

**PERCEPTIONS OF SYMPTOM DISTRESS IN LUNG CANCER
PATIENTS: CONGRUENCE AMONG PATIENTS, PRIMARY
FAMILY CAREGIVERS, AND NURSES**

SUBMITTED BY: MICHELLE MARIE LOBCHUK

September 1995

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**A thesis presented to the University of Manitoba
in partial fulfilment of the requirements for
the degree of Master of Nursing**

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PERCEPTIONS OF SYMPTOM DISTRESS IN LUNG CANCER PATIENTS:
CONGRUENCE AMONG PATIENTS, PRIMARY FAMILY CAREGIVERS, AND NURSES

BY

MICHELLE MARIE LOBCHUK

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

MASTER OF NURSING

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DEDICATION

TO MY HUSBAND TONY

FOR HIS ENCOURAGEMENT AND SUPPORT.

ABSTRACT

The purpose of this research was to describe how primary family caregivers' and nurses' interpretations of symptom distress compare with lung cancer patients' own perceptions of symptom distress. The other aim was to describe the cues that primary family caregivers and nurses respond to when assessing symptom distress in the lung cancer patient in the home setting. Due to the limited number of patients who received nursing services in their homes, a small number of nurses ($n = 7$) actually participated in this study. Therefore, analyses and interpretation of data collected from 41 patients and 37 primary family caregivers were the focus of this study.

Using a comparative descriptive design, a convenience sample of 37 patient-primary family caregiver dyads completed McCorkle and Young's (1978) Symptom Distress Scale (SDS). An open-ended data questionnaire was completed by family caregivers where they described cues that lead them to believe patients were experiencing distress from symptoms.

Findings from non-parametric analyses provide tentative support for the concept that family caregivers attribute a greater level of distress from symptoms than patients themselves, that may be related to their stereotypical view of an individual who is seriously ill and expected to suffer. Although the difference in global SDS scores was statistically significant, whether it reaches clinical significance is debatable.

Statistically significant differences in the assessment of distress from the symptoms, appearance, insomnia, and outlook were revealed and appear to be related to caregiver reliance on misleading behavioural cues. Several findings on the behavioural assessment of symptom distress contribute important preliminary data in an area of research that to date has been unexplored. First, family caregivers' limited multidimensional approach in the behavioural assessment of distress from individual symptoms indicates there is a need for family caregiver education and skill development in assessing patients' symptom status. Second, non-significant trends indicate that different cue categories have varied effects in relation to influencing caregivers' ability to accurately assess distress from symptoms.

Recommendations for nursing practice, education, and research are made based upon the study results.

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CHAPTER ONE

STATEMENT OF THE PROBLEM

Recent Canadian Cancer Statistics reports that lung cancer will account for 27% of all cancer deaths in 1995 (National Cancer Institute of Canada, 1995). The overall five-year survival rate for males with lung cancer is 15% and for females with lung cancer is 20%. Even with treatment (chemotherapy, radiotherapy, and surgery), the overall long-term survival rates remain dismal (Fergusson & Cull, 1991). Fifty percent of all patients present at diagnosis with metastases and 90% of all lung cancer patients will inevitably develop metastatic disease (Langston, 1992). Nearly all patients are treated with palliative intent. However, palliative therapy such as chemotherapy and radiotherapy may both be toxic and inconvenient. Therefore, the focus of treatment is now shifting to quality of life rather than merely duration of survival (Gough, Furnival, Schilder, & Grove, 1983).

Lung cancer is associated with a wide range of physical symptoms that affect the patient's everyday life. These symptoms are due to side-effects of chemotherapy, radiotherapy, and the natural progression of lung cancer. Several researchers have identified patients with lung cancer as experiencing the most symptom distress and dying significantly sooner than patients with other cancers (Degner & Sloan, in press; Kukull, McCorkle, & Driever, 1989; Oleske, Heinze, & Otte, 1990). Since the 1980s, assessment of general disease and treatment-related symptoms have

become integrated within clinical treatment trials (Bernhard, Phil, & Ganz, 1991). Disease and treatment-related symptoms have become recognized as one domain of the multidimensional construct of 'quality of life' (Moinpour, Feigl, Metch, Hayden, Meyskens, & Crowley, 1989).

In light of current trends in health care, patients with cancer are encouraged to look at alternatives to lengthy hospitalization for management of their disease. Increasing numbers of lung cancer patients who are receiving complex chemotherapy and radiotherapy interventions are being treated on an outpatient basis (McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour, & Goodell, 1989). Families are encouraged to become the major provider of care outside of institutions during treatment as well as during advanced stages of illness (Stetz, 1987). Successful symptom management of symptoms in the community often depends on the level of motivation of the primary caretaker and family (Billings, 1985).

A number of studies have documented the prevalence and severity of patient and family problems when coping with symptom management in the community (Stetz, 1987; Wright & Dyck, 1984). Symptom management and patient comfort have been identified by family members as their primary concerns in caring for the ill patient in the home (Kristjanson, 1986, 1989; Skorupka & Bohnet, 1982).

Purpose of the Study

Symptom distress is the degree of physical or mental upset, anguish,

or suffering experienced from a specific symptom (e.g., nausea, fatigue, and insomnia) (Rhodes & Watson, 1987). Nurses have traditionally concerned themselves with effective management of symptoms and symptom distress to maximize quality of life (Germino, 1987). In view of increasing numbers of patients being cared for by family members in the community, nurses are being challenged to provide interventions that not only bring comfort to patients, but also support family members who are endeavouring to alleviate the patient's distress or suffering.

Symptoms are subjective phenomena and are not directly observable by another person (Giardino & Wolf, 1993; Rhodes & Watson, 1987). Studies have identified that nursing and patient assessments of symptom distress report incongruent or divergent results (Davis, 1991; Holmes & Eburn, 1989; Larson, Viele, Coleman, Dibble, & Cebulski, 1993; Peruselli, Camporesi, Colombo, Cucci, Sironi, Bellodi, Cirillo, Love, & Mariano, 1992), indicating that symptoms and symptom distress may be perceived differently by different individuals. Discrepancies between patients' and nurses' perceptions can potentially prevent patients' symptoms from being managed effectively, depending on whose assessment is used as the basis of intervention (Larson et al., 1993).

Literature on assessment of symptom distress has focused primarily on patients' and nurses' perceptions. There is currently a dearth of knowledge regarding congruence of perceptions of symptom distress among patients, primary family caregivers, and nurses. This triad may

encounter decisional and ethical conflicts that may impact the process and outcomes of symptom management. Therefore, it is important to address specific problems and conflicts that may arise in the assessment of symptom distress. Studies conducted on symptom management indicate that a shared knowledge of mutual goals and the meaning of comfort among patients, family members, and nurses can lead to successful management of patient care in home settings. However, without sound empirical evidence related to how patients and others assess symptom distress, health care professionals may lack the knowledge to assist patients and families to make informed decisions about symptom management. As well, inpatient care for symptom management is costly and often lengthy, reinforcing the need for knowledge about how to improve care to assist patients and family members to cope with symptom management at home.

Given the paucity of research related to assessment of symptom distress in lung cancer patients by nurses and primary family caregivers, a descriptive comparative study is judged to be the most appropriate level of investigation to pursue. The aim of this research is to describe how primary family caregivers' and nurses' interpretations of symptom distress compare with lung cancer patients' own perceptions of symptom distress. This study will also describe the cues that primary family caregivers and nurses respond to when assessing symptom distress in the lung cancer patient in the home setting.

Research hypotheses:

The following research hypotheses will be asked in this comparative descriptive study:

1. There are no differences in perceptions of symptom distress among patients, primary family caregivers, and nurses.
2. There are no differences in cues identified by nurses and primary family caregivers when assessing symptom distress.

Summary

Empirically-based studies to understand congruence of perceptions on symptom distress in lung cancer patients among patients, nurses, and primary family caregivers are needed. Health care professionals caring for these patients in the community are challenged to help patients and family members cope with disease effects, treatment side-effects, and symptom progression. Until health care professionals have a clear understanding of how patients, primary family caregivers, and nurses assess symptom distress, approaches to care will be based on trial-and-error efforts. If incongruence is evident, then interventions to identify ways of reconciling divergent assessments can be designed and tested.

CHAPTER TWO

LITERATURE REVIEW

The literature reviewed for this study was grouped into four different areas: lung cancer, symptom distress, measurement issues, and family and symptom management. Each area will be examined separately.

Lung cancer

This section will present literature that was reviewed related to lung cancer: psychosocial issues, types and treatment, disease and treatment-related symptoms, and quality of life issues.

Psychosocial issues

Stanley and Stjernsward (1986) report that lung cancer and acquired immunodeficiency syndrome (AIDS) will likely be the most common chronic, life-threatening diseases in the early part of the coming century. Although there is a high incidence of lung cancer in industrialized countries, there is no systematic database related to psychosocial issues for the disease (Bernhard, Phil, & Ganz, 1989). There are several reasons for this paucity of psychosocial research in lung cancer. First, the high incidence of metastatic disease at time of diagnosis and limited survival time diminish the opportunity for psychosocial research. Second, the poor performance status and rapid disease progression in lung cancer patients inhibit studies that require patient attentiveness and

cognitive effort. Third, until recently lung cancer has affected primarily males who may be more reluctant to participate in research in which their emotions are discussed (Bernhard et al., 1989).

Despite the challenges that may occur when investigating this group of patients, research about the physical and psychological aspects of care of the lung cancer patient is needed. Specifically, research is required to facilitate the development of supportive interventions for the lung cancer patient and the family as they cope with cancer, its treatments, and its impact on everyday life.

Types and treatment

Lung cancer is not one disease with uniform treatment strategies. The general classification scheme, based on differences in presentation, natural history, and treatment response, describes lung tumors as either small cell lung cancer (SCLC) or non-small cell lung cancer (NSCLC) (Elpern, 1991).

Twenty to 30% of all lung cancers are SCLC (Elpern, 1991; Mackay, Lukeman, & Ordonez, 1991). NSCLC accounts for approximately 70% of all lung carcinomas, which includes squamous cell carcinomas, adenocarcinomas, and large cell carcinomas (Elpern, 1991; Linnoila, 1990). The five-year survival rate for SCLC is nil and NSCLC is between 10 and 60%, depending on the disease stage. Approximately 60% of the patients with NSCLC and 40% of the patients with SCLC present

with advanced disease or metastases at time of diagnosis (Langston, 1992; Harwood, 1987). Women have a better five-year survival rate than men for unknown reasons (Minna, Pass, Glatstein, & Ihde, 1990). The age patterns of new cases indicate that lung cancers occur primarily among Canadians who are 60 years of age and older (National Cancer Institute of Canada, 1995).

The strategy for treatment of lung cancer is based on consideration of several important prognostic factors that include histology, tumor extent, and the patient's physical condition (Elpern, 1990). The goal of surgical resection is to cure the patient by removing all of the tissue and involved lymph nodes. Even with early diagnosis, 50% of all lung cancer patients are inoperable (Langston, 1992). Another 25% of the patients will have lesions that cannot be completely removed. For the remaining 20 to 25% who undergo surgery, the five-year survival rate is approximately 25 to 35% (Sabiston, 1992). Generally, there is a limited role for surgery in SCLC due to its metastatic presence at time of diagnosis and its otherwise favourable response to chemotherapy and radiotherapy (Langston, 1992). For localized NSCLC (stages I and II), surgery is the treatment of choice because these lesions can usually be excised completely (Elpern, 1991).

Combination chemotherapy has become the treatment of choice for SCLC due to its high growth fraction, rapid dissemination, and sensitivity to chemotherapy (Glover & Miaskowski, 1994; Pate, 1992). Less than 10% of treated patients with SCLC will experience a two-year tumor-free

survival with systemic chemotherapy (Osterlind, 1985). The role of systemic chemotherapy for NSCLC remains unclear, with much controversy about the use of chemotherapy in treatment of advanced NSCLC. Response and survival rates remain unclear (Elpern, 1990; Pate, 1992). Chemotherapy has been used as a treatment for tumor shrinkage prior to surgery and as an adjuvant to surgery for treatment of early-stage NSCLC, but results are inconclusive (Pate, 1992).

Generally, the use of radiotherapy to improve prognosis for lung cancer patients is limited. Radiotherapy for inoperable NSCLC may be used in lieu of surgery when surgery is ruled out because the tumor is nonresectable or because of patient condition (Stewart, 1992). Most NSCLC demonstrates poor radiosensitivity and high doses of radiation are needed for cure (Elpern, 1990). Radiation therapy is commonly used for palliation or relief of symptoms such as pain, cough, hemoptysis, hoarseness, and shortness of breath (Haylock, 1987). SCLC is a highly responsive carcinoma to both chemotherapy and radiotherapy (Elpern, 1990; Fayers, Bleehen, Girling, & Stephen, 1991; Glover & Miaskowski, 1994).

For the majority of patients in advanced stages of lung cancer, palliative therapy has limited beneficial effect on the tumor or the patient's survival. Different treatment modalities may be both toxic and inconvenient in relation to a variety of symptoms and side-effects associated with them. Therefore, research is required to facilitate the

development of supportive interventions for the lung cancer patient and the family as they cope with cancer, its treatments, and its impact on quality of life.

Symptoms: disease and treatment-related

Most patients with lung cancer have symptomatic disease at time of clinical presentation. Twenty-five percent of the symptoms at presentation are related to the primary tumor. One-third of the patients have symptoms attributable to metastatic disease. An additional one-third of the patients have symptoms related to hormonal or paraneoplastic syndromes suggestive of cancer (Seale & Beaver, 1990).

Symptoms and symptom duration vary according to histologic type of lung carcinoma, the presence of metastases, systemic effects of hormonal syndromes produced by the cancer itself, and the location and extent of the tumor (Elpern, 1990; Epps, 1990; Seale & Beaver, 1990). Most people do not seek medical attention until after the onset of symptoms (Epps, 1990).

Anorexia, weight loss, and fatigue are suggestive symptoms of lung cancer. Other symptoms that are frequent at clinical presentation include cough (75%), chest pain (50%), hemoptysis (50 to 70%), dyspnea (65%), and wheezing. Symptoms of local metastases include hoarseness, chest or shoulder pain, dysphagia, or head and neck swelling (Elpern, 1990).

Oleske, Heinz, and Otte (1990) conducted a study with 68 cancer

patients, who were receiving nursing home care, to gain insight into the quality of life from the patient perspective. Patients were given diaries to record daily the occurrence of health problems for one month. The researchers found that those with lung cancer reported the highest average number of health problems per person and the greatest diversity of health problems. Common problems for lung cancer patients included dyspnea, digestive symptoms, and musculoskeletal symptoms.

McCorkle and Benoliel (1983) compared the levels of patient-reported symptom distress in two life-threatening diseases in the outpatient setting at one and two months post-diagnoses. Their sample consisted of 56 lung cancer patients receiving radiotherapy and 65 heart attack patients. Each participant completed a 13-item, five-point Likert-type Symptom Distress Scale (SDS) (McCorkle & Young, 1978). Cronbach's alpha coefficient was reported as .79 at interview one and .78 at interview two. Item responses ranged from one (no distress) to five (extreme distress). The total SDS score ranged from 13 to 65 when the 13 items were summed. The mean score on the SDS for lung cancer patients was 26.67 at one month and 26.13 at two months. For myocardial infarct patients, the mean SDS score at one month was 19.30 and at two months was 19.17. Both diagnostic groups identified fatigue as the most distressing symptom on both occasions. Lung cancer patients reported additional symptoms such as pain frequency, cough, lack of appetite, and insomnia.

Kukull et al. (1986) conducted a study on 53 inoperable lung cancer

patients who were receiving radiotherapy on an outpatient basis. They were interviewed at one and two months after diagnosis to obtain their level of symptom distress. The 13-item, five-point Likert-type Symptom Distress Scale (McCorkle & Young, 1978) was utilized. An internal consistency estimate using Cronbach's alpha coefficient of .79 was reported. Fatigue, pain frequency, appetite, cough, and insomnia were most problematic for these patients.

Sheppard (1993) conducted an exploratory study designed to investigate whether nursing diagnoses at discharge from hospital described the complexity of care required in the community for 196 lung cancer patients referred to community agencies. Using a multiple logistic regression model (significance level of $p < .05$), this researcher found two significant predictor diagnoses that include: altered nutrition: less than body requirements ($p = .00$) and high risk for infection ($p = .03$) for home care agency referrals. For hospice agency referrals, the model resulted in the following significant predictors that include anticipatory grieving ($p = .001$), impaired skin integrity ($p = .01$), and high risk for impaired skin integrity ($p = .00$). No magnitude coefficients were reported for these variables.

Researchers have cited numerous treatment-related side-effects for lung cancer patients that impact on the patient's sense of well-being. Both radiotherapy and combination chemotherapy have considerable side-effects well identified in literature (Kaasa, Mastekaasa, Stokke, & Naess, 1988).

Common side-effects associated with chemotherapy include myelosuppression, anorexia, weight loss, nausea and vomiting, alopecia, and fatigue (Bergman & Sorenson, 1990; Fayers et al., 1991; Penny & Shell, 1991).

Radiotherapy side-effects can include skin irritation, dyspnea (from pneumonitis or pulmonary fibrosis), dry cough, increased temperature, tenacious secretions, chest pain (from pericarditis), dysphagia, nausea, and fatigue (Stewart, 1992). Following surgery, patients often have incisional pain causing ineffective breathing patterns, ineffective airway clearance, and ineffective mobilization status.

This literature shows that lung cancer is associated with a wide range of serious physical symptoms that arise not only from natural disease progression, but also from treatment-related side-effects. In view of the limited survival time of patients with lung cancer, skilled professional intervention is needed to modify the patient's response to physical symptoms to enhance optimal quality of life. To modify the patient's distress from symptoms, a clear understanding of how patients, primary family caregivers, and nurses assess symptom distress is required. Otherwise, approaches to modify the patient's symptom distress will be based on trial-and-error efforts.

Quality of life issues

In the 1970s general disease and treatment-related symptoms were

studied using mainly non-experimental designs. In the 1980s investigators began to integrate assessments of symptoms in lung cancer with clinical treatment trials (Bernhard et al., 1991). Clinical trial cooperative groups, such as the European Organization for Research and Treatment of Cancer and the Southwest Oncology Group Cancer Control Research Committee, have established groups to study quality of life assessment. Because treatments for cancer are unpleasant, highly toxic, and frequently result in little if any prolongation of survival, many physicians have become interested in assessing the quality of life of patients (Jones, Fayers, and Simons, 1987).

Clinical cooperative groups are concerned that the benefits of a lung cancer treatment regime should outweigh its cost in patient suffering (Bergman & Sorenson, 1990; Cella, Orofiamma, Holland, Silberfarb, Tross, Feldstein, Perry, Maurer, Comis, & Orav, 1983; Fayers et al., 1991; Kaasa, Mastekaasa, & Thorud, 1988; Moinpour, Feigl, Metch, Hayden, Meyskens, & Crowley, 1989). There is growing interest in improvements to patient support services during treatment and in supplementing data in treatment efficacy. Researchers now believe they can make more informed decisions about risk-benefit trade-offs by including quality of life end-points to traditional end-points of overall survival, disease-free survival, tumor response, and toxicity (Kaasa et al., 1988; Moinpour et al., 1989). Quality of life has become a widely-used catch phrase and key word in clinical articles (Bernhard et al., 1991).

Physical functional status has historically been used as a proxy indicator of quality of life and clinical response to treatment in people undergoing treatment for lung cancer (Kaasa et al., 1988). Physicians routinely used the objective instrument, Karnofsky Performance Status scale as a measure of impact of illness and treatment (Kaasa et al., 1988; Sarna, 1993). However, there is growing consensus that quality of life is a subjective and multidimensional construct that may not be well indexed by the Karnofsky Performance status scale. Quality of life includes not only physical functional status, but also disease and treatment-related symptoms, psychologic functioning, social functioning, sexual functioning, spiritual or existential concerns, body image, and satisfaction with health care (Bernhard et al., 1991; Calman, 1987). However, there may be other factors yet undescribed that constitute evaluation of quality of life.

One component affecting quality of life that is most amenable to health care professional intervention is symptom distress. Therefore, further work to assess, understand, and intervene with respect to symptom distress may contribute to quality of life goals.

Symptom distress

Symptom distress is a concept that has not been well-defined or delineated in literature (Rhodes & Watson, 1987). Cancer nurses have been concerned with symptoms and human responses to cancer such as symptom distress (Germino, 1987). Nurses have focused on cancer,

cancer treatments, and symptom distress because each imposes changes on patients' lives so that patients' criteria for good quality of life may vary (Germino, 1987).

Basically, there is no one accepted definition of symptom distress. 'Symptoms' have been identified as subjective phenomena, indications, or characteristics of a disease or condition departing from normal function, sensation, or appearance (Blacklow, 1983; Giardino & Wolf, 1993). Symptoms are difficult for others to verify, observe, or perceive (Rhodes & Watson, 1987). Generally symptoms are evaluated according to their occurrence, and more specifically the frequency, duration, and severity of various symptoms (Giardino & Wolf, 1993; Rhodes & Watson, 1987).

'Distress' is defined as the ability to describe the amount of physical or mental suffering of the experienced symptoms (Morris, 1976). Leventhal (1979) defines distress as the amount of upset the sensations cause. 'Symptom distress' is defined as the degree of discomfort or physical and mental suffering from the specific symptom being experienced by the patient (McCorkle & Young, 1978).

Symptom distress is a subjective phenomenon where the individual can be the only proper judge of his or her symptom experience. Care of physical and emotional distress by nurses and primary family caregivers can be deemed unsatisfactory if assessments of symptom distress are incongruent with the patient's self-report of symptom distress. Therefore, interventions to identify ways of reconciling divergent assessments can be

designed and tested to ensure optimal patient comfort in the home setting.

Quality of life and survival issues

Nurse researchers are beginning to examine the potential relationship of symptom distress with quality of life (Germino, 1987; Watson, Rhodes, & Germino, 1987). The relationship between symptom distress and survival rates has also been explored in research studies (Degner & Sloan, in press; Kukull et al., 1989).

Holmes and Dickerson (1989) conducted a study of 72 oncology patients admitted to hospital. They assessed the severity of symptoms and the impact of these symptoms on activities of daily living. The concept 'quality of life' was conceptualized in this study as the ability to carry on with activities of daily living (i.e., functional or performance status assessed by the patient). The researchers found that patients achieving a low score on the Symptom Distress Scale also achieved low scores on the Activities of Daily Living scale ($r = .88$, $p < .001$). The original hypothesis was that the severity of symptoms has a significant impact on activities of daily living. Cutoff scores used to rank the Symptom Distress and the Activities of Daily Living scales were not reported.

Graham and Longman (1987) conducted a study that investigated the relationship between quality of life and symptom distress, social dependency, behavior-morale, and life change. The sample consisted of 60 malignant melanoma patients from outpatient settings. They utilized five

instruments to measure the relationships between variables: the Symptom Distress Scale by McCorkle and Young (1978); the Social Dependency Scale; the Behaviour-Morale Scale developed by MacElveen; and, the Life Change Scale. Graham and Longman (1987) developed a two-question instrument to measure the concept of quality of life. The questions rated the quality of the patient's life and the patient's degree of satisfaction with their current quality of life. A strong association between the two questions was reported ($r = .81$; $p < .0001$). All three hypotheses were supported: symptom distress was inversely associated with quality of life ($r = -.34$; $p = .004$); social dependency was inversely associated with quality of life ($r = -.28$; $p = .016$); and behavior-morale and quality of life was positively associated ($r = 0.38$; $p = .001$).

Just as symptom distress has been examined in relationship to quality of life, symptom distress has also been examined in relationship to survival rates in lung cancer patients. In two longitudinal studies of the lung cancer patient population, postdiagnosis symptom distress on the Symptom Distress Scale (McCorkle & Young, 1978) was found to be the most important predictor of survival (Degner & Sloan, in press; Kukull et al., 1986).

Degner and Sloan (in press) conducted a study using a consecutive sample of 434 newly diagnosed cancer patients, including 82 patients with lung cancer, recruited from two outpatient settings. Participants completed the Symptom Distress Scale developed by McCorkle and Young (1978).

The average symptom distress score of the lung cancer subsample was 26.97 (s.d. = 7.79). Symptom distress scores obtained shortly after diagnosis were associated with survival rates based on both the Wilcoxon Likelihood Ratio Test ($p=.0001$) and the log rank test ($p = .0001$). The correlation between symptom distress and time of survival from diagnosis was $-.49$ ($p = .0001$) and time of interview time was $-.54$ ($p = .0001$). The researchers concluded that symptom distress is a reasonable prognostic indicator.

Kukull et al. (1986) found that lung cancer patients ($n = 53$) who reported low distress scores on the Symptom Distress Scale (McCorkle & Young, 1978) shortly after diagnosis survived longer than patients with high postdiagnosis symptom distress scores. The mean symptom distress score reported was 26.8 (s.d. = 8.6), which is similar to Degner and Sloan's (in press) finding for the lung cancer subsample. Degner and Sloan (in press) suggest that patients with high distress scores at time of diagnosis have shorter survival times regardless of treatment and therefore may be a signal to health care professionals to assist patients and families prepare for life closure and initiate palliative care services.

Just as there are known biological prognostic factors for survival in lung cancer, symptom distress may prove to be an additional predictor of survival. Interventions targeted to lessen or eliminate distressing symptoms may improve the patient's outcome and overall quality of life. As well, study findings indicate that interventions aimed at eliminating or

decreasing patient symptom distress may be helpful in improving the patient's overall length of survival.

Factors influencing patient perception of symptom distress

Several studies have examined various factors that affect an individual's perception of symptom distress. Tishelman, Taube, and Sachs (1991) conducted a study to examine the relationship between symptom distress in a heterogeneous group of cancer patients and demographic, medical/clinical, individual/psychosocial variables, and variables related to the patient's view of care provided by the health care system. Semi-structured interviews were conducted with 46 patients and 29 significant others in a community setting. They employed four different measures. An expanded 15-item version of the Symptom Distress Scale (SDS), developed by McCorkle and Young (1978) was integrated into patient interviews (Cronbach's alpha coefficient = .81). The concise version of Sense of Coherence Questionnaire by Antonovsky was utilized. It is an objective measure that indexes sense of coherence and its causal relationship to health status (Cronbach's alpha coefficient = .78). The abbreviated version of the Social Provisions Scale, developed in 1978 by Russell and Cutrona, achieved a Cronbach's coefficient alpha of .87 and .77 respectively for each subscale. The Family Apgar, which measures a family member's satisfaction with five different aspects of family function, obtained a Cronbach's coefficient alpha of .89. A series of multiple

regression analyses were conducted with the intent of exploring relationships between a number of explanatory variables and the amount of distress experienced as indicated by scores on the SDS.

