

THE UNIVERSITY OF CALGARY

Determining the Unmet Needs of Outpatients with Lung Cancer
and the Relationship Between Unmet Needs and Quality of Life

by

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Abstract

Purpose: To identify the unmet needs of outpatients diagnosed with lung cancer and to determine the relationship between unmet needs and quality of life.

Methods: Consecutive outpatients with lung cancer at the Tom Baker Cancer Centre were approached to participate in this survey. Participation consisted of the completion of a needs questionnaire and quality of life questionnaires.

Results: Highest needs were identified in the health information, physical and daily living, and psychological domains. The majority of patients reported some need in each domain. No differences were noted by clinic attended, sex, age, place of residence, or disease severity. A weak to moderate relationship was found between the domains of unmet need and the dimensions of quality of life. The results are generalizable to the Alberta lung cancer population.

Conclusion: This study identified unmet needs of lung cancer patients which, with future study, may eventually improve patients' experiences with their illness.

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Dedication

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Mom, Dad, Suzanne and Anne-Marie – who have always encouraged me to follow my dreams, strive for excellence and believe in myself.

Nana – whose own experience with cancer introduced me to the world of oncology.

Aunt Norma – whose own journey with lung cancer helped me consider what unmet needs and quality of life mean to individuals living with the disease.

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List of Abbreviations

ACB	Alberta Cancer Board
CAM	complementary or alternative medicine
CNQ	Cancer Needs Questionnaire
EORTC	European Organization for Research and Treatment of Cancer
FULC	Follow-up Lung Clinic
HRQL	health-related quality of life
NPLC	New Patient Lung Clinic
QOL	quality of life
TBCC	Tom Baker Cancer Centre

Chapter 1: The Research Problem

Introduction

“Quality of life” is an important concept in health care and specifically in cancer care. Quality of life is a reflection of the effect of a disease and its treatment on a person (1) and is therefore an important consideration for patients with lung cancer. It is hypothesized that quality of life may be improved by fulfilling patient needs. Many patients have needs that may not be met by social support systems, health care providers, or the health care system. In the past, quality of life tools have assessed unmet needs. However, needs are not identified directly by these tools. Needs assessments have been developed to identify unmet needs in order to eventually meet these needs.

This study endeavored to identify the unmet needs of outpatients with lung cancer and to determine the relationship between unmet needs and quality of life. This project differs from other studies in that a specific tool, intended to directly identify unmet needs, was used rather than using a quality of life tool to infer patients’ unmet needs. While the quality of life of lung cancer patients has been assessed, their psychosocial needs have not been identified (2). This study assessed both unmet needs and quality of life.

Rationale and Relevance

This thesis study was completed in two phases. The 1998 pilot study determined the reliability and validity of the Cancer Needs Questionnaire among outpatients with lung cancer from the Tom Baker Cancer Centre in Calgary, Canada. The main study followed to assess unmet needs, quality of life, and their relationship.

People with lung cancer have unique needs (3). Further study is required in order to understand and meet these needs. As well, the Canadian Cancer Society has identified

that individuals with advanced or palliative cancer have particular needs. Given that lung cancer is considered incurable and patients may have, on diagnosis, advanced cancer or untreatable disease, the needs of advanced or palliative patients may be of particular importance.

Research has shown that most oncology patients have unmet needs, that is, needs that are not met by the care system. The identification of unmet needs may help the health care system address the needs of this group of patients and of individuals. Understanding unmet needs may unveil shortcomings in our health care system and in the care provided to outpatients. It may also provide an opportunity to develop strategies to meet the needs of lung cancer patients, thereby improving patients' quality of life. In clinical practice, a needs assessment may be used to prioritize an individual's needs and improve their experiences with their illness. Future studies will advance our understanding of the needs of oncology patients and of the means to meet their needs. Future interventions may, in turn, help improve patients' quality of life.

Purpose and Objectives

The purpose of this research was to identify the unmet needs of outpatients diagnosed with lung cancer and to determine if the presence of unmet needs impacts patients' quality of life. The sample was selected from the Tom Baker Cancer Centre (TBCC) New Patient and Follow-up Lung Clinics.

The main objectives of this study were:

1. to identify patients' unmet needs,
2. to measure patients' quality of life, and

3. to determine if there is a relationship between unmet needs and quality of life among these patients.

Unmet needs refer to patient-identified needs for which the patient believes he/she requires assistance (4). Met needs are goals that have been attained or barriers that have been removed resulting in the resolution of a problem such that the patient no longer requires assistance (5). Health-related quality of life is defined as subjective evaluations of one's ability to reach and maintain a certain level of well-being to enable the pursuit of life goals (6). Quality of life may be influenced by health status, health care, and health promoting activities (6). For the purposes of this study, the terms "quality of life" (QOL) and "health-related quality of life" (HRQL) will be used interchangeably.

Background

Epidemiology of Lung Cancer

Lung cancer accounted for 13% of all cancer diagnoses in Alberta in 1996. Only cancers of the breast and prostate were more prevalent (7). Lung cancer is also the leading cause of death from cancer in Alberta and Canada, accounting for 24% of all cancer deaths in Alberta (7)

Of the 1,249 new cases of invasive bronchus or lung cancer diagnosed in Alberta in 1996, 735 were men and 514 were women (7). Currently, the incidence of lung cancer is 44.8 and 29.9 per 100,000 for males and females respectively. Lung cancer has a poor prognosis: the five year survival rate in Alberta for all types of lung cancer is 15% (7). Factors contributing to this poor survival rate are that few patients have localized disease at diagnosis and approximately half of the cases are inoperable (8). Lung cancer (including cancers of the trachea and bronchus) was responsible for 1,052 deaths in

Alberta in 1996, a rate of 57.3 and 32.4 deaths per 100,000 men and women respectively (7).

Diagnosis

In general, there are two main types of lung cancer: small cell lung cancer (SCLC) and the more common non-small cell lung cancer (NSCLC). SCLC is a very aggressive disease that frequently metastasizes early and to distant sites (9). A two-stage classification system is used for SCLC (10). Limited-stage disease, which comprises approximately 30% of cases, includes lung tumors that have spread to specific lymph nodes whereas extensive-stage disease refers to cancer that has extended beyond those specific lymph nodes (10).

NSCLC is associated with a very high rate of disease recurrence, even for those in whom the disease is caught early. Metastases have been described as methodical and somewhat predictable (9). Staging of NSCLC is based on the TNM classification, a system used to determine the extent of the cancer (11). “T” reflects the size and extent of the primary tumor, “N” refers to lymph node involvement, and “M” describes any metastases. Prognosis and possible treatment options are determined by the stage of the illness (9,11). NSCLC classification is as follows: early stage tumors are stage I and II cancers; locally advanced tumors are stages IIIA and IIIB; and advanced lung cancers are stage IV tumors.

Both SCLC and NSCLC may spread initially to the lymph nodes and then most commonly spread to the brain, bone, liver, adrenal glands, skin, and the other lung (11).

Treatment and Follow-up

Treatment and follow-up for lung cancer are summarized by Humphrey et al. (11). Chemotherapy is the primary treatment for SCLC resulting in a tumor response rate of 70 to 90%. Relapse is common in up to 90% of patients who ultimately die of SCLC due to drug-resistant tumors. Prophylactic cranial irradiation is recommended for patients who achieve complete remission in order to prevent brain metastases. As well, for patients with limited-stage SCLC at diagnosis, radiation of the chest may be used to prevent recurrence at the primary tumor site.

The treatment of choice for early stage NSCLC and some stage IIIA tumors is surgery (11). About half of the NSCLC cases are resectable lung cancers. Radiotherapy and/or chemotherapy may also be used for regional and advanced NSCLC (12). A greater response to treatment is associated with a lower stage of disease (13). Significant prognostic factors for survival with NSCLC are a lower stage of disease and a higher performance status. In advanced disease, when a cure is not possible, the goal of treatment is palliation to provide relief from symptoms and to maintain the patient's quality of life (13).

The poor prognosis associated with lung cancer necessitates careful and frequent follow-up due to the high risk of a local recurrence, metastatic recurrence, or development of a second or third primary lung cancer (8). After treatment, comparisons of baseline and follow-up chest x-rays are used to monitor any changes in the lungs. Diagnostic tests may be performed if recurrent disease and/or metastases are suspected.

Lung Cancer Services in Southern Alberta

Most patients in Southern Alberta diagnosed with lung cancer are referred to the TBCC for their initial assessment, treatment, and follow-up. At the TBCC New Patient Lung Clinic, newly diagnosed patients are assessed initially by a medical oncologist, radiation oncologist, or oncology surgeon. A team conference is held and a plan for treatment is developed. Following this clinic visit, treatments including surgery, chemotherapy, and radiation may commence. During chemotherapy or radiation, patients are monitored through the daycare or radiation therapy departments.

Patients attending the Follow-up Lung Clinic have completed treatment and are monitored on an ongoing basis, with follow-up ranging from every six weeks to yearly. Family physicians monitor patients between clinic visits. Patients with palliative (untreatable) lung cancer are not always seen by TBCC oncologists as their acute needs and concerns can be adequately monitored by their family physicians. However, palliative radiation may be offered to those whose terminal disease is symptomatic. The goal of palliative radiation is to reduce the acute symptoms or complications from lung cancer, such as hemoptysis or superior vena cava syndrome (compression of the superior vena cava resulting in life-threatening swelling of the head, neck, and upper extremities).

Literature Review

Health-Related Quality of Life for Cancer Patients

In the past, quality of life was considered to be difficult to measure due to its subjective nature (14). However, QOL measures with vigorous psychometric testing have been developed. Therefore, QOL assessments are now commonly used in studies.

The Oncology Nursing Society has identified issues related to quality of life as one of its top research priorities (12). QOL has also been recommended as an outcome measure in the evaluation of treatment outcomes (15) and the effectiveness of nursing interventions (12). Given the clinical progression of lung cancer, QOL is an especially important consideration for these patients. HRQL has been found to be the strongest prognostic factor and subsequent predictor of survival in lung cancer (15).

