note 1. IC= Informal Caregiver Pt=Patient

According to the patients, most were married to or common-law partners with their ICs in the colorectal (93.3%) and smoking-related (73.6%) groups. The length of the caregiver relationship was reported to be between 0 to 9 months by 40% of the colorectal cancer patient group and only 21.1% of the smoking related illness group. Whereas, 13.3% of the colorectal cancer patient group reported that the caregiver relationship was longer than 36 months while 57.9% of the smoking related illness group reported that the caregiver relationship was longer than 36 months. The Mann-Whitney test compared the ranks of caregiver length of relationship between the two groups and revealed that the colorectal cancer patient group (mean rank =13.57) reported significantly shorter IC relationships than the smoking-related illness patients (mean rank 20.61) (U=83.5, z = -2.15, p=.04). Most patients (67.6% of the total sample; 73.3% of the colorectal cancer patient group; 63.2% of the smoking related illness group) reported that their IC knew how they thought and felt about their illness experience 'very well'. IC knowledge did

not differ between the colorectal cancer group (mean rank 18.87) and the smoking-related illness group (mean rank 16.42) (U=122, z = -.864, p=.39).

Overwhelmingly the patients reported that they lived with their IC (88.2% of the total sample; 93.3% of the colorectal cancer patient group; 84.2% of the smoking related illness group) and both groups were similar on the degree of contact with their IC. The Mann-Whitney test revealed that colorectal patients (mean rank 18.24) did not have any significant difference in amount of IC contact than the smoking-related illness patients (mean rank 18.24) (U=128.5, z = -.868, p=.632). The level of assistance provided by caregivers as reported by patients in the colorectal group ('frequently' to 'always'; 100%) was higher than the level of assistance provided by caregivers in the colorectal group as reported by patients ('frequently' to 'always'; 78.9%). However, the Mann-Whitney test revealed that this difference was not significant (U=116, z = -1.02, p=.37). The degree of talking openly about the illness experience as reported by patients in the colorectal group ('frequently' to 'always'; 86.7%) was greater than that reported by patients in the smoking related group ('frequently' to 'always'; 57.9%). Again, the Mann-Whitney test revealed that this difference was not significant between the colorectal cancer patient group (mean rank 19.10) and the smoking-related illness group (mean rank 16.24) (U=118.5, z = -.863, p=.41).

To summarize, according to the patients, most were married to or common-law partners with their ICs and almost all of the patients reported that they lived with their IC and had daily contact. Most patients reported that their caregiver knew how they thought and felt about their illness experience very well, and the level of assistance provided by ICs as reported by patients in the smoking-related group did not differ significantly from

the level of assistance provided by ICs in the colorectal group. The degree of talking openly about the illness experience as reported by patients in the colorectal group was not significantly different than that reported by patients in the smoking-related group The only relationship characteristic that differed significantly between the colorectal cancer patient group and the smoking related illness group was that colorectal cancer patients reported significantly shorter IC relationships than the smoking-related illness patients. Therefore, for the purposes of this study, length of caregiver relationship (as reported by the patient) will be the only patient / IC relationship variable that will be examined for the research questions.

Table 4.6

Informal Caregiver / Patient Relationship (reported by IC)

IC / Pt Relationship	Colorectal cancer group (n=15)	Smoking related illness group (n=19)	Total Sample (n=34)
IC Relationship to Pt			
Wife	6 (40.0%)	7 (36.8%)	13 (38.2%)
Husband	6 (40.0%)	5 (26.3%)	11 (32.4%)
Partner	2 (13.3%)	2 (10.5%)	4 (11.8%)
Parent	-	-	-
Daughter	-	4 (21.1%)	4 (11.8%)
Son	-	-	-
Sister	-	1 (5.3%)	1 (2.9%)
Brother	-	-	-
Friend	1 (6.7%)	-	1 (2.9%)
Length of Caregiving Relationship			
0 to 9 months	5 (33.3%)	4 (21.1%)	9 (26.4%)
10 to 18 months	4 (26.7%)	3 (15.8%)	7 (20.6%)
19 to 36 months	2 (13.3%)	1 (5.3%)	3 (8.8%)
Over 36 months	4 (26.7%)	11 (57.9%)	15 (44.1%)
IC knowledge of Illness			
A little	-	1 (5.3%)	1 (2.9%)
Somewhat	1 (6.7%)	1 (5.3%)	2 (5.9%)
Quite a bit	3 (20.0%)	8 (42.1%)	11 (32.4%)
Very well	11 (73.3%)	9 (47.4%)	20 (58.8%)
IC contact with pt			
Daily, live with caregiver	14 (93.3%)	15 (78.9%)	29 (85.3%)
Daily, but do not live with caregiver	1 (6.7%)	2 (10.5%)	3 (8.8%)
More than weekly	-	2 (10.5%)	2 (5.9%)
Less than weekly	-	-	-

Note 1. IC= Informal Caregiver Pt=Patient

Most ICs reported that they were married to or common-law partners with patients diagnosed with colorectal cancer (93.3%) or smoking-related illnesses (73.6%). Forty per cent of the caregivers in the colorectal group and 63.2% of the caregivers in the smoking-related group reported that the caregiver relationship was greater than or equal to 19 months. Although there was a trend for the ICs of patients in the colorectal cancer group to report shorter length of caregiver relationship (mean rank 15.13) than the smoking-related illness group (mean rank 19.37), unlike the data reported by the patient, the Mann-Whitney test revealed that this difference was not statistically significant (U=107, z = -1.29, p=.228). An overwhelming majority of ICs of colorectal patients (93.3%) and smoking related illness patients (89.5%) or 91.2% of the total sample reported that they knew how the patient thought and felt about the illness experience 'quite a bit' or 'very well'. The Mann-Whitney test revealed that knowledge of how they thought and felt about their illness experience as reported by the IC did not differ between the colorectal cancer group (mean rank 19.93) and the smoking-related illness group (mean rank 15.58) (U=106, z = -1.45; p=.215). The majority of ICs reported that they had daily contact and lived with the patient (85.3% overall). The Mann-Whitney test revealed that the amount of contact as reported by the IC did not differ significantly between the colorectal cancer patient group (mean rank 16.07) and the smoking-related illness group (mean rank 18.63) (U=121, z = -1.211, p=.47).

In summary, a cursory analysis reveals that the patient / IC relationship characteristics as reported by the IC mirrored those as reported by the patient. The only difference found was that the length of caregiver relationship as reported by the IC did

not differ significantly between the colorectal cancer group and the smoking-related illness group.

Reliability of Scales

In this exploratory study, internal consistency reliability of the empathic behaviour scales and stigma scales was estimated for both patient and IC groups using Cronbach's coefficient alpha. Reliability coefficients are an important indicator of an instrument's quality for group-level comparisons. The criterion for adequate reliability was established at >.70 (Polit & Beck, 2004). Cronbach's alpha coefficients for the empathic behaviour scales were acceptable to excellent, ranging from .69 to .91. The stigma scales proved to be reliable only within the colorectal cancer patient group (Cronbach's alpha coefficients were .89 and .73 for the patient and IC version respectively). The reliability coefficient estimates for the stigma scale were poor for the smoking-related illness group (Cronbach's alpha coefficients were .18 and -.02 for the patient and IC version respectively). The Cronbach's alpha coefficients for the empathic behaviour scales and the stigma scales are presented in Table 4.7.

Table 4.7

Internal Consistency Reliability

	Smoking Related Illness group				**Colorectal Cancer group**			
Empathic Behaviour Scale	PPS EB	PPIC EB	ICPS EB	ICPP EB	PPS EB	PPIC EB	ICPS EB	ICPP EB
Cronbach's Alpha	.80	.80	.80	.91	.79	.69	.71	.85
Stigma Scale	Pt Stigma Scale		IC Stigma Scale		Pt Stigma Scale		IC Stigma Scale	
Cronbach's Alpha	.18		-.02		.89		.73	

Note 1. PPSEB = Patient's Perception of Self Empathic Behaviour; PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour; ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour; ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour; IC= Informal Caregiver; Pt=Patient.

Research question one: Patient and IC Demographic Characteristics with Stigma and Empathic Behaviour

To answer the question, "What are the relationships between demographic characteristics of patients and ICs (age, gender, income, education, religion, smoking history, length of relationship) and patient and IC responses on stigma and empathic behaviour?" a series of Pearson's *r* Correlations were conducted. Correlations were done for the sample as a whole versus doing sub-group correlations. As well, Mann Whitney U tests were conducted on the variables of religion and gender. Due to the fact that almost all participants reported that they were either European or Canadian in ethnic origin, analyses regarding relationships between ethnic or cultural descent and other variables were unable to be conducted.

In particular, correlations were conducted between patient and IC demographic characteristics and total scores of empathic behaviour and stigma by the patient and IC in addition to discrepancy scores. Discrepancy scores were obtained by matching the patient score with their IC counterpart's score and then subtracting the IC's score from the patient's score. *Stigma discrepancy* is a calculation of the matched scores of the patient stigma total minus the IC stigma total. If the patient's stigma score is higher than the IC's score, the discrepancy score will be positive. If the patient's stigma score is lower than the ICs, the discrepancy score will be negative. *Informal caregiver empathic behaviour discrepancy* is the patient's perspective of the IC's empathic behaviour total minus the IC's perception of their own empathic behaviour total. If the patient rates the IC higher in empathic behaviour than the IC rates him/her self, then the discrepancy score will be

positive. If the IC rates him/her self as higher in empathic behaviour than the patient does then the discrepancy score will be negative. *Patient empathic behaviour discrepancy* is the patient's perception of their own empathic behaviour total minus the IC's perception of the patient's empathic behaviour total. If the patient rates him/herself higher in empathic behaviour then the IC does, then the discrepancy score will be positive. If the IC rates the patient as higher in empathic behaviour than the patient rates him/herself then the discrepancy score will be negative.

The correlations between the patient demographic variables and stigma are presented in Table 4.8, the correlations between IC demographics and stigma are presented in Table 4.9, the correlations between patient demographics and empathic behaviour are presented in Table 4.10, and the correlations between IC demographics and empathic behaviour are presented in Table 4.11. As well, the Mann-Whitney test of difference was conducted to determine if gender of patient or IC were related to measures of either stigma or empathic behaviour. Due to the small number of patients and caregivers who reported particular types of religion, analyses by type of religion were not possible, so the sample was broken down into two groups (presence / absence of preference for religion) and a Mann-Whitney test was conducted to determine if there was any relationship between religion on either stigma or empathic behaviour. Results of the Mann-Whitney tests of differences for patient and IC gender are presented in Table 4.12 and Table 4.13 for patient and IC religion. Additional analyses of correlations between patient demographic variable and IC demographic variables are presented in Table 4.14.

Table 4.8

Relationship between Patient Demographics and Stigma Pearson's *r*

	Pt age	Pt Ed	Income	Pt smoke	Length
Pt stigma	-.401 (.019) *	-.053 (.764)	.200 (.265)	.51 (.773)	-.108 (.543)
IC stigma	.089 (.615)	-.149 (.400)	-.280 (.114)	.170 .337	-.065 (.716)
Stigma discep	-.422 (.013) *	.019 (.916)	.321 (.069)	-.030 (.865)	-.072 (.685)

Note 1: Pt = Patient, IC= Informal Caregiver, Ed= Education, Length= length of IC relationship (reported by patient); Stigma Discrep=Stigma Discrepancy score

Note 2: Number in parentheses represent significance (2 tailed) * p <.05 ** p<.01

The only patient demographic variable that correlated with patient stigma was that patient age was negatively correlated with patient stigma (r= -401; p=.019). That is, the younger the patient, the more likely the patient reported stigma. Patient age was also negatively correlated with stigma discrepancy (r= -.422; p=.013) which means that the younger the patient, the greater the discrepancy between the patient and his or her respective IC on the stigma scale.

Table 4.9

Relationship between Informal Caregiver Demographics and Stigma Pearson's *r*

	IC age	IC Ed	IC smoke
Pt stigma	-.291 (.095)	.023 (.898)	.142 (.423)
IC stigma	-.026 (.886)	-.240 (.172)	.154 (.386)
Stigma discep	-.264 (.132)	.133 (.453)	.063 (.723)

Note 1: Pt = Patient, IC= Informal Caregiver, Ed=Education, smoke=smoking history; Stigma Discrep=Stigma Discrepancy score

Note 2: Number in parentheses represent significance (2 tailed)

There were no IC demographic variables that correlated significantly with reports of any stigma measures.

Table 4.10

Relationship between Patient Demographics and Empathic Behaviour Pearson's *r*

	Pt age	Pt Ed	In-come	Pt smoke	Len-gth
PPS EB	.153 (.389)	-.030 (.865)	.234 (.190)	-.041 (.820)	.206 (.242)
PPIC EB	-.179 (.311)	.365 (.034) *	.399 (.021) *	-.298 (.086)	-.149 (.401)
ICPS EB	-.112 (.527)	.217 (.218)	.096 (.595)	-.385 (.025) *	-.037 (.836)
ICPP EB	-.089 (.618)	.419 (.014) *	-.010 (.957)	-.452 (.007) **	.076 (.670)
Pt EB discrep	.180 (.319)	-.343 (.047) *	.177 (.324)	.316 (.069)	.093 (.599)
IC EB discrep	-.127 (.473)	.269 (.123)	.412 (.017) *	-.050 (.779)	-.153 (.389)

Note 1: Pt = Patient, IC= Informal Caregiver, Ed=Education, smoke=smoking history, length=length of patient / IC care relationship (as reported by patient), PPSEB = Patient's Perception of Self Empathic Behaviour, PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour, ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour, ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour, Pt. EB Discrep=Patient Empathic Behaviour Discrepancy score, IC EB Discrep= Informal Caregiver Empathic Behaviour Discrepancy score.