The SDS in this study was regressed on various subsets of the possible explanatory variables. Demographic characteristics (age, civil status, gender) accounted for 3% of the variance in symptom distress. Medical/clinical variables (diagnosis group, oncology treatment, comorbidity, number of weeks between notification of cancer registry and interview, disease stage) accounted for over 18% of the variance of the total SDS index and sub-indexes of appetite/nausea, functional aspects, and social aspects. Over 38% of the variance of the total SDS index was accounted for by individual/psychosocial variables (sense of coherence, assistance and non-assistance related provisions, family apgar, and source of support). The variables relating to the patient's view of care accounted for 6% of the total SDS index. The researchers found that disease stage was not related to distress, also as noted in the study by Ehkle (1988).

Limitations of this study as identified by the researchers include the use of a small sample size in relation to the number of possible explanatory variables included in the regression analysis. The researchers also state that patients with more dramatic disease processes are underrepresented in this study, which may lead to an underestimation of relationships between symptom distress and clinical/medical variables. Despite these concerns, this study is important because it provides support for further nursing

research in understanding the relationship of reported symptom distress and its influencing variables.

Ehkle (1988) conducted an exploratory study to determine the relationship between symptom distress and stage of illness, chemotherapy regime, external health locus of control, internal locus of control, perception of illness, and social support. Women ($n = 107$) with breast cancer who were receiving chemotherapy in the outpatient setting completed the following tools: the Multidimensional Health Locus of Control Scale, the Norbeck Social Support Questionnaire, a 13-item five-point Symptom Distress Scale, and a demographic data sheet. No internal consistency estimates were reported for these instruments. Three variables were significantly correlated with symptom distress: Chance Health Locus of Control ($r = .21$; $p = .03$); Internal Health Locus of Control ($r = -.36$; $p < .001$); and Perception of Illness ($r = .23$; $p = .01$).

The limitations to this study's findings as discussed by the researcher include: use of a convenience sample; severely distressed patients were not included; and the use of antiemetics was not controlled. Generalizability is limited because the sample consists of breast cancer patients receiving chemotherapy in an outpatient setting. Nevertheless, this study is important because it provides support for the influence of three variables on symptom distress. This study also serves as the basis for further nursing research concerning the severity of symptoms in relation to types of treatment and a comparison of reported symptom distress in other

types of cancer patients receiving chemotherapy.

These findings indicate that perception is unique to each individual. Depending on given situations, individuals may experience symptom distress in a unique manner. Despite the limitations of these studies as discussed, these study findings provide understanding about how an individual's perception of symptom distress is influenced by numerous variables. The patient age, gender, marital status, perception of illness, and the internal/external health locus of control are but a few potential influencing variables on self-reports of symptom distress. Awareness of potential influencing variables may assist caregivers in intervening to modify distress from symptoms or identifying patients at risk for developing severe symptom distress. Further research with larger sample sizes, other cancer patient populations, and tighter designs could provide more generalizable findings related to variables that influence self-reports of symptom distress.

Assessment issues

Few studies have been undertaken to examine nurses' assessments of symptom distress in cancer patients. The limited number of studies that have been done compare nurses' assessments of symptom distress and cancer patients' self-reports of symptom distress (Davis, 1991; Holmes & Eburn, 1989; Larson et al., 1993; Peruselli et al., 1992).

In an unpublished dissertation, Davis (1991) conducted a

replication study to investigate the congruence between hospitalized cancer patients' self-assessments of symptom distress and nurses' assessments of symptom distress in those patients. This researcher utilized a comparative descriptive design and a convenience sample of 32 nurse-patient pairs to complete the modified Symptom Distress Scale (Holmes, 1991). This scale was a 13-item questionnaire in the form of a visual analogue scale. A Cronbach's alpha coefficient of .83 for patients and .79 for nurses was reported. This form of the scale was utilized because previous research revealed that: it was simple, flexible, and easy to grasp; the rater can make finer discriminations without constraints in quantitative terms; it could be scored easily with many options for fineness of scores; and, it was more likely to accurately reflect the patient's true feelings (Holmes & Dickerson, 1987).

Nurses' and patients' assessments of symptom distress were compared by means of Student's t-test for paired data. Statistically significant differences in perception of pain ($t = 2.82$; $p < .05$) and mood ($t = 3.99$; $p < .001$) were reported. Because the modified SDS contained a large number of variables in relation to the small sample size, the Hotelling's T2 test was additionally conducted to test for statistically significant differences. The only statistically significant difference in ratings of SDS was found with the mood item ($F [1, 25] = 21.75$, $p < .001$). One other statistically significant finding was that as the number of years in nursing or cancer nursing increased, the difference between nurses' and

patients' symptom distress scores decreased. No adjusted R-square values were reported.

This researcher states that use of a small convenience sample limited the study's nursing implications. Comparison of nurses' and patients' responses to the SDS items was limited because questionnaire items were occasionally incomplete. Replication of this study with a larger homogenous sample of cancer patients in an outpatient setting is indicated. Future research on the relationship between the number of years in cancer nursing and congruence of symptom distress scores between nurses and patients may also be indicated.

Holmes and Eburn (1989) examined 53 nurse-patient dyads to obtain descriptions of symptom distress from a heterogeneous sample of cancer patients. They utilized a 13-item, linear analogue self-assessment (LASA) format of the SDS (McCorkle & Young, 1978). Cronbach's alpha coefficient reliabilities were .97 (patients) and .81 (nurses). Nurses tended to overestimate the degree of distress with regard to pain, nausea, appetite, sleep, concentration, and mood compared to patients' ratings of these symptoms ($p < .05$). The researchers attribute these discrepancies to an interpretation that nurses were less effective in perceiving the degree of distress associated with less 'visible' symptoms.

Larson et al. (1993) conducted a study comparing nurses' ($n = 28$) perceptions of symptom distress in patients hospitalized for bone marrow transplant (BMT) with perceptions of symptom distress held by

patients ($n = 30$) themselves. Patients and nurses responded to the Symptom Distress Scale (SDS) by McCorkle and Young (1978) at four time points: within 48 hours of BMT day one (T1); day 7-10 post-BMT (T2); day 20-23 post-BMT (T3); and day 30-34 post-BMT (T4). An expanded 17-item Likert-type modified SDS was used to include four symptoms common to patients undergoing BMT. The modified SDS Cronbach's alpha coefficient reliability estimates ranged from .81 to .91. At T1, nurses' perceptions of overall symptom distress were significantly lower than symptom distress indicated by patients ($p < .002$). At T3, nurses perceived patients as having somewhat greater symptom distress than the patients did themselves. No significant differences between the two groups were found at T2 and T4. The researchers speculate that patients at T1 may have been hypervigilant about their predicted symptoms and experiencing symptoms from the effects of their conditioning regime for the BMT at T1. Nurses' scores at T1 may have been influenced by prior experiences with BMT patients allowing them to predict that patients would experience greater symptom distress later. These experiences may have contributed to lower symptom distress ratings by nurses at T1 who judged symptom distress relative to future symptom distress expectations.

Peruselli et al. (1992) conducted a study to identify the discrepancies between nurses' diagnostic statements and patients' reports on the Symptom Distress Scale (SDS) (McCorkle & Young, 1978). The sample consisted of 40 patients with advanced tumors, who were receiving

home health care for a length of time ranging from one to 19 weeks. The SDS scale used was a 13-item linear analogue self-assessment (LASA) format. An internal consistency estimate using Cronbach's alpha coefficient of .78 was reported. After patients rated their symptoms on the SDS, these symptoms were divided into six groups and correlated with nursing diagnosis categories according to functional health patterns. Nurses completed a weekly report for each patient, recording the nursing diagnoses according to the North American Nursing Diagnoses Association (McLane, 1987). All patients included in the study were asked to complete a weekly self-report of their symptoms on the SDS. Complete and continuous assessments of patients' status until the end of the study occurred for 15 cases. Twenty-five patients did not have complete assessments due to increasing debilitation or refusal to complete the record.

Of the 15 patients having complete patient self-reports and nursing diagnoses, a total of 219 nurses' recordings agreed with patients' reports (63%). One hundred twenty-nine recordings showed no agreement (chi square = 23.28; $p < .001$). There was a significant difference between percentage of agreement in the group of nursing diagnoses under self-concept/perception pattern to concentration, appearance, and mood (lower than 50%) as compared with the remaining groups (cognitive/perceptual pattern to pain intensity and frequency; nutritional/metabolic pattern to intensity and frequency of nausea and appetite; elimination pattern to

bowel pattern; physical activity to breathing, coughing, and fatigue)(chi square = 6.41; $p < .02$). The researchers found it was easier for nurses to correctly assess the incidence of somatic symptoms in a patient than to assess more complex psychological patterns.

In most studies SDS scale items are evaluated separately or item scores are summed to provide an overall symptom distress score. In this study, items on the SDS scale were combined into categories (pain frequency and intensity) and compared with corresponding nursing diagnoses (cognitive/perception nursing diagnoses). The method used in this study to assess congruence of reports of symptom distress between nurses and patients is not similar to methods used in previous studies (Davis, 1991; Holmes & Eburn, 1989; Larsen et al., 1993), thereby making this study's findings tentative. As a result of the reported discrepancies between nurse and patient reports of symptom distress, the researchers indicate that nurses need to apply greater effort in improving their understanding of the objective and subjective needs of home care patients through ongoing communication and patient goal revision.

Numerous peripherally-related studies have examined variables purported to influence another person's perceptions of pain and psychological distress. Table 1 presents a summary of the findings of studies investigating these variables. Three of the studies were undertaken

Table 1

Variables influencing inferences of pain and psychological distress

<u>Authors, Year</u>	<u>Purpose</u>	<u>Sample</u>	<u>Design</u>
Wartman, Morlock, Malitz, and Palm (1983)	To examine how well physicians assessed acute and chronic illness patients' anxiety, discomfort, and activity limitation. To examine physicians' prescribing behaviors and patients' satisfaction with their treatment	n = 785 outpatients from the Department of Adult Medicine n = 582 outpatients from the Department of Urgent Care n = ? physicians	Questionnaires Telephone Survey

Major findings: Thirty five percent of physicians underestimated their patients' perceptions of pain, anxiety, and activity limitation. In less than 12% of the cases, physicians overestimated their patients' degree of pain, anxiety, and activity limitation. Physicians' underestimates were more common in emergency cases than in adult medicine.

Baer, Davitz, and Lieb (1970)	To examine social workers', nurses', and physicians' inferences of physical pain and psychological suffering in relation to verbal and non-verbal communication	n = 25 social workers n = 25 nurses n = 24 physicians	Vignettes n = 32
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Major findings: Social workers inferred the greatest degree of pain and nurses and doctors inferred the least ($p < .02$). There was a significant difference ($p < .01$) in the amount of pain inferred between verbal and non-verbal items. All groups inferred greater pain for verbal items ($p < .01$). The three groups did not differ significantly in the degree of psychological distress inferred ($p < .01$). A comparison of means for verbal and non-verbal items of psychological distress revealed all groups inferred greater psychological distress for non-verbal items.

Table 1 (cont'd)

<u>Authors, Year</u>	<u>Purpose</u>	<u>Sample</u>	<u>Design</u>
Lenburg, Glass, and Davitz (1970) ¹	To examine the inference of pain and psychological distress by nuns, teachers, physicians, and nurses in relation to stage of illness and occupation of perceiver	n = 36 nuns n = 32 teachers n = 30 physicians n = 33 nurses	Vignettes n = 36

Major findings: Occupational groups differed significantly from each other in inferences of degree of pain ($p < .01$) and degree of psychological distress ($p < .05$). Nuns inferred the greatest pain and distress, followed by teachers, nurses, and physicians. Inferences of pain and psychological distress were found to be significantly related to stage of illness ($p < .001$). Inspection of means for the four groups showed a higher inference of psychological distress than pain. Inspection of mean scores of the total sample for stages of illness indicate that onset of illness phase received the highest inference of both pain and psychological distress, followed by treatment and prognosis stages.

Davitz and Pendleton (1969)	Four related studies that considered variables that may influence nurses' inferences about patient suffering. The variables examined included: a) cultural and subcultural differences of nurses b) specialty areas of nurses c) patient diagnoses d) patient age, gender, socioeconomic class	Study 1: n = 32 Korean nurses, n = 30 Thailand nurses, n = 23 Puerto Rican nurses, n = 20 African-American nurses, and n = 20 American white nurses Study 2: n = 32 medical-surgical nurses, n = 25 pediatric nurses, n = 26 psychiatric nurses, and n = 33 obstetrical nurses Study 3: n = 94 various specialty nurses Study 4: n = 67 various specialty nurses	Vignettes - Study 1: n = 30 Study 2: n = 24 Study 3: n = 48 Study 4: n = 40
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Table 1 (cont'd)

Major findings: Inferences of suffering differ significantly according to cultural and subcultural background of the nurse ($p < .01$), patient diagnosis ($p < .05$), and socioeconomic background and age of the patient ($p < .05$). No statistically significant differences were found in inferences of nurses in relation to clinical specialty of the nurse and gender of the patient ($p < .05$).

<u>Authors, Year</u>	<u>Purpose</u>	<u>Sample</u>	<u>Design</u>
Reid-Point (1992)	To examine the relationship between empathy skills of their patients	n = 65 nurses n = 65 cancer patients on surgical units	Questionnaires

Major findings: There were statistically significant correlations between the nurse's age and responding verbally ($r = -.24$; $p = .03$); between education and perceiving/feeling/listening ($r = -.29$; $p = .01$); and, years of experience and responding verbally ($r = .27$; $p = .01$). There was a significant difference between male and female distress levels ($F = 3.82$; $p = .05$). No significant differences were found among cancer types and distress levels ($r^2 = .08$) before demographic variables were entered. Perceiving/feeling/listening did show a significant correlation ($p < .05$) with Profile of Moods Survey and Distress Visual Analogue Scale (the magnitude of the correlation was not reported). The direction of the correlation was not as predicted.

during the late 1960s and 1970s. Generally these studies were comprised of small sample sizes, varied diagnostic groups of patients, and patients and nurses from hospital settings. The questionnaires utilized were both researcher-prepared and standardized tools with acceptable reliability and validity values overall.

Despite these limitations, the study findings are useful because they provide information about the effect of influencing variables on another individual's perception of pain, distress, and suffering in the patient. Variables such as occupational status, cultural and subcultural background, and empathy skills were found to influence the nurse's or another person's perception of pain, distress, or suffering in the patient. Patient verbalization of pain, non-verbalization of psychological distress, stage of illness, socioeconomic background, and age showed statistically significant relationships with another individual's inference of pain and suffering in the patient. The findings of one physician-related study revealed that overestimation of the patient's degree of pain, anxiety, and activity limitation may be related to physician patient loads, demands on physician time, and interpersonal activities with their patients.

Giardino and Wolf (1993) state that the patient's subjective experiences with symptoms and desire for treatment may contrast greatly with nurses' objective determinations of the presence and severity of symptoms. The nurse must carefully weigh objective evidence against patients' subjective experiences. The authors warn that use of assessment

tools is helpful to determine the nature of symptoms, but do not measure the uniqueness of the whole person. Continual assessment of the patients' experiences is essential and the nurse must readjust care accordingly.

Vessey and Richardson (1993) state that the orientation (disease-specific or holistic) of the health care provider will influence the ability to analyze symptoms accurately and offer interventions appropriately. Other limitations to effective symptom assessment include environmental factors of the health care professional such as limited long-term contact with the patient and increasing specialization. This finding contrasts with the findings of Davitz and Pendleton (1969) who found no statistically significant relationship between the effect of clinical specialization and inferences of suffering ($p < .05$).

Despite McCorkle and Young's (1978) suggestion for further evaluation of congruency on perceptions of symptom distress among patients, family members, and nurses, no such research has been pursued. Several classic studies were conducted to identify demographic variables that influence nurses' and other individuals' perceptions of suffering in patients. There appears to be variation in the manner in which symptoms and pain are interpreted and communicated, depending on numerous variables that influence another individual's perceptions of pain and suffering.

Generalizability of these study findings is limited due to small sample sizes, heterogeneity of study samples, and the early dates of these

studies. Little replication of these studies has been done to date. However, the implication from these studies is that any discrepancy between the patient's and caregivers' perceptions may potentially prevent the patient's symptoms from being managed effectively. Interventions that assist caregivers to become more cognizant of variables that influence their assessments of symptom distress are needed to guide them in making more sensitive assessments of symptom distress in another individual.

Behavioural approaches to symptom distress measurement

To date, no research has used a behavioural approach to assess symptom distress. No studies have examined cues others may use when assessing distress arising from symptoms in another individual. The Symptom Distress Scale requires the patient and/or another individual to rate the distress the patient is experiencing with that particular symptom, for a total of 13 separate items. These symptoms include insomnia, fatigue, bowel, breathing, cough, concentration, nausea (frequency), nausea (intensity), pain (frequency), pain (intensity), outlook, appetite, and appearance. However, little is known about how the rater arrives at his or her assessment of symptom distress in the patient.

Numerous studies have examined behavioural approaches to assessing the subcomponent of pain (Chambers & Price, 1967; Teske, Daut, & Cleeland, 1983). These studies used standardized observational scales to measure the effectiveness of pain medication. Some of the items

on the scales include attention, anxiety, verbalization, pacing, guarding, holding, restlessness, tenseness, grimaces, frowns, perspiration, cries, moans, groans, sighs, grunts, and nausea. Teske et al. (1983) found agreement among nurses to be high when observing pain, but a low correlation between nurses' judgments of pain and patients' self-reports of pain.

Fatigue is another subcomponent of the Symptom Distress Scale for which numerous authors have provided objective and subjective manifestations that are useful in assessment. Aistars (1987) has divided these manifestations into six basic categories that include general appearance, subjective description, attitude, speech, activity, and concentration.

Fatigue (Aistars, 1987; Piper, Lindsey, & Dodd, 1987), dyspnea (Ajemian, 1991; Carrieri, Janson-Bjerklie, & Jacobs, 1984), nausea (Rhodes, Watson, and Johnson, 1984) and pain (Teske, Daut, & Cleeland, 1983) are generally identified as subjective symptoms that are not easily observed, verified, or perceived by other individuals. Perhaps unlike other symptoms such as cough, appetite, and appearance, it is unlikely that others would know whether the patient is experiencing these symptoms without information from the patient. However, apart from observing the occurrence of symptoms, the degree of distress experienced by the patient is not observable and "can only be conjectured by another human being" (Rhodes et al., 1984, p. 39).

In summary, there are numerous studies that have examined the behavioural measurement of several components of symptom distress indexed by the Symptom Distress Scale, such as pain and fatigue. However, further studies are required to examine behavioural measurement and cues that others respond to when assessing other subcomponents of symptoms measured by the Symptom Distress Scale.

Symptom distress and suffering

No studies to date have examined the relationship between the concepts of symptom distress and suffering. Ferrell (1993) states that quality of life is depicted as an inclusive concept that incorporates aspects of physical, psychological, social, and spiritual well-being. Suffering has been identified in the spiritual well-being domain of quality of life. However, Ferrell (1993) states that suffering transcends all domains of the quality of life model. Hinds (1992) states that the concept of suffering has been examined mainly in religion and philosophy. Little effort has been made in nursing to explore suffering. Generally, efforts to understand this phenomenon have been linked with pain (Cassell, 1982; Kahn & Steeves, 1986).

There are numerous variations on the concept of suffering and no comprehensive definition of suffering and its subcomponents exists (Battenfield, 1984). Copp (1974) defines suffering as "the state of anguish of one who bears pain, injury, or loss" (p. 491). Chapman and Gavrin

(1993) state that suffering refers to "a perceived threat to the integrity of the self, helplessness in the face of the threat, and exhaustion of psychosocial and personal resources for coping" (p. 5). Kahn and Steeves (1986) define the concept as "an individual's experience of threat to self and is a meaning given to events such as pain or loss" (p. 623). Suffering is also defined as "a negative affective state resulting from an event or situation that is perceived to be physically painful, uncomfortable, or psychologically distressing" (Benedict, 1989). Davitz and Davitz's (1981) definition, similar to Benedict's (1989) definition, states that suffering is "the degree of physical pain or discomfort and/or degree of psychological distress" (p. 12). Travelbee's (1971) definition is perhaps one of the earliest definitions captured by nursing, "an experience which varies in intensity, duration, and depth ... a feeling of displeasure which ranges from simple transitory mental, physical, or spiritual discomfort to extreme anguish, and to those places beyond anguish" (p. 62).

There are several components inherent in each definition of suffering captured by the concept of symptom distress. First, the definitions of suffering and symptom distress emphasize that each is subjective in nature. Individual meaning and personal values are involved in the individual's experience of symptom distress and suffering and in making inferences of suffering and symptom distress (Benedict, 1989; Davitz & Davitz, 1989; Holmes & Dickerson, 1987; McCorkle, 1987). Second, the concepts of suffering and symptom distress share descriptions

of negative emotions (Chapman & Gavrin, 1983). Third, within the respective definitions there is the exchange of common word descriptors to capture the essence of the experiences. For instance, in Davitz and Davitz's (1981) conceptualization, suffering is described as physical discomfort or psychological distress. In turn, symptom distress refers to the degree or amount of physical or mental upset, anguish, or suffering experienced from a specific symptom (Rhodes & Watson, 1987). The words 'distress' and 'suffering' are included in both definitions, indicating possible congruence or similarity in experiences of symptom distress and suffering.

Researchers have addressed various experiences that elicit suffering that are not unlike the experiences or symptoms described in McCorkle and Young's (1978) Symptom Distress Scale. Cassell (1982) states that suffering can occur in the presence of acute pain, shortness of breath, or other body symptoms. Chapman and Gavrin (1993) describe suffering that can accompany biological signs of distress, experience of pain, or other aversive symptoms such as sensory disturbances, treatment toxicities, excessive fatigue, sleep disturbances, anorexia, and other dysfunctions. Kahn and Steeves (1986) reviewed various definitions of suffering and found that "other sorts of things can induce suffering" rather than simply pain.

Benedict and Bird (1982) conducted a descriptive study involving 25 cancer patients who participated in interviews and 10 cancer patients

who completed written questionnaires related to personal suffering associated with their cancer experience. The researchers identified and categorized cancer patient experiences associated with suffering as physical, psychological, and interactional aspects. Physical aspects included physical pain, disability, changes in appearance, nausea and vomiting, bowel problems, coughing, and weakness/fatigue. Some of the psychological aspects included fear of recurrence, anxiety, powerlessness, change in daily activities, and depression.

In follow-up to this study, Benedict (1989) conducted research to investigate the occurrence of these three aspects of suffering in lung cancer patients. A nonprobability sample of 30 lung cancer patients from an outpatient setting were recruited. All subjects had been treated with chemotherapy, surgery, and/or radiation. Each patient participated in structured interviews to determine the incidence of suffering associated with lung cancer. Subjects also completed a five-point Likert-type scale used to rate the suffering associated with each of the three aspects. The points on the scale ranged from (0) "None" to (4) "Very Much" suffering.

This researcher compared the incidence of aspects of suffering obtained in Benedict and Bird's (1982) study to aspects of suffering associated with lung cancer. Not all aspects of suffering previously identified were associated with suffering in lung cancer, such as worry about procedures, problems with children and nurses, reluctance to talk, and insufficient information. The reported incidence of "very much"

suffering associated with physical aspects of the lung cancer experience was 50%, psychological aspects was 27%, and interactional aspects was 3%. The greatest suffering was associated with disability (50%), pain (40%), weakness/fatigue (33%), changed daily activities (34%), and anxiety (34%).

Benedict (1989) states that the predominance of physical suffering suggests that nurses should pay particular attention to physical aspects of the lung cancer experience. The researcher also identifies the need for further research that includes a search for additional aspects of suffering in lung cancer and further study to determine which items are consistently associated with high and low levels of suffering in lung cancer patients.

Although there are no studies that examine the relationship between symptom distress and suffering, it is hypothesized that one does exist. This study will hypothesize that the event of symptom distress includes aversive biological and psychological signals of distress that may cause suffering, which in turn affects the quality of life of an individual (Chapman and Gavrin, 1993). Therefore, this study will view the assessment of symptom distress as one means of assessing and/or measuring physical and psychological aspects of suffering as described by Benedict and Bird (1982).

Measurement issues

Symptom distress assessments are usually self-report measures by

the individual experiencing symptoms. Self-administered questionnaires are advantageous because they are not labour-intensive in terms of interviewer or rater training and avoid the potential problem of observer bias (McCorkle, 1987). Self-administered questionnaires help nurses to appreciate the patient's interpretation of the type, severity, and changes that symptoms bring to their lives (Giardino & Wolf, 1993).

There are a limited number of symptom assessment scales that have been designed specifically for cancer patients (McCorkle, 1987).

Three quality of life instruments that have been tested on a variety of cancer patient populations and/or are frequently discussed were evaluated for use in this study: the modified Symptom Distress Scale by Holmes and Dickerson (1987); the Symptom Distress Scale by McCorkle and Young (1978); and, the Lung Cancer Symptom Scale by Gralla and Burke (1985). These three scoring systems include the use of questionnaires, linear analogue scales, and/or Likert-type scales in assessing the quality of life in cancer patient samples.

Holmes and Dickerson (1987) conducted a comparative evaluation of an LASA scale and two Likert-type scales (five-point and six-point) based on the Symptom Distress Scale (SDS) developed by McCorkle and Young (1978). They utilized a questionnaire that was adapted to three different formats of rating scales consisting of two sections: an 11-item SDS scale and a 15-item Activities of Daily Living scale. Seventy-two in-hospital oncology patients completed one form of the questionnaire on two

occasions, 60 to 90 minutes apart. The three scales were allocated on a random basis to obtain 20 completed pairs for each type. Cronbach's alpha coefficients of .80 (total instrument), .90 (Symptom Distress Scale), and .70 (Activities of Daily Living scale) were obtained for the LASA format of the questionnaire. The highest test-retest reliability coefficient was obtained using the LASA (.97, $p < .001$) while the six-point scale had the lowest (.72, $p < .001$).

Analysis of variance showed no significant differences between responses obtained for any of the scales. Although the researchers found no statistical basis for selecting one scale over the other, use of the LASA instrument was associated with fewer problems. However, Frank-Stromberg (1988) states that some people may have difficulty conceptualizing a sensory phenomena in a straight line. Morgan-Eckley (1993) states that the LASA scale may be more difficult for an older population to understand. As well, the LASA has not been tested extensively in a variety of cancer populations.