The term “health-related quality of life” relates specifically to the objectives and goals of health care (12). There seems to be consensus on several aspects of HRQL. First, most authors agree that HRQL is a multi-dimensional concept comprised of functional, physical, emotional, and social dimensions (2,6,12,16-20). Second, it is a subjective evaluation (12,17,19). Third, HRQL is best measured by the affected individual rather than by a proxy (14,17,18,21). Lastly, HRQL changes over time, depending upon influences from the previously mentioned domains (17,19). Examples of various definitions of QOL that reflect these aspects are:

“an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (22, p. 153);

“the patient’s perception of his or her health described in terms of his or her ability to function physically, mentally, and socially, and the extent of both disease symptoms and treatment side effects” (23 p. 21); and

“people’s subjective evaluations of the influences of their current health status, health care, and health promoting activities on their ability to achieve and maintain a level of overall functioning that allows them to pursue valued life goals and that is reflected in their general well-being” (6, p. 7).

There are also many controversies in measuring quality of life. First, as noted above, there is no consensus on a standard definition of HRQL (12,19,24). As a result,

there is no consensus on the measurement of quality of life. Second, HRQL may be measured using a single instrument that measures one concept of HRQL or by using multiple instruments that measure multiple domains of HRQL (18,25). Additionally, QOL may be assessed using a questionnaire or by an interview. The trade-off may be between the convenience of a questionnaire and the quality of the data from an interview (26). Third, a generic or specific measurement instrument may be used (27). Strengths of using a generic instrument include that it assesses the dimensions of QOL and may be useful for comparisons across multiple populations. Generic instruments, though, are not be sensitive to specific changes (19), may be lengthy and therefore inappropriate for frail or unwell patients, or burdensome for repeated administrations (26,28). In addition, the lack of specificity may not sufficiently address the issues related to a specific disease or treatment that may affect one's QOL (26). On the other hand, a specific QOL instrument may assess areas that are most important for a specific disease, population, function, or problem, but as a result, may not allow for comparisons with other health conditions (19,27,28). A disease-specific questionnaire may detect treatment side effects or symptoms of the disease that a generic questionnaire may not detect (28). Aaronson (26) and Bowling (28) suggest combining a core (generic) module and a disease-specific or treatment-specific module to balance the assessment.

Many measures of HRQL have been developed and used in research and in clinical settings (23,29) and some have been tested specifically with lung cancer patients (30). Careful selection of an instrument to measure HRQL is important to ensure that the research question, study design, and the outcome of interest are adequately assessed by

the instrument, and the definition of quality of life is consistent between the instrument and the study's aim (17).

Unmet Needs of Cancer Patients

It is important to consider the issues that may predominantly affect patients with specific types of cancer. The assessment of quality of life is a very useful and important gauge of patients' experiences with cancer. However, QOL tools do not directly measure the needs that require assistance.

Needs assessments measure patient perceptions of issues or problems for which they need assistance to attain optimal health and quality of life (4). A needs assessment is useful for identifying areas which patients perceive as gaps in their care so that improvements to services can be made to deliver quality care (4). As well, the patient can directly express their perceived need for help, rather than relying on the health care provider's interpretation to determine the magnitude of the problem which may not coincide with the patient's need for assistance (5).

Consistency in the definition of terms is important. **Met needs** refer to goals that have been attained or the removal of barriers resulting in the resolution of a problem such that the patient does not require assistance (5). **Unmet needs** are needs a patient identifies for which the patient believes he/she requires assistance (5).

The needs of patients in Canada may differ from patients' needs in other countries. This may relate to factors such as culture and differences in health care systems. Additionally, while one may expect the needs of people from urban areas to differ from those in smaller communities, there are few comparative analyses available and the results are not consistent. For example, Charles et al. (31) found that there were

few differences between two geographic areas, one in Southern Ontario and the other in Northern Ontario. On the other hand, the Canadian Cancer Society (3) found that patients from rural areas had more need for practical assistance than their urban counterparts.

Wingate and Lackey (32) conducted a descriptive survey of the needs of cancer outpatients in the United States. Survey responses were coded for content analysis and categories of need were identified. Patients identified psychological, physical, and household management needs, whereas few needs were expressed for information, legal/financial, and spiritual needs (32). Patients' perceptions of the relative importance of the needs and the status of needs (met or unmet) were not assessed. However, this study was instrumental in identifying domains and categories of needs which provided guidance for further instrument development.

Alonso et al. (33) assessed the unmet needs of Spanish elderly and the relationship between unmet needs and subsequent mortality. The study rationale was based on previous studies which showed that unmet needs were predictors of mortality. The study used crude measures of unmet needs based on a positive response to any of the following domains: perceived health (based on a self-report of health as fair, poor, or very poor); chronic condition (defined as having two or more chronic conditions); and functional capacity (defined as being dependent in at least one of nine listed activities of daily living). People who reported chronic condition or functional limitation were more likely to have unmet needs than those without chronic condition or functional limitation. Additionally, they also had an elevated crude relative risk of dying (33). Despite this rudimentary assessment of need, this study is important. The people with lung cancer, as in the study sample, were older and as a result may have had different needs and

comorbid conditions than younger patients. Although this difference could be related to cultural and health care system differences, further studies may warrant an assessment of comorbid conditions and follow-up on the mortality of patients.

Other need studies have examined broader definitions of needs and unmet needs. A survey of the needs of persons with cancer in Pennsylvania was conducted by Houts et al. (34). The intent of the survey was to have input related to patient needs from those for whom services were intended and to estimate the demand for services if new services were provided. A random sample of patients from the state cancer registry (which included two regions of Pennsylvania) was used and phone interviews were conducted. The authors defined an unmet need as a problem for which patients reported that not enough help or assistance had been given. Four categories of unmet needs were used: emotional/social (including emotional, spiritual, social, and family needs), economic (including financial, insurance, and employment needs), medical staff (information and medical staff needs), and community needs (for transportation and home care). The authors found that patients had unmet needs in all categories but emotional needs were cited most frequently. Regression analysis showed that patients with lung cancer reported significant levels of unmet needs in all categories. They also found that unmet needs were inversely related to age (34). The study results have limited generalizability to a lung cancer population since few terminally ill people were surveyed. The authors suggested that the presence of unmet needs associated with specific cancer diagnoses may be related to factors such as the cause (or potential cause) of the cancer and the psychological effects of the particular type of cancer. The study was limited in scope as the registry had only two years worth of patient data. Despite this, the average number of

months since diagnosis was 16, allowing for some understanding of patients' unmet needs over time.

Given differences in countries' health care systems, it is important to assess patient needs in the Canadian health care setting. The Canadian Cancer Society commissioned a survey of the needs of people with cancer in Manitoba, Ontario, Quebec, and Prince Edward Island. The provincial results were combined and compiled in a single report (3). Lung cancer patients comprised five to eight percent of the participants in each province. Nineteen to 24% of the patients reported having advanced cancer of all types and four to six percent had palliative disease. Despite having few participants with lung cancer, they reported some of the greatest unmet needs.

Six areas of need for cancer patients were identified: the need for prompt medical attention, pain management, emotional support, information, practical assistance, and employment and financial assistance. The need for prompt medical attention for diagnosis and treatment was generally met for the participants in this survey. Pain management needs were associated with more advanced disease and with high levels of distress. Of concern was that severe pain was experienced by one-half to two-thirds of the patients at some point in their illness. Emotional support needs were particularly strong for people in the palliative stages of cancer and people in large cities and in remote areas. People may not be aware of the availability of services or how to access services in urban areas, or the services may not be available in rural areas.

Information needs were strongest following diagnosis, especially for patients with advanced disease (3). Needs were specifically related to disease, treatment, and emotional issues. Lung cancer patients specifically identified needs for information prior to and

following treatment. There were few needs for practical assistance except for transportation (local and out-of-town), and accommodation and childcare services for out-of-town patients. In addition, there were some needs for prostheses and wigs. These needs were higher for people with worse prognoses. Several areas of need related to employment and finances were also identified. Needs in this area affected 15 to 25 % of the patients surveyed and were associated with decreased quality of life. Financial problems were specific to out-of-pocket costs. Additionally, many patients reported that the illness, its treatments, and the side effects required employed patients to quit their jobs or to work part-time (3).

The findings from these four Canadian Cancer Society studies are informative and important because needs of the general oncology population were identified. As well, the results show some of the strengths and weaknesses in the way health care services are delivered. However, the results have limited generalizability to the main study sample because of the likelihood of under-representation of people with lung cancer and those with early malignant disease. This under-representation is not an uncommon problem when using provincial cancer registries. Many people on registries die prior to being contacted for studies and delays in registering patients result in accessing fewer patients in the early stages of disease. But as a result, long-term cancer survivors may have been over-represented in the sample, creating a more favorable outlook on patient needs. This report does provide general information on needs but doesn't further our understanding of the unmet needs of lung cancer patients.

In another study, the support needs of newly diagnosed cancer patients attending the Hamilton Regional Cancer Centre were examined (35). Face-to-face interviews were

conducted with 134 patients (86% of the eligible patients) to determine their physical and emotional health status, self-identified needs, and social and community resources. Forty-one percent of the patients reported needs for assistance with at least one daily living activity. Social concerns (such as the ability to care for one's home and to maintain relationships with friends and family) were reported by 66% of the patients. In terms of informational needs, most (84%) stated they wanted to be well-informed. However, only 29% of patients stated they had used community resources within the month prior to their visit. The regression analysis found higher symptom distress among younger patients, women, and/or patients with lung cancer. Lung cancer patients and those living with a partner/other(s) were more likely to experience psychological distress than those with other primary sites of cancer or other living arrangements (35). This study described the needs of first-time patients at a cancer centre. The generalizability of the results beyond the study centre may be limited. However, the research provided a framework for the Hamilton Regional Cancer Centre to plan interventions.