Note 2: Number in parentheses represent significance (2 tailed) * $p < .05$ ** $p < .01$

The patient's level of education had a moderate positive association with the patient's perception of their IC's empathic behaviour ($r = .365$; $p = .034$), and the ICs perception of the patient's empathic behaviour ($r = .419$; $p = .014$). In other words, when patients had a higher level of education, both patients and their ICs perceived patients as being more empathic. There was a moderately positive association found between the patient's reported gross annual income and the patient's perception of the IC's empathic

behaviour (r= .399; p=.021), meaning that the higher the patient's gross annual income, the more empathic the IC was perceived by the patient.

Patient's report of cigarette smoking was negatively correlated with both the IC's perception of self empathic behaviour (r= -385; p=.025) and the IC's perception of the patient's empathic behaviour (r= -.452; p=.007). This means that if the patient reported more cigarette smoking, the IC reported less empathic behaviour both from themselves and from the patient.

The following results describe significant associations between several variables and patient or IC discrepancy scores of empathic behaviour. There was a moderate negative association between patient level of education and the patient empathic behaviour discrepancy score (r= -.343; p=.047). In other words, when patients attained a higher level of education, there was less disagreement between the patient and their respective IC on their perceptions of the patient's empathic behaviour. The patient's gross annual income had a moderate positive association with the patient and IC discrepancy scores on the IC's empathic behaviour (r= .412; p=.017). In other words, greater disagreements between patients' and ICs' perceptions of IC empathic behaviour occurred when patients reported higher levels of income.

To summarize, patients with higher education perceived their IC as more empathic and had ICs who perceived the patient as more empathic, and the higher the gross annual income, the more empathic the IC was perceived by the patient. Patients who reported more cigarette smoking had ICs who perceived themselves as less empathic and also perceived the patients as less empathic. Concerning the discrepancy scores, when patients reported a higher level of education, there was less disagreement between

the patient and the IC on their perceptions of the patient's empathic behaviour. Conversely, greater disagreements between patients' and ICs' perceptions of IC empathic behaviour occurred when patients reported higher gross annual income.

Table 4.11

Relationship between Informal Caregiver Demographics and Empathic Behaviour Pearson's *r*

	IC age	IC Ed	IC smoke
IC Ed	.075 (.673)	—	
IC smoke	.095 (.593)	-.275 (.115)	—
PPS EB	-.039 (.827)	.355 (.039) *	-.093 (.600)
PPIC EB	-.108 (.542)	.418 (.014) *	-.278 (.112)
ICPS EB	-.241 (.170)	.057 (.749)	-.236 (.179)
ICPP EB	-.153 (.388)	-.100 (.574)	-.527 (.001) **
Pt EB discrep	.088 (.619)	.337 (.051)	.335 (.053)
IC EB discrep	.065 (.715)	.467 (.005) **	-.147 (.408)

Note 1: Pt = Patient, IC= Informal Caregiver, Ed=Education, smoke=smoking history, PPSEB = Patient's Perception of Self Empathic Behaviour; PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour; ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour; ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour; Pt. EB Discrep=Patient Empathic Behaviour Discrepancy score IC EB Discrep= Informal Caregiver Empathic Behaviour Discrepancy score.
Note 2: Number in parentheses represent significance (2 tailed) * p <.05 ** p<.01

IC education was positively correlated with the patient's perception of self empathic behaviour (r= .355; p=.039) as well as the patient's perception of the IC's empathic behaviour (r= .418; p=.014). This means that the higher the IC's education, the higher the patient perceived both their own and the IC's empathic behaviour. The IC's education was also correlated positively with IC empathic behaviour discrepancy

meaning that the more educated the IC, the greater the discrepancy between the ratings of the patient and their respective IC on IC empathic behaviour. As well, IC's report of smoking was negatively correlated with IC perceptions of patients' empathic behaviour (r= -.527; p=.001) meaning that ICs who had higher reported current or former cigarette smoking had lower reported perceptions of patient empathic behaviour.

In summary, the higher the IC's education, the higher the patient perceived their self and the ICs empathic behaviour and the greater the IC empathic behaviour discrepancy score. IC's who had higher reported smoking behaviour had lower reported perceptions of patient empathic behaviour.

Table 4.12

Participant Gender Mann-Whitney Test

	Patient Gender					Informal Caregiver Gender				
	F	M	*U*	*Z*	Sig	F	M	*U*	*Z*	Sig
Self EB	19.44	15.56	111.5	-1.148	.251	18.20	16.21	116.5	-.563	.574
Other EB	15.88	19.12	117.0	-.957	.339	16.50	19.33	110.0	-.796	.426
Stigma Total	16.65	18.35	130.0	-.514	.607	18.84	15.04	102.5	-1.107	.268

Note 1: Numbers in F or M column represent mean rank, *U*= Mann-Whitney U, *Z*= Z score, Sig= 2 tailed significance, F= female, M= male, Self EB= Empathic Behaviour ratings for self, Other EB= Empathic Behaviour for other (whether patient or informal caregiver), Stigma total = total score on stigma measure for self.

There was no significant effect for the patient or IC gender on the ratings of self empathic behaviour, other empathic behaviour or stigma scale. Subgroup analyses and analyses for any potential interaction effects for patient / IC gender were not conducted.

Table 4.13

Participant Religion Mann-Whitney Test

	Patient Religion					Informal Caregiver Religion				
	Relig	No Relig	*U*	*Z*	Sig	Relig	No Relig	*U*	*Z*	Sig
Self EB	19.27	13.25	77.5	-1.622	.105	19.55	13.75	87.0	-1.634	.102
Other EB	18.79	14.40	89.0	-1.183	.237	19.45	13.45	89.0	-1.556	.120
Stigma Total	15.27	22.85	66.5	-2.080	.047 *	15.07	21.96	78.5	-2.008	.045 *

Note 1: Numbers in Relig / No Relig column represent mean rank, *U*= Mann-Whitney U, *Z*= Z score, Sig= 2 tailed significance * $p<.05$ Relig= has preference for religion, No Relig= No preference for religion, Self EB= Empathic Behaviour ratings for self, Other EB= Empathic Behaviour for other (whether patient or informal caregiver), Stigma total = total score on stigma measure for self.

Patients who reported having no preference for religion scored higher on the stigma scale (mean rank 22.85) than patients who reported having a preference for religion (mean rank 15.27) (U=66.50, z = -2.080, p=.047). Similarly, ICs who reported having no preference for religion scored higher on the stigma scale (mean rank 21.96) than ICs who had a preference for religion (mean rank 15.07) (U=78.50, z = -2.008, p=.045). This means that patient or ICs that had no preference for religion scored higher on the stigma scale.

Table 4.14

Relationship between Patient and IC Demographic Data Pearson's *r*

	Pt age	Pt Ed	Income	Pt smoke	Length	IC age	IC Ed
Pt age	—						
Pt Ed	-.053 (.764)	—					
Income	-.451 (.008) **	.244 (.171)	—				
Pt smoke	.375 .029 *	-.288 (.098)	-.274 (.122)	—			
Length (pt)	.445 (.008) **	-.199 (.259)	-.514 (.002) **	.325 (.061)	—		
IC age	.511 (.002) **	.023 (.896)	.036 (.841)	.279 (.088)	.100 (.573)	—	
IC Ed	-.022 (.90)	.011 (.951)	.429 (.013) *	.095 (.593)	-.049 (.782)	.075 (.673)	—
IC Smoke	.087 (.624)	-.446 (.008) **	-.289 (.103)	.578 (.000) **	.168 (.342)	-.095 (.593)	-.275 (.115)

Note 1: Pt = Patient, IC= Informal Caregiver, Ed=Education, smoke=smoking history, length=length of patient / IC care relationship (as reported by patient).

Note 2: Number in parentheses represent significance (2 tailed) * p <.05 ** p<.01

Although not directly relevant to the research question, because there was some significant relationships between patient and IC demographic variables, these correlations are presented and discussed. The age of patients was negatively correlated to gross annual income (r= -.451; p=.008) and positively correlated to length of caregiver

relationship (r= .445; p=.008), IC age (r= .551; p=.002) and patient smoking history (r= .375; p=.029). In other words, the older the patient the smaller amount his or her gross annual income. On the other hand, older patients had older ICs, reported longer caregiver relationships and reported higher rates of former or continued cigarette smoking. IC reports of cigarette smoking was positively correlated with patient smoking (r= .578; p=.000) meaning that if the patient smoked cigarettes (currently or formerly), the IC was more likely to smoke cigarettes. Gross annual income is negatively correlated with length of caregiver relationship (r= -.514; p=.002). In other words the greater the patient's reported gross annual income, the less time they reported being in a caregiver relationship. Additionally, IC education was positively correlated with income (r= .429; p=.013) and IC smoking was negatively correlated with patient education (r= -.446; p=.008).

To abridge, older patients had older ICs, a longer relationship with their IC, less income, and higher reported current or former cigarette smoking. IC education was positively correlated with gross annual income. As well, patients who reported smoking were more likely to have ICs who reported smoking and IC smoking was negatively correlated with patient education.

To summarize, to answer the question, "What are the relationships between demographic characteristics of patients and caregivers (age, gender, income, education, religion, smoking history, length of relationship) and patient and IC responses on stigma and empathic behaviour?" there are several significant associations.

For stigma, the results suggested that the younger the patient, the more likely he or she was to report stigma and also patients with no religious preference reported more

stigma. The only IC demographic variable that was related to stigma was that ICs with no preference for religion reported more stigma. Regarding patient and IC discrepancy scores on stigma, the younger the patient, the greater the discrepancy found between perceptions of stigma by the patient and their respective IC.

Concerning empathic behaviour, patients with higher education perceived their ICs as more empathic, and had ICs who perceived the patient as more empathic, and the higher the gross annual income, the higher in empathic behaviour the IC was perceived by the patient. Additionally, patients who smoked had ICs who perceived themselves as less empathic and were perceived as less empathic by their ICs. With regards to IC demographic variables, the higher the IC's education, the higher the patient perceived both their own and their IC's empathic behaviour and IC's who had reported more smoking had lower reported perceptions of patient empathic behaviour. Less patient and IC discrepancy occurred on the patient's empathic behaviour when patients reported higher educational levels. Regarding discrepancy scores on IC empathic behaviour, the findings indicated that the discrepancy was greater when patients reported higher gross annual incomes.

Research question two: Empathic Behaviour

To answer the question "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour" a series of Pearson r correlations were conducted as well as an ANOVA. Analyses were not conducted on the individual questions, but only on the total group means, however, for descriptive purposes, mean scores from the two diagnostic groups (smoking-related illness group and colorectal cancer patient group) are presented for the four different empathic behaviour scales for each question on the scale in Table 4.15. The Pearson r correlations are presented in Table 4.16, the ANOVA tables are presented in Table 4.17 for the patient's empathic behaviour and Table 4.18 for the IC's empathic behaviour.

Table 4.15
Empathic Behaviour Smoking-related illness vs. Colorectal Cancer Group Comparisons

	Smoking-related Illness Group				Colorectal Cancer Patient Group			
	PPS EB	PPIC EB	ICPS EB	ICPP EB	PPS EB	PPIC EB	ICPS EB	ICPP EB
1. Understand my concerns	3.68 (.58)	3.89 (.32)	3.53 (.61)	3.26 (.81)	3. 60 (.63)	3.87 (.35)	3.67 (.49)	3.47 (.52)
2. Understand how I felt	3.42 (.77)	3.68 (.58)	3.47 (.51)	3.16 (.90)	3.67 (.62)	3.73 (.46)	3.73 (.46)	3.40 (.74)
3. Experience what I felt	3.42 (.61)	2.42 (1.39)	3.11 (.66)	2.95 (.70)	3.20 (.78)	3.2 (.94)	3.07 (1.03)	2.80 (1.01)
4. Imagine being in my shoes	3.42 (.84)	2.53 (1.17)	3.42 (.61)	3.05 (.70)	3.00 (1.36)	3.13 (1.19)	3.60 (.63)	3.20 (.56)
5. See things from my point of view	3.53 (.90)	3.11 (1.1)	3.58 (.51)	3.26 (.73)	3.47 (.74)	3.87 (.35)	3.80 (.41)	3.27 (.80)
6. Accept me as I am now	3.70 (.54)	3.95 (.23)	3.68 (.48)	3.68 (.58)	3.93 (.26)	3.93 (.26)	3.80 (.41)	3.73 (.46)
7. Help me by listening	3.58 (.77)	3.68 (.58)	3.58 (.51)	3.42 (.61)	3.60 (.63)	3.73 (.59)	3.87 (.35)	3.40 (.74)
8. Help me by doing something	3.53 (1.02)	3.79 (.42)	3.79 (.42)	3.74 (.56)	3.40 (1.12)	3.93 (.26)	3.87 (.35)	3.60 (.51)
9. Tries to figure out how to make me feel better	3.63 (.60)	3.53 (.90)	3.79 (.42)	3.47 (.61)	3.73 (.59)	3.73 (.59)	3.87 (.35)	3.47 (.64)
10. Tells me positive feelings towards me	3.11 (1.24)	3.00 (1.37)	3.37 (.76)	3.26 (.99)	3.73 (.46)	3.80 (.56)	3.60 (.63)	3.73 (.46)
Total	35.10 (1.09)	33.58 (1.04)	35.32 (.72)	33.26 (1.13)	35.33 (1.23)	36.93 (1.18)	36.87 (.82)	34.07 (1.28)

Note 1. PPSEB = Patient's Perception of Self Empathic Behaviour; PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour; ICPSEB = Informal Caregiver's

Perception of Self Empathic Behaviour; ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour; IC= Informal Caregiver; Pt=Patient.
Note 2. Number in columns represent group mean.
Note 3. Number in parentheses represent standard deviation / standard error.