The Lung Cancer Symptom Scale (LCSS) by Gralla and Burke (1985) was designed to address symptomatic distress, activity status, and overall quality of life issues in lung cancer patients receiving new chemotherapy regimes (Hollen, Gralla, Kris, & Potanovich, 1993). The LCSS consists of two instruments: the nine-item, 100 mm visual analogue patient scale and the six-item, five-point ordinal level observer scale. Initial psychometric testing of the LCSS was reported as: test-retest

reliability coefficient of $r > .75$; $p < .01$ for a sample of 52 patients and $r > .75$; $p < .01$ for interrater reliability except for cough ($r > .65$; $p < .01$) and weakness ($r > .54$; $p < .01$). Content validity was established with a high consensus between the 52 patients and four experts. For construct validity the correlation coefficients for the patient scale with the observer scale ranged between $r = .49$ (weakness) and $.74$ (cough); $p < .01$. The patient scale took eight minutes to complete and the observer scale took 2 minutes. As a result of the favourable results of initial psychometric testing, feasibility, reliability, and validity testing for the LCSS is ongoing.

There are many strengths associated with use of the LCSS for indexing symptom distress in lung cancer patients. The results of repeated testing for feasibility, reliability, and validity testing are encouraging (Hollen et al., 1993). The LCSS is unique in that it provides both subjective and observer scales to measure the same symptoms. Utilization of both scales provides "context and confirmation for patients' reports" (Hollen et al., 1993, p. S57). As well, the symptoms on the LCSS are limited to those of lung cancer.

The researchers also discuss one major limitation concerning the LCSS scale. Hollen et al. (1993) state that the LCSS is a quality of life scale that does not meet the development criteria for quality of life measures as described by Donovan, Sanson-Fisher, and Redman (1989). All four quality of life areas (physical, psychological, spiritual, and social) are not conceptualized in the LCSS, but are addressed in a summative

question. The intent of this scale is to evaluate physical and functional dimensions of quality of life, therefore making conceptualization of all quality of life areas irrelevant when testing treatment efficacy (Hollen et al., 1993).

Several issues have been considered in the evaluation of the appropriateness of the LCSS when conducting a study in lung cancer patients receiving palliative care in the home setting. First, psychometric testing remains ongoing despite favourable initial results. Second, the items included in the LCSS assist in testing chemotherapy efficacy in lung cancer patients. However, the purpose of this study is to address assessment of symptoms that are likely relevant to palliative care lung cancer patients in the home setting. Numerous items such as insomnia, bowel, appearance, and outlook are symptoms not indexed in the LCSS that are commonly experienced by lung cancer patients in the home setting (Benedict, 1989; Kukull et al., 1989; Oleske et al., 1990). Therefore, the LCSS scale may not be flexible enough to be used as the only measure in advanced lung cancer patients who are no longer receiving chemotherapy and are receiving nursing care in the home.

For this study it is important to consider using a scale that allows the home care nurse to assess common symptoms experienced by the palliative care lung cancer patient in the home setting. A scale that also allows in-depth assessment of the psychological dimensions of quality of life, while coping with advanced stages of lung cancer in the home setting, may be

more appropriate for this study's purposes.

The Southwest Oncology Group recommends use of the World Health Organization (1958) component-based definition of quality of life, with emphasis on the separate assessment of physical functioning, emotional functioning, and symptoms (Moinpour et al., 1989). This clinical group suggests the use of specific instruments that are based on patient reports, are brief, use a categorical format, and have acceptable psychometric properties. To measure the symptom component of quality of life, the Southwest Oncology Group has adopted the Symptom Distress Scale (McCorkle & Young, 1978). Reliability coefficients of .78 to .89 were reported from previous studies. Construct validity was demonstrated in that symptom distress was negatively correlated with a global measure of quality of life (Graham & Longman, 1987).

The Symptom Distress Scale (SDS) was developed in 1978 by McCorkle and Young to identify concerns of patients receiving active cancer treatments in an outpatient setting. The SDS has been used in a wide variety of patient populations (cancer, breast disease, myocardial infarction, and pregnancy) and in various settings (hospital and home) (McCorkle, 1987).

The SDS scale has demonstrated face and content validity for specific symptoms as identified by cancer patients themselves. Reliability coefficients ranging from .78 and .97 have been reported (Holmes & Eburn, 1989; McCorkle & Young, 1978). Convergent validity ($r = .90$)

was obtained when Ware's health perception questionnaire and the SDS were used with cancer patients who were tested over time (McCorkle, 1986). Discriminant validity was also obtained when the SDS was able to discriminate cancer patients from heart patient survivors (McCorkle and Benoliel, 1983) and lung cancer patients receiving home care from controls at 6-week intervals (McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour, and Goodell, 1989). The SDS takes about five to ten minutes to administer (Holmes & Eburn, 1989). Researchers who utilized the SDS report that one limitation of the scale is the lack of response option indicating that the symptom is not present. Both Morgan-Eckley (1993) and Degner and Sloan (in press) found that when patients reported no pain or nausea, they sometimes left the intensity subscale blank.

The SDS has been used to measure perceived distress from symptoms in a variety of cancer patients. This scale has been used with mixed diagnosis groups of cancer patients (Holmes & Dickerson, 1987; Holmes, 1989), single diagnosis groups (Kukull, McCorkle, & Driever, 1986; McCorkle et al., 1989), and single diagnosis groups undergoing different cancer treatments (Holmes, 1989). It has also been used to compare patients' and nurses' perceptions of symptom distress (Davis, 1991; Holmes & Eburn, 1989; Larson et al., 1993; Peruselli et al., 1992) and compare self-reports of cancer patients and patients who have had a myocardial infarction (McCorkle & Benoliel, 1983).

Various measures have been used by investigators to study the

occurrence of symptoms and symptom distress. The Symptom Distress Scale has been most widely used, particularly with cancer patient populations, and has been found to be a reliable measure to detect differences in symptoms experienced by cancer patients over time (Morgan-Eckley, 1993). This tool is brief, easy to understand, and has accepted psychometric properties that make it an appropriate measure for the study of symptom distress in lung cancer patients.

Family and symptom management in the community

Literature is replete with findings that reveal cancer is a disease that directly or indirectly affects everyone, including the patient and the family (Jansen, Halliburton, Dibble, and Dodd, 1993). Increasing numbers of cancer patients are receiving treatment on an outpatient basis and are being cared for in advanced stages by family members who become the primary caregivers in the home (Oberst, Gass, & Ward, 1989). Many studies have attempted to describe the needs or problems of patients and families/caregivers utilizing questionnaires and interviews.

Some of the roles identified by family members in their care for the cancer patient in the community include managing the physical care, treatment regime, and imposed changes (Stetz, 1987). Oberst et al. (1989) conducted a study to examine 47 caregivers' appraisals of the illness/caregiving experience in caring for patients receiving radiotherapy for cancer. Caregivers reported that the greatest time was spent in

transportation, giving emotional support, and extra household tasks.

Carey, Oberst, McCubbin, and Hughes (1991) conducted a study of 49 family caregivers of patients receiving chemotherapy to determine the time and difficulty spent on caregiving tasks. Caregivers reported that a great deal of time and effort was spent providing emotional support, managing illness-related finances, assisting with household tasks, and providing patient transportation.

Other studies have identified that families feel unprepared to provide patient care (Stetz, 1987; Wright & Dyck, 1984). Hileman, Lackey, and Hassanein (1992) found that caregivers expressed many unmet informational needs in relation to symptoms, the future, treatment side-effects, and community resources. Hinds (1985) reported that in the sample of 83 family caregivers, 25% required guidance in understanding the disease process, 22% perceived patient suffering as a source of much discomfort, and 15% felt insecure in being able to provide basic patient care. Similar findings of families' perceived need for relief of patient's pain and instruction on how to keep the patient comfortable were found in studies by Kristjanson (1986) and Skorupka and Bohnet (1982).

Hays (1986) conducted a descriptive, retrospective study on two randomly chosen groups of 50 patients from a hospice home care program, during the last 10 days of patients' lives. One group of patients who were in the home care group (HC) received only home care services for their hospice stay. Patients in the home care/inpatient group (HC/IP) received

both home care and inpatient services. Comparisons between the two groups were conducted on pain, nausea/vomiting, elimination, respiration, nutrition, mental status, family anxiety and fatigue, and resource utilization. The HC/IP group experienced significantly more pain ($t = -2.58$, $df = 67$, $p < .05$) and nausea/vomiting ($t = -3.52$, $df = 67$, $p < .001$) than the other group. During the last six days of life, HC/IP families displayed significantly more anxiety ($t = -3.52$; $df = 67$, $p < .001$) and fatigue ($t = -2.82$, $df = 61$, $p < .01$). In the HC/IP group, pain was significantly associated with family anxiety ($r = .47$, $p < .05$) and slightly less associated with fatigue ($r = .37$, $p < .10$). The researcher found that certain patients appeared predisposed to inpatient admission: those that experienced more kinds of symptoms and more combinations of symptoms during the final days of life. The significant others involved tend to exhibit anxiety and fatigue in response to uncontrolled symptoms in the last 10 days before death. They also had slightly higher demand for home-based services during this period.

Studies have also compared perceived patient needs and caregiver needs by patients, nurses, and family caregivers and found discrepancies. Wingate and Lackey (1989) conducted a descriptive, exploratory study using three groups of noninstitutionalized cancer patients, primary family caregivers, and nurses. Each were asked to complete two forms of an open-ended questionnaire. The Object Content Test (OCT) was used to elicit perceptions of needs of cancer patients and their primary family

caregivers. The OCT is an open-ended test with 20 numbered blank spaces for responses to questions for the patient that were "What are the needs for me as a patient?" and "What are the needs for the person caring for me?" Primary family caregivers and nurses were asked similar questions about the other subjects. The researchers found it important to work with an open-ended format to not bias subjects with predetermined ideas or categories of needs. Test-retest reliability coefficients from other studies were reported as ranging between .38 and .85 for the OCT. No reliability coefficients were reported for the OCT using this study's data. Numerous discrepancies were detected in subjects' reporting of their perceptions of the others' needs. Caregivers and nurses perceived greater informational care needs for the patient. Nurses and caregivers perceived fewer physical needs for the patient.

Disparity in congruence between perceived needs as generated by patients and caregivers has been noted in one other study. Hileman and Lackey (1990) conducted a study that described the needs of 15 patients with cancer at home and 15 home caregivers. Subjects completed a demographic information sheet and an OCT for both patients and primary family caregivers. No reliability coefficient for the instrument was reported in this study. Subjects were asked to list their own needs as a patient or caregiver on one OCT and list needs perceived of their counterparts on another OCT. A total of 505 need statements were generated and three oncology nurse researchers and three oncology clinical

nurse experts computer Q-sorted all need statements into a set of need categories established by Wingate and Lackey (1989). Only items that maintained interrater reliability coefficients of .66 or greater were retained in the model. Mean percentage agreement in matching statements to categories among sorters was 78.36%. According to criteria given by Lynn (1986), determination of the content validity of the instrument used in this study is questionable as to having been met. For six experts, a minimum interrater reliability coefficient of .86 should be achieved (Lynn, 1986). Primary family caregivers reported a similar frequency of psychological, physical, spiritual needs for patients as patients did for themselves. Discrepancies between patients' and primary family caregivers' perceptions of each others' needs arose in aspects of informational, household, and respite needs. The researchers suggest that discrepancies in each others' perceptions may indicate ineffective patient-caregiver communication.

These studies reveal that families have expressed serious concerns with symptom management in the community. Patient comfort and relief from symptoms have been expressed as priority concerns for family caregivers. Disparity in assessment of patients' and families' needs by patients, family members, and nurses has been revealed. This incongruence in assessment of each others' needs leads one to believe in the existence of ineffective communication between the parties involved. The implication is that without shared knowledge of common goals and meaning of comfort among patients, family members, and nurses,

management of cancer symptoms may be ineffective.

Conceptual Framework

Overall this study is guided by the concepts of symptom distress, suffering, and quality of life. The conceptual framework on nurses' inferences of suffering by Davitz and Davitz (1981) provides the foundation for conceptualization of this study.

Although no studies to date have examined the relationships among symptom distress, suffering, and quality of life, this investigator will hypothesize that they do exist. Researchers have identified physical, psychological, interactional, and spiritual experiences that elicit suffering (Benedict & Bird, 1982; Cassell, 1982; Chapman & Gavrin, 1992; Ferrell, 1993). Suffering is a negative affective state resulting from an event that is perceived to be physically painful, uncomfortable, or psychologically distressing (Benedict, 1989). One such event that may elicit suffering is symptom distress. Symptom distress involves aversive biological and psychological signals of distress that may cause suffering. Empirical evidence indicates that symptom distress is a concept underlying the broader construct 'suffering' and indexes the physical and psychological dimensions of suffering (McCorkle & Young, 1978).

Furthermore, suffering is viewed as a higher level construct that is hypothesized to predict the quality of life construct. Similar physical and psychological events identified with suffering have been described as

domains within the concept of quality of life (Calman, 1987). Ferrell (1993) states that suffering is identified in the quality of life domain as 'spiritual' well-being. However, the experience of suffering "transcends all domains of the [quality of life] model" (Ferrell, 1993, p. 1471). Therefore, this investigator hypothesizes that the construct 'suffering' may be negatively related to the construct 'quality of life' (Figure 1).

Figure 1 also indicates that the concept 'symptom distress' may be negatively related to the physical and psychological dimensions of quality of life. The physical and psychological dimensions of quality of life could be indexed by an appropriate quality of life measure (Functional Living Index - Cancer [FLIC]; Quality of Life Index [QLI]). Subsequent research could be mounted to test the relationship between symptom distress and quality of life. Graham and Longman (1987) identified that a statistically significant relationship ($r = -.34$; $p = .004$) between symptom distress and quality of life does exist.

However, the emphasis in this program of research is to examine the experience of symptom distress as perceived by the lung cancer patient, primary family caregiver, and nurse. In this study, the Symptom Distress Scale is a tool that will measure the physical and psychological dimensions of symptom distress. Symptom Distress Scale scores will be obtained from the lung cancer patient, primary family caregiver, and nurse caring for the patient in the home setting.

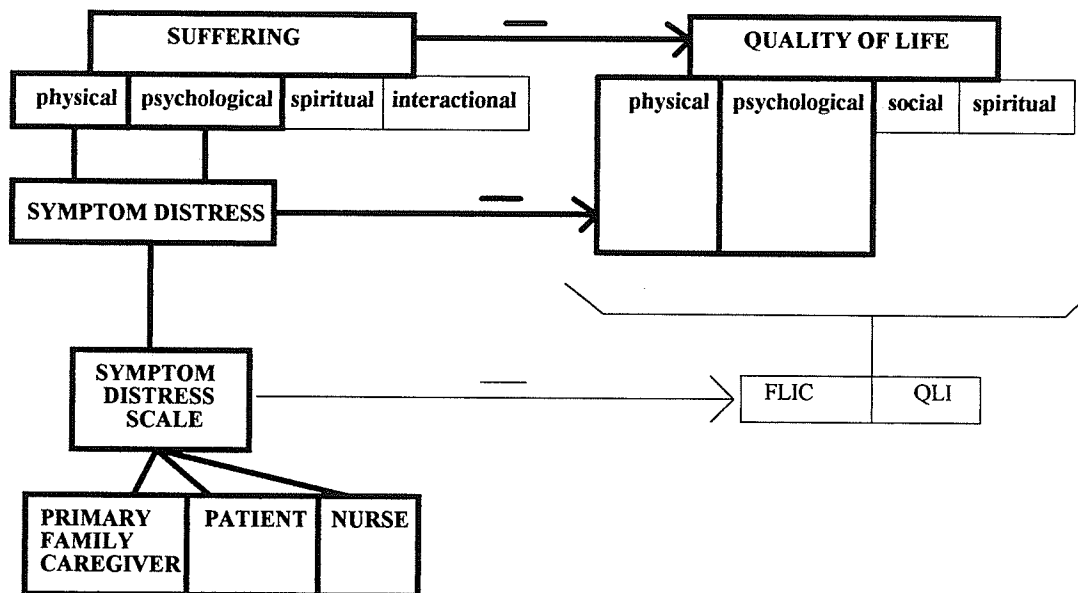


Figure 1. The relationships among symptom distress, suffering, and quality of life.

The overall conceptual framework provides the broader context within which this program of research is embedded. This framework is described as follows and illustrated in Figure 1. The event of symptom distress includes aversive biological and psychological signals of distress that may cause suffering. Suffering is a negative affective state resulting from symptom distress that is perceived to be physically painful, uncomfortable, or psychologically distressing. Suffering in turn may negatively affect the physical and psychological dimensions of quality of life.

Graham and Longman (1987) and Germino (1987) state that management of symptoms and symptom distress is within the nursing realm and the focus in oncology nursing. Symptom distress is also purported to be an indicator of the effectiveness of nursing interventions on patient quality of life (Watson, Rhodes, & Germino, 1987). Therefore, effective assessment of symptom distress is the first step in symptom management, amelioration of suffering, and achieving an optimal quality of life in the patient.

The conceptual framework that operationalizes this study is derived from the work of Davitz and Davitz (1981) on nurses' inferences of suffering. This framework was modified to conceptualize how individuals infer symptom distress in lung cancer patients. This study will assume that symptom distress includes aversive biological and psychological signals of distress that may contribute to suffering. For the cancer patient, an

interaction of biological/physical and psychological stressors commonly occurs (Benedict, 1989; Chapman & Gavrin, 1993). The concept of symptom distress will be used in this study to capture physical and psychological aspects of suffering in the lung cancer patient as perceived by the patient, primary family caregiver, and nurse.

Davitz and Davitz (1981) formulated several propositions as general guidelines for research in suffering:

1. "The suffering [or symptom distress] of another person is necessarily inferred rather than directly observed" (p. 12). In other words, the observer's judgment of the degree of symptom distress experienced by the lung cancer patient depends on an inference process, that, in turn, depends in part from observations of the patient in symptom distress.
2. "An inference made from observations requires a cognitive process that either explicitly or implicitly takes the following form: observation of cues; interpretation of these cues in terms of the experience of suffering [symptom distress]; judgment of the other person's suffering [symptom distress]" (p. 12).

Figure 2 is a schematic illustration (based on Davitz & Davitz, 1981) as depicted by Shapiro (1991) and adapted by this researcher to demonstrate the way in which the nurse and primary family caregiver may infer symptom distress in a lung cancer patient.

According to the model, adapted for use in this study, the individual first experiences a physical symptom or sensation that is an indication of a

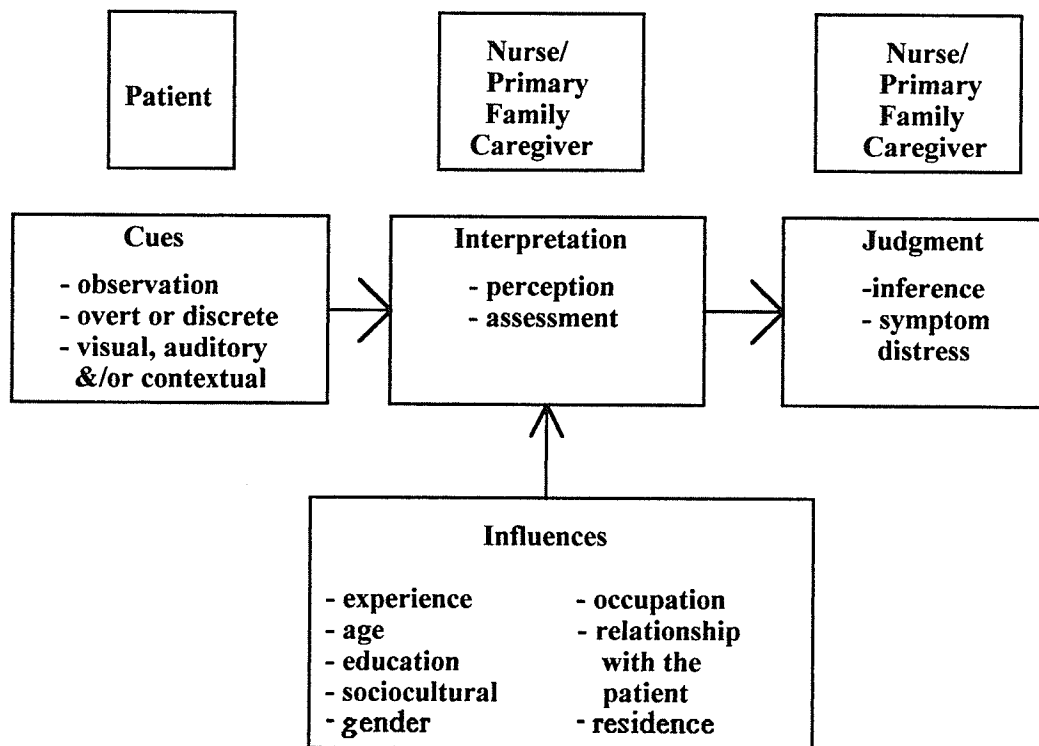


Figure 2. Primary family caregivers' / Nurse's inferences of symptom distress.

condition departing from normal function, sensation, or appearance. Once the individual experiences the occurrence of the symptom, additional perceptions include how frequently the symptom occurs, the duration, and how severe or intense it is (Rhodes & Waton, 1987). The amount of distress perceived from the symptom(s) may depend for example on the mere occurrence of the symptom, patient's age, gender, educational level, experience with the disease, ethnicity, marital status, medical treatment, stage of disease, and occupation (Rhodes & Watson, 1987; Tishelman et al., 1991).

The symptom experience, which may initiate distress in the patient, then may be followed by a variety of psychological or behavioural responses. These responses provide the observant nurse or primary family caregiver with cues as to the individual's state, condition, or experience. Some of these responses may be blatantly overt, such as self-report of nausea or pain. Cues can also be more subtle and difficult to observe such as those that require the patient's verbal communication about nausea, fatigue, and breathing (Holmes & Eburn, 1989; Peruselli et al., 1992; Shapiro, 1991).

Inference of symptom distress depends on knowledge of the context which provides valuable information that is useful in decision-making. For example, knowing the patient has just undergone chemotherapy can lead one to reasonably assume that the distress from nausea and decreased appetite will generally be present for the first 48 hours.

Following the observation of these cues, the observer then undergoes an inference process. This is a process of explaining or interpreting data gathered during the assessment in terms of symptom distress. Symptom distress can be defined as the degree of discomfort from a specific symptom being experienced by the patient (McCorkle & Young, 1978). The term 'symptom distress' refers not only to the frequency, duration, and severity of the symptom being experienced, but also to the degree that the symptom distresses the patient (Rhodes & Watson, 1987).

The interpretation of the individual's cues in terms of the experience of symptom distress is influenced by a number of factors. Some of these factors include for example, the observer's age, gender, education level, experience with the disease, ethnicity, occupation, and relationship with the patient (Baer et al., 1970; Davitz & Pendleton, 1970; Reid-Point, 1992; Rhodes & Watson, 1987).

The observer then makes an inferential judgment about the patient's symptom experience. Decisions are made about the frequency or presence of pain, nausea, outlook, insomnia, fatigue, appetite, breathing, cough, concentration, mood, concentration, and intensity of pain and nausea. Davitz and Davitz (1981) state that "presumably the inference is made on the basis of observed cues, but it is also influenced by one's characteristic inferential response to such cues" (p. 9). It would not be unreasonable for two observers to differ in their inferences of symptom distress.

SUMMARY

In summary, a review of the literature pertinent to the study of symptom distress in lung cancer patients has been presented. Several studies have been undertaken to examine the concept of suffering and related aspects to suffering in cancer patients. It appears from this literature review that suffering captures dimensions also encountered in symptom distress assessment and measurement by McCorkle and Young (1978), making a theoretical framework that includes both these constructs meaningful.

The symptoms of lung cancer are not only distressing for patients, but also for family members and nurses caring for them. Generally lung cancer patients present with multiple symptoms and metastatic disease at time of clinical diagnosis. Care and treatment for these patients are generally palliative. However, literature identifies that treatment does incur side-effects that are often toxic and inconvenient for the patient who may experience limited gains in survival.

Research findings that reveal incongruence in assessments of patients' and families' needs by patients, family members, and nurses suggest that ineffective patient-caregiver communication is present. Studies also reveal that discrepancies exist between nurses' assessments and patients' self-assessments of symptom distress. This has been attributed to the fact that symptoms and symptom distress are phenomena perceived only by the patient and not directly observed by others.

Currently there is no research that examines the congruence of perceptions of symptom distress among patients, primary family caregivers, and nurses. As well, the cues nurses and primary family caregivers use when assessing symptom distress have not been investigated in research studies.

The theoretical framework derived from Davitz and Davitz's (1981) work on nurses' inferences of suffering provides the basis for understanding how perceptions of symptom distress may vary among patients, nurses, and primary family caregivers. In this study, symptom distress is hypothesized to be a measure that can index physical and psychological dimensions of suffering. In turn, suffering may negatively affect an individual's quality of life; particularly the physical and psychological domains.

CHAPTER THREE

METHODOLOGY

Given the paucity of research investigating the congruence of perceptions of symptom distress among patients, primary family caregivers, and nurses, a descriptive comparative study was judged to be the most appropriate level of investigation to pursue. The purpose of this study was to identify: (a) whether a disparity in assessment of symptom distress exists among lung cancer patients, primary family caregivers, and nurses who care for these patients in the home care setting; (b) the cues primary family caregivers and nurses respond to when assessing symptom distress; and (c) whether there is a difference in the cues that primary family caregivers and nurses respond to when assessing symptom distress in the patient.

A comparative descriptive design allowed the researcher to ask the question, "What are the differences between groups when the groups represent different positions of the independent variable and why does this difference result?" (Brink & Wood, 1989, p. 87). In this study the dependent variables were: (a) the SDS scores (perceptions of symptom distress) and (b) the cues used by nurses and primary family caregivers to assess symptom distress. The independent variable was the category of individuals involved in the care of the patient (lung cancer patients, primary family caregivers, and nurses).

To answer the question, "Why do differences occur?", qualitative data was included in this study to provide a richer, deeper understanding of

how nurses and primary family caregivers assess and perceive symptom distress in the lung cancer patient. The cues that patients respond to when assessing symptom distress was not examined in this study because the concept of symptom distress is a subjective one. Apart from observing the occurrence of symptoms, the degree of distress experienced by the patient is not observable and "can only be conjectured by another human being" (Rhodes, Watson, & Johnson, 1984, p. 39). Therefore, it was deemed inappropriate to determine whether primary family caregivers and nurses respond to the same cues or signals of symptom distress as patients would themselves.