Charles et al. (31) conducted a study of the needs of adult survivors of cancer in two Ontario regions. Participants were randomly selected from a registry of people who had completed cancer treatment at least six months earlier, either at the Thunder Bay Regional Cancer Centre or the Hamilton Regional Cancer Centre. Patients were mailed a questionnaire and cover letter. The response rate for the Thunder Bay area was 77% and 61% from the Hamilton area. Except for the distance travelled to obtain cancer care, the two samples were not significantly different based on any demographic characteristics. The authors reported the frequency of needs associated with the patient's cancer experience and the needs that remained unmet. Few needs related to finances,

employment, physical changes, or emotional support were identified. The greatest magnitude of unmet needs were for information about the Canadian Cancer Society (50%) and for information related to encouraging and providing information to others who are experiencing cancer (50%). A significant difference was noted for patients from the Thunder Bay region regarding information about side effects and available emotional support services compared to the Hamilton patients. Time since diagnosis did not emerge as a significant predictor of need (31). This study is important because it describes Canadians' experiences and provides some evidence that unmet need is consistent across geographic settings.

Ashbury et al. (36) surveyed Canadian cancer patients to determine the prevalence of symptoms and the impact of those symptoms on their lives, the areas of need in accessing treatment and information, and patients' satisfaction with the care received. Participants were recruited by placing ads in newspapers requesting cancer patients to call, at which time they were screened for eligibility. Participants were required to have had cancer and completed treatment to be eligible. Self-report questionnaires were mailed to the participants and 913 responses were returned, yielding a response rate of 82%. Fatigue and anxiety were reported most often. Further, the presence of fatigue was most consistent among those who reported that their physical condition was affecting their daily life and among those who reported more frequent visits to health care practitioners. Information regarding the management of fatigue was most often sought by patients: over 50% found information and of those, one-half stated it was "good information" (36). This survey is important given that it assessed the needs of a broad group of cancer patients and further assessed how well these needs were being met. However, only physical and

informational needs were evaluated. The study provides some evidence that further research is needed to assess patient needs and the fulfillment of these needs.

It may be important to assess the needs of patients with progressive and recurrent disease separately from initially diagnosed patients. Dudgeon et al. (37) developed a self-assessment questionnaire for patients with initially diagnosed, recurrent, or progressive cancer. They found that patients with a second recurrence or progressive disease experienced greater physical needs related to housework and ambulation than patients upon initial diagnosis or first recurrence. No differences were noted between the two groups in terms of psychological problems, responses to recurrence, or patients' self-identified single greatest concern. However, the authors did note that methodological differences may explain why the results of some other studies conflict with these results. They concluded that patient needs may not be specific to palliative care, rather needs are experienced throughout the disease process (37).

Longman et al. (38) developed the Patient Needs Scale (PNS) to determine the needs of oncology patients and to assess whether each need had been met and the importance of each need. The PNS's 114 items of need relate to physical, psychological, and health services required for functioning at home. Items were identified through a review of the literature and from the investigators' knowledge. The PNS was then used to identify the needs of cancer outpatients attending a multi-disciplinary cancer centre. Needs were classified as very important if at least two-thirds of the sample identified the need. Patients identified personal care, involvement with health care, and interpersonal interactions as very important areas of need. Overall, participants reported that 12% of their needs were unmet; among individuals, the range of unmet needs was 0 to 25% (38).

A systematic replication of Longman et al.'s study was done by Silveira and Winstead-Fry (39) to specifically determine the needs of rural patients. Results showed that rural patients identified the same areas of need as participants in the study by Longman et al. (38). Three specific needs were identified by the rural sample: the need for good physical care, to know when to call the physician, and for others to be well-organized. Similarly to Longman et al.'s results, five percent of rural patients' needs were unmet.

Recently, the Patient Needs Assessment Tool (PNAT) was developed by Coyle et al. (40). This study was completed in two phases. First, interrater reliability, criterion validity, and construct validity were assessed. The second phase was to confirm the interrater reliability, to gain further evidence of the criterion validity, and to determine how training effects the use of the instrument. The PNAT is intended for use with oncology patients to determine the extent of needs or impairment related to the physical, psychological, and social dimensions of need, and symptom distress. It is a thorough, multi-dimensional tool that is administered and rated by a trained interviewer. Certain dimensions were found to correlate with previously validated questionnaires, such as the psychological dimension with the Beck Depression Inventory ($r=-0.69$, $p<0.001$) and the physical dimension with the Karnofsky Performance Scale ($r=0.89$, $p<0.001$). As well, there was evidence of sufficient interrater reliability (0.59–0.98). However, the authors made two assumptions: that there is a relationship between QOL and needs and that QOL may be maintained by identifying impairment in certain dimensions and providing early intervention.

The PNAT is not very practical for the proposed research or in a clinical setting. It employs a structured interview format that may take 20 to 30 minutes to complete, incurring high costs for administration. The authors of the PNAT did note that many of the questions form part of a routine clinical visit, therefore reducing the time required to complete the interview. Lattimore-Foot (5) described two other significant disadvantages of an interview format: they may not elicit personal or intimate needs and the interpretation of qualitative data may be more burdensome than that of quantitative data in a clinical setting.

Past research indicates that there is consensus regarding the importance of determining the unmet needs of cancer patients. With the development of the CNQ, health care providers may be able to help to bridge the gaps in service and care provision and identify threats to optimal quality of life.

Direction for Research

In preparation for the proposed research, a pilot study was undertaken at the Tom Baker Cancer Centre Follow-up Lung Clinic. The purpose was to assess the CNQ's validity, reliability, comprehensiveness, and completeness in the context of the Canadian health care system, specifically with ambulatory lung cancer patients. As well, the pilot study was used to determine if the proposed research methods were feasible and the sampling strategy was sufficient to recruit an adequate sample size. The results provided the basis for sample size calculations for the main study. The results of the pilot study are described in the following chapter.

Following the pilot study, the main study was undertaken to determine the unmet needs, quality of life, and relationship between unmet needs and quality of life.

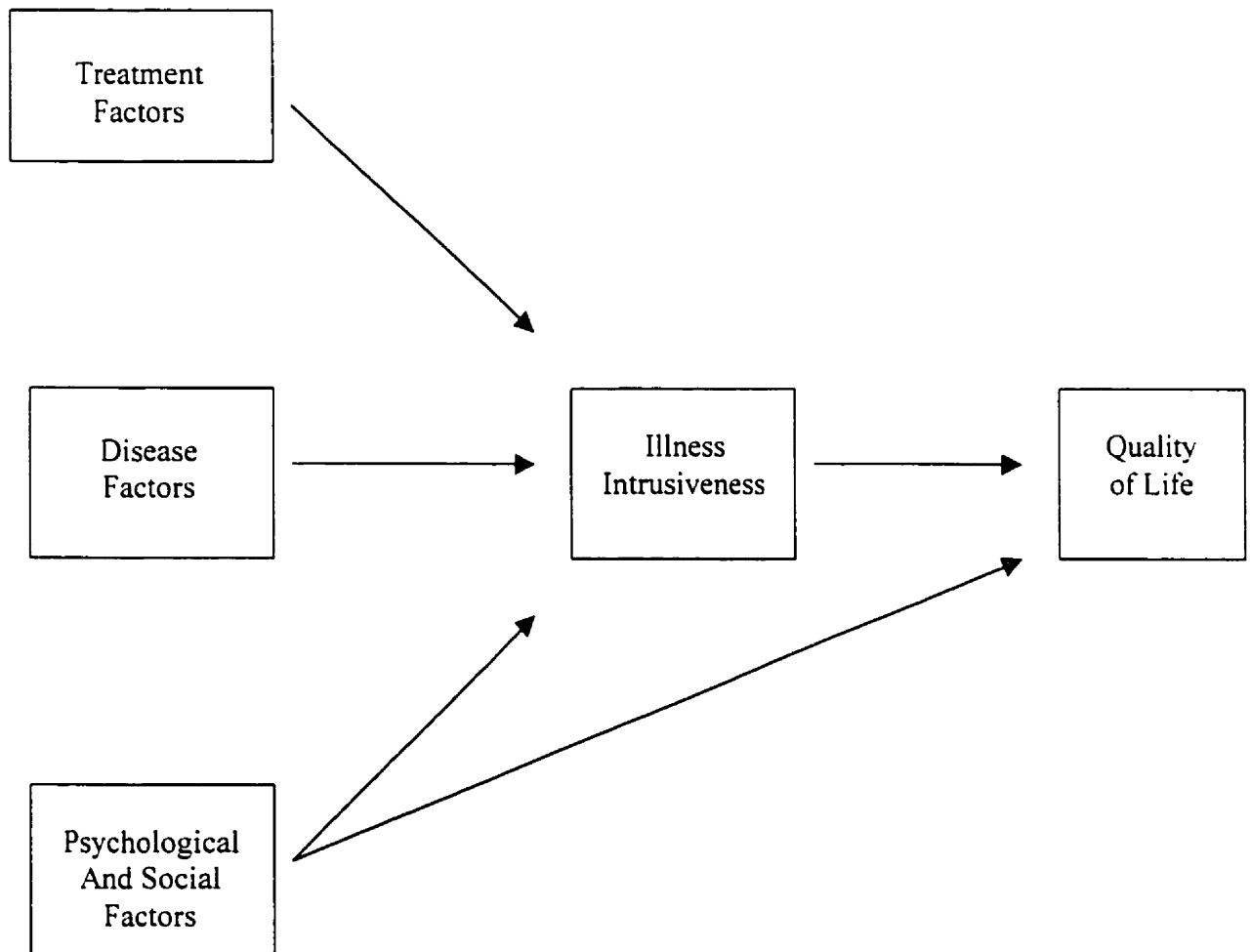
Conceptual Framework

One of the aims of this study was to determine if a relationship exists between unmet needs and quality of life for lung cancer patients. Conceptual frameworks and models exist for quality of life (16,41,42), and the Biopsychosocial Model of Adaptation to Cancer depicts unmet needs (5), yet a model for the hypothesized interrelationship of the two concepts has not been developed.

Cella and Tulsky (16) developed a model of QOL for cancer patients. The model depicts the four dimensions of QOL (physical, functional, emotional, and social) in a linear manner and as separate, unrelated dimensions. The authors recognized that this representation inadequately depicts QOL due to the actual overlap of the dimensions. They also noted that other components of QOL may not be sufficiently represented by the model, specifically work, sexuality, leisure, spirituality, and family functioning (16). However, the model does present a preliminary framework that can be further developed and revised as we gain further understanding of the concept of QOL.