Table 4.16

Relationship between Patient and IC Empathic Behaviour Pearson's *r*

	PPS EB	PPIC EB	ICPS EB	ICPP EB
PPS EB	—			
PPIC EB	.559 (.001) **	---		
ICPS EB	.254 (.147)	.587 (.000) **	---	
ICPP EB	.110 (.537)	.261 (.135)	.650 (.000) **	---
Pt EB discrep	.650 (.000) **	.210 (.234)	-.311 (.074)	-.684 (.000) **
IC EB discrep	.477 (.004) **	.746 (.000) **	-.102 (.567)	-.214 (.225)

Note 1: PPSEB = Patient's Perception of Self Empathic Behaviour, PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour, ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour, ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour, Pt. EB Discrep=Patient Empathic Behaviour Discrepancy score, IC EB Discrep= Informal Caregiver Empathic Behaviour Discrepancy score.

Note 2: Number in parentheses represent significance (2 tailed) * p <.05 ** p<.01

The results indicate significant associations between the patient's and the IC's perceptions of self and their partner's empathic behaviour. The patient's perception of self empathic behaviour was positively correlated with the patient's perception of the IC's empathic behaviour (r= .599; p=.001). In other words, patients who reported being more empathic also reported their ICs to exhibit more empathic behaviours. The patient's perception of the IC's empathic behaviour was positively correlated with the IC's perceptions of self empathic behaviour (r= .587; p=.000). This suggests that patients and

their ICs rated the IC's empathic behaviour similarly. The IC perception of self empathic behaviour was positively correlated with the IC's perception of the patient's empathic behaviour (r= .650; p=.000), meaning that ICs tended to rate their own and the patient's empathic behaviours in a similar manner.

Regarding empathic behaviour discrepancy there was a strong positive association between the patient's perception of self empathic behaviour and the discrepancy scores of the patient and their respective IC perceptions of the patient's empathic behaviour (r= .650; p=.000), and the ICs empathic behaviour (r= .477; p=.004). These findings suggest that when patients perceived they were being more empathic, they also experienced greater disagreements with their respective ICs on their perceptions of the patient's empathic behaviour. Similarly, when patients perceived they were being more empathic, they also experienced greater disagreements with their respective ICs on the perceptions of the IC's empathic behaviours.

The patient's perception of the IC's empathic behaviour was positively correlated with the IC empathic behaviour discrepancy score (r= .746; p=.000). In other words, there was more disagreement between the patient and their respective IC on their perceptions of the IC empathic behaviour when patients perceived their IC to be engaging in more empathic behaviours. A significantly strong negative association was found between the IC's perception of the patient's empathic behaviour and the discrepancy scores between patient and IC perceptions of the patient's empathic behaviour (r= -.684; p=.000). This finding suggests that there was less disagreement between patients and their respective ICs on their ratings of patient empathic behaviours when ICs perceived the patients to be engaging in more empathic behaviours.

To summarize, the higher the patient rated themselves on empathy, the higher they rated their ICs on empathy. In the same way, the higher the IC rated themselves on empathy, the higher they rated the patient. Additionally, the patient and IC both rated the IC's empathic behaviour similarly. Concerning the discrepancy scores, when patients perceived themselves as more empathic, there was greater disagreement with their respective IC both on the perceptions of the patient's empathic behaviour and their perceptions of the IC's empathic behaviour. As well, when the patients perceived their IC to be engaging in more empathic behaviours there was more disagreement between the patient and their respective IC on their perceptions of the IC empathic behaviour. Finally, when ICs perceived the patients to be engaging in more empathic behaviours there was less disagreement between patients and ICs on their ratings of patient empathic behaviours.

Table 4.17

Patient's Empathic Behaviour ANOVA

Patient's Empathic Behaviour	Type III Sum of squares	df	Mean square	F	Sig
Between groups	4.460	1	4.460	.171	.682
Within groups	1.388	1	1.388	.066	.799
Total	5.848	2			

Patient's empathic behaviour. For the between groups comparison, the mean scores of the patient's perspective of self empathic behaviour did not differ significantly whether the dyad was in the colorectal cancer group or the smoking-related illness group [$F(1,32)=.171$, $p=.682$]. As well, for the within group comparison, the perception of the patient's empathic behaviour did not differ significantly whether viewed by the patient or the IC [$F(1,32)=.066$, $p=.799$].

Table 4.18

Informal Caregiver's Empathic Behaviour ANOVA

Caregiver's Empathic Behaviour	Type III Sum of squares	df	Mean square	F	Sig
Between groups	100.846	1	100.846	4.325	.046*
Within groups	13.632	1	13.632	1.838	.185
Total	114.478	2			

Note 1. * $p<.05$

Informal Caregiver's empathic behaviour. For the between groups comparison, the mean score of the IC's empathic behaviour differed significantly when the IC was in the colorectal cancer group versus the smoking-related illness group [$F(1,32)=4.325$, $p=.046$]. That is, ICs in the smoking-related illness group were perceived by the patients as less empathic than the ICs in the colorectal cancer group. However, for the within group comparison, the perception of the IC's empathic behaviour did not differ significantly whether viewed by the patient or the IC [$F(1,32)=1.838$, $p=.185$].

In summary, to answer the question "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour", there were several significant associations found between patient and IC empathic behaviour. Firstly, the higher the patient rated themselves on empathic behaviour, the higher the patient rated the IC on empathic behaviour. Secondly, as patients or ICs rated their own empathic behaviour higher, they rated their counterpart's empathic behaviour higher. The discrepancy scores of the patient's empathic behaviour were greater when patients

reported higher empathic behaviour. Regarding discrepancy scores on IC empathic behaviour, the findings indicated that the discrepancy was greater when patients reported themselves as higher in empathic behaviour, and when the patient perceived the IC as higher in empathic behaviour. Finally, it appears that patients who have been diagnosed with smoking-related illnesses view their ICs as less empathic than patients in the colorectal cancer group.

Research Question three: Stigma

To answer the question "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?" statistical analysis involved a series of Pearson *r* correlations and an ANOVA. Although analyses were not conducted on individual questions, for interest, mean scores for individual item scores on the stigma scale are presented for patient and IC responses in the two diagnosis groups in Table 4.19. The results of the Pearson r correlations are reported in Table 4.20, the results of the ANOVA are presented in Table 4.21. As well, the results of the open ended question regarding the source of stigma are presented in Table 4.22.

Table 4.19

Stigma Scale by Diagnostic group

	Smoking-related Illness Group		**Colorectal Cancer Patient Group**	
	Patient	**Caregiver**	**Patient**	**Caregiver**
1. Feel blamed by Others	1.63 (1.06)	1.42 (.90)	1.13 (.52)	1.00 (0)
2. Feel you need to hide it	1.11 (0.32)	1.21 (.63)	1.40 (.83)	1.20 (.41)
3. Feel ashamed	1.00 (0)	1.00 (0)	1.33 (.90)	1.07 (.26)
4. Think disease is punishment	1.53 (1.02)	1.53 (.90)	1.33 (.90)	1.33 (.49)
5. Think people are uncomfortable around you	1.53 (0.77)	1.32 (.75)	1.87 (.74)	1.33 (.49)
6. Feel people avoid you	1.26 (.73)	1.05 (.23)	1.40 (.74)	1.40 (.51)
7. Fear you will lose friends	1.21 (.63)	1.11 (.46)	1.27 (.80)	1.07 (.26)
8. Fear that family will reject you	1.00 (0)	1.00 (0)	1.13 (.52)	1.00 (0)
9. Feel people do not want you around children	1.00 (0)	1.00 (0)	1.00 (0)	1. 00 (0)
Total	**11.26 (.79)**	**10.63 (.39)**	**11.87 (.89)**	**10.4 (.43)**

Note 1. Number in columns represent group mean
Note 2. Number in parentheses represent standard deviation / standard error

Table 4.20

Relationship between Patient Stigma and IC Stigma Pearson's *r*

	Pt stigma	IC stigma
IC stigma	.130 (.464)	—
Stigma discep	.887 (.000) **	-.342 (.048) *

Note 1: Pt = Patient, IC= Informal Caregiver, Stigma Discrep=Stigma Discrepancy score

Note 2: Number in parentheses represent significance (2 tailed) * p <.05 ** p<.01

Patient stigma is strongly positively correlated with stigma discrepancy (r= .887; p=.000) meaning that the higher the patient stigma, the greater the difference between perceptions of stigma held by the patient and their respective IC. Stigma discrepancy is negatively correlated with IC stigma (r= -.342; p=.048) meaning that the greater the IC's perception of stigma, the less the discrepancy on the stigma scale between the patient and their respective IC perceptions of stigma.

Table 4.21

Stigma ANOVA

Stigma score	Type III Sum of squares	df	Mean square	F	Sig
Between groups	.580	1	.580	.071	.792
Within groups	18.452	1	18.452	2.797	.104
Total	19.032	2			

For the between groups comparison, the total stigma score did not differ significantly whether the dyad was in the colorectal cancer group or the smoking-related illness group [$F(1,32)=.071$, $p=.792$]. Additionally, for the within group comparison, the perception of stigma did not differ significantly whether viewed by the patient or the IC, although there was a trend for the patient to report higher stigma [$F(1,32)=2.797$, $p=.104$].

Open ended stigma question

On the Patient Stigma Scale, there was an open ended question that asked, "If you experience stigma associated with your disease, can you identify the source of the stigma?" Similarly, on the Informal Caregiver Stigma Scale, there was an open ended question that inquired, "If you experience stigma associated with the patient's disease, can you identify the source of the stigma?" The responses to these questions were treated as qualitative data and the procedure utilized to analyze these data was based on content analysis to classify, summarize and tabulate the data into categories and to identify major themes (Hancock, 2002). The Investigator identified four major themes from the content analysis: responsibility for causing the illness, embarrassment, lifestyle change and

privacy. Patients or ICs who did not identify any stigma in the quantitative portion of the questionnaire did not reply to this open ended question. The number of participants who did respond to this question is presented for each group in Table 4.20 along with the results of the open ended stigma questions. Additionally, participants may have identified more than one source of stigma and therefore, their responses may be included more than once per participant. The number in brackets represents the number of participants who reported responses that were categorized into the major theme.

Table 4.22

Open ended stigma question results

Patients in smoking-related illness group (n=16 /19)		
Themes	**Major Categories**	**Minor Categories**
1. Responsibility for cause of illness (8)	Cigarette smoking	Patient smoking / not quitting smoking "in time"
2. Embarrassment (2)	Do not want to be seen with oxygen tank	Strangers uncomfortable around oxygen tank Family uncomfortable around oxygen tank
3. Lifestyle change (2)	Lose contact with those who smoke	Lose friends / family members who smoke
Patients in colorectal cancer group (n=12/15)		
Themes	**Major Categories**	**Minor Categories**
1. Responsibility for cause of illness (6)	Diet Other lifestyle	High fat, not good diet Smoking, overweight, "religious penance"
2. Embarrassment (3)	"Messy" illness	Colostomy bag /talk about bowels unpleasant Screening / surgery / after-effects all "icky"
3. Privacy (3)	Need for privacy	Private person Loss of "status" Do not want health to be an identifier of who I am
Informal caregivers in smoking-related illness group (n=12/19)		
Themes	**Major Categories**	**Minor Categories**
1. Responsibility for cause of illness (10)	Cigarette smoking	Patient smoking IC smoking
2. Embarrassment (2)	Embarrassed that patient is ill	Embarrassed by oxygen tank Embarrassed that patient cannot go to social functions
Informal caregivers in colorectal cancer group (n=9/15)		
Themes	**Major Categories**	**Minor Categories**
1. Responsibility for cause of illness (3)	Diet / other lifestyle	Poor diet / no exercise
2. Embarrassment (5)	"Messy illness" Others don't know what to say / how to help	Colostomy bag messy Talk about bowels unpleasant
3. Privacy (2)	Need for privacy	Private person / "status" loss

Of the patients in the smoking-related illness group, 16 of 19 patients responded to the open ended question. Responsibility for causing the illness (i.e. cigarette smoking) was identified by eight of those patients (50%). Embarrassment regarding being seen with an oxygen tank was identified by two patients (12.5%) and losing friends due to lifestyle change was identified by two patients (12.5%). Other responses to the open ended question were unspecified or did not fall into the major themes. In the colorectal cancer group, 12 of 15 patients responded to the open-ended question. Responsibility for causing the illness was identified by six patients (50%) due to diet or other lifestyle factors. Embarrassment was identified by three patients especially due to the "messiness" of the illness (25%) and hiding the illness due to the need for privacy was identified by three patients (25%). In the smoking-related illness group, 12 of 19 ICs responded to the open ended question. Responsibility for causing the illness (i.e. cigarette smoking) was identified by ten ICs (83.3%) with only one IC assigning responsibility to themselves for their own smoking as a cause of the patient's illness. Embarrassment about the illness related to the oxygen tank or decline in patient function was identified by two ICs (16.6%). In the colorectal cancer group, nine of 15 ICs replied to the open ended question. Responsibility for causing the illness was identified by three ICs (33.3%) due to diet or other lifestyle factors. Embarrassment regarding the illness because the illness is viewed as a "messy" illness was identified by five ICs (55.5%) and hiding the illness due to a need for privacy was identified by two ICs (22.2%).