Population and sample

The population under scrutiny consisted of lung cancer patients, primary family caregivers, and nurses caring for these patients in the home setting. The original aim of this study was to have eighty patient-family caregiver-nurse triads comprise the sample for this study. Sample size was based on a power analysis for the F test. A sample of 80, alpha of .05, d.f. = 2, results in a power of .94 for an effect size of .25 (medium effect).

All lung cancer patients admitted to palliative home care programs at St. Boniface General Hospital and Riverview Health Center who are receiving nursing home care were eligible for the study. In 1993, the palliative home care service at St. Boniface General Hospital served a caseload of 63 lung cancer patients (D. Kelly, personal communication,

March 20, 1994). However, fewer than 63 lung cancer patients received nursing service in their homes. To obtain a sample of approximately 40 lung cancer patients from each program, who meet the same criteria in a reasonable amount of time, inclusion of all subjects was judged to be most feasible. This would represent approximately 11 percent of the Manitoba population with lung cancer (Manitoba Cancer Treatment and Research Foundation, 1993).

Approximately half way into data collection (i.e., four months), the investigator determined that the accrual of participants was well below the target number of participants anticipated to be included in the study at that time. In addition to the two recruitment sites above described, participants were recruited from outpatient radiation and chemotherapy oncology departments with the Victoria General Hospital and The Manitoba Cancer Treatment and Research Foundation (MCTRF).

To be included in the study, patients met the following criteria: (a) must be medically diagnosed with lung cancer (small cell or non-small cell lung carcinoma); (b) must be 18 years of age or older to qualify as an adult; (c) must be able to speak, read, and write the English language; (d) must be well enough to participate and give no evidence of mental confusion in his or her interactions with health care professionals, family, and the research nurse; and (e) must be currently enrolled in the palliative home care program at either St. Boniface General Hospital or Riverview Health Center or must be currently enrolled as an outpatient with the Victoria

General Hospital Oncology Department or the MCTRF outpatient clinics at 100 Olivia Street or St. Boniface General Hospital.

The criteria for participation of primary family caregivers in this study included: (a) must be identified by the patient as being primarily involved in the care of the patient in the home setting (biological, legal, or functional relationships) and (b) must be able to speak, read, and write the English language.

Approximately 80 VON home visiting nurses were with the Palliative Home Care Programs at St. Boniface General Hospital and Riverview Health Center (D. Kelly, personal communication, April 12, 1994). A convenience sample of nurses who were assigned to care for lung cancer patients and consented to participate were included.

The criteria for participation of nurses in the study included: (a) must be a currently licensed registered nurse and (b) must be currently assigned by the home care agency to care for the patient. The investigator commenced data collection over the summer months. This was a time when many primary care nurses were on vacation. Therefore, it was deemed unreasonable to set an inclusion criterion that specified the registered nurse must be the primary care nurse for the patient.

One concern with this choice of research setting was the feasibility of coordinating home visits with nurses, primary family caregivers, and patients. In view of this concern, the investigator collected data over seven months. This time frame allowed the investigator a reasonable amount of

time to collect data.

Procedures for Data Collection

Verbal approval for the study from the coordinators of the Palliative Home Care Programs at St. Boniface General Hospital and Riverview Health Center and the Assistant Executive Director of VON Winnipeg was obtained. Written approval to access subjects in the home and clinic settings was obtained from the Provincial Office of Continuing Care, Access Committees at St. Boniface General Hospital, Riverview Health Center, Victoria General Hospital, and the MCTRF.

Recruitment of subjects from the home care setting

The following procedure for recruitment of subjects in the home care setting was discussed with VON Winnipeg and Palliative Home Care Coordinators and was generally acceptable.

Nurses. The investigator met with VON Nursing Area Managers at a meeting to explain the study and elicit their encouragement of voluntary participation in the study by their staff nurses. After the VON Nursing Area Managers approved the study, the investigator arranged to meet with nursing staff during scheduled periods when nursing staff from six geographic regions of the City of Winnipeg would come in to the office to confirm patient assignments and schedules for home visits for the week. At six meetings with nursing staff, the investigator discussed the purpose

of the project and asked for nurses' voluntary participation.

The nursing staff were also provided with written disclaimer forms. The disclaimer form provided a written explanation of the study and a response portion that all nurses could complete (see Appendix A). The response portion contained the words "Yes" and "No" with regard to the nurses' desire to participate in the study. Initially it was decided that nurses' responses would be returned to VON Area Managers. However, this procedure resulted in some nurses not returning their responses to VON Area Managers. It was then decided between the investigator and VON Area Managers that nurses could either return their responses to a staff member with Staff Development and Education with the VON or forward their responses to the investigator in a self-addressed, stamped envelope. Confidentiality of participation by nurses could not be assured because it was apparent during implementation of the study which nurses were included. However, their responses were kept confidential. Only the investigator had access to the nurses' responses to the invitation to participate.

Patients and primary family caregivers. The investigator provided Home Care Coordinators of the Palliative Care Programs with a list of inclusion criteria for patients and primary family caregivers who are eligible as participants in the study. Home Care Coordinators provided patients and primary family caregivers with a letter requesting permission to release their names to the investigator as possible participants in the

study (see Appendix B). If the patient and family member did not wish their names to be released they would contact the respective Home Care Coordinators. The Home Care Coordinators would then submit to the investigator a list of names and telephone numbers of patients and primary family caregivers who have not called the Home Care Coordinators about not wanting the release of their names. The investigator then contacted patients and/or primary family caregivers by telephone and provided further information about the study.

It was pointed out to the investigator by the Palliative Home Care Coordinators that a number of patients enrolled in their Programs were not receiving home care services. These patients were being eliminated as eligible participants by Home Care Coordinators because they did not meet the inclusion criterion of currently receiving nursing care in their homes. It was decided by the investigator and the Thesis Chairperson to include all eligible lung cancer patients, regardless of receipt of nursing services in patients' homes. In other words, if patients were receiving nursing care by VON nurses then the investigator attempted to include participating nurses in the study. If patients were not receiving VON nursing services in their homes, then only patients and their primary family caregivers participated in the study.

Recruitment of subjects from the outpatient clinic setting

The following procedure for recruitment of subjects from the

outpatient clinic setting was discussed with the Director of Nursing and clinic nurses at the MCTRF and was generally acceptable.

Nurses. The investigator met with the Director of Nursing and clinic nurses with the MCTRF to explain the study and their role in facilitating access to the patient population. The clinic nurse's role as a possible participant in the study was also explained. At this meeting, clinic nurses indicated that it would not be feasible for them to be involved as participants in the study due to heavy patient caseloads and time constraints. However, clinic nurses indicated their willingness in a role to assist the investigator in recruiting patients from the respective outpatient chemotherapy and radiation clinics (i.e., 100 Olivia Street site, St. Boniface General Hospital, and Victoria General Hospital).

Patients and primary family caregivers. At this meeting with clinic nurses, the investigator also obtained their input as to the following method used to recruit patients and family members from outpatient settings.

On scheduled clinic days for lung cancer patients, the investigator met with clinic nurses who identified, from the appointment list and patients' medical records, subjects who met the inclusion criteria. Clinic nurses then introduced the investigator to patients who were eligible as participants. The investigator then described the purpose of the study and elicited patients' voluntary participation in the study. If patients agreed to participate, then the investigator also determined if they were in receipt of

VON nursing services in order to plan for a home visit with participating nurses to the patient and his or her primary family caregiver.

Data Collection Protocol

Home care setting. The investigator initially provided VON Winnipeg with a list of patients and primary family caregivers who agreed to allow the investigator to make a home visit to them. This list was then submitted to VON Nursing Area Managers (by geographic location) who would inform nurses, who were assigned to care for lung cancer patients, that their patients had agreed to participate in the study. Up to that point in time, the investigator had awaited telephone contact from participating VON nurses who were assigned to care for patients who agreed to participate. However, in relation to loss of eligible patient participants due to unpredicted hospital admissions or death, the investigator felt it important to make more timely and efficient contact with VON nurses to schedule for home visits. It was then agreed upon by the investigator and VON Area Managers for the investigator to make direct contact with participating VON nurses in order to schedule for home visits.

If a home visit was scheduled to occur with a participating VON nurse, prior to administering written disclaimer forms and questionnaires, the investigator allowed the nurse time to assess and care for the patient. The investigator then provided a written consent for the patient (see Appendix C) and disclaimer for the primary family caregiver (see

Appendix D). Once the patient consent and primary family caregiver disclaimers were read and understood, all participants were asked to complete the questionnaires.

Clinic outpatient setting. If patients agreed to participate, either they would request the investigator to contact them at a later date to schedule a home visit or if convenient for them, patients and family caregivers would complete their questionnaires while at the clinic. Generally, when questionnaires were completed at clinic settings, staff accommodated the investigator by allowing patients and primary family caregivers to answer survey questions in a quiet clinic area or treatment room.

If participants verbally agreed to participate, the investigator then provided a written consent for the patient (see Appendix C) and disclaimer for the primary family caregiver (see Appendix D). Once the patient consent and primary family caregiver disclaimers were read and understood, all participants were asked to complete the questionnaires.

Instruments

Five types of measures were used in this study. The first instrument was a formal mental status examination of the patient and the second was a measure of the patient's functional status. The third instrument was a measure of symptom distress and the fourth measured the demographic characteristics of participants. The fifth measure was an open-ended

questionnaire that elicited qualitative data from primary family caregivers and nurses regarding the cues they respond to when assessing symptom distress in the patient.

One reason for blending quantitative and qualitative data is that they are complementary (Polit & Hungler, 1991). Qualitative data may assist the investigator to derive meaning from statistical findings. In this study, responses to the open-ended questionnaire (qualitative data) yielded some understanding as to 'why' perceptions of symptom distress or symptom distress scores (quantitative data) may vary among patients, primary family caregivers, and nurses. Polit and Hungler (1991) explain that an integrated model enhances "interpretability of results" and is a "mechanism of substantive validation" (p. 522).

The Folstein Mini-Mental Status Examination

The Folstein Mini-Mental Status Examination was administered to assure that data is collected from patients capable of responding reliably. This examination was administered by the investigator to the patient prior to the administration of the patient demographic data form and SDS (Folstein, Folstein, & McHugh, 1975) (see Appendix E). Patients with minimal scores greater than or equal to 24 of 30 were eligible to participate in this study. Similar cut-off scores on the minimal examination were used in studies involving patients capable of responding reliably on self-reports of pain intensity (Bruera, Fainsinger, Miller, &

Kuehn, 1992; Grossman, Sheidler, McGuire, Geer, Santor, & Piantadosi, 1992; Grossman, Sheidler, Swedeen, Mucenski, & Piantadosi, 1991). This examination took approximately five to ten minutes to complete.

The Karnofsky Performance Status

The Karnofsky Performance Status (KPS) has a long history of use with the measurement of functional status in patients with cancer, particularly those with lung cancer (Coward, 1991; Karnofsky & Burchenal, 1949; Sarna, 1994) (see Appendix F). The KPS has also been widely used as an indicator of quality of life (Clark & Fallowfield, 1986; Ganz, Schag, & Cheng, 1990; Stanley, 1980) and examined in relationship to survival time (Ganz, Lee, & Siau, 1991; Sarna, 1994). In this study, this scale assisted the investigator in clarifying the patient stage of illness. In subsequent studies, the KPS will assist the investigator in examining the relationship between survival time and KPS scores. Completion of this instrument took approximately one minute by the investigator.

Demographic Data Forms

Demographic data was obtained to describe the sample and determine if relationships existed between certain data items and the dependent variable (group SDS scores). Potential influencing demographic data were based on a literature review of variables purported to have an effect on the patient's and another individual's perceptions of

symptom distress (see Table 2). Completion of demographic data forms took less than five minutes.

The Patient Demographic Data Form. The patient demographic data form was used to collect information concerning: patient age, gender, marital status, diagnosis (small cell lung cancer or non-small cell lung cancer), stage of illness, time since diagnosis, current treatment, previous treatment, ethnicity, educational level, occupation, occupational status, income level, and length of time receiving present nursing home care (see Appendix G).

In all instances demographic data were elicited from patients, primary family caregivers, and nurses. The investigator also obtained permission to access patients' charts in the patient disclaimer. In instances of lack of clarity in demographic information (stage of illness, date of diagnosis), chart review for clarification and accuracy of demographic data ensued.

The following staging systems of lung cancer were used in this study for SCLC and NSCLC respectively. The TNM staging system developed by the American Joint Committee for Cancer Staging and End Results Reporting is: (a) commonly used in classifying the cancer by tumor size, presence or absence of nodal involvement, presence or absence of metastases; (b) useful in prognosis and planning treatment; and (c) useful in predicting surgical resectability in lung cancer (Otto, 1994; Tabbarah, Lowitz, & Casciato, 1988). The TNM system can be applied to classify all

Table 2

Variables examined as covariates with symptom distress scores

<u>Variable</u>	<u>Individual Perception Affected</u>	<u>Author(s), Year</u>	<u>Findings</u>
Patient Age	Cancer Patients (Heterogenous) n = 434	Degner and Sloan (in press)	Age was weakly correlated with symptom distress ($r = -.11$; $p = .026$). Older patients had less distress than those who were younger.
	Cancer Patients (Heterogenous) n = 46	Tishelman et al. (1991)	Distress was significantly increased in younger persons (no magnitude coefficients reported).
	Nurses n = 67	Davitz and Pendleton (1969)	Nurses' inferences of suffering differ accordingly to age of the patient ($p < .05$). Inferences of suffering were greater in younger than older patients
	Nurses n = 161	Mason (1981)	Nurses inferred a greater amount of pain in children than in patients older than 65 years at a statistically significant level ($p < .05$). Patients 30-45 years of age were inferred to have the greatest amount of psychological suffering at a statistically significant level ($p < .001$).
Nurse Age	Nurses n = 161	Mason (1981)	The age of the nurse was not a statistically significant factor in influencing inferences of suffering ($p < .05$)
Patient Gender	Cancer Patients (Heterogenous) n = 434	Degner and Sloan (in press)	Women reported more distress than men ($t = -2.05$, $p = .041$)
	Cancer Patients (Heterogenous) n = 65	Reid-Pointe (1992)	Distress levels between men and women were significantly different ($F = 3.82$; $p = .05$)

Table 2 (cont'd)

<u>Variable</u>	<u>Individual Perception Affected</u>	<u>Author(s), Year</u>	<u>Findings</u>
Patient Gender (cont'd)	Cancer Patients (Heterogenous) n = 46	Tishelman et al. (1991)	Distress was significantly higher in women (no magnitude coefficients reported)
	Nurses n = 67	Davitz and Pendleton (1969)	There was no statistically significant difference in inferences of suffering according to the gender of the patient ($p < .05$).
Patient Marital Status	Cancer Patients (Heterogenous) n = 46	Tishelman et al. (1991)	Distress is significantly increased in patients not married (no magnitude coefficients reported)
Nurse Ethnicity	Nurses Korean n = 32; Thailand n = 30; Puerto Rican n = 23; African American n = 20; American Caucasian n = 25	Davitz and Pendleton (1969)	Nurses' inferences of suffering differ significantly according to cultural and subcultural background of the nurse ($p < .01$)
Patient Ethnicity	Nurses n = 40	Davitz and Davitz (1981)	There were statistically significant relationships between nurses' inferences of suffering and the ethnic background of patients ($p < .05$).
Occupation (observer)	Nurses n = 33; Physicians n = 30; Nuns n = 36; Teachers n = 32	Lenburg et al. (1970)	Occupational groups differed significantly from each other in inferences of pain ($p < .01$) and psychological distress ($p < .05$). Nuns inferred the greatest pain and distress, followed by teachers, nurses, and physicians

Table 2 (cont'd)

<u>Variable</u>	<u>Individual</u> <u>Perception</u>	<u>Author(s), Year</u>	<u>Findings</u>
	<u>Affected</u>		
Activity Status (full-time or part-time)	Nurses n = 161	Mason (1981)	The activity status of the nurse was not found to be a statistically significant factor influencing inference of suffering ($p < .05$).
Stage of Illness	Cancer Patients (Heterogenous) n = 434	Degner and Sloan (in press)	Patients with advanced disease had significantly more distress than those with early disease ($t = -5.44$, $p = .000$)
	Nurses n=33; Physicians n = 30; Nuns n = 36; Teachers n = 32	Lenburg et al. (1970)	Inspection of mean scores indicated that onset of illness phase received the highest inference of both pain and psychological distress, followed by treatment and prognosis stages. There were statistically significant differences between stages of illness and inferences of suffering by nurses, nuns, physicians, and teachers ($p < .001$)
	Cancer Patients (Heterogenous) n = 46	Tishelman et al. (1991)	Disease stage was not shown to be significantly related to reports of distress (standardized beta coefficient = $-.052$; $p \leq .10$)
	Breast Cancer Patients n = 107	Ehlke (1988)	Disease stage was not shown to be significantly related to symptom distress ($r = .17$; $p = .06$)
Patient loads	Physicians n = unknown	Wartman et al. (1983)	Thirty-five percent physicians underestimated patients' perceptions of pain, anxiety, and activity limitation. The researchers attribute the reliability of physicians' estimates of patients' distress to the effects of physicians' patient loads, demands on physicians' time, and interpersonal activities with their patients

Table 2 (cont'd)

<u>Variable</u>	<u>Individual Perception Affected</u>	<u>Author(s), Year</u>	<u>Findings</u>
Experience with the illness	Nurses n = 28	Larson et al. (1993)	Statistically significant differences in reports of symptom distress were reported between nurses and bone marrow transport (BMT) patients ($p < .002$). The researchers attribute these findings to an interpretation that nurses are influenced by prior experiences with BMT patients.
Oncologic Treatment	Cancer Patients (Heterogenous) n = 46	Tishelman et al. (1991)	Oncologic treatment (surgery, chemotherapy, radiotherapy) is significantly related to symptom distress (standardized beta coefficient = .556; $p \leq .01$)
Socioeconomic background	Nurses n = 67	Davitz and Pendleton (1969)	Nurses' inferences of suffering differ significantly according to the patients' socioeconomic class ($p < .05$). Greater suffering was inferred in middle or lower class patients. There was no significant difference in inferred suffering between middle and lower class patients.
Years of nursing experience	Nurses n = 32	Davis (1991)	As the number of years in nursing or cancer nursing increased, the differences between nurses' and patients' scores decreased (no adjusted R-square values reported).
	Nurses n = 161	Mason (1981)	Nurses with less than one year of nursing experience and nurses with six to ten years of experience differed in inferences of patient physical suffering ($p < .05$). Nurses did not vary in their inferences of psychological distress in relation to length of professional experience.
Educational Preparation	Nurses n = 161	Mason (1981)	The educational preparation of nurses was not a statistically significant factor in influencing inferences of patient suffering ($p < .05$).

types of lung cancer except SCLC. This system has limited usefulness with SCLC because only five percent SCLC patients have operable (Stage I or Stage II) disease (Glover & Miaskowski, 1994).

Stages I and II describe limited or localized NSCLC for which surgery is the treatment of choice. Stage I reveals a mass limited to the organ of origin (Van Houtte, Salazar, Phillips, & Asbury, 1983). Stage II shows evidence of local spread into surrounding tissue and first-station lymph nodes (Snyder, 1986). Stage III describes local advanced disease and reveals an extensive primary lesion with fixation to deeper structures and lymph nodes exhibit evidence of malignant invasion (Snyder, 1986). Stage III is divided into two categories: when the disease is limited to the thorax and when it presents with metastatic spread into mediastinal structures and outside the thorax (Van Houtte et al., 1983). Occasionally, patients with localized chest wall involvement are candidates for surgery (Van Houtte et al., 1983; Groenwald, 1980). Stage IV patients have disseminated disease or distant metastases to the brain, bone, abdominal organs (liver), skin, adrenal glands, kidneys, or the other lung, and are poor surgical candidates for resection of a primary lung lesion (American Joint Committee on Cancer, 1988; Cohen, 1978; Langston, 1992).

The TNM system is not useful in classifying SCLC as the disease has already reached Stage III (Engelking, 1987) or Stage IV (Glover & Miaskowski, 1994) at diagnosis. The Veterans Administration Lung Cancer Study Group developed a two-stage system that is most frequently

used in classifying SCLC (Zelen, 1973). 'Limited' disease refers to lung cancer limited to one lung, with or without regional lymph node involvement. 'Extensive' disease refers to lung cancer beyond 'limited' disease and may involve metastases to the liver, bone, bone marrow, brain, adrenal glands, and lymph nodes (Otto, 1994).

The Primary Family Caregiver Demographic Data Form. The primary family caregiver demographic data form was used to collect information from the family caregiver concerning: age, gender, ethnicity, educational level, occupational status (e.g., full-time, part-time), occupation, length of time caring for the patient, residence (with or without the patient), and his or her relationship with the patient (e.g., spouse, sister, brother, parent, friend) (see Appendix H).

Nurse Demographic Data Form. The nurse demographic data form was used to collect information from the home visiting nurse concerning: age, gender, ethnicity, occupational status (e.g., full-time, part-time), educational level, number of years in nursing, number of years in home care, cancer nursing experience, whether he or she is the primary nurse to the patient, when the last visit was made to the patient, average number of patients visited daily, number of patients to be seen today, the average demand on the nurse's time, the demand on the nurse's time today, and the nurse's perception of the patient's financial stress (see Appendix I)

The Symptom Distress Scale

The Symptom Distress Scale (SDS) by McCorkle and Young (1978) was completed by the patient, primary family caregiver, and nurse during the home visit by the investigator (see Appendix J). Subjects were asked to rate the symptom distress experienced by the patient on the day of the investigator's visit. Cohen and Mount (1992) state that quality of life ratings or questions concerning 'the past two or three days' may be the best frame of reference. However, the nurse participating in this study was not necessarily the primary care nurse who had recent contact with the patient (within the past two or three days), thereby making the suggested frame of reference inappropriate.

The participants were given the SDS in a 'flash card' format. This format consisted of five by seven cards; each bearing a single symptom on a Likert-type scale from one (least amount of distress) to five (extreme distress). Thirteen cards representing thirteen symptoms were administered one at a time to patients. If patients felt they did not need the investigator's assistance, they were asked to read each card and provide a written response as to the number that most closely measured how they perceived their distress for each symptom on that day. Otherwise, if patients indicated they required the assistance of the investigator then they would provide a verbal response to each SDS item and the investigator would complete the SDS scale. These patients completed the SDS in a separate room where their responses were not heard by the family member

(and nurse). This format of the SDS was chosen to prevent undue burden on lung cancer patients who are generally an older population and known to have diminished energy and attention span.

Cronbach's alpha coefficient reliability estimates range from .78 to .97 as established in previous studies (Holmes & Eburn, 1989; Larson et al., 1993; McCorkle & Benoliel, 1983; McCorkle & Young, 1978). Convergent validity ($r = .90$) was obtained when Ware's health perception questionnaire and the SDS were used with cancer patients who were tested over time (McCorkle, 1986). Discriminant validity was also obtained when the SDS was able to discriminate cancer patients from heart patient survivors (McCorkle & Benoliel, 1983). The SDS scale has demonstrated face and content validity for specific symptoms as identified by cancer patients themselves (McCorkle & Young, 1978). This scale was easily completed in five to ten minutes, which was important to consider when studying a population that is greater than 55 years of age and has diminished attention span and limited energy levels (McCorkle & Young, 1978).

In addition to the brief written instructions attached to the SDS, detailed instructions for completing the item questions were given by the investigator using a standardized format and sample item typed on a 5 x 7 inch card. Various marks on the Likert-type scale were explained as an example of where individuals with varying degrees of distress might indicate their responses. The primary family caregiver (and the nurse)

were asked to rate the patient according to how they perceived the patient was feeling with regard to each symptom. After the participants verbalized an understanding of the procedure, they were instructed to complete the questionnaires. The investigator was available to answer any questions about the questionnaires and the study. The presence of the investigator was also necessary to ensure the participants refrained from discussing symptoms on the instruments until after they were returned to the investigator.

Open-ended Questionnaire

An open-ended paper and pen questionnaire was administered to primary family caregivers (and nurses) to determine the cues they respond to when assessing symptom distress in lung cancer patients (see Appendix K). Primary family caregivers (and nurses) were able to complete this questionnaire within ten to fifteen minutes. This information was used to augment the data from the SDS. The following question was asked: "What things lead you to believe the patient is having distress from the following symptoms - fatigue, bowel, concentration, appearance, breathing, outlook, cough, nausea, appetite, insomnia, and pain?" (Subjects to include any visual, auditory, and written cues). This question was based on Shapiro's (1991) research on nurses' judgments of pain intensity in term and preterm newborns.

Protection of human subjects

Written permission to conduct this study was obtained from the Ethical Review Committee, Faculty of Nursing at the University of Manitoba prior to implementation. Written permission from the Provincial Office of Continuing Care to access VON Winnipeg and from Access Committees at St. Boniface General Hospital, Riverview Health Center, Victoria General Hospital, and MCTRF to access patients, primary family caregivers, and patients' charts for data collection was also obtained.

Only those subjects who voluntarily agreed to participate in the study were included. A verbal explanation of the purpose of the study and its risks and benefits was given to each participant. The investigator stressed that patients and primary family caregivers could withdraw at any time during the study with no effect on their care or treatment. A written explanation of the study was included in the disclaimer for patients, primary family caregivers, and nurses.

All information was gathered from patients, family caregivers, and nurses themselves. Permission to access patients' charts was sought in the patient disclaimer form for instances where a lack of clarity in demographic data existed. Demographic data was obtained to describe the representativeness of the sample and in subsequent studies determine the relationship between certain data items. For example, Sarna (1994) found statistically significant differences in physical function by income level on the KPS scale ($F = 2.8, p = .01$). Female lung cancer patients ($n = 69$) with

the lowest level of income had the lowest function level. In this study the level of income was asked to compare findings with other studies conducted in the United States where income level appears to play a significant role in patient quality of life. Prior research with advanced cancer patients and family members indicates that this question, worded as a categorical variable, is generally acceptable to subjects and results in less than five percent missing data (Kristjanson, 1986; 1989). In this study, the level of income question was accepted by the majority of subjects and resulted in two percent missing data.

Confidentiality of the information was guaranteed by the researcher. In any instance where demographic variables had a frequency lower than five, data was reported with larger group data to protect the anonymity of participants. A code number for each patient, primary family caregiver, and nurse was assigned and written on all questionnaires. Participants were instructed not to write their names on the forms and were reassured that no names will appear in written reports of the study. The list connecting participants with code numbers was kept separately under lock and key. The researcher's advisor and thesis committee were the only other persons having access to the data.