Devins (41) developed a conceptual model depicting the psychosocial impact of a chronic life-threatening illness (Figure 1). The model was presented in the context of end-stage renal disease but seems applicable to other chronic illnesses. The model depicts the treatment, disease, psychological, and social factors that influence QOL, and the mediating factor, called illness intrusiveness. Illness intrusiveness is defined as “the lifestyle disruptions, attributable to an illness and/or its treatment, that interfere with continued involvement in valued activities and interests” (p. 252). It is hypothesized that since QOL is not directly affected by disease and treatment factors, efforts to improve the psychosocial burden of an illness may reflect the extent to which illness intrusiveness is decreased (41).

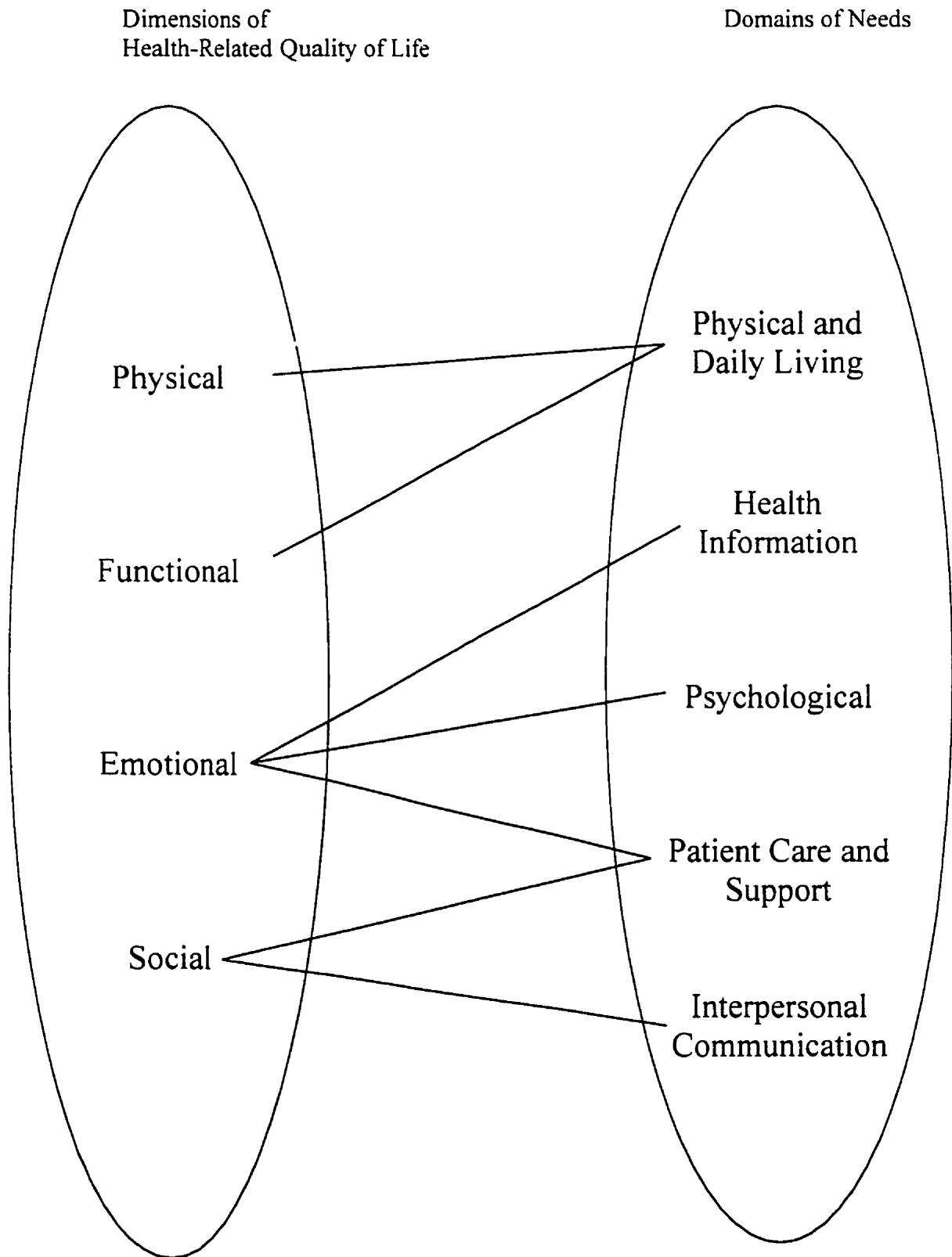
Figure 1: Hypothesized Relations Among Illness Intrusiveness, its Determinants, and Quality of Life



Disease factors in this model include variables such as pain, fatigue, and disability. Treatment factors, such as the type of treatment and the treatment schedule, are also included. Both disease and treatment factors are features of the disease that may result in a change in QOL (41). Psychological and social factors, such as social support, illness-related concerns, and intellectual and coping resources, may affect the illness intrusiveness experienced by an individual. Illness intrusiveness is hypothesized to interfere with QOL in relation to the following 13 factors: health, diet, work, active recreation, passive recreation, financial situation, marital relationship, sex life, family relations, other social relations, self-expression/self-improvement, religious expression, and community and civic involvement. Devins (41) acknowledged the significance of other features, such as coping resources and exogenous variables (e.g. gender and socioeconomic status), that have yet to be included in the model. Other factors that deserve consideration in relation to their effect specifically on HRQL include patient satisfaction, hope, and anticipated survival. This overview of quality of life, as part of a greater construct, is important as it incorporates ideas and concepts that may improve our understanding of the psychosocial factors affecting people during an illness.

A conceptual framework was developed to guide this study (Figure 2). It depicts HRQL based on its previously identified dimensions, the domains of needs as identified by Foot and Sanson-Fisher (4), and the proposed relationships between the two concepts.

Figure 2: Conceptual Framework - Model of the Relationship Between Health-Related Quality of Life and Unmet Needs



The following explanations of the individual dimensions of QOL are provided in order to help understand the proposed relationships between QOL and unmet needs. The physical dimension of quality of life reflects changes to one's bodily functioning that may be perceived or observed (16). This includes both disease symptoms and side effects from treatment. The functional dimension is related to the physical dimension, but refers specifically to one's societal role and performing associated activities. These may include activities of daily living as well as family, social, and work activities, and responsibilities. The emotional dimension incorporates both one's well-being or positive affect and distress or negative effect. Lastly, relationships with family, friends, and acquaintances refer to the social dimension of QOL (16).

Foot and Sanson-Fisher (4) developed a framework of five domains of need. They are: physical and daily living, patient care and support, psychological, health information, and interpersonal communication needs. These domains will be described in detail in Chapter 2.

In this model, the directions of the relationships between the dimensions of HRQL and unmet needs are unknown. It is expected that both the physical and role dimensions of HRQL will be related to physical and daily living domain of needs. Health information needs may be related to the cognitive and emotional dimensions as information may provide further insight into the effect of the illness on patients' daily lives. The emotional dimension may also be related to patient care and support needs and psychological needs. Patient care and support needs and interpersonal communication needs are expected to be related to the social dimension. The data analysis assessed the presence or absence of these relationships.

Summary

Patients with lung cancer may face issues related to the symptoms of the illness, its treatment, and for many, concerns related to palliative care and death. Clearly, lung cancer poses a significant health problem for many Albertans with unique challenges for patients and health care providers. Cancer treatments may increase a patient's length of life, but the side effects may result in a worsening of the quality of life. As a result, quality of life has become a key consideration in disease management and in cancer care relating to morbidity outcomes. The identification of unmet needs may unveil the shortcomings in our health care system and offer methods for improving services and care for these patients. However, as proposed in this study, it is important to assess unmet needs in conjunction with HRQL in order to gain an overall perspective of the patient's experience with lung cancer.

The Cancer Needs Questionnaire is an instrument with the potential to unveil some of the shortcomings in the provision of care for lung cancer patients. The research was guided by the conceptual framework to identify the unmet needs of lung cancer patients and to determine the relationship between unmet needs and health-related quality of life.

Chapter 2: Research Methods

Study Design and Research Questions

A cross-sectional survey was undertaken to determine the unmet needs of outpatients with lung cancer and to determine the relationship between unmet needs and quality of life. The Cancer Needs Questionnaire (CNQ) was used to assess unmet needs, and the European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 and QLQ-LC13 were used to assess quality of life. Consecutive Tom Baker Cancer Centre outpatients from the New Patient Lung Clinic (NPLC) and Follow-up Lung Clinic (FULC) were approached at their clinic appointments and asked to participate in the survey. Subject participation included completing the three questionnaires at home, mailing the questionnaires (postage pre-paid), and participating in a brief follow-up phone call.

This study addressed two research questions. While the primary interest was in the relationship between unmet needs and health related quality of life, this could not be answered until unmet needs were assessed. The questions that resulted were:

1. What are the unmet needs of individuals with lung cancer? and
2. Is there an association between unmet needs and health-related quality of life?

In addition, two subquestions were considered:

1. What are the similarities and differences in unmet needs for individuals with newly diagnosed lung cancer and those with previously diagnosed disease? and
2. Are unmet needs and health-related quality of life of lung cancer patients associated with gender, age, place of residence, or severity of illness?

For the purposes of this study, unmet needs will be referred to generally as “needs” and specific unmet needs as “need items.” Study subjects will be referred to as patients because they are attendees at the lung clinics.

In preparation for the main study, a pilot study was undertaken to determine the validity and reliability of the Cancer Needs Questionnaire, the tool used to assess needs for the main study. The methods and results of the pilot study will be discussed later in this chapter.

Sample and Study Procedures

Subject eligibility criteria included: 1. aged 18 years or older, 2. diagnosed with primary or recurring lung cancer, 3. able to speak, read, and write English well enough to give informed consent and complete the self-administered study questionnaires, and 4. outpatient at the time of attending clinic. Individuals were excluded if the primary tumor site was not the lung. Originally, patients that participated in the pilot study (n=60) were to be excluded to avoid burdening them unless they were particularly willing to participate. However, the pilot study patients were generally amenable to participate in the main study and did complete the questionnaires for the main study.