To answer the question "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?" there were some significant

associations found regarding patient and IC discrepancy scores on stigma. It was found that the greater the patient stigma, the greater the discrepancy between perceptions of stigma by the patient and their respective IC. Conversely, the greater the IC's perception of stigma, the less discrepancy was found between patient and their respective IC perceptions of stigma There was no significant differences found within or between groups on perceived stigma. That is between diagnostic groups, the stigma score did not differ significantly whether the dyad was in the colorectal cancer group or the smoking-related illness group. Additionally, for the within group comparison, the perception of stigma did not differ significantly whether viewed by the patient or the IC, although there was a trend for the patient to report higher stigma.

Although there were no significant differences in the quantitative portion of the analysis, some interesting themes emerged by analyzing the open-ended question including: responsibility for causing the illness, embarrassment, need for privacy, and lifestyle change. It is interesting that 50% of patients in both the smoking-related illness and the colorectal cancer group cited responsibility for the cause of the illness as a source of stigma. However, 83.3% of the ICs in the smoking-related illness group cited patient or IC responsibility for causing the illness while only 33.3% of the ICs in the colorectal cancer patient group cited patient or IC responsibility for the causing the illness.

Research Question Four: Relationship Between Stigma and Empathic Behaviour

To answer the question, "what is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking-related illness group and colorectal cancer groups?" a series of Pearson *r* correlation analyses were conducted. The relationships between empathic behaviour and stigma are presented in Table 4.23 for

the entire sample, Table 4.24 for the smoking-related illnesses, and Table 4.25 for the colorectal cancer group. An examination of the correlations for the entire sample revealed that there were no significant correlations between any of the empathic behaviour measures with either of the stigma measures employed with patients and ICs.

Table 4.23

Relationship between Empathic Behaviour and Stigma Pearson's *r* (Entire Sample)

	PPS EB	PPIC EB	ICPS EB	ICPP EB	Pt. EB Discrep	IC EB Discrep
Pt. Stigma	.046 (.796)	-.019 (.917)	.066 (.709)	.009 (.960)	.027 (.880)	-.078 (.663)
IC Stigma	-.254 (.147)	-.200 (.256)	-.085 (.634)	-.082 (.645)	-.214 (.486)	-.177 (.318)
Stigma discrep	.162 (.361)	.075 (.671)	.102 (.565)	.047 (.794)	-.124 (.486)	.009 (.961)

Note 1: Pt = Patient; IC= Informal Caregiver; PPSEB = Patient's Perception of Self Empathic Behaviour; PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour; ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour; ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour; Pt. EB Discrep=Patient Empathic Behaviour Discrepancy score; IC EB Discrep= Informal Caregiver Empathic Behaviour Discrepancy score; Stigma Discrep=Stigma Discrepancy score.

Table 4.24

Relationship between Empathic Behaviour and Stigma Pearson's *r*

(Smoking-related Illness)

	PPS EB	PPIC EB	ICPS EB	ICPP EB	Pt. EB Discrep	IC EB Discrep
Pt. Stigma	-.238 (.327)	-.092 (.709)	-.261 (.280)	-.531 (.019) *	.230 (.343)	.088 (.721)
IC Stigma	-.029 (.906)	-.037 (.881)	.022 (.929)	-.112 (.648)	.063 (.798)	-.062 (.801)
Stigma discrep	-.219 (.367)	-.064 (.794)	-.284 (.238)	-.452 (.052)	.184 (.450)	.139 (.570)

Note 1: Pt = Patient; IC= Informal Caregiver; PPSEB = Patient's Perception of Self Empathic Behaviour; PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour; ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour; ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour; Pt. EB Discrep=Patient Empathic Behaviour Discrepancy score; IC EB Discrep= Informal Caregiver Empathic Behaviour Discrepancy score; Stigma Discrep=Stigma Discrepancy score.

Note 2: $*p < .05$

In the smoking-related illness group, there was only one significant association found. Patient stigma was negatively correlated with IC perspective of patient empathic behaviour (r= -.531; p=.019). This means that within the smoking-related illness group, the higher stigma the patient reported, the lower the patient's empathic behaviour was perceived by the IC.

Table 4.25

Relationship between Empathic behaviour and Stigma Pearson's *r*

(Colorectal cancer)

	PPS EB	PPIC EB	ICPS EB	ICPP EB	Pt. EB Discrep	IC EB Discrep
Pt. Stigma	.228 (.413)	-.039 (.889)	.265 (.340)	.394 (.146)	-.127 (.651)	-.292 (.291)
IC Stigma	-.552 (.033) *	-.527 (.044) *	-.203 (.468)	-.023 (.935)	-.472 (.076)	-.358 (.191)
Stigma discrep	.405 (.134)	.146 (.602)	.318 (.248)	.376 (.168)	.045 (.873)	-.148 (.598)

Note 1: Pt = Patient; IC= Informal Caregiver; PPSEB = Patient's Perception of Self Empathic Behaviour; PPICEB = Patient's Perception of Informal Caregiver's Empathic Behaviour; ICPSEB = Informal Caregiver's Perception of Self Empathic Behaviour; ICPPEB= Informal Caregiver's Perception of Patient's Empathic Behaviour; Pt. EB Discrep=Patient Empathic Behaviour Discrepancy score; IC EB Discrep= Informal Caregiver Empathic Behaviour Discrepancy score; Stigma Discrep=Stigma Discrepancy score.

Note 2: $*p < .05$

In the colorectal cancer group, IC stigma was negatively correlated with both patient perception of self empathic behaviour (r= -.552; p=.033) as well as patient perception of IC empathic behaviour (r= -.527; p=.044). This means that within the colorectal cancer group as the IC stigma was higher patient's perception of both self and IC empathic behaviour was lower or when ICs perceived less stigma the patients perceived themselves and their ICs to be engaging in more empathic behaviours.

In summary, to answer the question, "what is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking-related illness group and colorectal cancer groups?" upon examination of the entire sample, there appears to be no relationship between stigma and empathic behaviour by patients or ICs.

However, when a sub-group analysis by diagnostic group was conducted, several significant associations were found regarding relationships between stigma and empathic behaviour. In particular, in the smoking-related illness group, higher patient stigma was related to lower patient's empathic behaviour as perceived by the IC. Similarly, within the colorectal cancer group, higher IC stigma was related to lower patient's perception of both self and IC empathic behaviour.

Summary

The analysis and interpretation of data collected from 19 patients diagnosed with smoking related illnesses and their ICs, and 15 patients diagnosed with colorectal cancer and their ICs were the focus of this pilot study. A description of the recruitment process and the number of eligible participants who participated in the study was provided. The socio-demographic characteristics of participants in the diagnostic groups were described. Acceptable internal consistency reliability estimates on the empathic behaviour tools were established for both diagnostic groups; however, the stigma tool was only shown to be reliable with the colorectal cancer patients and ICs. A variety of statistical techniques, including within and between diagnostic group analyses were employed to determine relationships and differences between patient and IC responses on perceived stigma and empathic behaviour.

Patients in the entire sample were typically married or living common-law, of European or Canadian descent, and 63.61 years old. There was an equal representation of female and male gender. It was determined that patients in the colorectal cancer patient group were significantly younger and reported significantly higher incomes than the smoking related illness group. ICs in the entire sample were typically married or living

common-law, of European or Canadian in ethnic descent, 58 years old and female. There were no significant differences in socio-demographic characteristics between ICs in the smoking-related illness group and ICs in the colorectal cancer group. Analyses of associations between socio-demographic characteristics revealed that older patients had older ICs, longer lengths of patient / IC relationships, less income, and higher reported cigarette smoking. IC education was positively correlated with gross annual income. As well, patients who reported smoking were more likely to have ICs who reported smoking and IC smoking was negatively correlated with patient education.

In accordance with patient reports on the patient / IC relationship across diagnostic groups, most patients were married to or common-law partners with their IC, lived with their IC, in daily contact with their IC, and felt that their IC knew how they thought and felt about their illness experience very well. Across diagnostic groups, patients reported similar levels of assistance being provided by their ICs, and degree of open communication about the illness experience. However, colorectal cancer patients reported a significantly shorter length of patient / IC relationship with their IC than did the smoking-related illness patients. The IC also provided data on the patient / IC relationship that appeared to be in concordance with information reported by the patient. However, the length of the patient and/ IC relationship as reported by the IC did not differ significantly between the colorectal cancer group and the smoking-related illness group.

To answer research question number one, "What are the relationships between demographic characteristics of patients and informal caregivers (age, gender, income, education, religion, smoking history, length of relationship) and patient and IC responses

on stigma and empathic behaviour?" a number of significant findings were reported. The only patient variables that correlated with stigma were that the younger the patient, the more likely they were to report stigma and patients with no religious preference reported more stigma. The only IC demographic that was related to stigma was that ICs with no preference for religion reported more stigma. With regards to empathic behaviour, patients with higher education were perceived as being more empathic by themselves and their ICs. As well, patients who reported higher gross annual incomes also reported higher empathic behaviour by the IC. Patients reported more empathic behaviour by themselves and their ICs when the IC attained a higher level of education. Additionally, patients who smoked had ICs who perceived themselves and patients as being less empathic. As well, IC's who reported more smoking behaviour had lower reported perceptions of patient empathic behaviour. The discrepancy scores of the patient's empathic behaviour were greater when patients reported higher empathic behaviour and lesser when patients reported higher educational levels and when the IC perceived the patient as having higher empathic behaviour. The discrepancy scores on IC empathic behaviour was greater when patients reported higher gross annual incomes, when the patient reported themselves as higher in empathic behaviour, and when the patient perceived the IC as higher in empathic behaviour.

To answer research question two "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour?" an ANOVA was conducted. The results suggested that patients who have been diagnosed with smoking-related illnesses viewed their ICs as less empathic than patients in the colorectal cancer

group. No other significant differences were found involving either 'within' or 'between' group comparisons.

To answer research question three "what are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on perceived stigma?" an ANOVA was conducted. For the between diagnostic group comparison, there were no significant differences in perceived stigma by patients and ICs. For the within group comparison, there were no significant differences in perceived stigma between patients and ICs; however, there was a trend for the patients' reports of perceived stigma to be higher than ICs' reports of perceived stigma. Content analysis by the Investigator of patient and IC responses to the open ended question about sources of perceived stigma revealed four major categories that included: responsibility for causing the illness, embarrassment, lifestyle change and privacy. Interestingly, of those participants who identified a source of stigma, responsibility for the cause of the illness was identified by 50% of patients in both the smoking-related illness group and the colorectal cancer group; however, responsibility for causing the illness was identified by 83.3% of the ICs in the smoking-related illness group and only 33.3% of the ICs in the colorectal cancer patient group.

To answer the research question number four, "what is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking related illness group and colorectal cancer groups?" a series of Pearson *r* correlation analyses were conducted . In the smoking-related illness group, the IC perceived the patient to engage in less empathic behaviour when the patient reported more perceived stigma. In

the colorectal cancer group, patients perceived themselves and their ICs to engage in less empathic behaviour when the IC reported more perceived stigma.

CHAPTER V

DISCUSSION

Introduction

The study was designed to expand our knowledge on the relationship between stigma and empathic behaviours by patients with smoking-related illnesses and their ICs. A comparison group of patients diagnosed with colorectal cancer along with their ICs was included to test whether linkages among the patient's or IC's perceptions of stigma, empathic behaviours and demographic variables differed between smoking-related illnesses and a non smoking related illness. This study was guided by an exploratory framework developed by the author based on the review of the empirical literature. This exploratory framework consisted of the key concepts of stigma and empathic behaviour.

Major findings are interpreted in this chapter and subsequent conclusions are presented. Briefly, the results of this study added to our understanding of empathic behaviour, and suggested that empathic behaviour may be positively related to patient and IC education and patient income, and negatively associated to patient or IC smoking history. Additionally, this study suggested that stigma appears to be negatively correlated with the age of the patient and the absence of preference for religion. The feasibility of conducting research with the target population of COPD patients, lung cancer patients and colorectal cancer patients has been demonstrated. The reliability of the four empathic behaviour scales has been proven with this target sample; however, the reliability of the stigma scales has only been demonstrated with the colorectal patient / IC group. Patient

recruitment procedures, the demographic data of the patient and IC sample are addressed, followed by a discussion regarding scale reliability and a discussion regarding each research question. The relevant findings from this study are discussed in relation to existing empirical literature. The study's limitations, clinical implications, and suggestions for future research are outlined. Finally, a dissemination plan for the research results is presented.

Patient recruitment

Patients and ICs were recruited from three sites in Winnipeg, Manitoba over a six month time period. The participation rate was high with 40 of the 49 eligible patients who returned completed envelopes agreeing to speak to the Investigator about the study. However, due to the busy clinic settings, the primary clinic contact was not able to gather data with respect to the number of patients who received or refused an invitation letter, or the number of patients who did not return the invitation letter to clinic staff. A sampling bias might be present as patients were allowed to self-select to participate in the study.