Data Analysis

Both quantitative and qualitative methods of data analysis were used in this study. Data analysis included six steps. Descriptive statistics

such as frequency distributions, ranges, means, and standard deviations were used to describe the overall sample characteristics in terms of demographic and disease variables and symptom distress. Parametric and non-parametric tests provided statistical analysis of factors (e.g., age, gender, ethnicity) purported in other studies to affect the dependent variable (SDS scores). Internal consistency reliability of the SDS for the patients, primary family caregivers, and nurses were analyzed using Cronbach's alpha.

Research hypothesis one stated, "there is no difference in perceptions of symptom distress among patients, primary family caregivers, and nurses." However, the limited number of nurses who participated in this study precluded statistical analysis of nurse data. Therefore, based on the non-normal distribution of patient and caregiver data, appropriate non-parametric tests were conducted to test for differences in perceptions of symptom distress among patients and primary family caregivers.

Research hypothesis two stated, "there is no difference in the cues identified by primary family caregivers and nurses when assessing symptom distress." Statistical analysis involving cues identified by nurses was precluded due to the small number of nurse participants. However, a content analysis of primary family caregiver data was conducted. Content analysis is a method for quantifying the content of communications in a systematic and objective way (Polit & Hunger, 1991). Content analysis was conducted on the open-ended questionnaire data with respect to the

cues that primary family caregivers identified they respond to when assessing symptom distress in the lung cancer patient. The investigator reviewed the questionnaires to discover and record the occurrence of each of the cues identified. The cues were compared with each other and assigned to clusters or categories according to obvious fit (Stern, 1980). Frequency counts of the occurrence of cues within each category were kept for scoring and performing quantitative procedures. Miles and Huberman's (1984) qualitative matrix analysis was used as a method to compare SDS responses and frequency counts of the occurrence of cues within each category. Matrix displays are an "especially economical way" to determine whether relationships exist between variables (Miles & Huberman, 1984).

Additional non-parametric tests were conducted to determine the effects of cues on discrepancy scores between patients' and primary family caregivers' ratings of symptom distress. The research question tested was, "Is there a difference in discrepancy scores in relation to primary family caregiver use of particular cue categories?" In other words, the investigator tested whether there was a difference in discrepancy scores between groups of family caregivers who referred to specific cue categories and family caregivers who did not refer to similar cue categories.

SUMMARY

This paper has outlined the methods that was used to carry out a

comparative descriptive study aimed at exploring differences in patients', primary family caregivers', and nurses' perceptions of symptom distress and the cues used by primary family caregivers and nurses when assessing symptom distress in lung cancer patients. In light of the small number of nurse participants, statistical analyses of only patient and primary family caregiver data were conducted.

The theoretical framework of this study was used to predict cause-and-effect relationships, however both the independent (comparison groups) and dependent (SDS scores and cues used to assess symptom distress) variables were observed as they occurred naturally without investigator interference (Brink & Wood, 1989). Group differences in the SDS scores were explored, where the groups represented different positions of the independent variable. Statistical hypotheses that predicted the outcomes for the groups were developed based on theoretical knowledge that exists on perceptions of symptom distress, psychological distress, and pain.

A formal mental status examination, functional ability questionnaire, interval scale, open-ended questionnaire, and demographic data form were used to collect the data. Results of reliability and validity assessments for the SDS scale were discussed indicating that psychometric criteria were met. The subject criteria and data collection protocol used were discussed. The data analysis plan was described that will answer the questions, "What is the difference among the groups?" and "Why does this

difference occur?". The procedure for assuring subject protection was also described.

CHAPTER FOUR

RESULTS OF DATA ANALYSIS

The purpose of this study was to:

1. examine patients', primary family caregivers', and nurses' judgments of symptom distress in lung cancer patients.
2. describe the cues that primary family caregivers and home care nurses use to assess the possible presence of symptom distress in lung cancer patients.

There were approximately 80 home care nurses who received information regarding their voluntary participation in this study. Ninety-six percent ($n=77$) nurses responded to the invitation to participate. Thirty-six percent ($n=28$) nurses refused and 64% ($n=49$) agreed to participate as subjects in this study. Due to the limited number of nurses who participated in the study ($n=7$), only patient and primary family caregiver data were analyzed.

This chapter describes the characteristics of both the patient and the primary family caregiver samples and reports on the reliability of the instrument with each group. Statistical analysis of the research question is presented in conjunction with a report of the major findings.

The specific hypothesis tested was:

There is no difference in patients' symptom distress scores and

primary family caregivers' symptom distress scores.

Data for this study was collected over a seven month period between August 1994 and March 1995. Sites for recruitment of subjects in this study included: the St. Boniface General Hospital Palliative Care Program, the Riverview Palliative Care Program, and the Manitoba Cancer Treatment and Research Foundation radiotherapy and chemotherapy outpatient departments at St. Boniface General Hospital, Health Sciences Center site at 100 Olivia Street, and Victoria General Hospital. Data collected from each of the participants included the Symptom Distress Scale and demographic data questionnaires. The investigator completed the Karnofsky Performance Status Examination and the Folstein Mini-Mental Status Examination for each participating patient. Family caregivers were requested to complete the open-ended questionnaire that asked them to describe the cues they use that lead them to believe the patient was experiencing distress from symptoms. The data from the open-ended questionnaire were hand scored by the investigator, coded, and transferred into a computer file. The computer package SPSS 6.1 for Windows was utilized to analyze the results.

Description of the samples

Demographic Characteristics of Patients

A total of 79 patients were approached for participation in the study. Forty-one patients were included as participants. Thirty-eight patients

were not surveyed for numerous reasons (Table 3). The most frequently cited reasons for refusal were, "it's not the right time for me to do a survey," "this study is of no benefit to me," and "I am participating in another study."

A convenience sample of 13 (31.7%) women and 28 (68.3%) men comprised the patient population for this study. The majority of the patients were over 59 years of age (68.3%, n=28). Fifty-one percent (n=21) described their ethnic origin as Canadian. Sixty-three percent (n=26) of the patients were retired. The majority of the patients (51.2%, n=21) were employed (past or present) as labourers. Fifty-four percent (n=22) of the patients reported having less than high school education. Sixty-three percent (n=26) reported an annual family income of less than \$30,000 per year. Eighty-three percent (n=34) stated their annual family income was adequate in helping them to cope with their illness and 80.5% (n=33) stated their annual family income was not causing them any stress. Sixty-eight percent (n=28) reported receiving no nursing care in their home at the time of the survey. Sixty-one percent (n=25) of the patients were married.

Seventy-one percent (n=29) of the patients in the sample had non-small cell lung cancer and 55.2% (n=16) of these patients had Stage III (advanced) disease at time of diagnosis. Twenty-seven percent (n=11) of the patients had small-cell lung cancer and 63.6% (n=7) of these patients had limited disease at time of diagnosis. Forty-two percent (n=17) lived

Table 3

Reasons for Non-Participation of Patients (n=38)

A. Recruitment difficulty	Number of Patients
Died before survey	6
Cognitive inability	1
Language barrier	1
Difficulty making telephone contact	1
Hospital admission	8
B. Refusal to Participate	21
TOTAL	38

with the diagnosis of lung cancer for less than six months; 22% (n=9) lived with the diagnosis of lung cancer between six months and one year; and 37% (n=15) lived with the lung cancer diagnosis for more than one year.

The mean mini-mental status examination score for the entire group was 28.37 (s.d. 2.05). Patients with scores greater than or equal to 24 of 30 were eligible to participate in this study. Similar cut-off scores on the mini-mental status examination were used in studies involving patients capable of responding reliably on self-reports of pain intensity (Bruera, Fainsinger, Miller, & Kuehn, 1992; Grossman, Sheidler, McGuire, Geer, Santor, & Piantadosi, 1992).

The Karnofsky Performance Scale mean score for the sample was 72.44 (s.d. 15.13). Ratings from 0 to 100 were made by the investigator, 100 being normal with no evidence of the disease and 0 being the terminal point of the scale, (i.e., death). The mean score of 70 indicates that subjects were able to care for themselves but unable to carry on normal activity.

Table 4 reveals the treatment that patients had undergone, both at time of survey and in the past. The majority of the patients (51.2%; n=21) had received radiotherapy in the past. At the time of interview, the majority of patients (56%; n=23) reported receiving no treatment at all. Of the patients who reported receiving treatment currently (44%; n=18), the majority were receiving chemotherapy (67%; n=12).

Table 4

Treatments reported by subjects (n = 41)

Type of Treatment	Number of Patients receiving treatment past/present	
	<u>Past</u>	<u>Present</u>
chemotherapy (intravenous)	10 (24%)	12 (29%)
radiotherapy	21 (51%)	4 (9%)
surgery	11 (27%)	0
other (e.g., oral antineoplastics)	0	2 (5%)
none	12 (29%)	23 (56%)

Demographic characteristics of primary family caregivers

A convenience sample of 28 (75.7%) women and nine (24.3%) men comprised the primary family caregiver population for this study. The majority of primary family caregivers were less than 60 years of age (51.3%, n=19). Forty-three percent (n=16) described their ethnic origin as Canadian. Forty-one percent (n=15) of the primary family caregivers were retired and 41% (n=15) were employed as full-time employees. Of the 36 individuals who reported their occupation, 11 (30.6%) stated they were employed (past or present) as labourers. Nineteen (52.8%) of the 36 primary family caregivers who reported their educational level stated they had obtained high school education. Forty-nine percent (n=18) of the primary family caregivers reported their relationship to the patient as the wife. Seventy-six percent (n=28) of the primary family caregivers lived with the patient. Thirty-five percent (n=13) of family members reported caring for the patient for less than six months. Eleven percent (n=4) reported caring for the patient between six months and one year and 20 (54%) reported caring for the patient for more than one year. The majority of caregivers (n = 36 out of 37) stated that the length of time caring for the patient was the same period as the time since diagnosis of lung cancer. One family member did not respond to this question as she did not feel she was the appropriate (i.e., primary) caregiver to answer same.

Instrument Reliability

Internal consistency reliability of the Symptom Distress Scale was estimated for both the patient and the primary family caregiver groups using Cronbach's coefficient alpha. The criterion for adequate reliability was established at $>.70$. Reliability coefficients of .90 for the primary family caregiver group and .88 for the patient group were obtained providing evidence of the internal consistency reliability of the scale.

Analysis of the Research Questions

Research Question 1. Is there a difference in perceptions of symptom distress between patients and primary family caregivers?

The average global SDS score for patients was 27.20 (s.d. 9.20) and primary family caregivers was 31.09 (s.d. 10.38) as displayed in Tables 5 and 6. The most distressing symptoms for patients in rank order of mean scores included: fatigue (2.95, s.d. 1.26), cough (2.56, s.d. 1.07), pain frequency (2.34, s.d. 1.26), breathing (2.20, s.d. 0.99), outlook (2.20, s.d. 1.27), and insomnia (2.15, s.d. 1.24). The experience of nausea intensity, nausea frequency, and concentration were the least distressing symptoms for this sub-sample (23 or 56% of the subjects were not receiving active treatment). The frequency of severely distressing symptoms is also shown in Table 5. Fatigue, cough, and breathing were three symptoms rated most

Table 5

Patient Symptom Distress Scale: Average Scores for Each Symptom And
Frequency of Severely Distressing Symptoms

RANK	SYMPTOM	MEAN $\pm$ SD	MINIMUM TO MAXIMUM SCORE	% RATED "3-5"	RANK ORDER OF SERIOUS DISTRESS
1	FATIGUE	2.95 (S.D. 1.26)	1-5	63.4% n=26	1
2	COUGH	2.56 (S.D. 1.07)	1-4	46.3% n=19	2
3	PAIN (frequency)	2.34 (S.D. 1.26)	1-5	31.8% n=13	4
4	BREATHING	2.22 (S.D. 0.99)	1-4	41.5% n=17	3
5	OUTLOOK	2.20 (S.D. 1.27)	1-5	31.8% n=13	4
6	INSOMNIA	2.15 (S.D. 1.24)	1-5	31.8% n=13	4
7	APPETITE	2.12 (S.D. 1.17)	1-4	26.3% n=12	6
8	BOWEL	2.00 (S.D. 1.38)	1-5	24.5% n=10	7
9	APPEARANCE	1.85 (S.D. 0.91)	1-4	24.5% n=10	7
9	PAIN (intensity)	1.85 (S.D. 0.94)	1-4	26.9% n=11	5
10	CONCENTRATION	1.73 (S.D. 1.03)	1-4	17.1% n=7	10
11	NAUSEA (frequency)	1.70 (S.D. 0.85)	1-4	19.5% n=8	8
12	NAUSEA (intensity)	1.68 (S.D. 0.89)	1-4	17.5% n=7	9
	GLOBAL SCORE	27.20 (S.D. 9.20)	13-46	(rated > 26) 54% n = 22	

Table 6

Primary Family Caregiver Symptom Distress Scale: Average Scores For
Each Symptom And Frequency Of Severely Distressing Symptoms

RANK	SYMPTOM	MEAN $\pm$ SD	MINIMUM TO MAXIMUM SCORE	% RATED "3-5"	RANK ORDER OF SERIOUS DISTRESS
1	FATIGUE	3.19 (S.D. 1.22)	1-5	70.3% n=26	1
2	OUTLOOK	2.75 (S.D. 1.23)	1-5	54.0% n=20	2
3	INSOMNIA	2.65 (S.D. 1.32)	1-5	43.2% n=16	4
4	COUGH	2.62 (S.D. 1.19)	1-4	54.0% n=20	2
5	PAIN (frequency)	2.61 (S.D. 1.36)	1-5	41.7% n=15	5
6	BREATHING	2.47 (S.D. 1.16)	1-4	50.0% n=18	3
7	APPETITE	2.41 (S.D. 1.19)	1-4	43.2% n=16	4
8	APPEARANCE	2.38 (S.D. 1.26)	1-4	43.2% n=16	4
9	PAIN (intensity)	2.26 (S.D. 1.12)	1-4	40.0% n=14	6
10	BOWEL	2.17 (S.D. 1.25)	1-5	27.8% n=10	7
11	NAUSEA (intensity)	2.06 (S.D. 1.13)	1-4	40.0% n=14	6
12	NAUSEA (frequency)	1.81 (S.D. 0.89)	1-4	21.6% n=8	8
13	CONCENTRATION	1.78 (S.D. 0.87)	1-4	16.2% n=6	9
	GLOBAL SCORE	31.09 (S.D. 10.38)	14-50	(rated > 26) 65% n = 24	

frequently in the upper portion of the response scale (≥ 3 ; higher distress). Nausea frequency, nausea intensity, and concentration were reported as the least distressing symptoms.

The most distressing symptoms rated by primary family caregivers for patients by rank order of mean scores included: fatigue (3.19, s.d. 1.22), outlook (2.75, s.d. 1.23), insomnia (2.65, s.d. 1.32), cough (2.62, s.d. 1.19), pain frequency (2.61, s.d. 1.36), and breathing (2.47, s.d. 1.16). Nausea frequency, nausea intensity, and concentration as perceived by primary family caregivers were rated as the least distressing symptoms. This is consistent with the patients' reports. The frequency of severely distressing symptoms perceived by family caregivers is shown in Table 6. Fatigue, outlook, cough, breathing, appetite, and insomnia were symptoms rated most frequently in the upper portion of the response scale (≥ 3 ; higher distress). Nausea intensity, bowel, nausea frequency, and concentration were rated by family caregivers to be the least distressing symptoms.

Normality of SDS item distributions

Visual inspection of the data and the Kolmogorov-Smirnov normality test for individual SDS item distributions and global SDS score distributions for patients and primary family caregivers in this study were conducted to determine if the results conformed to a normal distribution. Two of the 13 SDS items for patients and seven of the 13 SDS items for

primary family caregivers achieved a normal distribution ($p > .05$). The total SDS score distributions for patients and primary family caregivers met the criterion for normality ($p > .05$) as tested by the Kolmogorov-Smirnov test for normality; two-tailed $p = .68$ and $p = .96$, respectively.

Differences between global and individual item SDS scores

Based on results of the normality test, a decision was made to use the Wilcoxon test to test differences in SDS ratings (i.e., ordinal data) between patients and primary family caregivers for individual SDS items and the total SDS scores.

The Wilcoxon test involves "taking the difference between paired scores and ranking the absolute difference" (Polit & Hungler, 1991, p. 442). The Wilcoxon test revealed that there was a statistically significant difference ($p < .05$) in global symptom distress scores provided by patients and caregivers ($Z = -2.92$; $p = .004$).

The average difference in global SDS scores between patients and family caregivers was 6.19 (s.d. = 5.37). The range of differences was between zero and 22. Of those family caregivers who rated the patients' distress higher (72.97%; $n = 27/37$) than patients themselves, the mean increase in global SDS scores was 6.67. Of the family caregivers who gave lower global SDS scores (18.9%; $n = 7/37$) than patients themselves, the mean decrease in caregiver scores was seven.

The relationship between the global symptom distress scores of

patients and that of their caregivers is displayed in the scatterplot in Figure 3. Given the normal distribution of the global SDS variables, use of the Pearson Product Moment Correlation was deemed appropriate for this analysis. Patients' and primary family caregivers' global scores on the SDS for the total group were significantly correlated ($r = .71$; $p < .000$). The SDS score of one member of the dyad accounts for almost half of the variance in the other member of the dyad's score (Shott, 1990).

The Wilcoxon test for paired ordinal data was performed on individual SDS items for patients and primary family caregivers (appropriate for non-normal distributions). The findings are presented in Table 7. Statistically significant differences ($p < .05$) in self-reports of symptom distress were noted for insomnia, outlook, and appearance.

Percentage agreement between the patients' and caregivers' global SDS scores (range of 13 to 65) and individual SDS item scores (range of 1 to 5) was also determined. Percentage agreement was: a) the number of occurrences that patients and family caregivers agreed on the SDS rating for individual items and global SDS scores; b) divided by the total number of responses; and, c) multiplied by 100. The results of this analysis are presented in Table 8. Findings revealed that the highest percentage agreement occurred on two symptoms. Fifty-six percent ($n = 19/34$) of family caregivers agreed with patients regarding nausea intensity and 56% ($n=20/36$) of caregivers agreed with patients on the rating of nausea frequency. The lowest percentage agreement occurred with fatigue where

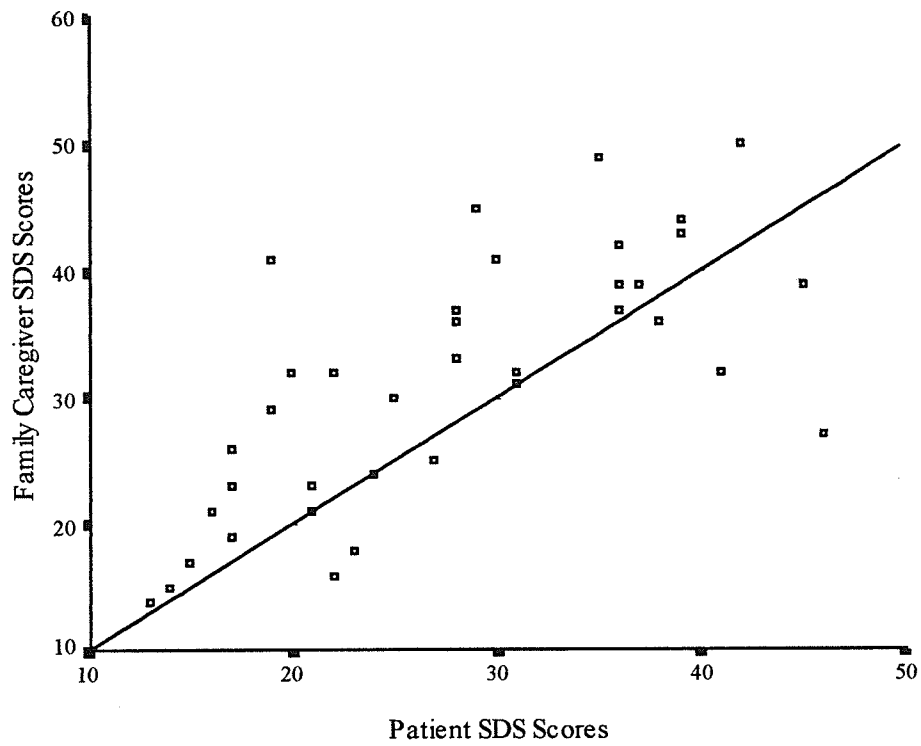


Figure 3. Scatterplot of Patients' and Primary Family Caregivers' Ratings on the Symptom Distress Scale.

Table 7

Patient and Primary Family Caregiver Discrepancy Scores on the SymptomDistress Scale -- Wilcoxon test

Symptom	n	Mean raw patient score	Mean raw primary family caregiver score	Z	p-value
Insomnia	37	2.15	2.65	-2.21	.03*
Fatigue	37	2.95	3.19	-1.31	.19
Bowel	36	2.00	2.17	-0.66	.50
Pain (intensity)	35	1.85	2.26	-1.79	.07
Outlook	36	2.20	2.75	-2.30	.02*
Appetite	37	2.12	2.41	-1.53	.13
Appearance	37	1.85	2.38	-2.35	.02*
Nausea (freq.)	36	1.70	1.87	-0.41	.68
Nausea (intensity)	34	1.68	2.11	-1.45	.15
Pain (freq.)	36	2.34	2.61	-0.70	.49
Breathing	36	2.20	2.47	-1.18	.24
Cough	37	2.57	2.62	-0.35	.73
Concentration	36	1.73	1.78	-0.33	.74

* $p < .05$

Table 8

Comparison of the frequency with which primary family caregivers
reported distress from specific symptoms

Symptom	# of caregivers underestimate	Same	# of caregivers overestimate
Nausea (intensity)	4 (n=34) 12%	19(n=34) 56%	11(n=34) 32%
Nausea (frequency)	7(n=36) 19%	20 (n=36) 56%	9(n=36) 25%
Pain (frequency)	7(n=36) 17%	18(n=36) 50%	11(n=36) 31%
Concentration	9(n=36) 25%	18(n=36) 50%	9(n=36) 25%
Appetite	6(n=37) 16%	18(n=37) 49%	13(n=37) 35%
Appearance	4(n=37) 11%	18(n=37) 49%	15(n=37) 41%
Breathing	8(n=36) 22%	16(n=36) 44%	12(n=36) 33%
Pain (intensity)	6 (n=35) 17%	14 (n=35) 40%	15 (n=35) 43%
Cough	10(n=37) 27%	14(n=37) 39%	13(n=37) 35%
Insomnia	6(n=37) 16%	14(n=37) 39%	17(n=37) 46%
Outlook	5(n=36) 14%	13(n=36) 36%	18(n=36) 50%
Bowel	9(n=36) 25%	13(n=36) 36%	14(n=36) 36%
Fatigue	7(n=37) 18%	13(n=37) 35%	17(n=37) 46%
Global SDS Scores	7(n=37) 18%	3(n=37) 8%	27(n=37) 73%

35% ($n = 13/37$) of caregivers agreed with patients' self-reports.

Caregivers tended to overestimate patients' distress from symptoms with greater frequency on all SDS items, except for concentration. In this instance, caregivers tended to over- and underestimate with equal frequency.

In addition to the above report on the proportion of cases for which patients and primary family members agreed on symptom distress ratings, Cohen's kappa statistic was used to compare patients' and family caregivers' ratings of low (<3) and high (≥ 3) SDS scores for individual items. Cohen's kappa is a measure of agreement that allows "you to compare the ratings of two observers for the same group of objects" (Norusis, 1994). Kappa allows correction to be made for the amount of agreement expected by chance. The following guidelines were used to evaluate the relative strength of agreement associated with kappa statistics for individual SDS items (Landis & Koch, 1977).

<u>Kappa Statistic</u>	<u>Strength of Agreement</u>
< 0.00	Poor
0.00 - 0.20	Slight
0.21 - 0.40	Fair
0.41 - 0.60	Moderate
0.61 - 0.80	Substantial
0.81 - 1.00	Almost perfect

Contingency coefficient was used to test the relationship between

patient and primary family caregiver ratings on the categories, low and high seriousness of distress for individual SDS items (Table 9). This is a non-parametric test that can be used to measure the relationship between two nominal level variables (Munro, Visintainer, & Page, 1986).

Table 9 depicts that significant correlations resulted with symptoms rated by patients and primary family caregivers as most seriously distressing (see Tables 5 and 6), such as fatigue, appetite, pain frequency, cough, insomnia, breathing, and outlook. Kappa statistic results between patients and primary family caregivers were also highest on these individual symptoms, except for the symptom, outlook that achieved a fair or marginal kappa rating. Nausea frequency, rated as least distressing by patients and primary family caregivers, achieved a significant correlation and a moderate kappa rating. No significant correlations and fair to slight kappa ratings resulted with symptoms pain intensity, concentration, nausea intensity, and bowel, which were rated by patients and primary family caregivers as least distressing. The symptom appearance, rated as more seriously distressing by family caregivers than patients themselves, achieved a fair kappa rating and no significant correlation.

Demographic, illness, and treatment-related variable effects on SDS ratings

The theoretical framework of this study describes how patient and primary family caregiver interpretations of symptom distress are influenced

Table 9

Relationships between patient and primary family caregiver high and low
SDS scores

Symptom	r	p-value	kappa
Fatigue	.54	.000*	.63
Appetite	.53	.000*	.60
Pain frequency	.49	.001*	.55
Cough	.46	.002*	.52
Nausea frequency	.42	.005*	.47
Insomnia	.41	.01*	.43
Breathing	.38	.01*	.41
Outlook	.35	.02*	.33
Pain intensity	.31	.05	.31
Appearance	.31	.05	.31
Concentration	.28	.07	.30
Nausea intensity	.28	.08	.26
Bowel	.18	.27	.18

*p < .05

by numerous factors such as demographic, illness, and treatment-related variables. To determine the effects of these variables on patient and primary family caregiver ratings, several tests were conducted.

The relationships of symptom distress with numerous demographic, illness, and treatment variables were tested using Kendall's tau. Kendall's tau is a nonparametric measure that is used when measuring the relation between two ranked (ordinal) variables (Munro et al., 1986).

Analysis indicated that there was a low, positive relationship ($p < .05$) between primary family caregiver global SDS scores and stage at diagnosis ($r = .36$; $p = .008$). The functional status examination scores (on the Karnofsky Performance Scale) were significantly correlated with patient and primary family caregiver SDS scores ($r = -.37$; $p = .002$; $r = -.36$; $p = .004$, respectively). A low, positive correlation was also obtained between discrepancy SDS scores and time since diagnosis ($r = .35$; $p = .008$).

Scatterplots of the relationships between primary family caregiver and patient SDS scores and stage at diagnosis were produced to explore reasons for the non-significant relationship between patient SDS scores and stage at diagnosis. Four outlier cases were discovered on the scatterplot that depicted the relationship between patient SDS and stage at diagnosis. Two cases involved patients who were in limited disease stage of SCLC and early disease stage of NSCLC respectively and scored high (> 40) on the SDS. The other two cases involved patients who were in

advanced stages (Stage III and IV respectively) of NSCLC and scored low (< 26) on the SDS.