A delimitation of the study design was that the sample included only patients seen by an oncologist at the TBCC. As a result, the sample included residents of Southern Alberta and Southeastern British Columbia that received treatment and/or follow-up at the TBCC. It did not include patients managed only by their family physician and/or another specialist in the community. Of particular significance is that many palliative care patients are cared for only by their family physicians and, therefore, may not be well

represented in the sample. Assessment of the representativeness of the sample will be presented in a later chapter.

The sampling strategy in a survey is very important in order to minimize bias (43). The lung clinic patient population is a particularly difficult group to approach due to the nature of the disease trajectory. Recruitment was facilitated by eliciting cooperation from the physicians and Registered Nurses involved with the patients' care. Meetings were held with the oncologists and RNs of the TBCC Outpatient Lung Clinics to explain the project and to elicit their cooperation. The clinic nurses were given the discretion to determine which patients were suitable to be approached for study enrollment. During the data collection period, the primary nurse of the NPLC and FULC of the Outpatient Department provided names of patients attending the weekly clinics. The clinic nurse asked patients if they were willing to meet the researcher or research assistant. Consecutive consenting patients who met the eligibility criteria were approached at the clinic, resulting in a non-probability sample of lung cancer patients. The study was explained to the patients and the consent form was reviewed.

The sample comprised of newly diagnosed patients (NPLC) and those already diagnosed and being monitored (FULC), resulting in patients at various stages of illness. Heterogeneity is important in this study since the primary data collection instrument has not been widely used in a lung cancer population. The sample did not include patients under active treatment who were not attending the outpatient clinic because of difficulties accessing the patients. It was hypothesized that unmet needs of patients may differ by time since diagnosis as a result of changing disease impact and different experiences with

the health care system, for example, contact with oncology services provided at the NPLC or the FULC.

The sample included both urban and non-urban residents. Urban patients were defined as people who live in communities where at least some Alberta Cancer Board services are available. The urban centres affiliated with the TBCC are Calgary, Red Deer, Medicine Hat, and Lethbridge. Non-urban patients were those who live in communities where no Alberta Cancer Board cancer services are available. This urban/non-urban distinction was made based on a potential difference in access to services by place of residence.

The data collection period was between June and October 1999 over 20 weeks. Given that this was a descriptive study, the sample size was based on the characteristics of the population from which the sample would be drawn. Approximately 120 patients attend the Follow-up Lung Clinic each month (personal communication, Nancy Grainger, 1998). Results from the pilot study suggested that 15% of the clinic patients would not be eligible for the study, and 80 to 85% of the eligible patients approached at clinic would agree to participate. Of these, a response was expected from 70%. Rigorous follow-up was built into the methodology to maximize the response rate. It seemed reasonable to expect to recruit a sample of approximately 75 patients per month from the FULC and to obtain data from 52 patients. A sample of 300 patients from the FULC was sufficient to assess the types of needs of lung cancer patients. This sample size would yield confidence interval widths for proportions of no more than $\pm 6\%$. The power would be sufficient (90%) to detect correlations above 0.2.

Twenty-eight patients are seen per month at the NPLC (personal communication, Nancy Summers, 1998). Due to the nature of the NPLC and patients' associated distress, it was expected to be more difficult to recruit patients from this clinic than from the FULC. However, it was hoped that by using more than one recruitment strategy, participation could be maximized. Expecting that 15% of the patients would not be eligible for the study and only 50% of the eligible patients would agree to participate, recruitment was estimated to yield 12 patients per month.

Consecutive outpatients attending the NPLC and FULC at the TBCC were asked by a clinic nurse for permission for the researcher or research assistant to explain the study. Agreeable patients were approached at the lung clinic and a verbal explanation of the study and consent form were given (Appendix 1). The researcher or research assistant obtained written consent from patients at the lung clinic. Patients agreed to complete the two questionnaires and gave permission for the researcher to obtain demographic and illness information from the patient's chart. Patients were given the three self-administered questionnaires (the CNQ, the EORTC QLQ-C30, and the EORTC QLQ-LC13), instructions related to completion and return of the questionnaires, and a return self-addressed, stamped envelope. Some patients who were interested in participating could not meet the researcher in clinic. In these situations, the researcher called the patient at home about one to three days later to explain the study. Patients who agreed over the phone to participate were mailed two copies of the consent form (one copy to sign and return, and one copy for the patient's records), the questionnaires, and a return envelope.

Patients were asked to complete and mail the questionnaires within three days. A reminder letter was sent if the questionnaires had not been returned within two weeks of distributing the questionnaires. If, two weeks later, a response had still not been obtained, a phone call was made to the patient. If, two weeks later, the completed questionnaires had not been received, another package of questionnaires was sent.

A brief (five minute) follow-up phone call was made to each respondent after receiving the completed questionnaires. As the study identified unmet needs, this phone call was a debriefing opportunity for all patients. Patients with high needs or those who personally identified a need for follow-up were given an opportunity for referral to the clinic nurse and/or the Department of Psychosocial Resources at the TBCC if they wished. No new information was elicited from patients during the telephone conversation as it was a clinical phone call, not intended to improve the quality and completeness of the data.

Demographic and illness data were collected from participants and their charts (Appendix 2). Variables included time since diagnosis (months), presence (and location) or absence of metastases, treatment intent (curative or palliative), remission status, types of treatment ever received, types of treatment received in the past month, prior diagnoses of cancer (year and type(s)), last hospitalization, date of birth, gender, and patient's type and stage of lung cancer. Patients were also asked to provide the following information: types of complementary or alternative therapies regularly used, marital status, highest attained level of education, employment situation before and after the cancer diagnosis, usual occupation, distance travelled to come to the clinic, number of children and adults

residing in the household, current care in the home by a Registered Nurse, relationship of the person(s) residing with the patient, and total household annual income.

Patients who declined participation were asked to provide a reason for not participating in the study. Demographic data from the non-participants was collected from the clinic nurse or the patient's chart (Appendix 3). This information was used to help determine the representativeness of the participants.

Measures

The choice of HRQL scales for this study was based on several factors. These included: 1. demonstrated psychometric properties, 2. a lung cancer specific scale (due to the complexities of the illness), 3. multi-dimensional, 4. a generic cancer scale (to compare lung cancer patients with patients with other types of cancer in future research), 5. self-administered (to ensure the patient's experience is reflected rather than a proxy's point of view), and 6. relatively brief (to minimize patient burden since the questionnaires would be given simultaneously). In addition, the analysis compared QOL scores to unmet need scores, thus a response scale (versus open-ended questions) for the instrument was desirable. Lastly, it was important that the tool would reflect needs based on geography or culture.

An overall or aggregate score may be desirable under circumstances, such as clinical trials, where QOL is correlated with another measure. However, from a clinical perspective, a global, single measure is less useful since the nurse, physician, or other health care provider is unable to determine how or when to provide support or care to improve the patient's QOL.

Based on these criteria, the questionnaires selected for use in this study were the Cancer Needs Questionnaire, and the European Organization for Research and Treatment of Cancer quality of life questionnaire core module (QLQ-C30) and the lung cancer module (QLQ-LC13). It was estimated that the three questionnaires could be completed within 50 minutes.

Cancer Needs Questionnaire

Foot and Sanson-Fisher (4) developed the Cancer Needs Questionnaire to assess the unmet needs of adult oncology patients. The authors developed the questionnaire based on information from existing literature on patient needs, patient satisfaction, QOL, and from interviews with cancer patients.

The instrument consists of five domains of needs: psychological, health information, physical and daily living, patient care and support, and interpersonal communication needs. Psychological needs are those related to the emotional and psychological aspects of the disease such as anxiety, anger, and depression. Health information needs are related to needs for information about the disease, its treatment, and prognosis. Coping with physical symptoms and side effects, loss of independence, and activities of daily living refer to physical and daily living needs. Patient care and support needs are related to clinic and hospital staff sensitivity to both physical and emotional needs, privacy, and choice of specialists. Lastly, interpersonal communication needs refer to interacting and communicating with others (4).

The need items are based on a five point Likert scale. Respondents rate their need for help as follows: 1. no need for help on a given item because the need has not been experienced or is not applicable; 2. no need for help on a given item because the need has

already been satisfied; or some need for help where need is rated as a 3. low, 4. moderate, or 5. high need for help. The reliability and validity of the CNQ were assessed initially by Foot and Sanson-Fisher (4). As well, the TBCC pilot study in preparation for the main study included an assessment of reliability and validity. The CNQ consists of 52 need items, two questions about access to services and support persons, and demographic questions (Appendix 4).

In the initial testing in Australia, the CNQ was tested with 480 consecutive patients at an outpatient cancer clinic (4). The response rate was 75% (n=358). Content validity was assessed by a team of experts. Factor analysis, a method to determine the consistency and coherence of the items within a particular factor, indicated construct validity of five distinct domains of need measured by the CNQ. The domains and their associated items are listed in Appendix 5. Further, a Cronbach's alpha coefficient of at least 0.90 was found on domains one to four and 0.78 on domain five, demonstrating evidence of internal reliability. External reliability was assessed by test-retest procedure with a subsample of 124 patients. The weighted Kappa showed that the intercorrelations of all items were greater than 0.4 and statistically significant.

In the initial studies, most patients reported unmet needs. These needs were usually related to health information, psychological adjustment, and the need for care and support. As well, the authors found that patients reported more needs as the stage of cancer increased, suggesting the instrument discriminates disease stage (4). Patients with metastatic cancer reported unmet needs in each domain, with items relating to interpersonal communication and psychological issues identified as having the greatest magnitude of need (4).

The authors recommended wider use of the questionnaire to establish the tool's validity and reliability, particularly with specific cancer groups (e.g. breast and prostate cancers), diverse treatment forms, and patients at different stages of disease (4). The CNQ also needs to be used in different health care delivery systems and with different populations. The authors suggested that the CNQ could be used in outcome studies along with quality of life and patient satisfaction surveys to better understand the morbidity associated with cancer (4). Some of the CNQ's weaknesses have been identified, including the absence of need items related to spirituality and sexuality. However, given that it is otherwise relatively comprehensive, the CNQ fulfills the requirements of a needs questionnaire for this study.