Due to recruitment across different sites, another bias may have been introduced to threaten internal validity to the study findings. That is, the two recruitment sites for the COPD and lung cancer patients were a rehabilitation centre and a respiratory clinic where patients were often recruited during follow-up appointments. Colorectal cancer patients were recruited from an outpatient cancer clinic. Although some colorectal cancer patients were follow up patients, they were often patients who were recently diagnosed with their illness and many of them were still undergoing active treatment. A cursory analysis of the length of time since diagnosis revealed that the colorectal cancer patients did have a shorter length of time since diagnosis and a *t*-test for Independent Means confirmed that

the smoking-related illness patients did have a longer time since diagnosis (mean=5.42 years) than the colorectal cancer patients [(mean=1.2 years); $t(32)=4.41$, $p=.000$].

Although there were no significant associations or differences found regarding length of time since diagnosis and perceptions of stigma and empathic behaviours (possibly due to the small size of diagnostic sub-groups) it is nonetheless important to consider the potential impact of 'response shift' on responses by patients and ICs who having been dealing with their respective illnesses for a varying length of time. This concept is outlined by Sprangers and Schwartz (2000) who suggested that patients undergo a process of 'response shift' whereby their internal standards, values and conceptualization of quality of life change over the illness trajectory and those changes are necessary to accommodate their illness experience. The concept of response shift will be addressed later within the discussion of research question number three.

Smoking history

The patient / IC dyads were divided into two groups: a smoking related illness group that included patients diagnosed with either COPD or lung cancer along with their ICs, and a non-smoking related illness group that included patients diagnosed with colorectal cancer and their ICs. Not surprisingly, there was a highly significant difference between the two groups with patients in the smoking-related illness group reporting more cigarette smoking. Additionally, there was a similar significant difference in IC smoking behaviours between the two groups with ICs in the smoking-related illness group versus non-smoking related illness group reporting more cigarette smoking. As well, for the entire sample, patient smoking and IC smoking behaviours were strongly positively correlated ($r=.578$, $p=.000$) which adds to the literature that cigarette smoking

is often a behaviour that is engaged in within a social context where patients and their ICs have a common smoking history (Palmer, Baucom & McBride, 2000). This social context was explored by Badr and Carmack Taylor (2006) in their literature review who found that living with a cigarette smoking family member means repeated exposure to smoking cues and ready access to tobacco products. These factors make it more difficult for patients to quit smoking and more likely that they will relapse.

Demographic data

In this study's sample, it was determined that patients in the colorectal cancer patient group (mean age 57.2) were significantly younger and reported significantly higher incomes than the smoking-related illness group (mean age 68.68). Because the colorectal cancer patients were younger, most patients and ICs of the dyad were still employed while most patients and ICs from the smoking-related illness group had retired. As there was a significant difference between the mean age of the patients, the related occupational status difference may partially account for the disparity in income between the groups.

Regarding patient age, according to the Canadian Cancer Society / National Cancer Institute of Canada (2008) the median age for diagnosis of both colorectal cancer and lung cancer is between the ages of 70-79 years. As well, according to the Canadian Public Health Agency the median age for diagnosis of COPD is between 55-64 years old. So, in this study's sample, lung cancer patients were younger than expected (mean age 62 years) and COPD patients (mean age 71.07 years) were older than expected (although none of these patients were newly diagnosed). As well, the colorectal cancer patients in this study were younger (m = 57.2 years old) than the age that would be expected within

the colorectal cancer population. It is possible that the previously discussed differences in recruitment sites, along with the related difference in time since diagnosis resulted in greater numbers of older COPD patients who had not been recently diagnosed participating in this study than expected by the Investigator. Additionally, due to a self-selection bias, younger colorectal cancer patients may have been less likely to have comorbidities that would have otherwise prohibited them from participating in the study. Finally, five of 15 patients in the colorectal cancer group were under the age of 50 years and represented a full one-third of the colorectal cancer patient sample. This sub-sample of patients might have skewed the results towards a younger patient age in the colorectal cancer group.

Most caregivers in the entire sample were married or living common-law, of European or Canadian in ethnic descent, mean age 58 years old, and there were more females than male ICs. For the entire sample, patient and IC age were positively correlated (r=. 511; p=.002). Statistics are not gathered on IC age; however, because patient age and IC age were positively correleated and this study's sample has the above noted age differences between diagnostic groups it is likely that the ICs in this sample followed the same trend as the patients.

Across diagnostic groups, there were limited differences in patient / IC relationship factors that might impact perceptions of stigma and empathic behaviours. The only relationship characteristic that differed significantly between the colorectal cancer patient group and the smoking-related illness group was that smoking-related illness patients reported significantly longer IC relationships than did colorectal cancer patients. Again, this difference is logical as the smoking-related illness patients had a

longer time since diagnosis and were older than the colorectal cancer patients and were mainly married to their ICs. The ICs also reported a longer length of relationship in the smoking-related illness group versus ICs in the colorectal group but this difference was not significant. One caveat in self-reports of length of caregiving relationship that was not controlled for in the study was that some participants may have viewed the IC relationship within the context of the entire relationship previous to the illness, while participants may have defined the length of caregiving relationship within the context of the patient's illness. Due to the homogeneity of the majority of caregiving relationship factors within the study, only the length of IC relationship (as reported by the patient) was examined in relation to perceptions of stigma and empathic behaviours.

Reliability

In this study, Cronbach's alpha coefficients for the four empathic behaviour scales were acceptable to excellent, ranging from .69 to .91; however, the stigma scales were reliable only for the colorectal cancer patient group (.89 and .73 for the patient and IC version respectively) and poor for the smoking-related illness group (.18 and -.02 for the patient and IC version respectively). Cronbach's alpha is an estimate of the reliability of the scores on a test and is an indication of the degree to which the item response scores correlate with the total test scores (Reinhardt, 1991). The stigma scale utilized for this study was developed for use with HIV/AIDS patients and did not demonstrate reliability within the sample of those diagnosed with a smoking-related illness. Upon speaking to the participants in the smoking-related illness group, anecdotal evidence was provided to the Investigator by the patients and the ICs that they were having difficulty in completing the stigma scale. For example, several patients stated that they used to feel ashamed of

their illness or they felt they had to hide it when they were first diagnosed but that this did not matter to them anymore. Additionally, some patients stated that due to their illness diagnosis (or for many, the related factor of quitting smoking upon diagnosis) they had already lost friends and family and no longer feared this occurrence. The fact that the stigma scales were not demonstrated to be reliable with either patients or ICs in the smoking-related illness group indicates that relationships found with perceived stigma must be interpreted with caution with this study's sub-group analyses.

Research question one: Patient and IC Demographic Characteristics with Stigma and Empathic Behaviour

The following will discuss significant associations found in relation to addressing Research Question #1, "What are the relationships between demographic characteristics of patients and caregivers (age, gender, income, education, religion, smoking history, length of relationship) and patient and IC responses on stigma and empathic behaviour?" Significant associations were found between stigma and patient age as well as religion. In addition, empathic behaviour was found to be associated with patient and IC education as well as patient income. The findings are discussed below.

Stigma. This study's results revealed a strong association between age and stigma where younger patients were more likely than older patients to self-report perceptions of being stigmatized. Two older articles were located in the research literature that examined age and stigma. Macdonald and Anderson (1984) studied perceptions of stigma and quality-of-life in patients with rectal cancer (n=420) and they found that younger patients, particularly men, felt more stigmatized than older patients. Similarly, Menec and Perry (1995) studied 249 university students' reactions to stigma utilizing vignettes

where they manipulated the age of the stigmatized person and the type of stigmatized condition. These authors found that older persons with a stigmatized condition elicited less anger than younger persons with the same stigma, particularly in the case of blindness, lung cancer, amputation, unemployment and depression. Additionally, these authors found that the study participants were more likely to help an older rather than a younger person with a leg amputation. Therefore, the current study's results that revealed a negative correlation between age and stigma is consistent with previous research.

Additionally, there was a weak association between both the patient's and the IC's respective perceptions of stigma with religious preference. Those patients and ICs with no preference for religion reported more stigma than patients and ICs who reported a preference for religion. There have been few studies to examine stigma and religion. For example Green and Banerjee (2006) studied attitudes of undergraduate students (n=485) and found that high religious intensity by those perceiving the person was predictive of more negative attitudes towards people with AIDS and those who were homosexual. One qualitative study in Africa (n=97) found that in a faith based health promotion program women perceived stigma as a barrier to screening for cervical cancer or HPV virus because of the association between the virus and promiscuity (Matthews, Berrios, Darnell & Calhoun, 2006). The relationship between the concepts of religion and stigma is not well understood in the research literature and this study's findings seem to contradict the previous studies on stigma and religion. These inconsistent results are explained by Nyblade et al. (2004) who outlined that religion has the potential to either exacerbate or mitigate stigma as religion fuels views of socially unacceptable behaviour

and may marginalize already vulnerable groups. On the other hand, with acceptance for others as a core value of many religions, religion can encourage compassion and care.

Empathic behaviour. Regarding empathic behaviour, patients with higher education had perceived their ICs as being more empathic. In addition, ICs of patients with higher education also perceived these patients as being more empathic towards them. Another study finding was that patients who reported a higher gross annual income also perceived their ICs to be more empathic towards them. Also, the higher the IC's education, the higher the patient perceived both their own and their IC's empathic behaviour.

There were no known studies identified by the Investigator that directly examined the relationship between empathic behaviour and demographic variables between patients and ICs. However, education and income are related variables (Cheeseman-Day & Newburger, 2002) and will be discussed together regarding their association with perceived empathic behaviour. A model of empathic accuracy within dyadic relationships had been proposed by Ickes and Simpson (1997, 2001). These authors proposed that there is an upper and lower limit of empathic accuracy within relationships with three factors affecting interactions between the dyad that included: whether the partner's thoughts and feelings are likely to cause the other distress, the clarity or ambiguity of cues regarding the partner's feelings, and the degree to which the partner feels threatened. In general, in non-threatening day-to-day interactions, greater empathic accuracy should predict greater relational satisfaction. Literature on empathic accuracy (Simpson, Ickes and Blackstone, 1995; Ickes & Simpson, 1997; Ickes & Simpson, 2001) are suggestive that the core processes of empathic behaviour are mentally effortful and

require considerable cognitive energy to take the viewpoint of another individual to comprehend what that person is experiencing. Simpson, Ickes and Blackstone (1995) found that individuals in dating relationships with higher grade point averages tended to attain enhanced empathic understanding of the other's experiences. In their review of the literature, Ickes and Simpson (1997) reported an association between IQ and perspective-taking and explained this finding by the impression that empathic behaviour involves a number of underlying cognitive abilities such as a mental capacity to hold and differentiate many viewpoints at the same time.

The present study may be viewed as one that examined the broad view or "average" empathic accuracy within the patient / IC dyad according to the Simpson and Ickes model. The study findings suggested that the more educated the patient or IC, the more likely he or she will engage in or be aware of empathic behaviours; however, these results were not consistent with all measures of empathic behaviour. This study made an important preliminary contribution to the empathy literature by having examined not just the patient's or the IC's respective responses, but also conducted a comparison of dyadic responses on the partner's empathic behaviours. This type of research has received limited attention in the literature to date. More research with larger samples is needed to clarify the effects of education and other demographic and relationship factors on patient and IC empathic behaviour.

Concerning cigarette smoking, this study found that there were three measures of empathic behaviour that were negatively correlated with smoking. Patients who smoked had ICs who perceived themselves as less empathic and were perceived as less empathic by their ICs. Additionally, ICs who had reported more smoking had lower reported

perceptions of patient empathic behaviour. This study provides suggestive evidence that engaging in a stigmatized behaviour (i.e. cigarette smoking) places the patient / IC dyad at risk of suboptimal empathic behaviour. A review of the literature conducted by Palmer, Baucom and McBride (2000) outlines that there many possible interactions between partner smoking status and support between marital couples especially if there is discordance in smoking status. In their study of lung cancer patients and ICs, Lobchuk, McClement, McPherson and Cheang (2008) found that judgments of responsibility for illness and anger placed the IC at risk for dysfunctional helping behaviour when the patient still engaged in smoking. In the present study, although attributions of blame and anger were not captured, it is plausible that a similar process is occurring and the patient is detecting blame and anger from the IC in relation to his or her smoking behaviours that posed a hazard for both members of the dyad to offer empathic, supportive behaviour toward the other. These findings suggest that clinical attention to dissention or conflicts in relation to the patient's smoking behaviours might be warranted in order to enhance empathic communication between patients and their ICs.

Research question two: Empathic Behaviour

Research Question #2, "What are the relationships and differences between patient and IC responses within diagnosis groups (smoking related illnesses or colorectal cancer), and between groups on empathic behaviour?" will be addressed in the following. Analyses conducted on the group as a whole revealed that there were several significant positive associations found between patient and IC empathic behaviours. The higher the patient rated themselves on empathic behaviour, the higher the patient rated the IC on empathic behaviour and vice-versa. Additionally, the higher the patient rated their IC on

empathic behaviour, the higher the IC rated him/herself on empathic behaviour meaning that the patient and IC agree on the IC's empathic behaviour. There was no empirical literature located that examined the perceptions of empathic behaviour by both counterparts of the dyad with which to compare the results. However, empirical research with empathic accuracy conducted by Maragoni, Garcia, Ickes and Teng (1995) who studied undergraduate students (n=80) found that empathic accuracy is modifiable with practice and providing feedback. It is possible that factors such as these occurred in the present study as the length and closeness of the relationship (mainly spousal) may lead to greater empathic understanding through practice and feedback that aid with empathic behaviour.