The two patients who were diagnosed in early and limited stages of the disease reported their income as less than \$10,000 per annum and had a score of 60 on the Karnofsky Performance Scale. Both patients reported that their income was not adequate to help them cope with their illness and a source of stress to them. The two patients who were diagnosed in advanced disease stages of their illness reported their income ($> \$21,000$) as adequate and not stressful and scored 70 and 100 respectively on the Karnofsky Performance Scale. When these four patients were removed from the correlation analysis, stage at diagnosis was significantly correlated with patient SDS scores ($r = .36$; $p = .01$).

Further analysis was conducted to test the relationships between demographic, illness, and treatment variables and patient and primary family caregiver global SDS scores and demographic, illness, and treatment variables and discrepancy scores between patients and primary family caregivers. The Mann-Whitney and Kruskal-Wallis tests were used to determine whether there were significant differences in mean SDS scores in relation to demographic, illness, and treatment variable effects.

The Mann-Whitney test is a non-parametric procedure for testing the difference between two independent samples when the dependent variable is measured on an ordinal scale (Polit & Hungler, 1991). The Kruskal-Wallis test is a procedure that is analogous to the parametric

ANOVA for use with ordinal-level data or when markedly non-normal distribution renders parametric tests inadvisable. The Kruskal-Wallis test, a generalized version of the Mann-Whitney test, is used to test the difference among three or more independent groups and is based on rank scores (Polit & Hungler, 1991). If the hypothesis of identical populations was rejected as a result of the Kruskal-Wallis test, Bonferroni-adjusted Mann-Whitney tests were conducted to compare two populations at a time to detect differences between groups (Shott, 1990).

Neither the Kruskal-Wallis one-way analysis of variance nor the Mann-Whitney test detected statistically significant effects of demographic, illness, and treatment variables on SDS scores except for the following as presented in Tables 10, 11, and 12.

The results for patient data revealed that there were statistically significant differences ($p < .05$) in SDS scores in relation to income causing stress and the adequacy of income. Patients who stated that their income was not causing them stress reported significantly lower SDS scores ($n = 33$; mean = 26.10; s.d. = 8.76) than those patients who responded their income was causing them stress ($n = 8$; mean = 36.67; s.d. = 10.23). Patients who reported their income was adequate to cope with their illness responded with lower SDS scores ($n = 34$; mean = 26.33; s.d. = 8.93) than those patients who reported their income was not adequate to cope with their illness ($n = 7$; mean = 37.40; s.d. = 9.32).

The results for primary family caregiver data revealed that caregiver

Table 10

Income Effects on Patient SDS Ratings

Group	n	Mean	S.D.	Z	p
Income causing stress					
Yes	8	36.67	10.23	-2.09	.04
No	33	26.10	8.67		
Adequacy of Income					
Yes	34	26.33	8.93	-2.05	.04
No	7	37.40	9.32		

Table 11

Current Treatment, Patient Diagnosis, and Stage at Diagnosis Effects on
Primary Family Caregiver SDS Ratings

Group	n	Mean	S.D.	Z	p
Current Treatment					
No	22	34.06	10.93	-1.99	.045
Yes	15	28.08	8.93		
Patient Diagnosis					
Small Cell	9	22.71	8.32	-2.87	.00
Non-Small Cell	27	34.62	9.46		
Stage at Diagnosis					
early/limited	13	25.76	10.04	-2.20	.028
advanced/ extensive	22	33.68	8.85		

Table 12

Time Since Diagnosis, Current Chemotherapy, and Current Treatment
Effects on Discrepancy Scores of Patient and Caregiver SDS Ratings

Group	n	Mean	S.D.	Z	p
Time since diagnosis					
≤ 6 months	14	0.50	6.77	8.25	.02
≥ 1 year	15	6.86	7.24		
Current Chemotherapy					
Yes	10	2.78	2.39	-2.79	.01
No	27	7.45	6.15		
Current Treatment					
Yes	15	1.07	4.20	-2.62	.01
No	22	5.86	8.55		

scores differed significantly ($p < .05$) in groups according to whether patients were receiving current treatment and patient diagnosis. Primary family caregivers inferred higher symptom distress ($n = 22$; mean = 34.06; s.d. = 10.93) in patients they were caring for who were not receiving any current treatment than caregivers who inferred lower scores ($n = 15$; mean = 28.08; s.d. = 8.93) in patients who were receiving treatment currently. Primary family caregivers inferred greater symptom distress in patients they were caring for who were diagnosed with non-small cell lung cancer ($n = 27$; mean = 34.62; s.d. = 9.46) than caregivers who were caring for patients with small cell lung cancer ($n = 9$; mean = 22.71; s.d. = 8.32). Of the sample population of patients with NSCLC, 69% ($n = 20/29$) patients were diagnosed in advanced stages (Stage 3 and 4) versus 36% patients with SCLC who were diagnosed in advanced stages of the disease ($n = 4/11$). There were also significant differences in primary family caregiver SDS scores in relation to stage at diagnosis. Family caregivers reported higher SDS scores for patients diagnosed in advanced disease stages ($n = 22$; mean = 33.68; s.d. = 8.85) versus patients diagnosed in early disease stages ($n = 13$; mean = 25.76; s.d. = 10.04).

A question was posed to examine whether a relationship existed between time since diagnosis and degree of discrepancy between family caregiver and patient SDS scores. Adjusted Bonferroni Mann-Whitney tests found a significant difference ($p < .02$) in discrepancy scores for one of the three relationships tested. A significant difference between time

one (< 6 months) ($n = 14$; mean = 0.50; s.d. = 6.77) and time three (> 1 year) ($n = 15$; mean = 6.86; s.d. = 7.24) was achieved. No significant differences were found between discrepancy scores at time one and time two or at time two and time three.

To understand the difference between discrepancy scores at time one and time three, further analysis was conducted to determine if supports that were available at these two times had an effect on discrepancy scores. At time one, 29% ($n = 5$ out of 17) patients were receiving formalized nursing home care support. (Fifty-nine percent or 5 out of 17 patients were in extensive or advanced disease stages). At time three, 26% ($n = 4$ out of 15) patients were receiving nursing home care support. (Sixty-four percent or 9 out of 14 patients were in extensive or advanced disease stages). No significant differences in discrepancy scores occurred overall with the presence of nursing home care services.

Significant differences ($p < .05$) in discrepancy scores of SDS totals for patients and primary family caregivers occurred in groups of patients who were receiving chemotherapy currently ($n = 10$; mean = 2.78; s.d. = 2.39) and not receiving current chemotherapy ($n = 27$; mean = 7.45; s.d. = 6.15). Significant differences in discrepancy scores occurred as well in patient groups who were receiving current treatment ($n = 15$; mean = 1.07; s.d. = 4.20) and patient groups not receiving current treatment for the disease ($n = 22$; mean = 5.86; s.d. = 8.55).

The Kruskal-Wallis test was conducted between all demographic,

illness, and treatment-related variables (patient and family caregiver) and patient and primary family caregiver SDS scores and discrepancy scores to determine if any group differed in mean scores. The results did not reveal any statistically significant difference other than those indicated in the above results.

In conclusion, non-parametric analysis indicated that differences in patient SDS scores and primary family caregiver SDS scores occurred. Patients' self-reports and primary family caregivers' perceptions of symptom distress as indexed by global SDS scores and individual SDS item scores for appearance, outlook, and insomnia, revealed statistically significant differences. Primary family caregivers inferred higher distress from symptoms than patients themselves on the global SDS and on the 13 individual SDS items. Significant correlations and substantial to moderate kappa ratings occurred with regard to symptoms, fatigue, insomnia, appetite, pain frequency, cough, breathing, and nausea frequency. The symptom, outlook achieved a significant correlation and only a fair or marginal kappa rating. Except for the symptom nausea frequency (rated by patients and family caregivers as least distressing), fatigue, insomnia, appetite, pain frequency, cough, breathing, and outlook were symptoms patients and primary family caregivers rated as most seriously distressing.

Analysis of the relationships of symptom distress with demographic, illness, and treatment-related variables (patient and primary family caregiver) revealed several significant findings. Analysis indicated that

there was a low, positive relationship between patient and family caregiver SDS scores and stage at diagnosis. A low, negative relationship between Karnofsky functional status scores and patient and primary family SDS scores was revealed. A low, positive correlation also was obtained between discrepancy scores and time since diagnosis.

Statistically significant differences existed between patient SDS scores and income causing stress and adequacy of income. Significant differences in primary family caregiver SDS scores were found with current treatment, diagnosis of patient, and stage at diagnosis. Significant relationships were found between discrepancy scores and time since diagnosis, current treatment, and current chemotherapy.

Research Question 2 What are the cues used by primary family caregivers to assess the possible presence of symptom distress in lung cancer patients?

The content of each of the 37 primary family caregivers' answers to the open ended questions was reviewed by the investigator. These responses were then placed into one of seven categories for scoring by frequency counts (Table 13). These categories were based upon the literature (Chapko, Syrjala, Bush, Jedlow, & Yanke, 1991) and the investigator's personal experience in working with cancer patients. The operational definitions of the cues caregivers used when assessing distress from symptoms in an other individual are provided in

Table 13

Frequency of Cues Used to Identify Distress from Symptoms by Primary Family Caregivers

Symptom	Somatic Interventions	Impaired Functioning	Avoidance of work/ social activities	Verbal Cues	Non-verbal cues	Behaviors to reduce distress from symptom	Contextual Cues	Total
Appearance	nil	13 (22%)	nil	5 (8%)	31 (53%)	1 (2%)	9 (15%)	59
Appetite	4 (8%)	31 (61%)	nil	6 (12%)	nil	1 (2%)	8 (16%)	50
Bowel	8 (19%)	1 (2%)	nil	23 (55%)	4 (10%)	nil	6 (14%)	42
Breathing	5 (9%)	17 (31%)	nil	5 (9%)	16 (29%)	4 (7%)	8 (15%)	55
Concentration	nil	35 (70%)	3 (6%)	1 (2%)	1 (2%)	1 (2%)	8 (17%)	47
Cough	nil	2 (4%)	nil	4 (9%)	33 (70%)	1 (2%)	7 (15%)	47
Fatigue	nil	23 (35%)	1 (2%)	20 (31%)	9 (14%)	11 (17%)	1 (2%)	65
Insomnia	4 (7%)	22 (39%)	nil	9 (16%)	1 (2%)	6 (11%)	15 (26%)	57
Nausea	5 (12%)	2 (5%)	nil	14 (33%)	5 (12%)	nil	17 (40%)	43
Pain	9 (17%)	nil	nil	29 (56%)	7 (13%)	5 (10%)	2 (4%)	52
Outlook	nil	3 (8%)	1 (3%)	20 (54%)	8 (21%)	2 (5%)	3 (8%)	37
TOTAL	35 (6%)	147 (27%)	5 (0.9%)	136 (25%)	115 (21%)	32 (6%)	84 (15%)	554

Table 14.

Trustworthiness of the content analysis

Auditability. Guba and Lincoln (1981) propose that auditability is a criterion of rigor or trustworthiness relating to the consistency of qualitative findings. Study findings are auditable "when another researcher can arrive at the same or comparable but not contradictory conclusions given the researcher's data" (Sandelowski, 1986). This process is known as the 'audit trail'. The audit trail allows outside reviews to confirm that conclusions are credible by being able to trace data or facts and figures back to the original sources. Outside reviewers are also able to confirm the logic behind interpretations of study findings (Guba, & Lincoln, 1989). To assure auditability of the content analysis, operational definitions of cues used by primary family caregivers are provided.

Confirmability. Confirmability is a criterion of neutrality that "refers to the freedom from bias in the research process and product" (Sandelowski, 1986). Confirmability is concerned with assuring that data, interpretations, and outcomes of inquiry can be traced back to the original sources and not to the objective or subjective stance of the researcher. The aim is to attempt to enhance the validity of the content analysis and to guard against research bias. To this end, two nurse peers were asked to examine the open-ended data questionnaires completed by family caregivers to ascertain if they could identify the same meaning units or

Table 14

Definitions of the seven categories of cues

1. somatic intervention - reference to use of medication and prescribed therapies to reduce or eliminate distress from symptom

2. behaviors to reduce symptom - reference to intentional behavior of the patient that is not a direct result of distress from the symptom (e.g., unable to bend forward due to back pain) but serves as a protective function to reduce or eliminate distress from symptom (e.g., use of a pillow to reduce back pain)

3. impaired functioning - reference to functional deficits or behaviors that reflect the effect of distress from a symptom that interferes with normal function (e.g., decreased ability to walk short distances due to increased SOBOE)

4. avoidance of occupational commitments/ interpersonal relationships - reference to decreased work/social activity

5. verbal cues - reference to patient's verbal expression of distress from symptom

6. nonverbal cues - reference to physiologic signs of distress from symptom (e.g., skin color, respiratory rate, weight loss)

7. contextual cues - reference to information from the patient's environment (i.e., health history, secondary effects from treatments, medications, and other symptoms, lab results and procedures)

properties in the data.

Interrater agreement for cue categories identified with 11 SDS symptoms was calculated utilizing the percentage agreement formula. Percentage agreement ranged from 67% (i.e., 2 out of 3 raters) to 100% (i.e., 3 out of 3 raters) for cue categories identified with all symptoms except the symptom, bowel. The symptom, bowel achieved a 100% percentage agreement between raters (i.e., all cues were identified as being verbal cues). The greatest frequency of inconsistency (percentage agreement, 67%) occurred with symptoms, cough, insomnia, and breathing in relation to cue categories, impaired functioning, non-verbal cues, and contextual cues.

The categories of impaired functioning (n=145; 27%) and verbal cues (n=134; 25%) were most frequently identified as indicative of symptom distress in the patients. The least frequent cue categories included avoidance of work/social activities (n=3; 0.5%), somatic interventions (n=35; 6%), and behaviors intended to reduce distress from symptom (n=32; 6%) (see Table 13).

Primary family caregivers used primarily non-verbal cues (n=30; 56%) to assess patient distress from appearance. Non-verbal cues addressed by family caregivers in this study included references to weight loss or gain, hair loss, face drawn and pale, and grooming/hygiene references.

With regard to insomnia, family caregivers referred to the cue of

impaired functioning (n=22; 39%). Impaired functioning cues referred to included descriptions of sleep patterns at night (e.g., hours slept), rising from bed, movement or restlessness in bed, and body position .

In assessing appetite, primary family caregivers referred to the cue impaired functioning (n=31; 61%). Impaired functioning cues used included references to intake at mealtime or in a 24 hour period and preference for certain food types.

Primary family caregivers primarily referred to use of verbal cues (n=14; 33%) and contextual cues (n = 17; 40%) for nausea. Verbal cues related to nausea included, "she tells me she feels nauseated all of the time" and "states she is feeling sick to the stomach." Contextual cues were usually in reference to treatment side-effects: "only after chemotherapy," "if she ever was sick it usually is from a change in medication or addition of same," and "certain types of food will do it sometimes."

Primary family caregivers primarily referred to use of verbal cues for pain (n=29; 56%), outlook (n=20; 54%), and bowel (n=23; 55%). Verbal cues used to assess pain included, "he tells me if he's having pain," "I ask him if he is having pain," and "he tells me he is having sharp pain." To assess patient outlook, primary family caregivers used verbal cues such as, "she talks about her acceptance that she's dying," "she tells me when things bother her," and "he advises me of long-range plans." Verbal cues referred to when assessing the symptom bowel included, "he tells me," "he'll tell me to buy fruit then I know he's constipated," and "I ask him and

he tells me."

When assessing breathing, primary family caregivers most often referred to impaired functioning cues or behavior that indicated functional limitations in relation to lung cancer (n=16; 29%). Impaired functioning cues included, "his breathing gets heavy when he moves around" and "he has to stop sometimes while on his feet to get his breath."

Primary family caregivers referred to impaired functioning cues to assess distress from concentration (n=35; 70%) and fatigue (n = 23; 35%). Impaired functioning cues for concentration included, "we might be talking and he'll forget to answer me" and "he used to read by the hour but now never picks up a book." Primary family caregivers referred to the following impaired functioning cues for fatigue: "he is not able to do usual activities," "she gets tired from standing doing dishes . . . she needs my help," and "he can't do simple things like making a cup of tea."

Primary family caregivers used primarily non-verbal cues for assessing the cough symptom (n=33; 70%). Non-verbal cues for assessing cough included references to cough frequency, presence of sputum, difficulty expectorating sputum, and color of sputum.

Further analysis of the above findings was conducted to derive understanding of the effects of cues, used by observers to assess symptom distress, on discrepancy scores of patient and primary family caregiver self reports of symptom distress. Multiple Mann-Whitney tests were conducted for testing statistically significant ($p < .05$) differences in mean difference

scores in relation to use of cue categories. The research question asked, "whether there was a statistically significant difference in discrepancy scores in relation to use of a particular cue category by the primary family caregiver?"

This analysis revealed that the only statistically significant difference in discrepancy scores occurred in relation to use by family caregivers of contextual cues when assessing pain ($p = .03$). The mean discrepancy score of pain for primary family caregivers who used contextual cues was higher (mean = 16.50; s.d. = 7.78) than for caregivers who did not use contextual cues as a reference (mean = 5.60; s.d. = 4.70). Contextual cues referred to by caregivers when assessing the symptom pain included references to cause of pain (i.e., surgery, back pain).

From the data available for comparison of discrepancy scores in relation to use of cue categories for each SDS item (i.e., either there was only one response or no response per cue category thereby precluding a comparative analysis within all cue categories for SDS symptoms), 53% (25/47) of the time mean discrepancy scores were higher when cues were referred to by primary family caregivers. Forty-seven percent (22/47) of the time, when cues were referred to by primary family caregivers, the result was a lower discrepancy score.

Generally, reference to the cue category somatic interventions resulted in higher mean discrepancy scores for individual symptoms. No reference to somatic interventions as a cue category resulted in lower mean

discrepancy scores overall. Similarly, reference to impaired functioning and non-verbal or physiological cues for most symptoms resulted in higher mean discrepancy scores. References to contextual cues, verbal cues, and behaviours to reduce distress from symptoms resulted in lower mean discrepancy scores for most symptoms where data was available. As there was insufficient data available for analysis of the cue category of avoidance behavior, no meaningful comparison of discrepancy scores could be conducted.

In conclusion, these results indicate that cues of impaired functioning and verbal cues were most frequently identified by primary family caregivers as indicators of the amount of distress patients were experiencing from symptoms. Differences in frequencies were noted for individual SDS items as to cue categories commonly used by family caregivers to assess symptom distress in patients. Primary family caregivers commonly referred to verbal cues for assessing distress from the SDS symptoms bowel, pain, nausea, and outlook. Family caregivers most frequently reported non-verbal cues in assisting them to assess distress from the symptoms appearance and cough. Impaired functioning was the most frequently used cue category by primary family caregivers in assessing distress from the symptoms appetite, breathing, concentration, fatigue, and insomnia.

The only significant difference in discrepancy scores occurred with primary family caregiver reference to use of contextual cues to assess the

distress from the symptom pain. Primary family caregivers who referred to contextual cues to assess distress from pain had higher discrepancy scores than those who did not use contextual cues as a reference.

CHAPTER FIVE

DISCUSSION

Summary

This study was designed to describe and compare patients', primary family caregivers', and nurses' judgments of symptom distress in lung cancer patients, and cues used by primary family caregivers and nurses when assessing symptom distress in patients. However, due to the limited number of nurses who participated ($n=7$) in this study, nurses were eliminated from data analysis. Overall, this study was guided by the concepts of symptom distress, suffering, and quality of life. The conceptual framework depicting nurses' inferences of suffering by Davitz and Davitz (1981) provided the foundation for conceptualization of this study.

Major findings are interpreted in this chapter and subsequent conclusions are presented. Following a statement of the study's limitations, nursing practice implications and recommendations for further research are offered.

Discussion of the Findings

In this study, descriptive statistics revealed that the most distressing symptoms for patients included fatigue, cough, pain frequency, breathing, insomnia, and outlook. These symptoms are similar to those reported in

previous studies with lung cancer patients (see Table 15).

Fatigue in this study was reported as the most distressing symptom overall which is supported in Sarna's (1994) and McCorkle and Benoliel's (1983) studies with lung cancer patients. Sarna (1994) reported fatigue in more than 50% of the subjects. In this study sample more than 60% reported profound fatigue.

In this study the null hypothesis which stated, "there is no difference in patients' symptom distress scores and primary family caregivers' symptom distress scores" was rejected. A statistically significant difference was found between family caregiver SDS scores and patients' self-reports of symptom distress. The difference in SDS scores was reflected in the mean scores of primary family caregivers which were generally higher than patient SDS scores. The study by Holmes and Eburn (1989) found similar discrepancies in SDS scores between nurses and patients. Nurses consistently tended to overestimate the degree of distress when compared with patients' self-reports of symptom distress. As these researchers state, the reasons for such differences are not explained easily.

Wright (1960) conceptualized 'mourning' to explain differences in perception between disabled individuals' perceptions of themselves and others' perceptions of them, including caregivers. Mason and Mullenkamp (1976) and Jennings and Muhlenkamp (1981), in their studies on emotional needs of oncology patients, shared Wright's view that the higher estimation of patient anxiety and depression arises from caregivers' need to

Table 15

Symptoms commonly reported by lung cancer patients

Authors, Year	Sample	Treatment	Findings
Sarna (1993)	n = 69 women (78% with NSCLC; 68% were in early disease)	43% receiving current treatment (n = 6 radiotherapy; n = 17 chemotherapy; and, n = 3 combined modality therapy)	Most prevalent distressing symptoms included: - fatigue - frequent pain - poor outlook - dyspnea - insomnia
Benedict and Bird (1989)	n = 30 (n = 19 with metastatic disease; n = 11 with no metastatic disease) - ? Type of lung cancer	Chemotherapy; radiotherapy; surgery; or, combined modality therapy	The greatest suffering was most frequently associated with: - disability - pain - anxiety - changed activities of daily living - weakness/fatigue
Kukull et al. (1986) ^a	n = 53 Newly diagnosed, inoperable All in advanced disease - 90% NSCLC - 8% SCLC - 2% other	Radiotherapy	- fatigue - pain frequency - appetite - coughing - insomnia
McCorkle and Benoliel (1983) ^b	n = 67 Newly diagnosed ? Type of lung cancer ? Stage	Radiotherapy	- fatigue - pain frequency - cough - lack of appetite - insomnia

^aThe data reported here were gathered as part of a larger multivariate investigation of patients newly diagnosed with lung cancer or myocardial infarction (McCorkle & Benoliel, 1983^b).

reassure themselves that their value systems are still meaningful and important. Jennings and Muhlenkamp (1981) describe that "when the security of caregivers depends upon maintaining their own physical wellbeing, they have a need to emphasize the negative aspects of disability." Caregivers need to view the ill person as less fortunate and that the patient is expected to suffer. As a result, there is the expectation that patients are seen as feeling worse than they really are.

Another attempt at understanding the reason why caregivers tend to overestimate patient distress from symptoms is possibly related to caregivers' ability to empathize with the patient who is in symptom distress. Morse, Miles, Clark, and Doberneck (1994) compare numerous processes as explanatory concepts that enable the nurse to 'sense' the patient's needs. These processes include 'inference' and 'emotional empathy.'

The concept of inference involves the processing of information that is attributed to cognitive responses in the caregiver. The process of inference, an integral part of the conceptual framework for this study, is described as a process of diagnostic reasoning used by nurses to make judgments about the state of a patient. However, due to the close emotional attachment family caregivers have with patients, 'emotional empathy' may be a process of 'sensing' patients' needs that is more appropriate to family caregivers.

Primary family caregivers are viewed generally to be in a more intimate relationship with patients where they are afforded the opportunity

to subjectively experience and share in another's psychological state, emotions, or feelings. However, this psychological identification can present certain hazards to the accurate assessment of a patient's condition. Zderad (1969) describes that this identification can result in 'empathetic distress' in the caregiver, which in turn can influence caregiver perceptions of patient distress.

Although a significant difference in mean global SDS scores was found between patients and primary family caregivers, it is remarkable that the dyads' perceptions of seriousness of distress from symptoms were similar. On average, the global SDS scores of patients and primary family caregivers were within the serious range (i.e., greater than 26).

Moderate correlations and substantial to moderate kappa ratings for symptoms rated as most seriously distressing by patients and primary family caregivers implies that patients and family caregivers were able to achieve greater congruency on SDS ratings for symptoms they perceived to be most distressing (e.g., fatigue, appetite, pain frequency, outlook, cough, breathing, and insomnia) versus symptoms they similarly rated as least distressing (e.g., pain intensity, appearance, concentration, nausea intensity, and bowel). In other words, symptoms rated as most distressing were manifesting more obvious signs of distress that increased the likelihood of family caregivers to observe difficulties in symptom management. It is likely that as patients exhibited more cues that signaled distress from symptoms, family members were able to detect this distress

with greater accuracy, thus resulting in higher correlations and kappa ratings.

Nausea frequency was one least seriously distressing symptom (rated by patients and family caregivers) that achieved a significant correlation and a good kappa rating between patients and family caregivers. Many of the cues associated with the presence of distress from the symptom, nausea included the more obvious ones such as decreased appetite, use of antiemetics, and verbal cues. These cues appeared to be reasonable indicators of distress that resulted in good kappa ratings for this symptom.

It is noteworthy that caregivers were able to assess distress from symptoms within a similar range of seriousness indicating that some form of effective communication appeared to exist between patients and family caregivers. One can surmise that this communication exists in large part to the fact that the majority of caregivers in this study were either married to or living with patients they were providing care to.

It can be reasonably concluded that a caregiver who lives with the patient can profess a certain degree of familiarity with the patient's symptom experience in a global sense and therefore, closely match the patient's estimate of distress from symptoms in terms of level of seriousness. Although on average there was a difference of six between patient and primary family caregiver global SDS scores, some may argue that the small size of this difference has little practical relevance in

situations where the need to rely on caregiver assessments of symptom distress is warranted.

Furthermore, a question that was asked by O'Brien and Francis (1988) in their study involving next-of-kin who estimated pain in cancer patients, has particular relevance to this study: "How much agreement is sufficient to allow for the valid use of next-of-kin as proxies?" This is a question that has not been well addressed in literature. However, this question has clinical significance, particularly to home care nurses who often rely on caregiver assessments of patient distress from symptoms when the patient is unable to communicate with the nurse (e.g., due to weakness or cognitive inability).