As a result of the pilot study, several minor changes were made to the illness information questions on the CNQ so that the information could be compared with data from the Alberta Cancer Registry, including response differences by specific type of lung cancer and time since diagnosis. Based on patient's comments, no items were added to the questionnaire. However, the wording of several questions was modified.

Feedback from content experts regarding the pilot version of the CNQ was considered prior to finalizing the items for the main study. The names of content experts and their credentials are listed in Appendix 6. Their advice was incorporated in the final version of the CNQ. As a result of their suggestions, one need item was added to the questionnaire (dealing with shortness of breath/breathlessness) and the wording of several items was modified.

EORTC QLQ-C30 (Version 3.0)

The European Organization for Research and Treatment of Cancer has developed a core, disease-specific instrument for cancer patients, the quality of life questionnaire (QLQ-C30). The instrument also has a lung cancer module (QLQ-LC13). These tools were developed to assess the quality of life of people with cancer who were participating in clinical trials. The 30-item version of the core module, the QLQ-C30, (Appendix 7) is currently recommended by the EORTC Study Group on Quality of Life, although the 36-item version has been used in most published studies (44). It is a self-administered, multi-dimensional instrument.

The core module addresses global quality of life, functional dimensions (physical, role, cognitive, emotional, and social functioning), symptom dimensions (fatigue, pain, and nausea and vomiting), specific concerns for cancer patients (sleep disturbance, loss of appetite, constipation, diarrhea, and dyspnea), and financial concerns (1). A four-point Likert scale is used for all questions. When tested with 305 lung cancer patients from 12 countries, the QLQ-C30 was found to respond to changes in health status over time, as well as being a valid and reliable indicator of a patient's quality of life (1). The core module can be completed in approximately ten minutes (1). The items are intended to address HRQL in the previous week (45).

EORTC QLQ-LC13

The QLQ-LC13 was developed to supplement the core module in order to address problems unique to lung cancer (46). The module measures pain, symptoms associated with lung cancer, and side effects resulting from treatment (Appendix 8). This brief, disease-specific module addresses the person's condition in the past week (46). The

authors determined that the QLQ-LC13 can discriminate between subgroups of patients who differ in initial performance status. To a lesser extent, the QLQ-LC13 has been shown to discriminate between subgroups of patients based on different stages of disease (46). In combination, the core module and the lung cancer specific module have been found to be clinically valid and reliable (4,15,46). This suggests that the lung module is sensitive to the health status of patients with lung cancer related to specific symptoms and treatments.

Pilot Study

A pilot study was undertaken to assess the reliability and validity of the CNQ.

The objectives of the study were:

1. to assess the validity, reliability, comprehensiveness, and completeness of the CNQ in the context of the Canadian health care system, specifically with ambulatory lung cancer patients,
2. to determine the feasibility of the proposed research methods, and
3. to determine if the sampling strategy is sufficient to recruit an adequate sample size.

A convenience sample of patients at the Follow-up Lung Clinic at the TBCC were asked to participate in the pilot study from September to November 1998. Even though the sample was a select group of patients, it was sufficient to test the validity and reliability of the CNQ.

Participants were given the CNQ and an evaluation form to complete at home within three days. A self-addressed, stamped envelope was provided. One week after

receipt of the completed questionnaires, another copy of the CNQ was mailed. Follow-up was done to ensure a high response rate.

The pilot study results indicated the feasibility of the sampling and recruitment strategies for the FULC, and the research methods, and that an adequate sample size could be recruited for the main study. As well, the CNQ was shown to be valid, reliable, comprehensive, and complete. Sixty patients were recruited for the pilot study; eleven patients (15%) refused to participate. The response rate was 83% (n=50). A respondent was defined as a person who returned both the test (time 1) and retest (time 2) questionnaires. The elapsed time between completion of the test and retest questionnaires was approximately two weeks. Four patients returned only the first questionnaire, and two did not return either questionnaire. A detailed description of the sampling and recruitment strategy is shown in Table 1.

Table 1: Sample Derivation and Response Rate From the Pilot Study

	N	Other comments
Patients attending clinic	149	
Missed patients/ not appropriate	78	64 - missed 14 - not appropriate: - too ill (7) - RN stated there were "too many other issues" (3) - confused (2) - patient very upset (1) - moving out of province (1)
Available patients	71 (47.7% of patients in clinic)	
Refused	11	
Patients that consented	60 (84.5% of patients approached)	
Returned both questionnaires	50 (Response rate = 83.3%)	
Returned only one questionnaire	4	
Did not return either questionnaire	2	
Withdrawals	3	- unable to complete due to exacerbation of illness (2) - felt questionnaire was not suitable (1)
Unable to use	1	Completed by patient's daughter

It was thought that the good response was due, in part, to the personal contact between the researcher and the patients, as well as the clinic nurse's introduction of the study and the researcher to each patient. Due to the lack of space at the clinic and the number of patients attending each week, time was very limited for clinic visits. For this reason, many patients were missed and, therefore, not approached at clinic. In order to minimize these losses, a research assistant was hired to help with patient recruitment at the clinics for the main study. Another recruitment strategy for the main study was to have clinic nurses introduce the study to the patients that could not be approached at the clinic. Nurses asked permission for the researcher to contact them by phone to explain the study.

The demographic and illness characteristics of the pilot sample are described below. The average age of the participants was 67 (Table 2). Fifty-six percent of the

sample was male. The majority of the patients were married (70%) and had completed high school or further education (90%). Prior to being diagnosed with lung cancer, 50% were retired and 32% were full-time employees. At the time of the pilot study, 72% were retired and 6% were employed full-time. Twenty-eight percent of the sample reported average gross family incomes of less than \$20,000 per year.

Table 2: Demographic Characteristics of the Pilot Study Sample

Characteristic	% (frequency) (n=50)
Age:	
Mean	67
SD	10
Range	43 – 83
Gender:	
Female	44 (22)
Male	56 (28)
Marital status:	
Single/never married	2 (1)
Married/common-law	70 (35)
Separated	0
Divorced	12 (6)
Widowed	16 (8)
Highest level of education:	
Elementary	10 (5)
High school	66 (33)
Community/technical college	14 (7)
University/teacher's college	10 (5)
Prior employment status:	
Retired	50 (25)
Full-time	32 (16)
Household	8 (4)
Part-time	4 (2)
Other	4 (2)
Medical leave/disability	2 (1)
Looking for work	0
Current employment status:	
Retired	72 (36)
Medical leave/disability	8 (4)
Full-time	6 (3)
Household	6 (3)
Other	4 (2)
Part-time	2 (1)
Looking for work	2 (1)
Current yearly gross family income:	
< \$20,000	28 (14)
\$20,000 - \$39,999	34 (17)
≥ \$40,000	30 (15)
Not answered / don't know	8 (4)

Eighty percent of the sample (n=40) was diagnosed with NSCLC, of which ten patients had early stage, 17 had locally advanced, and four had advanced lung cancer (Table 3). Diagnoses of SCLC comprised 16% of the sample. Approximately half of all patients (44%) had been diagnosed within the past year. Forty-four percent had metastatic

lung cancer. Few patients had received any type of treatment in the month prior to the clinic. The most common types of treatment patients had ever received were radical radiation (54%), chemotherapy (32%), palliative radiation (28%), and surgery (26%). Most patients had never been admitted to hospital for lung cancer related care (42%). Over one-quarter of patients had been diagnosed with another type of cancer during their lifetime.

Table 3: Illness Characteristics of the Pilot Study Sample

Characteristic	% (frequency) (n=50)
Time since diagnosis:	
< 3 months	6 (3)
3-6 months	12 (6)
6-12 months	26 (13)
1-2 years	20 (10)
2-3 years	16 (8)
>3 years	20 (10)
Type of lung cancer:	
SCLC	16 (8)
NSCLC	80 (40)
Other lung cancer	4 (2)
Stage of lung cancer:	
SCLC	
Limited	8 (4)
Extensive	2 (1)
Not written	6 (3)
NSCLC	
Early	20 (10)
Locally Advanced	34 (17)
Advanced	8 (4)
Unable to determine	16 (8)
Not written	2 (1)
Presence of metastases:	
Yes	44 (22)
No	48 (24)
Not confirmed but suspected	8 (4)
Prior treatment(s):*	
Radical radiation	54 (27)
Chemotherapy	32 (16)
Palliative radiation	28 (14)
Surgery	26 (13)
Prophylactic cranial radiation	8 (4)
Other	8 (4)
No treatment ever	2 (1)
Treatment(s) used in the last month:	
No treatment in past month	88 (44)
Chemotherapy	6 (3)
Palliative radiation	4 (2)
Surgery	2 (1)
Radical radiation	0
Diagnosis of another cancer (prior to or after lung cancer diagnosis):	
Yes	26 (13)
Types (n=13):	
Skin	5
Bladder	3
Cervix in situ	2
Breast	1
Lung	1
Parotid gland	1

(Table 3 continued)

Last admission for lung cancer:	
Last 6 months	14 (7)
7-12 months ago	12 (6)
1-2 years ago	12 (6)
More than 2 years ago	20 (10)
Never	42 (21)

*Some subjects had more than one treatment, therefore, the percent total is greater than 100%.

Validity is the degree to which an instrument measures what it intends to measure. Comments from the evaluation forms suggested that the instrument and items of the CNQ were clearly worded and easy to follow, and that the questions and response categories were appropriate. The average length of time to complete the questionnaire was 35 minutes (SD=22 minutes), with times ranging from ten to 120 minutes. Many patients commented that the questionnaire was comprehensive and thorough. The questionnaire appeared to have face and content validity. One drawback to the use of the questionnaire is that a written questionnaire may be difficult for older or visually impaired people. However, there were few concerns related to this.

Internal consistency (reliability) is the degree to which an item correlates with items of the same concept and with the overall scale score. Cronbach's alpha coefficients were assessed as a measure of the consistency of the items within each domain using the linearly transformed data. The rationale for this transformation and the procedure will be explained in the data analysis section. The Cronbach's alpha results (greater than 0.88) suggested that the domains were highly correlated (Table 4).