On the other hand, the between group analysis of differences revealed that patients who had been diagnosed with a smoking-related illness viewed their ICs as being less empathic than patients in the colorectal cancer group Again, this finding provided additional support for the notion that engaging in a stigmatized behaviour (i.e. cigarette smoking), or in this case belonging to a group that is stigmatized, placed the patient / IC dyad at risk for suboptimal empathic behaviour by ICs. This finding is supported by Weiner, Perry, and Magnusson (1988) who found that stigmas deemed to be caused by controllable factors elicited more anger, less pity and less willingness to help. As well, Lobchuk, McClement, McPherson and Cheang (2008) and Lobchuk, Murdoch, McClement, and McPherson (2008) found that in the context of smoking behaviour by patients, IC attributions of patient responsibility for controlling the illness and anger placed the IC at risk for impaired helping behaviour. It is plausible that this attributional process was present in this study. That is, patients with smoking-related illnesses

perceived their ICs to be angry or blame the patient that, in turn, negatively impacted on their rating of empathic behaviour by ICs towards patients.

Research Question three: Stigma

Research Question #3, "What are the relationships and differences between patient and IC responses within diagnosis groups (smoking-related illnesses or colorectal cancer), and between groups on perceived stigma?" will be addressed next.

Quantitative results. In relation to quantitative analyses results, the Investigator was surprised that there were no significant differences found within or between the non-smoking and smoking related diagnostic groups on perceived stigma. That is, the stigma score did not differ significantly whether the dyad was in the colorectal cancer group or the smoking-related illness group. Additionally, for the within group comparison, the perception of stigma did not differ significantly when viewed by the patient or the IC but there was a trend for the patient to report higher stigma

Based on increasing societal stigma toward individuals who smoke or smoked cigarettes, it is plausible for patients diagnosed with a smoking-related illness (like lung cancer and COPD) to report more perceived stigma than individuals diagnosed with a non-smoking related illness like colorectal cancer. However, there are several factors that might explain why this result was not found in this study. First, the poor reliability estimates of the stigma scale utilized in this study suggested challenges in attempting to reliably capture the stigma responses of patients and their ICS in the smoking related diagnosis group. On the other hand, the responses on the stigma scale employed in this study appeared appropriate in capturing stigma as experienced by patients and ICs dealing with colorectal cancer.

Second, and as discussed earlier, it is also plausible that patients and ICs who had been living with the diagnosis of lung cancer and COPD longer than patients and ICs with colorectal cancer had adapted to other people's responses toward them, and thus no longer felt the negative effects of stigma over time. In other words, these patients and ICs might have developed supportive relations with others that buffered negative societal responses toward them over the course of the illness. On the other hand, patients and ICs dealing with colorectal cancer were still in an early stage of adaptation to the diagnosis that made them more sensitive to stigmatizing reactions of others to the diagnosis.

Third, it is important to consider the possibility that the construct of stigma is sensitive to response shift by patients and ICs in this study who have dealt with their chronic, smoking-related illness over a long period of time. Response shift captures a process that patients and even ICs undergo during the illness trajectory whereby internal standards, values and conceptualization of quality-of-life change as one learns to adapt and accommodate the illness experience (Sprangers & Schwartz, 2000). Richards and Folkman (2000) further integrated response shift into the concept of adaptive coping whereby the individual relinquishes unrealistic beliefs about how things are, revises those beliefs and adopts new beliefs. This process involves attaching positive meaning to their new beliefs and revising core beliefs about the self and what is valued and meaningful. The authors contended that a person's coping mechanisms can create and maintain the phenomenon of response shift. There was one study that found suggestive evidence of stigma related response shift while examining small cell lung cancer (SCLC) patients and reports of fatigue. Westerman, The, Sprangers, Groen, van der Wal and Hak (2006) found that most SCLC patients showed a discrepancy in fatigue reporting and all patients

demonstrated evidence of response shift by recalibration (i.e., they used a different comparison standard over time) and a change in perspective. This change in perspective involved distancing themselves from a stereotypical cancer patient by underreporting fatigue as well as adopting protective and assertive behaviour to counteract stigma. For the present study, it should be noted that patients diagnosed with colorectal cancer reported similar perceptions of stigma as patients in the smoking-related illness group. It is plausible that patients and ICs who have been dealing with lung cancer and COPD for a considerable length of time have experienced a response shift in their values and beliefs and they experienced a similar level of stigma as that reported by newly or recently diagnosed patients with colorectal cancer. Further longitudinal studies are required to examine and compare reports of stigma and response shift in patients diagnosed with smoking-related and non-smoking related diseases over time.

Fourthly, a corollary explanation is that due to this study's convenience sampling procedure, patients in the smoking related diagnostic group who were highly stigmatized might not have volunteered to participate in the study. Patients and IC participants in both groups in this study had low stigma scores (ranging from a mean score of 10.4 for the ICs of the colorectal cancer group to a mean score of 11.87 for the patients in the colorectal cancer group). These numbers suggest that participants were not highly stigmatized individuals as the lowest possible score on the stigma scale was nine out of a possible score of 36. This finding is supported by the literature on stigmatized conditions where individuals often attempt to hide their stigmatized condition (e. g. The United States Department of Health and Human Services, 1999; Chesney & Smith, 1999; Fortenberry, McFarlane & Bleaky, 2002; Halter, 2004; Tod, Craven & Almark, 2007).

Similarly, those who felt highly stigmatized by their illness were not likely to have chosen to participate in this study.

Open ended question. A number of qualitative themes and categories emerged from the Investigator's analysis of qualitative responses to the open ended question that asked, ""If you experience stigma associated with your disease (or the patient's in the case of the IC) can you identify the source of the stigma?" These qualitative responses were helpful in interpreting the quantitative responses by patients and ICs on the stigma and empathic behaviour scales.

Four major themes emerged that included patient and ICs responses of responsibility for causing the illness, embarrassment, need for privacy, and lifestyle change. It is interesting that 50% of patients in both the smoking-related illness and the colorectal cancer group cited him/herself as being responsible for the cause of the illness as a source of stigma; smoking cigarettes by patients with lung cancer, COPD, and colorectal cancer, and dietary habits and lack of exercise by patients with colorectal cancer. These findings suggested that health promotion and disease prevention messages had a powerful and wide-reaching influence in perpetuating the current 'blame the victim' paradigm for individuals who had a cigarette smoking history and who were diagnosed with diseases that were either directly or indirectly linked with cigarette smoking. LoConte, Else-Quest, Eickhoff, Hyde and Schiller (2008) found that while lung cancer patients reported more perceived cancer-related stigma, regardless of cancer type, the belief that one caused one's own cancer is related to an increase in guilt, shame, anxiety and depression and that patients who smoked cigarettes had more guilt and shame (also despite the type of tumour).

ICs in the two groups were more disparate in their views of responsibility for causing the illness. In the smoking-related illness group, 75% of the ICs cited patient responsibility for causing the illness (and one IC cited their own smoking history) while only 33.3% of the ICs in the colorectal cancer patient group cited patient responsibility for the causing the illness due to controllable factors. ICs in the colorectal cancer group cited uncontrollable factors for the source of the stigma as the "messiness" of the illness, embarrassment about the illness or a need for privacy as a source of stigma. Ascribing controllability or responsibility for causing the illness within the patient / IC dyad may have ramifications for dysfunctional helping behaviour within this population. For example, Weiner, Perry, and Magnusson (1988) found that stigmas ascribed to controllable factors elicited more anger, less pity and less willingness to help as compared to stigmas ascribed to uncontrollable factors. Similarly, Lobchuk, McClement, McPherson and Cheang (2008) found that IC attributions of patient responsibility for controlling the illness and anger placed the IC at risk for impaired helping behaviour especially if the patient had a cigarette smoking history or continued smoking.

Research Question Four: Relationship Between Stigma and Empathic Behaviour

Research Question #4, "what is the relationship between patient and IC perceptions of stigma on their empathic behaviour in the smoking-related illness group and colorectal cancer groups?" will be addressed in the following. Upon the Investigators' analyses of associations involving responses for the total sample, there appeared to be no relationship between stigma and empathic behaviour by patients or ICs. However, when sub-group analyses by diagnostic group were conducted, several significant associations were found between stigma and empathic behaviour.

In the smoking-related illness group, higher patient stigma was related to lower patient empathic behaviour as perceived by the IC. This means that within this group, patients with higher reported stigma were perceived by the IC as having lower empathic behaviour. As suggested by the open-ended question, many ICs ascribed a controllable cause for the illness (i.e. cigarette smoking) to patients with smoking-related illnesses. Perhaps the patient may be sensing these negative and stigmatizing attitudes from their IC, explaining the IC's perception of the patient's lower empathic behaviour towards them. Conversely, within the colorectal cancer group, higher IC stigma was related to lower patient's perception of both self and IC empathic behaviour. Conceivably, IC embarrassment due to the messiness of the illness or responsibility for the cause of the illness may impact the patient's empathic behaviour towards the IC and the IC's empathic behaviour towards the patient.

Stigma and empathic behaviour may involve a complex (and as yet, undefined) interplay between patients' and ICs' affect and communication capabilities. Further research is needed to understand the association between these factors. However, these results are suggestive that stigma negatively impacts empathic behaviour between patients and ICs within both the smoking-related and colorectal cancer groups. There were no studies located that examined the impact of stigma on empathic behaviour with which to compare this study's results.

Limitations of the study

This study utilized a convenience sample to recruit participants that posed as a limitation to this study's generalizability of results (Polit & Beck, 2004). In addition, the Investigator recruited patients from three separate recruitment sites (two sites provided

access to patients who were in follow-up or rehabilitation phases of their disease, and the third site provided access to patients who were in early disease stages and receiving active treatment); thus, a sample bias might have been created whereby patients with colorectal cancer were newly diagnosed and patients with smoking-related illnesses were diagnosed for a longer period of time. The Investigator's accrual aim for this study was 35 patient / IC dyads per diagnostic group. However, due to time constraints, the Investigator accrued a sample size that was approximately half of the accrual aim of dyads per diagnostic group. This small study size further placed limits on the generalizability of study results. Cultural or ethnic factors could not be examined in relation to perceptions of stigma and empathic behaviours as this study's patient population was mainly European or Canadian in ethnic descent. As well, due to the lack of variability in patient and IC responses on the caregiving relationship (such as type of relationship, amount of contact, and degree of speaking openly about the illness experience), further analyses of relationship factors were not possible. Finally, although the reliability of the empathic behaviour scales was demonstrated for use with smoking-related illnesses and colorectal cancer groups, the stigma scales were shown to be reliable only with colorectal cancer patients and their ICs.

Clinical Implications

The results of this study suggest that younger patients and patients and ICs with no preference for religion may be at risk for higher perceived stigma when dealing with lung cancer, COPD, and/or colorectal cancer. It is also important for clinicians, like nurses, physicians, and social workers to be aware that patients diagnosed with non-smoking related diseases like colorectal cancer can experience similar perceptions of

stigma to patients diagnosed with smoking-related illnesses like lung cancer and COPD. Regardless of the type of disease, perceptions of stigma may exist in association with the patient having engaged in stigmatized behaviours like cigarette smoking or poor dietary habits that is perceived as having been controllable by the patient or the IC. In turn, perceptions of being stigmatized (i.e., feeling judged and a target for another person's anger) by the patient and/or the IC have the potential to interfere with optimal dyadic empathic behaviour. This finding may ultimately drive interventions to assist to modify empathic behaviour between patients and ICs to adequately identify and address each other's concerns when dealing with the disease or illness.

This research suggests that efforts must be made by those who engage in health promotion and disease prevention (in particular with mass media campaigns) to avoid stigmatization of patients while at the same time promoting healthy behaviours. For example, individuals who have engaged or continue to engage in cigarette smoking, or those with less than optimal dietary habits should be encouraged by clinicians with non-judgmental attitudes (or non-stigmatizing attitudes) to disclose unhealthy behaviours such as cigarette use so that clinicians can assist with symptom management issues, assistance with modification of unhealthy behaviours as desired, identification and assessment of the need for early illness screening, and education in early symptom recognition of smoking-related or other diseases so that early diagnosis is possible. The language of health promotion can be replaced with words that emphasize the need to reduce illness risk rather than prevent illness so that those who do become ill will not feel explicitly or implicitly blamed by others (health care professionals, family, support persons, and friends) for causing their illness. Clinicians who engage in health promotion

or risk reduction efforts should ensure that their communication styles utilize non-blaming and non-judgmental language when talking with individuals who have engaged in smoking or other behaviours such as unhealthy diet or lifestyle. Positive communication can be utilized to encourage a dialogue about early detection of screening for illnesses for both smoking-related and non-smoking related illnesses. For example, to counteract stigmatizing factors such as the innate "messiness" of screening, treatment and surgical outcomes identified by colorectal patients and ICs , the Manitoba Colorectal Cancer Screening Program could utilize humour in an effort to destigmatize the colorectal cancer screening process by advertisements that refer to fecal occult blood tests as "poop on a stick" or a "poopsicle".