This study demonstrated significant differences between patients' and family caregivers' perceptions of distress with regard to the symptoms outlook, appearance, and insomnia. Holmes and Eburn (1989) described differences in pain, nausea, appetite, sleep, concentration, and outlook as not surprising as these are the 'least' visible symptoms included in the Symptom Distress Scale. In other words, because these symptoms are not readily apparent it is possible that a close family member would not realize the patient was experiencing distress from those symptoms. This in turn would lead one to conclude that observers would rate distress from least visible symptoms to be less than how patients would rate these symptoms. However, in this study and other studies (Holmes & Eburn, 1989; Husted & Johnson, 1985; Jennings & Muhlenkamp, 1981; Nehemkis, Gerber, &

Charter, 1984), it was found that caregivers rated distress from symptoms as higher than patients themselves.

Attempting to understand why discrepancies in the assessment of patient distress from the symptom, insomnia occurred between patients and observers is difficult to due to a paucity of research in this area. Silberfarb, Hauri, Oxman, and Lash (1985) describe that the relationship of insomnia with cancer as one area of research that is virtually untouched despite the fact that it is a common problem for cancer patients as identified by oncologists.

The cue category most frequently cited by caregivers in this study when assessing distress from the symptom, insomnia was impaired functioning. The cues reported within this category included disturbed sleep patterns at night, rising from bed, and movement or restlessness in bed. However, caregiver reference to these cues did not result in any difference in discrepancy scores between patients and primary family caregivers. Furthermore, the difference in SDS ratings for the symptom, insomnia could not be accounted for by reference to any cue category identified by family caregivers.

In the study conducted by Silberfarb et al., (1985) involving 14 lung cancer patients, nine who claimed to be good sleepers and five who claimed to be poor sleepers, no differences were found in the group means for sleep latency, REM latency or percentage of time spent in Stage 1 versus Stage II sleep. Instead, the perception of whether cancer patients

slept well or poorly was related to the amount of delta sleep or "deep sleep associated with a dreamless stage from which an individual is not easily aroused " (Mosby's Medical & Nursing Dictionary, 1986).

These researchers cite that non-cancer patients who are poor sleepers usually relate poor quality of sleep to their sleep efficacy or time spent sleeping in bed. Therefore, sleep efficacy as a cue may not necessarily be helpful to observers in their assessment of the level of distress experienced by patients from the symptom insomnia. As the measurement of delta or deep sleep can only be subjectively experienced by patients themselves, it is not surprising that caregivers were unable to accurately assess distress from the symptom insomnia. The amount of time spent sleeping in bed (a cue frequently used by family caregivers in this study) does not necessarily equate to an accurate assessment of quality of sleep.

With regard to the symptom, appearance there were significant differences in SDS ratings between primary family caregivers and patients. However, family caregiver reference to non-verbal or physical appearance cues of weight loss and hair loss did not account for any effect on discrepancy scores.

Wagner and Gorely (1979) describe the importance of hair as an important contributor towards body image, which in turn provides human beings with a basis for identity. These authors report that sudden changes in body image such as hair loss are perceived as threats and arouse anxiety.

However in this study, family caregivers appeared to place more importance on changes in appearance than patients themselves, as suggested by the comparison of mean ranks of seriousness of distress from the symptom, appearance.

As suggested by Wagner and Gorely (1979), patients may experience a change in values and they no longer place great importance on appearance. Perhaps patients have learned to refocus on aspects of themselves that are more meaningful. Patient education and strong support from health care professionals may have made an impact on assisting the patient to view the threat to body image as less negative than would otherwise be anticipated. In turn, patients were able to place greater value not on appearance, but on an appreciation for efforts to maintain quality and quantity of life. Depending on the quality of communication and skill in recognizing behavioural signs of a good sense of self, family caregivers may not accurately infer the level of distress from the symptom, appearance.

In relation to outlook, primary family caregivers rated distress related to this symptom as higher than patients themselves. It is not surprising in light of the fact that outlook is a psychological symptom that is probably the least visible symptom for caregivers to assess. One might expect differences to occur in relation to any distress patients may be feeling in relation to anxiety, depression, or fear unless the relationship is such that the patient is able to freely communicate his or her fears and

feelings to the family caregiver.

Husted and Johnson (1985) found that nurses' perceptions of clients' levels of anxiety and depression were significantly higher than clients' self-reports of anxiety and depression. These researchers offer Wright's conceptualization of mourning whereby caregivers need to view the patient as less fortunate and therefore expected to suffer as an explanation for the nurses' overestimation in affective states of oncology patients. In this study, family caregivers appear to be overconcerned or overprotective as reflected in their assessments of distress from the symptom, outlook. This overestimation might be influenced by the caregiver's need to value the patient who is afflicted with a dire disease. Family caregivers may be influenced by their own assessment of the patient illness situation and intuitively rather than objectively sense the distress from the symptom, outlook. Projection of their own distress may have ultimately influenced their perception of distress from the symptom, outlook.

As discussed in other literature, reliance on verbal cues to assess patients' affective states may not always be the most reliable method. Patients themselves may feel a need to protect family caregivers from distress by denying their feelings and fears in relation to the illness. Denial by patients of any distress from the symptom outlook itself has potential to contribute towards a skewed assessment by family caregivers (Husted & Johnson, 1985). In other words, family caregivers' reliance on verbal versus behavioural cues may lead to an inaccurate assessment of the

symptom, outlook in light of patients' verbal denial of distress. A common complaint by caregivers in this study was that it was difficult for them to assess distress from the symptom, outlook because of male patients' inability or reluctance to express their true feelings. Therefore, family caregivers may benefit from becoming more familiar with assessment criteria that exists in literature on depression and anxiety that can help them make more objective versus intuitive assessments of distress from the symptom, outlook.

The conceptual framework of this study is based on an inference process where patients' self-reports and observers' perceptions of symptom distress may be influenced by numerous demographic, illness, and treatment-related variables. Part of this study was undertaken to replicate previous analyses conducted in other studies to find support for the effects of these variables on the assessment of symptom distress in patients.

Stage at diagnosis was found to have a significant effect on patients' and primary family caregivers' perceptions of symptom distress. In advanced and extensive stages of lung cancer the symptom distress of patients was more pronounced and identifiable by both patients and primary family caregivers. This finding is not surprising because with progression of disease individuals may expect symptom exacerbation. These findings are supported by previous research conducted by Degner and Sloan (in press) and Lenburg et al. (1970).

An incidental finding detected on the correlation and scatterplot

analysis of the relationship between patient SDS scores and stage at diagnosis involved the discovery of four outlier cases. Two cases involved patients who were diagnosed in limited stage of the disease, but who scored high (greater than 40) on the SDS. Descriptive data revealed that these two patients reported their income as being stressful and not helpful in assisting them to cope with their illness. Both patients reported their income as less than \$10,000 per year. Further analysis revealed that patient perceptions of income had a negative effect on patient reports of symptom distress. Patients with higher mean SDS scores reported that their income level was causing them hardship in their lives and in coping with the disease.

This finding is supported by Sarna (1994) who found significant differences in ratings of symptom distress by income, with those patients who reported the lowest income (< \$10,000 a year) experiencing the most distress. This researcher states the demands of poverty may limit the resources necessary for symptom control and perhaps heighten the patient's perception of distress from symptoms.

In interpreting the effect of income on symptom distress in this study, it appeared that it was the patient's perception of adequacy or stress associated with income and not necessarily the level of income itself that had an impact on level of distress from symptoms. In this study, the level of income did not have a significant effect on SDS scores of patients and primary family caregivers or on discrepancy scores. However, out of the

nine patients who reported an income of less than \$10,000 per annum, four stated their income was adequate to help them cope with their illness and was not causing them any stress.

Another finding revealed a negative relationship between SDS scores of patients and primary family caregivers and the functional status of patients. This relationship indicated that, the higher the score on the SDS for patients and primary family caregivers, the lower the functional status score on the Karnofsky Performance Scale for patients. Sarna (1993) found a similar relationship in her study on correlates of symptom distress in women with lung cancer. It is understandable that with increased distress from symptoms, patients will experience increased difficulties in their ability to engage in activities of daily living due to the extra effort or exertion required.

However, the relationship between symptom distress and functional status is not consistent upon further examination of the data. Twenty-nine percent patients, who had a global SDS score less than 26 (not serious), scored less than 60 on the Karnofsky Performance Scale. In this sub-sample, lower levels of symptom distress did not have a positive effect on patients' functional status. Primary family caregivers on the other hand appeared more sensitive to the relationship between patient symptom distress and the functional status of patients. Ninety-two percent of family caregivers reported SDS scores greater than 26 for patients they cared for who had functional status scores less than 60.

Time since diagnosis was found to have a significant positive correlation with discrepancy scores between patients and primary family caregivers. Significant differences in discrepancy SDS scores between time one (≤ 6 months) and time three (≥ 1 year) were found. The mean discrepancy scores indicated that differences in SDS scores between patients and family caregivers were significantly lower near time of diagnosis than time three. This finding is not surprising in light of the complexity of assessing numerous symptoms and their interaction effects as they manifest themselves with disease progression. Statistical control of stage of illness and treatment effects would have allowed this investigator to adjust for differences in SDS ratings between the two time periods that might be related to these two variables.

Further analysis was conducted to test the effect of the presence of home care services at time one and time three. McCorkle, Jpeson, Malone, Lusk, Braitman, Buhler-Wilkerson, and Daly (1994) found that cancer patients who received home care demonstrated statistically significant improvement in mental health and dependency. McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour, and Goodell (1989) revealed that patients who received nursing home care revealed less symptom distress and greater independence over time. In this study, however, there was no significant relationship between presence of home care and discrepancy scores at times one and three. No significant correlations or differences between the presence of home care and mean discrepancy scores were

revealed.

Current treatment is a treatment-related variable that achieved a statistically significant relationship with both primary family caregiver SDS scores and discrepancy scores. It is interesting to note that primary family caregivers who cared for patients currently receiving treatment at time of survey reported lower ratings of symptom distress than those who cared for patients who were not receiving treatment.

This investigator expected caregivers to rate higher distress from symptoms that are the result of treatment side-effects. This expectation arises from knowledge that chemotherapy is an aggressive treatment intervention that often results in distressing symptoms such as nausea and change in appearance. Radiotherapy is often used as palliative intervention that is intended to reduce distress from symptoms. (A greater percent of patients in this sample were receiving chemotherapy at time of survey versus radiotherapy). However, primary caregivers may have projected their positive attitude and hope in current treatment onto their perception of patient symptom distress at time of survey.

A particular challenge in this type of research is the issue of reporting stage of disease from treatment effects on symptom distress and congruence of symptom distress assessments. The effects of treatment are difficult to separate from the disease process (Ehlke, 1988). It was not the aim of this study to conduct an experimental project to determine the effect of treatment on symptom distress while controlling for stage of disease. As

well, ethical concerns related to designing a study to control for treatment effects across different stages limit understanding about this issue. The central issue in this research is not the source of symptom distress but the symptom distress experience from whatever source (i.e., the disease, the treatment, or a combination of factors) and the congruence between patients' and primary family caregivers' perceptions of symptom distress. Of relevance, may be the perception about symptom distress individuals hold if they are receiving treatment/not receiving treatment. This perception could be tapped through a self-report.

Another explanation for lower family caregiver SDS scores in dyads where patients were receiving active treatment comes from understanding the type of support patients and family caregivers received during the course of treatment. Jaakkimainen, Goodwin, Pater, Warde, Murray and Edna (1990) reported that those patients with advanced lung cancer who were not treated have increased symptom management problems than those coping with side-effects of treatment. These researchers state, "untreated patients not experiencing the side-effects of chemotherapy might not receive the same vigilant nursing assessment."

Similarly in this study, primary family caregivers who cared for patients not receiving current treatment, likely did not receive the specialized support of health care professionals from outpatient oncology departments. Therefore, family caregivers probably experienced greater difficulty in managing patient symptoms and thus perceived patients to

experience higher symptom distress.

Discrepancy scores were lower in groups where patients were currently receiving treatment (no specification of treatment) and current chemotherapy. In relation to the above discussion, lower discrepancy scores can be explained by the fact that primary family caregivers had the advantage of greater accessibility to symptom management information from health care professionals at outpatient clinics where patients were receiving treatment (Jaakkimainen et al., 1990).

McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour, and Goodell (1989) found that patients who received home nursing care were assisted to forestall distress from symptoms. In particular, these researchers found that patients who received specialized home care showed trends of fewer hospital admissions for symptoms and complications of the malignancy. Nurses experienced in the speciality area of oncology nursing were most likely able to prevent certain symptoms and complications in a way that standard nurse care providers could not. As a result of specialized nursing support, primary family caregivers' assessments of distress from symptoms were more congruent with self-reports of actively treated patients, which was reflected in lower discrepancies between SDS scores.

Significant differences in SDS scores were found where primary family caregivers inferred greater symptom distress in patients who were diagnosed with non-small cell lung cancer than patients with small cell

lung cancer. Initially this finding seemed surprising in light of knowing that most patients with SCLC have extensive disease upon diagnosis and thus are expected to experience more distress from symptoms (Glover & Miaskowski, 1994). However, because this study did not control for the confounding variables stage of disease and current treatment, it was difficult to determine the effects of diagnosis.

In this study a greater majority of SCLC patients were in limited disease stage versus NSCLC patients who were diagnosed in advanced disease stages. The expectation was that if primary family caregivers were influenced by the type of lung cancer, higher ratings of distress from symptoms would have been reported for patients with small cell lung cancer. However, because it is likely that patients in limited stage of SCLC were receiving active treatment and manifesting less distress from symptoms than patients in advanced stages of NSCLC, primary family caregivers inferred less symptom distress in SCLC patients. (Eighty-six percent or six out of seven SCLC patients in limited disease stage had SDS scores < 26 ; 38% or eight out of twenty-one NSCLC patients in advanced disease stages had SDS scores < 26).

A second part of this study attempted to describe cues family caregivers may use when assessing distress arising from symptoms in the lung cancer patient. Because little is currently known about how the rater arrives at his or her assessment of symptom distress, this study was an attempt to broaden the knowledge base regarding family caregivers'

assessment of symptom distress.

The only cue category that had an effect on discrepancy scores was contextual cues that family caregivers referred to when assessing distress from the symptom pain. However, reference to use of contextual cues such as causes of pain did not diminish discrepancy scores between patients and family caregivers. Findings revealed that higher discrepancy scores were associated with family caregivers who relied on contextual cues versus those who did not. Primary family caregivers who expressed a knowledge of the patient's medical or health history appeared to value this information as an important influence on the patient's level of distress from the symptom pain. In turn, these primary family caregivers had inflated perceptions of distress from the symptom pain.

On the whole, cue categories commonly referred to by primary family caregivers in relation to the symptoms being assessed were not surprising, but appeared to be based on common sense. However, primary family caregiver reference to these cues did not contribute towards any significant difference in individual SDS item scores as might be expected. It was the hope of this investigator to describe cue categories for each individual symptom, that reduced the amount of discrepancy between patient and primary family caregiver SDS scores.

Initial interest in correlations between verbal and non-verbal cues of distress from symptoms arose in investigations about pain. Researchers were interested in non-verbal cues of pain as perhaps a more reliable

measure versus self-reports that are subject to exaggeration by patients and undue influence by emotional factors (Teske, Daut, & Cleeland, 1983). These authors cite that there is no single best measure of pain because pain is an experience that cannot be directly measured.

The findings in this study did not reveal that references to cue categories contributed towards reducing discrepancy scores between patients and primary family caregivers. Past studies on correlations between pain behavior and self-reports of pain have produced inconsistent findings (Keefe & Block, 1982; Richards, Nepomuceno, Riles, & Suer, 1982). As suggested by Ahles, Coombs, Jensen, Stukel, Maurer, and Keefe (1990), "the pattern of results [on correlations between self reports and pain behaviour] suggests that the factors which influence responses to self-report and behavioural observation pain measures are partially independent." Depending on patient populations and/or certain situations, characteristics associated with patients and primary family caregivers may pose as influencing factors on patients' self-reports and family caregivers' behavioural assessment of distress from symptoms (Keefe, 1989). Therefore, to test the relationship between patients' self-reports and behavioural measurement of symptom distress, it would be important to control for the confounding influence of patient and observer characteristics (e.g., age, gender, cultural background, etc.).

No correlation analysis was conducted in this study between family caregiver SDS scores according to cue category and patients' self-reports of

symptom distress. However, the finding that generally no differences occurred in discrepancy scores when cue categories were referred to by caregivers, indicated that behavioural observation did not have a significant influence on closing the gap between patient and family caregiver SDS scores on individual symptom items. For future studies, a partial correlation analysis might be helpful in determining the relationship between cue categories (behavioural assessment) and patient SDS scores after statistically controlling for the influence of other influencing variables (i.e., occupation, gender, and ethnic background).

One can conclude from this preliminary analysis that different cue categories have different effects in relation to influencing caregivers' ability to accurately assess distress from symptoms. Somatic interventions, impaired functioning, and non-verbal cues appear to have a less reliable effect in assisting caregivers to assess distress from symptoms (i.e., higher mean discrepancy scores). In contrast, the cue categories of contextual, verbal, and behaviors to reduce distress from symptoms were more reliable in assisting caregivers to make more accurate inferences in patient symptom distress (lower mean discrepancy scores). These preliminary findings suggest that certain behavioural measures for assessing symptom distress may be clinically useful to observers.

Limitations of the Study

The investigator has identified several limitations of this study that

will be addressed. The generalizability of this study is limited by the small sample size of 37 patient-primary family caregiver pairs. Although a homogeneous sample of patients with primary lung carcinoma was sought, the small sample size makes it questionable whether this study's sample of lung cancer patients is representative of a larger population. The homogeneity of this sample, which consisted only of lung cancer patients, limits the generalizability of study findings beyond the larger population of lung cancer patients. Smaller sample sizes also tend to increase the chances of sampling error and produce less accurate estimates than larger samples (Polit & Hungler, 1991).

It was also difficult to reveal significant relationships between demographic, illness, and treatment-related variables with the patient and caregiver populations due to the small sample size. As this study's design was not an experimental one, it was difficult to test the effects of numerous variables (e.g., stage of disease and current treatment) on reports of symptom distress. Ehlke (1988) states, "the SDS measures total symptom distress, some of which may be due to disease and some due to treatment or other variables. The effects of treatment are difficult to separate from the disease process . . .". For example the symptom, fatigue may be the result from either the disease, the treatment, or a combination of factors.

Another limitation was related to the SDS instrument used. Most patients reported little or no difficulty completing the instrument. Some patients requested the investigator to read the questions to them and then

they would indicate their choice of responses. One patient refused to answer nausea frequency and nausea intensity items because he felt he was not experiencing distress from nausea but retching or dry heaves. On some SDS items, such as those referring to bowel function and outlook, primary family caregivers would write on the symptom item page that they could not assess the distress from the particular symptom because they simply did not know how to answer the question. Other family caregivers would circle two responses for some symptoms despite the fact that both the investigator and instructions on the SDS explained that only one answer per symptom was requested. To remedy this, the investigator tossed a coin to provide one response to the respective SDS items where two responses were given.

In order to prevent the loss of data available for data analysis involving global SDS scores (i.e., that would have been the result of missing data on certain SDS items), the following measure was taken by the investigator. Under the guidance of a statistician, the investigator 'normalized' or prorated and percent corrected global SDS data where missing responses on individual SDS items were identified. The formula below provided another dependent variable based on the global patient and primary family caregiver scores. The formula was as follows:

x	=	Number of missing data
Prorated & Percent Corrected SDS Score	=	Patient / Primary family caregiver global score x 13 divided by: (13 - x)

The lack of a response item indicating that the symptom was not present was another problem with the use of the SDS scale in this study. This is a problem that is often cited in other studies that have used the SDS scale. The investigator frequently had to explain that if the patient or primary family caregiver perceived no distress from a particular symptom, then the first response option would be appropriate.

One important issue to consider, in light of the concepts of 'mourning' and 'empathetic distress', is the possibility that primary family caregivers were not rating patients' symptom distress, but their own distress arising from the patient's symptom experience. Primary family caregivers may have responded to or were influenced by their own distress as empathetic observers of symptom distress in patients, thus resulting in inflated SDS ratings.

Although it may not be possible separate family caregivers' distress responses in their role in symptom management from their assessment of patient symptom distress, it is possible to determine the effects of individual characteristics that influence their responses (i.e., empathetic distress), that in turn effect their behavioural assessment of symptom

distress. As mentioned in the above, demographic, illness, and treatment-related variables were tested in their relationship with primary family caregiver SDS scores, however this study's small sample size may have affected the ability to reveal statistically significant findings.

A major limitation with the questionnaire that asked primary family caregivers to describe cues they used to assess distress from symptoms, lies in the open-ended nature of the survey. Frequently primary family caregivers expressed difficulty commencing or completing the survey because of the apparent abstract nature of the question. The characteristics of the family caregiver sample, such as educational experiences, may not have allowed respondents to reasonably answer the questions accurately and meaningfully. As described by Polit & Hungler (1991), the language used and level of information requested are two considerations that may have interfered with the ease and reliability of respondents in answering the open-ended data questionnaire. Unlike health care professionals who are trained in behavioural assessment of distress from symptoms, primary family caregivers expressed that what the questionnaire requested of them was something they never gave much thought about. After learning of the difficulty caregivers were experiencing with the questionnaire, the investigator would explain what was meant by the question with a hypothetical case. In other instances, it was obvious that the questionnaire was not understood by caregivers and that they did not seek clarification of the question. For example, a small number of primary family caregivers

would answer the question by writing 'good' in the space provided instead of qualifying that answer by describing how they knew the patient was feeling 'good' or not feeling distress from individual symptoms.

Another interesting but unexpected interpretation by family caregivers of the question was that not only did they opt to describe cues they use that indicated distress behaviour but wellness behavior as well. In addition, the cues that caregivers described pertained not only to the level of distress patients were perceived to be experiencing on the day of the survey, but also cues they commonly referred to on an ongoing basis (both past and present).

Because of the exploratory nature of this question, the open-ended format was appropriate in allowing family members to answer the question as flexibly as possible. However, one disadvantage to the open-ended nature of the questionnaire is that it may not have prompted caregivers to identify all cues they commonly use when assessing distress from symptoms. For instance, if family members were given a close-ended, multiple choice questionnaire that asked them to choose the cues they commonly used, then perhaps their understanding of the question would have improved.

Nonetheless, the difficulty primary family caregivers expressed in not knowing how to answer the questionnaire indicated the unease and unfamiliarity they felt in their role as observers of patient distress experienced from symptoms. The behavioural assessment of symptom

distress by unskilled caregivers could potentially lead to miscommunication and conflicts with other health care professionals who are also concerned with symptom management of the patient.

Implications for Practice

This study has implications for nursing care of not only lung cancer patients but family caregivers as well. The need to provide support and education about symptom management to patients and primary family caregivers is becoming increasingly relevant in times of early discharge of patients who are in need of more complex symptom management in the home setting. Consequently, with the increasing number of home care patients, home care nurses may find themselves with less time to assess and manage distress from symptoms in an efficient and effective manner. Nurses may find themselves having to rely increasingly on primary family caregiver assessments and management of symptoms. Therefore, as members of a team, patients, primary family caregivers, and nurses need to feel assured that the knowledge and skill each possesses in symptom management will lead to successful management of patient symptom distress.

First, as health care educators on symptom management, nurses need to become more sensitive in appreciating that lung cancer is not only associated with more obvious symptoms of pain, fatigue, and difficulty breathing. A greater appreciation and understanding of the least visible

symptoms such as outlook and insomnia ought to occur to ensure that family caregivers understand the need to manage distress from all symptoms commonly experienced by cancer patients. Otherwise, certain symptoms that are less prominent visibly to observers can become seriously overlooked and mismanaged. Nurses can educate family caregivers that management of one symptom often impacts the experience of another symptom.

To address the finding that primary family caregivers tend to overestimate symptom distress, nurses can become involved in educating primary family caregivers about factors that may influence their perceptions of symptom distress in the patient. For example, nurses can help caregivers to understand their own empathetic distress in their role in symptom management. Rowat and Knafl (1985) identified, in their study on the impact of patients' chronic pain (i.e., due to back pain, neuralgia, rheumatoid arthritis, etc.) on spouses, that 50% of the spouses in the high distress group rated their mate's pain as higher than patients themselves. High distress spouses reported feeling stressed in a greater number of dimensions of their lives than low distress spouses. The extent to which spouses felt knowledgeable about factors that contributed to or relieved pain was found to distinguish the low from high distress groups. Uncertainty and helplessness were two themes found to be central as influencing factors to the distress experienced by spouses in Rowat and Knafl's study.

Rhodes and Watson (1987) indicated that the structure of a conceptual framework is seriously lacking in nursing practice in relation to "the appropriate use of symptoms and symptom distress." Nursing conceptual frameworks, that are based on the general systems theory, such as King's Open Systems Framework would be helpful in terms of guiding the nurse in understanding the concept of perception and its relationship with symptom distress. Nurses would benefit in understanding King's (1971) concepts of interaction, communication, and perception which are inherent to managing symptom occurrence and symptom management. King (1971) depicts the concept of perception as being vital to helping caregivers understand themselves and the behaviours of others. Nurses (and family caregivers) need to be aware of factors that influence perception and inferences made in relation to patients on the basis of a few behavioural cues. Otherwise, with inaccurate perceptions and unmet goals, conflicts and increased stress in both patients and caregivers may occur.

Although other study findings are mixed in relation to the correlation between self-reports of distress from symptoms such as pain and behavioural measurement, researchers continue to search for evidence that supports the valid use of behavioural observation in circumstances where patients are unable to communicate meaningfully with caregivers. It is noted from this study that caregivers tend to limit the number of cue categories used. This indicates that there is a need to educate family

caregivers about the use of a multidimensional approach or a broader repertoire of cues in assessing symptom distress.

Recommendations for Future Research

Future research can include larger sample sizes to compare the assessment of symptom distress by patients, primary family caregivers, and health care professionals, such as home care nurses. These are key players in effective team management of distress from symptoms in the home setting. Any incongruence in assessment of symptom distress between members of this team can negatively influence effective symptom management and patient quality of life. Replication studies could also be done with larger sample sizes to determine the effects of demographic, illness, and treatment-related variables on patients' and others' perceptions of symptom distress.

Future longitudinal research designs are needed to investigate the effects of stage of disease, disease type, and treatment over time on symptom distress. Control of extraneous variables that threaten the conclusion that a particular variable produced measured changes in symptom distress would strengthen the understanding of the relationships between the above variables and the experience of distress from symptoms. Ethical concerns arise, particularly in the investigation of effects of treatment, when treatment is withheld from one control group of patients who serve as comparison to another group of patients who are receiving

treatment.