Table 4: Cronbach's Alpha Coefficients for the Domains of Need Within the Cancer Needs Questionnaire

Factor Number	Factor Title (Domain)	Alpha for Test Questionnaire	Alpha for Retest Questionnaire
1	Psychological needs	0.9668	0.9805
2	Health information needs	0.9490	0.9578
3	Physical and daily living needs	0.9118	0.9077
4	Patient care and support needs	0.9071	0.9453
5	Interpersonal communication needs	0.8846	0.9091

Test-retest reliability is the degree to which an instrument measures what it intends on repeated administrations, demonstrating the consistency and reproducibility of the measurements. Two-way analyses of variance were conducted to determine the differences in unmet needs, by domain, identified in the first and second administrations of the CNQ. These ANOVA calculations failed to detect a statistically significant change in the assessment of unmet needs from time 1 to time 2 for each of the five domains, suggesting that patients' unmet needs did not change over time (Table 5). The intra-class correlation coefficients were calculated to indicate the reliability of the measurements over time, that is between time 1 and time 2. The results, ranging from 0.69 to 0.88, indicated good test-retest reliability.

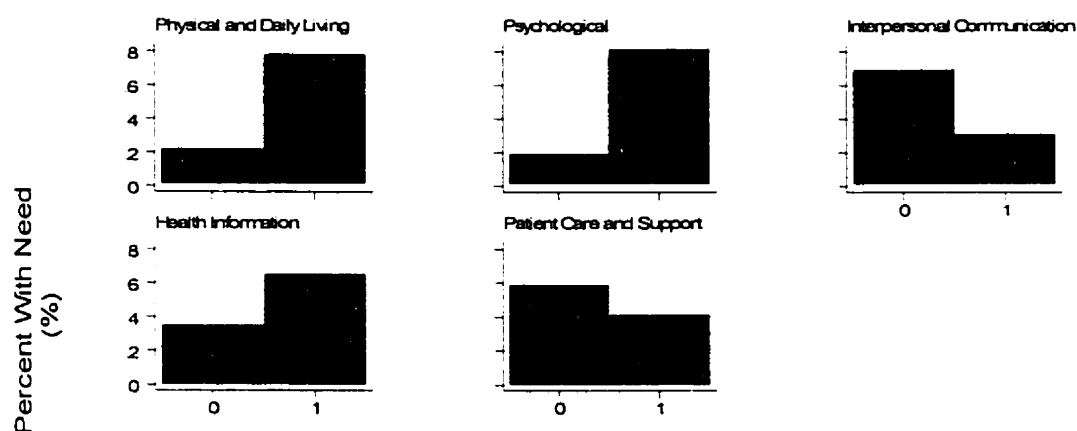
Table 5: ANOVA Results Comparing Test and Retest Administrations of the CNQ by Domain and the Associated Intra-Class Correlation Coefficients (ICC)

Factor #	Factor Title (Domain)	F statistic	P value	ICC
1	Psychological needs	0.59	0.4465	0.88
2	Health information needs	3.71	0.0599	0.87
3	Physical and daily living needs	1.55	0.2189	0.79
4	Patient care and support needs	0.58	0.4495	0.85
5	Interpersonal communication needs	1.83	0.1829	0.69

Figure 3 shows the prevalence of patient needs in each domain. Need was classified as having “no need” (=0) or “some need” (=1). This analysis was done in the same format as Lattimore-Foot (5) in which all domain scores equaling zero were coded

as “no need” and all scores greater than zero were coded as “some need”. These graphs demonstrate that for the psychological, health information, and physical and daily living need domains, some needs were experienced by over 60% of the sample.

Figure 3: Prevalence of Patient Needs by Domain



No need = 0, Some need = 1

This pilot study provides psychometric evidence supporting the use of the CNQ with the selected patient population. In addition, the recruitment and research methods were feasible. As a result, the methods and procedures for the main study were developed in accordance with the pilot study findings.

Data Management

Patients returned the questionnaires by mail. The data from the CNQ and the EORTC QLQ-C30 and QLQ-LC13 were entered into separate computer files using EpiInfo software. Each case was entered twice by the research assistant according to the patient's assigned study identification number, and validation was performed to ensure

data entry accuracy. In cases of an apparent error, the original questionnaires were consulted and corrections were made as necessary. The files were then imported into the Stata 5.0 data analysis program. Non-participant data was also managed in this manner. All records were entered by the patient's study identification number to ensure confidentiality. Paper questionnaires are kept in a locked room.

Scores for the need domains and QOL dimensions were calculated according to the formulas established by the questionnaire developers. A computerized file of Alberta lung cancer patient data was obtained from the Alberta Cancer Registry. All patients alive on January 1, 1998 or diagnosed in that year were included. No identifying information was requested.

Data Analysis

The analyses for this study included assessment of the demographic and illness data, determining the unmet needs and QOL of the sample, and determining the relationship between unmet needs and QOL. The data collected from the survey was analysed in several ways including descriptive and correlational analyses.

One of the primary objectives of the analysis was to determine the needs of outpatients with lung cancer. Analysis showed that the groups (FULC and NPLC) could be combined since they were similar with respect to demographic and illness characteristics. For the analyses of quality of life and unmet needs, the samples were compared by gender, age, place of residence, and disease severity.

Assessment of demographic and illness data

The data were analysed to describe the sample according to their demographic and illness characteristics. The NPLC and FULC patients were compared. Initially, the

data were displayed graphically to view the data. Histograms of each variable and scatter diagrams of pairs of variables were assessed. This provided an opportunity to see the distribution of the data and to assess normality.

Summaries of the demographic and illness data are presented in tables. Statistics used included frequency distributions and summary statistics (as applicable) of the following factors: age, gender, marital status, education, prior and current employment status, distance travelled to attend clinic, relationship of the person(s) residing with the patient, and family income. These statistics were also used to describe the following illness variables: length of illness, types of treatment ever received and received in the past month, types of alternative therapies regularly used, current care in the home by an RN, last hospitalization, intent of treatment, and disease severity. A literature search did not find any type of classification for disease severity to reflect a patient's current disease state. For the purposes of this research, disease severity was defined by stage of illness at diagnosis and presence or absence of metastases when approached at clinic. The criteria for lower disease severity was early or locally advanced NSCLC or limited stage SCLC without metastases; a higher disease severity was any advanced NSCLC or extensive stage SCLC and/or the presence of metastases.

Categorical variables were analysed using chi-square tests and the Fisher's Exact Test between groups. For continuous, normally distributed variables, tests for equal variances were used. If the variance was equal (i.e. a non-significant difference between the standard deviations of the two groups), a t-test for equal variances was done. If the variance was unequal, a t-test for unequal variances was done using Welch's formula to determine the approximate degrees of freedom. Confidence intervals were also calculated

for each mean. For comparisons of more than two groups (including comparisons of participants, non-participants, and non-respondents, and age category analyses), ANOVA tests were done. For statistically significant ANOVA results, pairwise comparisons were done to determine which comparisons were statistically significant. For continuous variables that were not normally distributed, the Mann-Whitney two-sample statistic (Wilcoxon rank-sum test) was used to compare the medians of two individual samples.

The Alberta Cancer Registry data were used to compare the study sample to the Alberta lung cancer population. The data were comprised of all registrants with lung cancer alive on January 1, 1998 and all registrants diagnosed with lung cancer between January 1, 1998 and December 31, 1998. Registry data from 1998 were used because the data for 1999 were incomplete at the time of the analysis. Summary statistics of the following variables were calculated: age, gender, place of residence, histological type of lung cancer (using the ICDO morphology), and diagnosis date.

Assessment of needs

The unit of analysis of the unmet need data was the domain of need, where each of the five domains was composed of a number of need items. The items for a given domain were based on Lattimore-Foot's (5) determination of items with a primary loading factor for that domain. As a result, some items were not used in the domain analyses. One difference between the pilot and the main study analyses was that question 53, related to shortness of breath, was added to the physical and daily living domain for the main study. The raw data, which were ordinal (1 to 5), were transformed into a linear scale (0 – 100) to facilitate analysis and interpretation by broadening the range of scores (Appendix 9).

Once reclassified to the linear scale, scores for the items within each domain were averaged. Thus, each patient had an average score for each domain and this score was used for the analyses. Descriptive statistical analyses were used to generate frequency distributions, summary statistics, and the variability of each domain of need. However, questions related to access to services and resources (e.g. parking and respiratory therapy) and additional help and support with cancer-related problems (e.g. clinic staff and family) were assessed by item as the domains are not applicable to these questions. Analyses included the assessment of the need in each domain, as well as comparative analyses with the QOL data.

Osoba et al. (20) discussed the issue of missing data in HRQL scales. The discussion may also apply to the assessment of unmet needs. The authors wrote that it is ideal if missing data is less than five to ten percent of the entire data set. Aaronson et al. (1) suggest the following treatment of missing data for the EORTC. This procedure was used for the CNQ as well. When less than half the items from a particular scale were answered, the scale score was set to missing. When at least half the items from a scale were answered, the scores of the completed items were used to calculate the scale score and the missing items were ignored. However, if an item measured by a single question was not completed, the scale score was set to missing.

Assessment of quality of life

A scoring method for the QLQ-C30 and QLQ-LC13 was developed by Aaronson et al. (1). Averaging the scale items produced a raw score for each of the scales. The scale scores and the single item scores were then converted to a linear (1 – 100) scale, again for ease of interpretation. The formulas are shown in Appendix 10. These formulas are based

on two assumptions: that the items are linear and that each item has equal weight (1). The justification given by the developers is that there is no evidence to suggest that the items are not linear. Although the developers are considering alternative scoring methods, the unweighted scoring is currently recommended (1).

The higher the score, the greater the attribute being measured. A higher score on functioning scales and overall global QOL suggested better function and QOL; conversely, higher scores on the symptom scales suggested more symptomatology. Even though an overall QOL score was estimated and used in the analyses, basing QOL assessments on this score is not recommended since quality of life is multi-dimensional and not accurately reflected by a single score (47).