Additionally, this study's results suggested that patients who have engaged in a stigmatized behaviour or have been diagnosed as having a stigmatized illness have a greater risk of suboptimal dyadic empathic behaviour within their caregiving relationship. Efforts should be made to assess the degree of support provided by the IC as well as the patient's other available social support systems. Finally, efforts should be made to develop interventions to alleviate or ameliorate any detrimental effects of stigma on IC / patient empathic behaviour, and intervention outcomes may be assessed for effectiveness. Such interventions might include dyadic counselling sessions where patients and ICs are taught how to role-play or perspective-take (i.e., take the partner's perspective) in order to encourage empathic understanding and validation of the partner's viewpoint on how stigma that is associated with the disease and/or illness effects his or her quality of life and coping experiences.

Future Research

There are a number of suggestions for future research as a result of the completion of this thesis study. For example, this study could be replicated with a larger study sample and with patients who have been diagnosed with other types of illnesses (e.g., diseases whereby the cause is perceived as being uncontrollable or controllable by the patient or the IC). Additionally, the use of a different stigma measure (e. g. LoConte, Else-Quest, Eickhoff, Hyde & Schiller, 2008) that has been shown to have excellent psychometric properties (Crobach's alpha 0.75) in lung cancer, prostate cancer and breast cancer patient populations can provide further insight into how stigma and demographic variables are associated with empathic behaviour. Research with larger samples is needed to clarify the interaction effects of demographic and relationship factors on empathic behaviour. As well, longitudinal or prospective studies are needed to examine whether stigma is amenable to response shift. 'At risk' patient/IC dyads (especially younger patients, patients or ICs with no preference for religion or patients with a perceived controllable cause of their illness such as cigarette smoking history) can be identified and interventions may be created and implemented to determine whether interventions to ameliorate stigma can be beneficial to improve empathic behaviour. The results of such future studies can assist health care professionals to promote adaptive coping responses by patients and ICs to combat any detrimental effects of stigma on empathic behaviour.

Dissemination of Results

The investigator will conduct an oral presentation of the results of this study at two of the recruitment sites in order to disseminate the study findings to healthcare

providers. A written summary of the results of the study will be provided to those patients and their ICs who indicated an interest in receiving the study results on their informed consent document. The investigator will also publish the study's results in a peer-reviewed nursing journal. Finally, an abstract of the study's results will be submitted for oral and/or poster presentation at a national or international nursing conference.

Summary

The purpose of this thesis study was to examine relationships among demographic variables, perceptions of stigma, and reports of empathic behaviour by patients and ICs with smoking-related illnesses as compared to a colorectal cancer group. Participants consisted of thirty-four patients (19 diagnosed with a smoking-related illness and 15 diagnosed with colorectal cancer) along with their ICs. Reliability estimates on the scales utilized revealed that the four empathic behaviour scales demonstrated good reliability with both diagnostic groups; however, the stigma scale used was reliable only with the colorectal cancer group and had poor reliability in the smoking-related illness group. With regard to stigma, younger patients and patients or ICs with no preference for religion reported more stigma. There were no reported differences in either patient or IC stigma between diagnostic groups. However, there was a trend for patients to report more stigma than ICs. If stigma was identified, the source of the stigma was most often revealed by patients and their ICs as the patient's responsibility for causing the illness due to smoking in the smoking-related illness group and diet and other lifestyle factors in the colorectal cancer group or embarrassment regarding the "messiness" of the illness. Regarding empathic behaviour, it was found that empathic behaviour was positively related to patient and IC education, patient income, and negatively associated with both

patient and IC smoking histories. In addition, patients diagnosed with smoking-related illnesses viewed their ICs as being less empathic than patients in the colorectal cancer group. The two diagnostic groups differed in the correlations between stigma and empathic behaviour as reported by patients and their ICs. For instance, in the smoking-related group, patient stigma was negatively correlated with the IC's perception of the patient's empathic behaviour. Conversely, in the colorectal cancer group, IC stigma was negatively correlated with both the patient's self perception of empathic behaviour and the patient's perception of the IC's empathic behaviour. The study findings suggested that perceptions of stigma may be affected by the phenomenon of response shift which warrants further investigation. Longitudinal studies that find an association between stigma and response shift would indicate a need for clinicians to provide patients and ICs with resources to enhance their relational coping responses to help them adapt to or deal with sources of stigma in relation to their respective illness experiences. At risk patient / IC dyads, such as younger patients or patients and ICs with smoking histories or no preference for religion may be identified and interventions may be implemented to modify or adapt to the perception of stigma or enhance empathic behaviour in order to advance patient / IC communication and ultimately improve patient coping outcomes.

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Appendix A
Invitation to Patients and Informal Caregivers
(University of Manitoba letterhead)

My name is Freya Hansen, RN, BN and I am a Master of Nursing Student at the University of Manitoba conducting my Master's thesis project about patients' illness experiences, and the ways family members or other caregivers view the patient's illness and how these views may impact the caregiving relationship. In particular, this study involves looking at stigma surrounding various illnesses and how patient and caregiver perspective-taking are related to smoking and non-smoking related illnesses. This study involves the participation of both the patient and an informal caregiver (who may or may not be a family member) on a one-time basis. The main purpose of this study is to understand patients and caregivers combined experiences in order to help health care professionals improve supports for patients and caregivers. The study is expected to take approximately 30 minutes to complete and will be conducted at a time and location convenient to you, either in the clinic setting (if space is available) or in your home. This study has received ethical approval from the Education Nursing Research Ethics Board at the University of Manitoba.

I would like to talk to you about the study to see if you might be interested in participating in it. Please indicate whether or not you would be willing to find out more about participating in this study on the 2nd page of this invitation, place it in the attached envelop, seal it, and return it to your clinic nurse or clinic clerk. If I am available in the clinic, you can speak to me today, or leave your name and telephone number with the clinic nurse or desk clerk so that I can call you about the study. The information that you leave on the 2nd page of this invitation should be strictly voluntary and you are not obliged to provide this information.

If you agree to talk to me today, or decide to leave your name and contact information on this letter of invitation it does not mean that you agree to participate in this study. Only when you have read, understood, and signed the letter of consent will I enrol you as an individual who has agreed to participate in this study.
Should you decide to participate, all the information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by your decision to take part in the study or not take part in the study.

Thank you for considering this request. If you have any questions about the research study I may be reached at (204)284-8298.

Invitation to Patients and Informal Caregivers

(A study by Freya Hansen, Faculty of Nursing, University of Manitoba, Winnipeg, Manitoba, Canada)

This information is to be provided by you strictly on a voluntary basis

_____ Yes, I agree to speak with Ms. Hansen about participating in the study

NAME _____

TELEPHONE NUMBER_____

_____ No, I do not agree to speak with Ms. Hansen about participating in the study

My reason (optional)

_____

_____

WHEN COMPLETED, PLEASE PLACE THIS FORM IN THE ATTACHED ENVELOPE, SEAL IT AND RETURN IT TO YOUR CLINIC NURSE OR DESK CLERK

Appendix B
Patient Consent Form

(University of Manitoba Letterhead)

Thesis Project Title: An exploratory study of patient and informal caregiver stigma and perspective-taking in smoking and non-smoking related diseases

Researcher: Freya Hansen, Graduate Student, University of Manitoba, Faculty of Nursing

Thesis Advisory Committee: Dr. Michelle Lobchuk (chair), University of Manitoba, Faculty of Nursing; Dr. Diana Clarke, University of Manitoba, Faculty of Nursing; Dr. Janice Richman-Eisenstat, University of Manitoba, Faculty of Medicine

Sponsor: This study is supported by a student stipend provided to Ms. Freya Hansen with funds awarded to Dr. Michelle Lobchuk by the National Cancer Institute of Canada
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.

What is the nature and purpose of the study?
You are invited to take part in a study about patients' and caregivers' illness experiences, and the ways family members or other caregivers view the patient's illness and how these views may impact the caregiving relationship. In particular, this study involves looking at stigma surrounding various illnesses and how patient and caregiver perspective-taking are related to smoking and non-smoking related illnesses. Ms. Hansen is interested in understanding the patient's and caregiver's combined experience with illness to help health care professionals improve supports for patients and caregivers.

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 agree to answer the questions that Ms. Hansen will ask you, and fill out the questionnaires that she will give you in the home or clinic setting on a one-time basis.
Ms. Hansen will first ask you eleven short questions that relate to your thinking, memory, and concentration abilities. 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?" Ms. Hansen will also ask you to complete four questionnaires in a room where your verbal responses to questions cannot be heard by your caregiver.

Patient initials _____ **Date** _____

She will ask you questions as to your age, marital status, occupation, caregiving relationship, and cigarette smoking history such as "Which of the following statements best describes your cigarette smoking status?"

You will also complete a questionnaire about how you feel about other's perceptions of your illness. A third questionnaire is about how your caregiver behaves and acts towards you to help him or her understand how you are feeling, and a final questionnaire will ask you how you behave and act towards your caregiver to help him or her to understand how you are feeling. It is expected that answering Ms. Hansen's questions and filling in the four questionnaires will take about 30 minutes of your time. If you require assistance in reading or filling out any of the forms, Ms. Hansen will be pleased to assist you.

If you consent to take part in this study, you are also giving Freya Hansen permission to access your chart at CancerCare Manitoba, Riverview Health Centre, or the Respiratory Hospital of the Health Sciences Centre (whichever clinic the researcher contacted you at) for medical information. The medical information that will be sought includes: the type of illness that you have; the stage of your disease; the actual date of your diagnosis, the type of treatment you may be receiving, and the types of treatment you may have received in the past. Ms. Hansen will access this information under the direction of the nurse who runs the clinic that you usually attend who will be provided with a copy of your signed consent form. 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 Freya Hansen 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 not to access your chart will be respected.

Once Ms. Hansen has finished collecting information from you, she will conduct a similar process with your caregiver. When both you and your caregiver have completed the questionnaires, Ms. Hansen 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.

How will the information be handled during and after the study?

Any information that you provide to Ms. Hansen will be kept confidential. The only exception would be if Ms. Hansen 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. Your physician(s) or nurse(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, Freya Hansen. Only Freya Hansen, will know the names of those who have agreed to take part in the study.

Patient initials _____ **Date** _____

Freya Hansen, Dr. Michelle Lobchuk, and the data analyst will have access to the questionnaires that you and the caregiver completed, however, only a code number (and not your name) will be on the questionnaires. During and after the study, all consents and questionnaires will be securely locked up in Freya Hansen's home office. Study data will be kept for seven to ten years, destroyed, and treated as confidential waste.
The results from this study may be published, and/or 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. Any publications or presentations that are produced as a result from this study will not provide the specific names of the clinic that you were recruited from but instead will report that patients and caregivers were invited to participate from three clinic sites in the City of Winnipeg, Manitoba.

What are the 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, Freya Hansen will provide you with information on resources at Cancer Care Manitoba, Health Sciences Centre, or Riverview Health Centre, such as the Psychosocial Oncology Department or Department of Social Work that you can contact to help you deal with issues or answer questions that may arise as a result of participating in this study.

What if I want to withdraw from participating from the study?
You are free to withdraw your participation at any time during the course of the study without consequences. If you decide to withdraw from participating, the responses to questionnaires that you have provided will be destroyed and your information will not be used for the study results. If either the patient or the caregiver decides to withdraw from participating in the study, the questionnaires from both will not be used and will be shredded.

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.

Patient initials _____ **Date** _____

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 Freya Hansen's thesis advisor, Dr. Michelle Lobchuk who can be reached by telephone at 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, Health Sciences Centre, and Riverview Health Centre. If you have any concerns or complaints about this project, you may contact the Human Ethics Secretariat at (204) 474-7122 or email margaret_bowman@umanitoba.ca. 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.

☐ permission for Freya Hansen, Master of Nursing Student to access my medical record at CancerCare Manitoba, Respiratory Hospital at the Health Sciences Centre or Riverview Health Centre to collect information for the study as outlined in this consent.

[CancerCare Manitoba, Respiratory Hospital at the Health Sciences Centre or Riverview Health Centre accessed by Freya Hansen, Master of Nursing student to collect information for the study as outlined in this consent.

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 C
Caregiver Consent Form
(University of Manitoba Letterhead)

Thesis Project Title: An exploratory study of patient and informal caregiver stigma and perspective-taking in smoking and non-smoking related diseases

Researcher: Freya Hansen, Graduate Student, University of Manitoba, Faculty of Nursing

Thesis Advisory Committee: Dr. Michelle Lobchuk (chair), University of Manitoba, Faculty of Nursing; Dr. Diana Clarke, University of Manitoba, Faculty of Nursing; Dr. Janice Richman-Eisenstat, University of Manitoba, Faculty of Medicine

Sponsor: This study is supported by a student stipend provided to Ms. Freya Hansen with funds awarded to Dr. Michelle Lobchuk by the National Cancer Institute of Canada 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.

What is the nature and purpose of the study?
You are invited to take part in a study about patients' and caregivers' illness experiences, and the ways family members or other caregivers view the patient's illness and how these views may impact the caregiving relationship. In particular, this study involves looking at stigma surrounding various illnesses and how patient and caregiver perspective-taking are related to smoking and non-smoking related illnesses. Ms. Hansen is interested in understanding the patient's and caregiver's combined experience with illness to help health care professionals improve supports for patients and caregivers.