Most studies that have explored the effects of income level on quality of life, functional status, and symptom distress of cancer patients are based in the United States (Klemm, 1994; Sarna, 1993; Sarna, 1994). However, this study's significant finding on the relationship between perceptions of income status and symptom distress indicates the need for further investigation on effects of income status on symptom management in the Canadian health care setting. It is well documented that the Canadian health care system differs from that in the United States, mainly in its universal health care insurance coverage that ensures uniform, one-tier standards of care for all Canadians. Therefore, differences in the quality of care, accessibility, and cost control experienced by Canada and the United States warrant further investigation in relation to the effects of income level and experience of symptom distress experienced by Canadian patients.

Other ideas for future research in symptom management could include exploring the relationship between symptom distress, suffering, and quality of life. Evidence exists in previous study findings that there is a possible association between symptom distress and the broader construct suffering, particularly with physical and psychological aspects of suffering. Suffering in turn may negatively affect the physical and psychological dimensions of quality of life.

Future research studies can explore the processes by which family

caregivers and health care professionals 'sense' the needs of patients. As described in the discussion, this study suggests that family caregivers who have an emotional attachment to patients use the process of emotional empathy to sense patient needs, whereas nurses use the inference process that is cognition based. Comparative descriptive studies may involve questionnaires, based on research findings that describe components inherent to inference and emotional empathy processes, to determine the process of assessment commonly used by nurses and primary family caregivers to 'sense the needs of patients'. Based on these findings, correlational analyses can be conducted to test the relationship between the processes used by nurses and primary family caregivers and symptom distress ratings by patients.

Furthermore, depending on future research findings that determine the accuracy of various assessment processes (e.g., inference, emotional empathy, intuition) that assist caregivers to judge patient distress from symptoms, nurses and family caregivers may develop skills in the particular assessment process. For example, if the concept of emotional empathy is proven to be the more reliable method of assessment, Hughes (1990) describes that empathy can be taught in empathy skill-training programs.

As addressed in the discussion section, studies have not adequately addressed how much agreement is necessary between patients' and caregivers' ratings of distress from symptoms. Future studies, that explore congruence between patients' and family caregivers' perceptions of

symptom distress, need to clearly state the criteria used and rationale regarding acceptable levels of agreement. As pointed out by O'Brien and Francis (1988), "until a standard is attained, such as with confidence intervals, the reader will be uncertain as to how much agreement is necessary" so that family caregivers (as proxies in reporting distress from symptoms) are beneficial. However, it is important to understand that precise agreement is not likely to occur due to the number of factors that influence perceptions of symptom distress that reduce the likelihood of congruence of perceptions between groups (Molzahn & Northcott, 1989).

Future exploratory studies would be beneficial in finding support for the cues that nurses and primary family caregivers commonly use when assessing distress from symptoms. A multiple-choice questionnaire method of eliciting responses from family caregivers in particular could be used to guide caregivers in describing their own assessment behavior. As well, correlation analyses can also be conducted between observer SDS scores according to cue category and patients' self-reports of symptom distress. Further examination of relationships between cue categories and demographic, illness, and treatment-related variables could be conducted. (Studies have suggested that responses to the behavioural assessment of distress from symptoms can be influenced by factors intrinsic to the observer; for example, experience with the disease).

Conclusion

Numerous studies describe that lung cancer is a downhill progressive illness that is associated with increased symptom distress, increased suffering, and serious disruption to one's quality of life. Successful management of patients with lung cancer requires that health care professionals and family caregivers be knowledgeable and skilled in the management of a wide range of symptoms associated with the disease and the effects of treatment. Numerous studies indicate that symptom management is a primary concern of family caregivers. However a lack of research, focused on the management of symptoms by patients and family in the home setting, currently exists. In particular, it was determined from the literature review that a paucity of research exists in determining the level of congruence between patient and primary family caregiver assessment of symptom distress.

Overall, primary family caregivers' and patients' assessments of global symptom distress were not congruent. Significant differences in patient and primary family caregiver assessment of distress from the symptoms appearance, insomnia, and outlook were revealed. However, patients and primary family caregivers were remarkably similar in assessing the level of seriousness related to the symptoms fatigue, cough, and breathing. In general, primary family caregivers tended to overestimate patients' distress from individual SDS items and on global SDS scores.

Moderate correlations and good kappa ratings were achieved for the symptoms fatigue, appetite, pain frequency, nausea frequency, cough, breathing, and insomnia. The symptom, outlook as well achieved a significant correlation and only a marginal kappa rating. These were symptoms rated by patients and primary family caregivers as most seriously distressing, except the symptom, nausea frequency that was rated as least seriously distressing by patients and family caregivers. This study also identified a paucity of research that addresses what is an acceptable level of agreement in perceptions of symptom distress between patients and primary family caregivers. Future study findings, that address an acceptable level of agreement as a standard, are particularly relevant to home care nurses who need to know that they can rely on primary family caregivers as proxies who are able to report patient symptom distress with a reasonable degree of accuracy.

This study suggests that stage of illness has a low, positive effect on both patient and primary family caregiver assessments of symptom distress. Patient and primary family caregiver assessments of symptom distress appeared to have a negative relationship with patient level of functional status. SDS scores between patients and primary family caregivers were more congruent at time one (≤ 6 months) than at time three (≥ 1 year since diagnosis). Primary family caregivers inferred greater symptom distress in patients diagnosed with advanced stage NSCLC versus early stage SCLC. Family caregivers gave reports of higher distress from symptoms for

patients they cared for who were not receiving current treatment for lung cancer. Discrepancy scores between patient and primary family caregiver assessments of symptom distress were lower in groups of patients who were receiving current treatment (no specification of treatment) and current chemotherapy.

A particularly significant finding was that patients' perceptions on adequacy of and stress associated with income level appeared to have a significant effect on patients' self-reports of symptom distress. A majority of studies on the relationship between income level and symptom distress, quality of life, and functional status have been conducted in the United States. However, findings such as this one warrant the need for a greater understanding of the relationship between income level and symptom management within the Canadian context of health care and symptom management.

Impaired functioning and verbal cue categories were most frequently reported by primary family caregivers as indicators of the level of distress they perceived patients to be experiencing from symptoms. Future studies on behavioural assessment of symptom distress would be helpful to confirm this study's results in an area of research that is relatively unexplored.

Overall, cue categories commonly referred to by family caregivers in their assessment of distress from individual symptoms appeared to be based on the nature of how caregivers might expect distress to reveal itself

from particular symptoms. No statistically significant differences in discrepancy SDS scores existed between groups of family caregivers who referred to certain cue categories and those who did not, except with regard to the symptom, pain. The mean discrepancy score of pain for primary family caregivers who used contextual cues was higher than for caregivers who did not use contextual cues as a reference. Reference by primary family caregivers to certain cue categories resulted in high discrepancy mean scores (e.g., somatic interventions, impaired functioning, and non-verbal cue categories). Reference by primary family caregivers to cue categories, contextual, verbal, and behaviours to reduce distress from symptoms resulted in low discrepancy mean scores.

Findings from this study provided tentative support for the concept that primary family caregivers attribute a greater level of distress from symptoms than patients themselves. This study's findings on behavioural assessment of symptom distress contributed important baseline data in an area of research that to date has been unexplored.

Several implications for nursing practice, education, and research have been identified. Larger study samples with patients diagnosed with lung cancer and other cancer patient populations would be helpful in terms of generalization of study findings. Further refinement of methodology used would be of benefit in providing knowledge on how primary family caregivers assess symptom distress in cancer patients. For instance, use of a close-ended questionnaire format with family caregivers may be more

helpful in terms of gaining their understanding of what is asked of them and prompting them in their unease or unfamiliarity as observers of patient symptom distress, as found in this study.

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APPENDIX A

NURSE DISCLAIMER

**Title: Perceptions of Symptom Distress in Lung Cancer Patients:
Congruence Among Patients, Primary Family Caregivers, and Nurses**

I am inviting you to participate in a study comparing patients' self-reports of symptom distress and nurses' and primary family caregivers' perceptions of symptom distress in the lung cancer patient. The results of the study may be helpful to health professionals in providing information about how to improve the care they give to patients and primary family caregivers who are coping with symptom management in the community.

You will complete three short questionnaires in the patient's home at the same time the patient and primary family caregiver complete their questionnaires. One questionnaire is a short demographic data form. Another questionnaire is a 13-item instrument that asks you to rate the symptom distress you perceive the patient to be experiencing that day. You will also be asked to complete a simple open-ended questionnaire that asks what cues or signs did you respond to when assessing the patient for symptom distress. The three questionnaires can be completed within ten minutes. You will be asked to refrain from discussing the symptoms you perceive the patient to be experiencing while completing the

questionnaires. There are no known risks involved with participating in the study. The study offers no direct benefits to the participants. You will receive answers to any questions you may have about the study at any time.

Your participation is voluntary and you may withdraw from the study at any time by simply telling the researcher. Only myself as the investigator will know who has consented to participate/not participate. Your specific responses to the questionnaires will be kept confidential. During and after the research, all questionnaires will be securely locked up, and kept for seven to ten years and then destroyed. Your name will not be used in any reports about the study or in any future publications. Only myself and my thesis committee members (listed below) will have access to questionnaire information.

You can indicate whether you would like to participate in the study by completing the attached response portion of this form and returning your response directly to me in the self-addressed, self-stamped envelope.

This study is being conducted as part of my course work for the Master of Nursing Program at the University of Manitoba. The following agencies and committees have given approval for the study: Ethical Review Committee, Faculty of Nursing at the University of Manitoba; Access Committees at St. Boniface General Hospital, Riverview Health Center, Victoria General Hospital, and the Manitoba Cancer Treatment and Research Foundation; Provincial Office of Continuing Care - Home Care Branch; and the Assistant Executive Director, VON Winnipeg. If

you choose to participate, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

The researcher can be reached at _____ The researcher's
advisor is Dr. Linda Kristjanson (_____), University of Manitoba,
Faculty of Nursing.

Michelle M. Lobchuk, R.N., B.N.
Graduate Student
Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

Thesis Committee:

Dr. Linda Kristjanson
Associate Professor
Faculty of Nursing
University of Manitoba

Dr. Lesley Degner
Professor
Faculty of Nursing
University of Manitoba

Dr. Paul Blood
Assistant Professor
Faculty of Medicine
Radiology Department
University of
Manitoba

Title: Perceptions of Symptom Distress in Lung Cancer Patients:
Congruence Among Patients, Primary Family Caregivers, and Nurses

I _____ (name) have read and
understood the study as described in the disclaimer form. The following
indicates my decision to participate or not participate in the study:

_____ Yes. I agree to participate in the study

_____ No. I do not agree to participate in the study

Please send me a copy of the summary of the research report.

Send to: _____ (name)

_____ (address)

APPENDIX B**LETTER TO SUBJECTS REQUESTING PERMISSION TO
RELEASE NAMES (PATIENTS AND PRIMARY FAMILY
CAREGIVERS)**

Name
Home Care Coordinator
Hospital Address
Winnipeg, Manitoba

Dear

I am mailing you this letter on behalf of Michelle Lobchuk, RN, a master of nursing student at the University of Manitoba. She is interested in learning about lung cancer patients' symptoms and the ways nurses and family members view the patients' symptoms. She is also studying how primary family caregivers and nurses assess the distress patients may be feeling from symptoms.

I am writing to obtain your consent to give Michelle Lobchuk your name and the name of the person who is most involved in caring for you in your home (like a family member or friend), as possible participants in the study. If you do not wish your names to be given to Michelle, please call me at _____ by _____. If I do not hear

from you, I will assume that it is alright to give Michelle your names. Michelle will then contact you by telephone and provide further information about the 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 or not take part in this study.

Thank you for considering this request. If you have any questions about the research study Michelle can be reached at

Sincerely,

Name
Home Care Coordinator

APPENDIX C

PATIENT CONSENT TO PARTICIPATE

**Title: Perceptions of Symptom Distress In Lung Cancer patients:
Congruence Among Patients, Primary Family Caregivers, and Nurses**

I am inviting you to take part in a study about patients' symptoms and the ways nurses and family members view patients' symptoms. The results of the study may be helpful to health professionals (like nurses) who want to know how to improve the care they give to patients and family members. Your signature below indicates only that you agree to participate in the study and allow the investigator access to your chart for demographic data.

As part of the normal routine for all patients in this study, I will first ask you eleven short questions that relate to your thinking, memory, and concentration abilities. I will ask you questions like, "Can you tell me what day it is today?" and "Can you tell me what season we are in?". I will then ask you about your ability to work and perform normal activities and need for assistance. I will also ask you simple questions as to your age, marital status, occupation, etc. These questionnaires (three) will take about five to ten minutes to complete.

I will then ask you to complete a short questionnaire in a room

where your verbal responses to questions cannot be heard by your family member (and the VON nurse). This questionnaire will have thirteen questions about how you are feeling today in regard to symptoms you may be having. The questionnaire will take about five to ten minutes to complete.

Your participation is voluntary and you may withdraw from the study at any time by simply telling the researcher. Your specific responses on the questionnaires will be kept confidential. Your name will not be used in any reports about the study or in any future publications. Only myself and my thesis committee members (listed below) will have access to questionnaire information. During and after the research, all questionnaires will be securely locked up, and kept for seven to ten years and then destroyed. Your decision to take part or not take part in this study will not affect your care.

There are no known risks involved with participating in the study. This study offers no direct benefits to you. You will receive answers to any questions you may have about the study at any time.

This study is being conducted as part of my course work for the Master of Nursing Program. The following agencies and committees have given approval for the study: Ethical Review Committee, Faculty of Nursing at the University of Manitoba; Access Committees at St. Boniface General Hospital, Riverview Health Center, Victoria General Hospital, and the Manitoba Cancer Treatment and Research Foundation; Provincial

Office of Continuing Care - Home Care Branch; and the Assistant Executive Director, VON Winnipeg. If you choose to take part, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

The researcher can be reached at _____ The researcher's advisor is Dr. Linda Kristjanson (_____), University of Manitoba, Faculty of Nursing.

Michelle M. Lobchuk, R.N., B.N.
Graduate Student
Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

I agree to participate in this project.

Your signature _____ Date _____

Interviewer signature _____ Date _____

Thesis Committee:

Dr. Linda Kristjanson
Associate Professor
Faculty of Nursing
University of Manitoba

Dr. Lesley Degner
Professor
Faculty of Nursing
University of Manitoba

Dr. Paul Blood
Assistant Professor
Faculty of Medicine
Radiology Department
University of
Manitoba

Please send me a copy of the summary of the research report.

Send to: _____ (name)

_____ (address)

APPENDIX D

PRIMARY FAMILY CAREGIVER DISCLAIMER

**Title: Perceptions of Symptom Distress in Lung Cancer Patients:
Congruence Among Patients, Primary Family Caregivers, and Nurses**

I am inviting you to take part in a study about patients' symptoms and the ways nurses and family members view patients' symptoms. You have been identified by the patient as the person most involved in caring for him or her in his or her home. The results of the study may be helpful to health professionals (like nurses) who want to know how to improve the care they give to patients and family members. You will be giving your consent to participate when you respond to items on the questionnaires.

I will ask you to complete three questionnaires in the patient's home at the same time the patient (and nurse) complete their questionnaires. One questionnaire is a short demographic data form. The second form is a 13-item questionnaire that asks you to rate the distress from symptoms you think the patient is experiencing. You will also be asked to complete a simple open-ended questionnaire that asks what cues or signs told you the patient is having distress from symptoms. The three questionnaires can be completed within ten to fifteen minutes. You will be asked to not discuss the symptoms you believe the patient to be feeling while completing the

questionnaires.

Your participation is voluntary and you may withdraw from the study at any time by simply telling the researcher. Your decision to take part or not take part in this study will not affect the patient's care. Your name will not be revealed and your confidentiality will be maintained in all reports about the study or in any publications. Your specific responses to the questionnaires will be kept confidential. During and after the research, all questionnaires will be securely locked up, and kept for seven to ten years and then destroyed. Only myself and my thesis committee members (listed below) will have access to questionnaire information.

There are no known risks involved with your participation in this study. This study offers no direct benefits to you. You will receive answers to any questions you may have about the study at any time.

This study is being conducted as part of my course work for the Master of Nursing Program. The following agencies and committees have given approval for the study: Ethical Review Committee, Faculty of Nursing at the University of Manitoba; Access Committees at St. Boniface General Hospital, Riverview Health Center, Victoria General Hospital, and the Manitoba Cancer Treatment and Research Foundation; Provincial Office of Continuing Care - Home Care Branch; and the Assistant Executive Director, VON Winnipeg. If you choose to participate, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

The researcher can be reached at _____ . The researcher's
 advisor is Dr. Linda Kristjanson (_____), University of Manitoba,
 Faculty of Nursing.

Michelle M. Lobchuk, R.N., B.N.
 Graduate Student
 Faculty of Nursing
 University of Manitoba
 Winnipeg, Manitoba

Thesis Committee:

Dr. Linda Kristjanson	Dr. Lesley Degner	Dr. Paul Blood
Associate Professor	Professor	Assistant Professor
Faculty of Nursing	Faculty of Nursing	Faculty of Medicine
University of Manitoba	University of Manitoba	Radiology Department
		University of
		Manitoba

Please send me a copy of the summary of the research report.

Send to: _____ (name)

_____ (address)

APPENDIX E

Subject No. _____

MINI-MENTAL STATE

Maxi-
mum
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 patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record.
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 F

Subject No. _____

KARNOFSKY PERFORMANCE STATUS EXAMINATION

Able to carry on normal activity; no special care is needed.	100	Normal; no complaints, no evidence of disease
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home, care for most personal needs; a varying amount of assistance is needed	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his needs.
	50	Requires considerable assistance and frequent medical care.

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	40	Disabled; requires special care and assistance
	30	Severely disabled; hospitalization is indicated, although death not imminent.
	20	Very sick; hospitalization necessary; active supportive treatment is necessary.
	10	Moribund, fatal processes progressing rapidly.
	0	Dead.

APPENDIX G

Subject No. _____

PATIENT DEMOGRAPHIC DATA FORM

1. Age: _____ 18 - 29 years _____ 60 - 69 years
_____ 30 - 39 years _____ 70 - 79 years
_____ 40 - 49 years _____ 80 and over
_____ 50 - 59 years
2. Marital status (please check one): _____ married/common-law
_____ never married
_____ divorced/separated
_____ widowed
3. Gender: _____ female _____ male
- *4. Diagnosis: _____ small cell lung cancer
_____ non-small cell lung cancer
- *5. Stage of illness:
- Small cell lung cancer _____ limited
_____ extensive
- or
- Non-small cell lung cancer _____ Stage I
_____ Stage II
_____ Stage III
_____ Stage IV

***6. Date of initial diagnosis:**

*7. Current treatment: _____ radiotherapy _____ surgery
 _____ chemotherapy _____ other, please
 specify:

1

*8. Previous treatment: _____ radiotherapy _____ surgery
 _____ chemotherapy _____ other,
 please specify: _____

.....

9. Ethnic background: _____ European _____ Aboriginal peoples
 _____ British _____ Asian
 _____ Isles _____ other, please specify
 _____ French _____
 _____ Canadian _____

10. Highest Educational Level:

☐ Less than High School

☐ High School

☐ Diploma/Degree

11. Occupational status: ☐ full-time ☐ medical
 ☐ part-time ☐ leave
 ☐ retired
 ☐ unemployed

12. Type of occupation: ☐ clerical ☐ retired
 ☐ labourer ☐ retail
 ☐ management ☐ professional
 ☐ homemaker ☐ other, please
 specify

13. a) Family Income: below \$10,000/year ☐
 \$11,000-\$20,000/year ☐
 \$21,000-\$30,000/year ☐
 \$31,000-\$40,000/year ☐
 \$41,000-\$50,000/year ☐
 \$51,000-60,000/year ☐
 \$61,000-\$70,000/year ☐
 over \$71,000/year ☐

b) Is your income level adequate to allow you to cope with your illness? ☐ Yes ☐ No

Is your income level a source of stress to you?

_____ Yes _____ No

14. Length of time receiving present nursing home care?

* Data was obtained from the patient, primary family caregiver, and nurse.
In instances of lack of clarity in responses to the above items, data was
obtained from the patient's chart with the patient's permission.

APPENDIX H

Subject No. _____

PRIMARY FAMILY CAREGIVER DEMOGRAPHIC DATA FORM

1. Age:
- | | |
|------------------------------------|--|
| <input type="text"/> 18 - 29 years | <input type="text"/> 60 - 69 years |
| <input type="text"/> 30 - 39 years | <input type="text"/> 70 - 79 years |
| <input type="text"/> 40 - 49 years | <input type="text"/> 80 years and over |
| <input type="text"/> 50 - 59 years | |
2. Gender: female male
3. What ethnic group(s) do you belong to?
- | | |
|--------------------------------------|--|
| <input type="text"/> European | <input type="text"/> Aboriginal peoples |
| <input type="text"/> British Isles | <input type="text"/> Asian |
| <input type="text"/> | <input type="text"/> other, please specify _____ |
| <input type="text"/> French Canadian | |
4. Highest Education Level:
- | | |
|----------------------|--|
| <input type="text"/> | <input type="text"/> Less than High School |
| <input type="text"/> | <input type="text"/> High School |
| <input type="text"/> | <input type="text"/> Diploma/Degree |

5. Type of occupation: ☐ clerical ☐ retired
 ☐ labourer ☐ retail
 ☐ management ☐ professional
 ☐ homemaker ☐ other, please
 specify _____
6. Occupational status: ☐ full-time ☐ medical
 ☐ part-time ☐ leave
 ☐ retired ☐ unemployed
7. Length of time caring for the patient:

8. Residence: ☐ I live with the patient
 ☐ I do not live with the patient
9. Relationship with the patient: ☐ wife ☐ daughter
 ☐ husband ☐ son
 ☐ sister ☐ friend
 ☐ brother ☐ other,
 ☐ parent please specify:

_____ Master of _____ (please specify)

6. How many years have you been in nursing? _____

7. How many years have you been in home care? _____

8. Describe your experience in providing care to cancer patients:

9. Are you the regular nurse who cares for the patient?

_____ Yes _____ No

10. When was the last visit made by yourself to the patient?

11. a) Average number of patients seen daily: _____

b) Describe the demands on your time on an average daily basis
(including care required with home visits and/or office duties)

_____ light _____ average _____ heavy

12. a) Total number of patients to be seen today _____

b) Describe the demands on your time today (including care required with home visits and/or office duties)

____ light ____ average ____ heavy

13. Do you perceive that this patient/family is experiencing financial stress? ____ Yes ____ No

APPENDIX J

Subject No. _____

SYMPTOM DISTRESS SCALE**Instructions**

Below are five different numbered statements. Think about what each statement says, then place a circle around the one statement that most closely indicates how you have been feeling lately (how you perceive the patient to be feeling lately). The statements are ranked from one to five, where number one indicates no problems and number five indicates the maximum amount of problems. Numbers two through four indicate you feel (you perceive the patient to feel) somewhere in between these two extremes. Please circle one number for each symptom.

SYMPTOMS

DEGREE OF DISTRESS

1. Nausea (frequency)	1 I seldom feel nausea at all	2 I am nauseous once in a while	3 I am often nauseous	4 I am usually nauseous	5 I suffer from nausea almost continually
2. Nausea (intensity)	1 When I do have nausea, it is very mild	2 When I do have nausea, it is mildly distressing	3 When I have nausea, I feel pretty sick	4 When I have nausea, I feel very sick	5 When I have nausea, I am as sick as I could possibly be
3. Appetite	1 I have my normal appetite	2 My appetite is usually but not always pretty good	3 I don't really enjoy my food like I used to	4 I have to force myself to eat my food	5 I cannot stand the thought of food
4. Insomnia	1 I sleep as well as I always have	2 I have occasional spells of sleeplessness	3 I frequently have trouble getting to sleep and staying asleep	4 I have difficulty sleeping almost every night	5 It is almost impossible for me to get a decent night's sleep
5. Pain (frequency)	1 I almost never have pain	2 I have pain once in a while	3 I frequently have pain several times a week	4 I am usually in some degree of pain	5 I am in some degree of pain almost constantly

SYMPTOMS

DEGREE OF DISTRESS

6. Pain (intensity)	1	2	3	4	5
	When I do have pain it is very mild	When I do have pain it is mildly distressing	The pain I do have is usually fairly intense	The pain I have is usually very intense	The pain I have is almost unbearable
7. Fatigue	1	2	3	4	5
	I am usually not tired at all	I am occasionally rather tired	There are frequently periods when I am quite tired	I am usually very tired	Most of the time I feel exhausted
8. Bowel	1	2	3	4	5
	I have my normal pattern	My bowel pattern occasionally causes me some concern	I frequently have discomfort from my present bowel pattern	I am usually in discomfort because of my present bowel pattern	My present bowel pattern has changed drastically from what was normal for me
9. Concentra- tion	1	2	3	4	5
	I have my normal ability to concentrate	I occasionally have trouble concentra- ting	I often have trouble concentra- ting	I usually have at least some difficulty concentra- ting	I just can't seem to concentrate at all

SYMPTOMS

DEGREE OF DISTRESS

10. Appearance	1 My appearance has basically not changed	2 My appearance has gotten a little worse	3 My appearance is definitely worse than it used to be, but I am not greatly concerned about it	4 My appearance is definitely worse than it used to be and I am concerned about it	5 My appearance has changed drastically from what it was
11. Breathing	1 I usually breathe normally	2 I occasionally have trouble breathing	3 I often have trouble breathing	4 I can hardly ever breathe as easily as I want	5 I almost always have severe trouble with my breathing
12. Outlook	1 I am not fearful or worried	2 I am a little worried about things	3 I am quite worried, but unafraid	4 I am worried and a little frightened about things	5 I am worried and scared about things
13. Cough	1 I seldom cough	2 I have an occasional cough	3 I often cough	4 I often cough and occasionally have severe coughing	5 I often have persistent and severe coughing

APPENDIX K

Subject No. _____

OPEN-ENDED QUESTIONNAIRE**INSTRUCTIONS:**

Please complete this questionnaire that asks, "What things lead you to believe the patient is having distress from the following symptoms (listed below)?" In other words, describe what you saw or heard that warned you the patient is having discomfort from the symptoms listed below (for example, the patient's facial expression, behavior, physical signs, body movements, or something the patient has said). Please feel free to describe any other cues or signs that helped you to assess the patient's comfort.

1. Fatigue

2. Bowel

3. Concentration

4. Appearance

5. Breathing

6. Outlook

7. Cough

8. Nausea

9. Appetite

10. Insomnia

11. Pain