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 agree to answer the questions that Ms. Hansen will ask you, and fill out the questionnaires that she will give you in the home or clinic setting on a one-time basis.
Ms. Hansen will first ask you eleven short questions that relate to your thinking, memory, and concentration abilities. 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?" Ms. Hansen will also ask you to complete four questionnaires in a room where your verbal responses to questions cannot be heard by the patient. She will ask you questions as to your age, marital status, occupation, caregiving relationship, and cigarette smoking history such as "Which of the following statements best describes your cigarette smoking status?"

Caregiver initials _____ **Date** _____

You will also complete a questionnaire about how you feel about other's perceptions of the patient's illness. A third questionnaire is about how the patient behaves and acts towards you to help him or her understand how you are feeling, and a final questionnaire will ask you how you behave and act towards the patient to help him or her to understand how you are feeling. It is expected that answering Ms. Hansen's questions and filling in the four questionnaires will take about 30 minutes of your time. If you require assistance in reading or filling out any of the forms, Ms. Hansen will be pleased to assist you.

Once Ms. Hansen has finished collecting information from the patient, she will assist you with your questionnaires. When both you and the patient have completed the questionnaires, Ms. Hansen will be willing to spend additional time with you and the patient to answer any questions that you and the patient might have about your responses to your questionnaires.

How will the information be handled during and after the study?

Any information that you provide to Ms. Hansen will be kept confidential. The only exception would be if Ms. Hansen discovered abuse in the course of the study, in which case she is legally bound to report 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) or nurse(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, Freya Hansen. Only Freya Hansen, will know the names of those who have agreed to take part in the study. During and after the study, all consents and questionnaires will be securely locked up in Freya Hansen's home office. Freya Hansen, Dr. Michelle Lobchuk, and the data analyst will have access to the questionnaires that you and the patient completed, however, only a code number (and not your name) will be on the questionnaires. Study data will be kept for seven to ten years, destroyed, and treated as confidential waste. The results from this study may be published, and /or 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. Any publications or presentations that are produced as a result from this study will not provide the specific names of the clinic that you were recruited from but instead will report that patients and caregivers were invited to participate from three clinic sites in the City of Winnipeg, Manitoba.

What are the 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.

Caregiver initials _____ **Date** _____

There are no known risks involved with participating in the study. However, Freya Hansen will provide you with information on resources at Cancer Care Manitoba, Health Sciences Centre, or Riverview Health Centre, such as the Psychosocial Oncology Department or Department of Social Work that you can contact to help you deal with issues or answer questions that may arise as a result of participating in this study.

What if I want to withdraw from participating from the study?

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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 Freya Hansen's thesis advisor, Dr. Michelle Lobchuk who can be reached by telephone at 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, Health Sciences Centre, and Riverview Health Centre. If you have any concerns or complaints about this project, you may contact the Human Ethics Secretariat at (204) 474-7122 or email margaret_bowman@umanitoba.ca. 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 _____

Appendix D

MINI-MENTAL STATUS EXAMINATION

PATIENTS AND INFORMAL CAREGIVERS

Maximum score	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 person to say 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.
		Trials _____
		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)

_____

TOTAL SCORE

ASSESS level of consciousness along a continuum.

_____

Alert Drowsy Stupor Coma

Appendix E
Patient – Demographic Survey

Dyad # _____

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 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:
2.	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) _____
3.	How far did you go in school?	1. Less than High school 2. High School Graduate 3. Partial College or University (at least one year) 4. College or University Graduate 5. Graduate/Professional Training
4.	What is your marital status?	1. Married 2. Common-law 3. Never Married 4. Widowed 5. Separated 6. Divorced
5.	What is your age?	
6.	What is your gender?	1. Female 2. Male

7.	What is your occupational status?	1. Full-time 2. Part-time 3. Medical leave 4. Unemployed 5. Retired
8.	What is your current (or previous) employment?	1. Clerical 2. Labourer 3. Homemaker 4. Professional 5. Management 6. Skilled trades 7. Other (Specify) _____
9	What is your annual gross household income?	1. Below $20,000 2. $20,000 - $39,999 3. $40,000 - $59,999 4. $60,000 - $79,999 5. $80,000 - $99,999 6. Over $100,000
10.	What type of primary illness do you have?	1. Lung cancer 2. COPD 3. Colorectal cancer 4.
11.	What stage is your disease?	_____ _____
12.	What is the actual date of your diagnosis?	
13.	What type of treatments have you had for your illness?	1. Chemotherapy 2. Surgery 3. Radiation 4. Medication 5. Other (please specify) _____
14.	If you had surgery for your primary illness, what was the date of your surgery?	
15.	Are you currently receiving treatment for your illness?	1. Yes 2. No
16.	If yes, what type of treatment are you receiving?	_____ _____
17.	Are you currently receiving medication related to your illness?	1. Yes 2. No

18.	If yes, what type of medication are you receiving?	_____ _____
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 the patient-caregiver relationship

21.	How are you related to the caregiver?	1. Wife 2. Husband 3. Partner 4. Parent 5. Daughter 6. Son 7. Sister 8. Brother 9. Friend 10. Other (specify) _____
22.	How long has your caregiver been caring for you? (Months)	1. 0 to 9 2. 10 to 18 3. 19 to 36 4. more than 36
23.	How well do you think your caregiver knows how you think and feel about illness experience?	1. Not at all well 2. A little 3. Somewhat 4. Quite a bit 5. Very well
24.	How much contact do you have with your caregiver?	1. Daily, I live with my support person 2. Daily, but I do not live with my support person. 3. More than weekly 4. Weekly 5. Less than weekly
25.	What is the extent to which your caregiver assists you in coping with your medical condition and illness experiences?	1. Rarely 2. Seldom 3. Frequently 4. Most of the time 5. Always

26.	Do you and your caregiver talk openly about your thoughts and feelings are in regard to your illness experiences?	1.Rarely 2.Seldom 3.Frequently 4.Most of the time 5.Always

Question about smoking history

1.	Which statement best describes your smoking status?	1. I never smoked. 2. I smoke about the same now as I did before finding out my diagnosis. 3. I have cut down since finding out my diagnosis. 4. I have quit smoking since the time of my diagnosis. 5. I am a former smoker and wasn't smoking around the time of my diagnosis

Appendix F
Caregiver – Demographic Survey

Dyad # _____

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 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:
2.	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) _____
3.	How far did you go in school?	1. Less than High school 2. High School Graduate 3. Partial College or University (at least one year) 4. College or University Graduate 5. Graduate/Professional Training
4.	What is your marital status? (Have you ever been married?)	1. Married 2. Common-law 3. Never Married 4. Widowed 5. Separated 6. Divorced

5.	What is your age?	_____
6.	What is your gender?	1. Female 2. Male 3.

7.	What is your occupational status?	1. Full-time 2. Part-time 3. Medical leave 4. Unemployed 5. Retired
8.	What is your current (or previous) employment?	1. Clerical 2. Labourer 3. Homemaker 4. Professional 5. Management 6. Skilled trades 7. Other (Specify) _____

Questions about the patient and caregiver relationship

9.	How long have you been providing support to or caring for the patient? (Months)	1. 0 to 9 2. 10 to 18 3. 19 to 36 4. More than 36
10.	What is your relationship to the patient?	1. Wife 2. Husband 3. Partner 4. Parent 5. Daughter 6. Son 7. Sister 8. Brother 9. Friend 10. Other (specify)_____

11.	How well do you think you know how the patient thinks and feels about his or her illness experience?	1. Not at all well 2. A little 3. Somewhat 4. Quite a bit 5. Very well
12.	How much contact do you have with the patient?	1. Daily, I live with the patient 2. Daily, but I do not live with the patient 3. More than weekly 4. Weekly 5. Less than weekly

Question about smoking history

1.	Which statement best describes your smoking status?	1. I never smoked. 2. I smoke about the same now as I did before finding out the patient's diagnosis. 3. I have cut down since finding out the patient's diagnosis. 4. I have quit smoking since the time of the patient's diagnosis. 5. I am a former smoker and wasn't smoking around the time of the patient's diagnosis

Appendix G
Perspective-taking Scale
(Patient Perception of Caregiver Empathic Behaviour)

Dyad #_____

How well do the following statements describe your caregiver's behaviour and actions with you on a scale of 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 caregiver very well				Does describe my caregiver very well

1. My caregiver tries to understand my concerns.	0	1	2	3	4
2. My caregiver tries to understand how I felt.	0	1	2	3	4
3. My caregiver tries to experience what I was feeling.	0	1	2	3	4
4. My caregiver tries to imagine him/herself in my shoes.	0	1	2	3	4
5. My caregiver tries to see things from my point of view.	0	1	2	3	4
6. My caregiver tries to accept me as I am now.	0	1	2	3	4
7. My caregiver tries to help me by listening to me.	0	1	2	3	4
8. My caregiver tries to help me by doing something for me.	0	1	2	3	4
9. My caregiver tries to figure out what would make me feel better.	0	1	2	3	4
10. My caregiver tries to comfort me by telling me about their positive feelings for me.	0	1	2	3	4

Appendix H
Perspective-taking Scale
(Patient Perception of Self Empathic Behaviour)

Dyad #_____

How well do the following statements describe your own behaviour and actions towards your caregiver on a scale of 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 your caregiver.

0 Does not describe me very well	1	2	3	4 Does describe me very well
1. I try to understand my caregiver's concerns.	0	1	2	3	4
2. I try to understand how my caregiver felt.	0	1	2	3	4
3. I try to experience what my caregiver was feeling.	0	1	2	3	4
4. I try to imagine myself in my caregiver's shoes.	0	1	2	3	4
5. I try to see things from the the caregiver's point of view.	0	1	2	3	4
6. I try to accept my caregiver as he or she is now.	0	1	2	3	4
7. I try to help my caregiver by listening to him or her.	0	1	2	3	4
8. I try to help my caregiver by doing something for him or her.	0	1	2	3	4
9. I try to figure out what would make my caregiver feel better.	0	1	2	3	4
10. I try to comfort my caregiver by telling him or her about my positive feelings for them.	0	1	2	3	4

Appendix I
Perspective-taking Scale
(Caregiver Perception of Patient Empathic Behaviour)

Dyad #_____

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

0	1	2	3	4
Does not describe patient very well				Does describe patient very well

1. The patient tries to understand my concerns.	0	1	2	3	4
2. The patient tries to understand how I felt.	0	1	2	3	4
3. The patient tries to experience what I was feeling.	0	1	2	3	4
4. The patient tries to imagine him/herself in my shoes.	0	1	2	3	4
5. The patient tries to see things from my point of view.	0	1	2	3	4
6. The patient tries to accept me as I am now.	0	1	2	3	4
7. The patient tries to help me by listening to me.	0	1	2	3	4
8. The patient tries to help me by doing something for me.	0	1	2	3	4
9. The patient tries to figure out what would make me feel better.	0	1	2	3	4
10. The patient tries to comfort me by telling me about their positive feelings for me.	0	1	2	3	4

Appendix J
Perspective-taking Scale
(Caregiver Perception of Self Empathic Behaviour)

Dyad #_____

How well do the following statements describe your own behaviour and actions towards the patient on a scale of 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 Does not describe me very well	1	2	3	4 Does describe me very well
1. I try to understand the patient's concerns.	0	1	2	3	4
2. I try to understand how the patient felt.	0	1	2	3	4
3. I try to experience what the patient was feeling.	0	1	2	3	4
4. I try to imagine myself in the patient's shoes.	0	1	2	3	4
5. I try to see things from the the patient's point of view.	0	1	2	3	4
6. I try to accept the patient as he or she is now.	0	1	2	3	4
7. I try to help the patient by listening to him or her.	0	1	2	3	4
8. I try to help the patient by doing something for him or her.	0	1	2	3	4
9. I try to figure out what would make the patient feel better.	0	1	2	3	4
10. I try to comfort the patient by telling him or her about my positive feelings for them.	0	1	2	3	4

Appendix K
Stigma scale – Patient Version

Dyad #_____

There are some ways that people may feel about an illness. When you think about having your illness, and how it impacts you, please tell me how you feel. How much do you:

	Not at all	Just a little	Somewhat	Very much
A. Feel blamed by others	1	2	3	4
B. Feel that you need to hide it	1	2	3	4
C. Feel ashamed	1	2	3	4
D. Think the disease is punishment for something	1	2	3	4
E. Think other people are uncomfortable around you.	1	2	3	4
F. Feel people avoid you.	1	2	3	4
G. Fear you will lose your friends	1	2	3	4
H. Fear that your family will reject you	1	2	3	4
I. Feel that people do not want you around their children	1	2	3	4

If you experience stigma associated with your disease, can you identify the source of the stigma?

Appendix L
Stigma scale – Caregiver Version

Dyad #_____

There are some ways that people may feel about an illness. Thinking about the patient's illness and how it impacts you, please tell me how you feel. How much do you:

	Not at all	Just a little	Somewhat	Very much
A. Feel blamed by others	1	2	3	4
B. Feel that you need to hide it	1	2	3	4
C. Feel ashamed	1	2	3	4
D. Think the disease is punishment for something	1	2	3	4
E. Think other people are uncomfortable around you.	1	2	3	4
F. Feel people avoid you.	1	2	3	4
G. Fear you will lose your friends	1	2	3	4
H. Fear that your family will reject you	1	2	3	4
I. Feel that people do not want you around their children	1	2	3	4

If you experience stigma associated with the patient's disease, can you identify the source of the stigma?