Assessment of the relationship between unmet needs and quality of life

A correlation is a measure of linear association between two continuous variables. The degree of association or the strength of the correlation is measured by the correlation coefficient (r) that can range from -1.0 to $+1.0$. In order to assess the statistical relationship between unmet needs and quality of life, the correlations between the following dimensions of QOL (based on the EORTC QLQ-C30) and domains of need (based on the CNQ) were calculated:

physical functioning dimension	and	physical and daily living domain,
role functioning dimension	and	physical and daily living domain,
cognitive functioning dimension	and	health information domain,
emotional functioning dimension	and	health information domain,
emotional functioning dimension	and	psychological domain,
emotional functioning dimension	and	patient care and support domain,

social functioning dimension and patient care and support domain, and
 social functioning dimension and interpersonal communication
 domain.

Since the distributions of the variables were not normally distributed, the Spearman's rank correlation coefficient (ρ) was used to assess relationships. This is a non-parametric correlation coefficient that may be used with any type of distribution.

Ethical Considerations

The researcher obtained ethical approval for this project from the TBCC Research Advisory Committee and the University of Calgary Conjoint Health Research Ethics Board prior to initiation of patient recruitment. Names of patients from the TBCC clinics were kept confidential. Participation was voluntary. Patients were assured that their medical treatment and care would not be affected by participation or non-participation in this study.

Informed consent was obtained from each participant recruited from the clinic. Each participant was assigned a unique number for identification purposes to ensure confidentiality. Names were not incorporated into the database. All identifying materials, such as questionnaires, were kept in a locked room.

During the follow-up phone call, patients were debriefed about their needs. Patients who requested follow-up services or who were identified by the researcher as having serious or high levels of unmet needs were given the opportunity to be referred for further follow-up. Agreeable patients were referred directly to the Department of Psychosocial Resources at the TBCC or concerns were communicated to the patient's clinic nurse. Patients that were not agreeable were encouraged to follow-up with the

Department of Psychosocial Resources and/or their clinic nurse and the contact numbers of each were provided. Patients were also encouraged to phone the researcher at the conclusion of their participation if they wished further debriefing regarding their unmet needs.

Permission to use the Cancer Needs Questionnaire, the QLQ-C30, and the QLQ-LC13 were obtained from the developers/authors (Appendix 11).

Chapter 3: Results

Overview

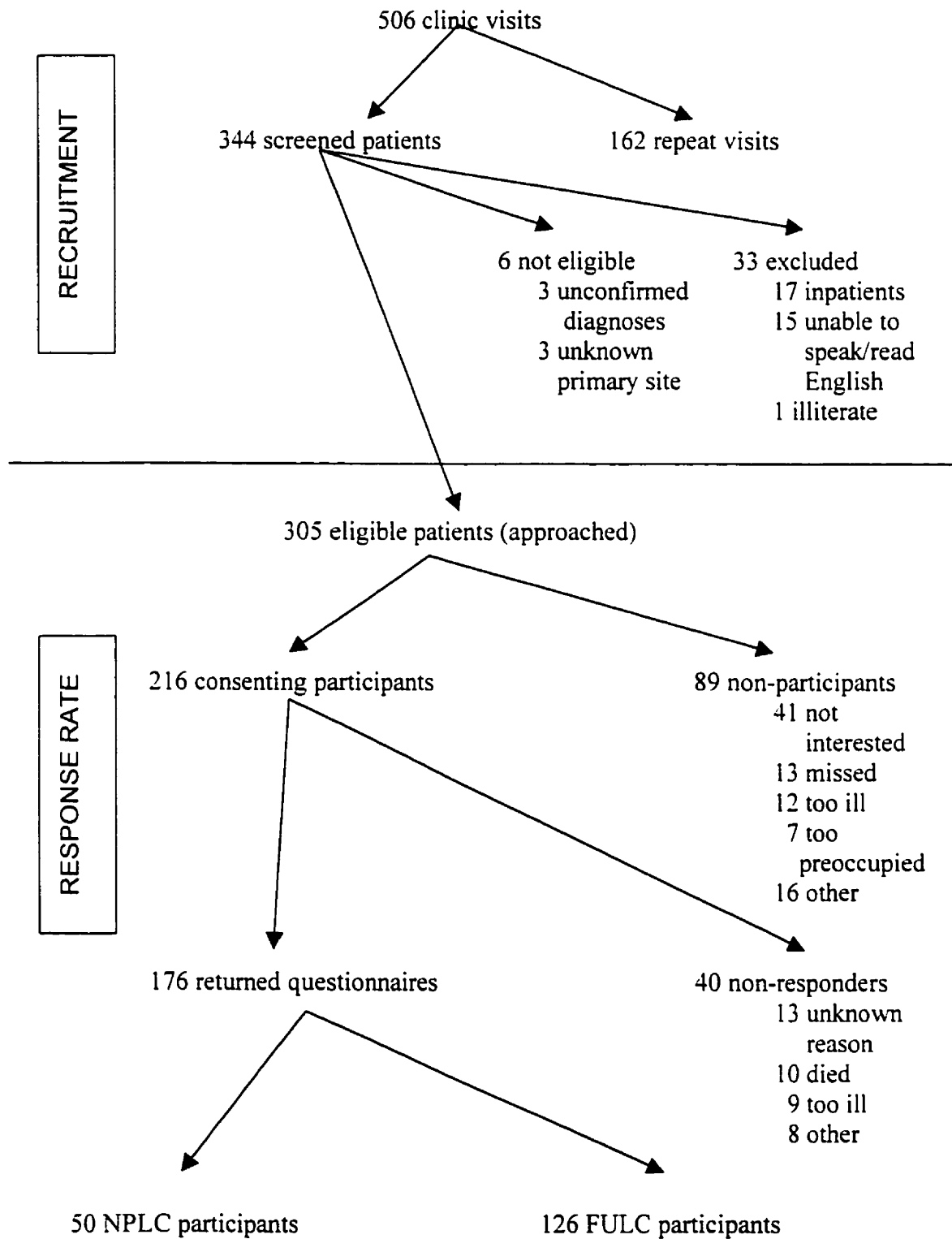
The results of this study are presented in three sections. First, the clinic population is described, including the participants (those that returned completed questionnaires), non-participants (patients that refused to participate), non-responders (patients that did not return the questionnaires), and the Alberta population of lung cancer patients. In section two, a description of the treatment of missing data for both the analyses of unmet needs and quality of life is presented. This is followed by separate analyses of unmet needs and QOL. Lastly, the relationship between unmet needs and quality of life is assessed in section three.

Clinic Population

Clinic Recruitment

A total of 506 patient visits were logged at the lung clinics during the five-month data collection period, 121 from the NPLC and 385 from the FULC (Figure 4). Of these, 162 visits were repeat visits. As a result, there were 344 patients that attended the clinics, of which 104 and 240 patients were screened at the NPLC and FULC respectively. Six patients were ineligible for the following reasons: three patients had unconfirmed and clinically uncertain diagnoses of cancer, and three patients had unknown primary sites of disease. A total of 33 patients were excluded: 17 were inpatients at the time they attended clinic, 15 could not speak or read English, and 1 patient was illiterate. As a result, 305 of the 344 clinic patients were eligible for the study, 90 patients from the NPLC (86.5% of 104 patients) and 215 from the FULC (89.6% of 240 patients).

Figure 4: Clinic Recruitment



Response Rate

A total of 65 NPLC patients and 151 FULC patients agreed to participate (Table 6). This yielded a participation rate of 71% and 70% for the NPLC and FULC respectively. Of the 65 NPLC participants, 50 (77%) returned the questionnaires, and 126 of the 151 (83%) FULC participants returned the questionnaires. A slightly higher percentage of FULC patients returned the questionnaires than NPLC patients. This may have been a result of several factors unique to the NPLC patients: a new diagnosis of lung cancer, a feeling of uncertainty of the needs they are experiencing, and/or a focus on treatment rather than other aspects of the disease.

Table 6: Response Rate

Characteristic	New Patient Lung Clinic % (frequency)	Follow-up Lung Clinic % (frequency)	Total % (frequency)
Consenting participants	65	151	216
Participants (returned questionnaires)	50	126	176
Not returned	23.1 (15)	16.6 (25)	18.5 (40)
Reasons for not returning the questionnaires:			
Unknown	40.0 (6)	28.0 (7)	32.5 (13)
Died	20.0 (3)	28.0 (7)	25.0 (10)
Too ill	13.3 (2)	28.0 (7)	22.5 (9)
Only EORTC questionnaires returned	0	8.0 (2)	5.0 (2)
Only CNQ questionnaire returned	13.3 (2)	0	5.0 (2)
Did not pertain	0	4.0 (1)	2.5 (1)
Moved	6.7 (1)	0	2.5 (1)
Returned blank	6.7 (1)	0	2.5 (1)
Depressed	0	4.0 (1)	2.5 (1)
Response rate	50/65 = 76.9%	126/151 = 83.4%	176/216 = 81.5%

The overall response rate was 82%. This response rate is clinically significant as it suggests the questionnaires were acceptable to the patients. This is also testament to the rigorous follow-up procedures used in this study. These strategies were easy to administer and provided reminders to the patients in a non-threatening manner.

One patient was later found not to have lung cancer but was left in the analysis because the patient was under the impression that she did have lung cancer at the time of completing the questionnaires.

Originally, it was anticipated that 300 patients would be recruited from the FULC and 50 patients from the NPLC resulting in confidence intervals for a proportion of $\pm 6\%$. With the smaller sample size, the confidence interval widths for proportions were expected to be no more than $\pm 9\%$, a 50% increase in the width of the confidence intervals.

Non-participant Data

Non-participants were patients that refused to participate in the survey. Almost 30% of the eligible patients refused to participate. Of these, 28% ($n = 25$) were from the NPLC and 72% ($n = 64$) were from the FULC. Most of these patients declined participation stating they were not interested in the study: 28% from the NPLC and 53% from the FULC (Table 7). Fifteen percent were missed at their clinic appointment. Fourteen percent were too ill at the time of clinic to participate. This is clinically important as the needs of ill patients may not be reflected by well patients. A further eight percent stated they were too preoccupied with their illness or home situation to participate. Other non-participant reasons included being unable to reach patients by

phone to elicit their cooperation, not being emotionally ready to complete such a questionnaire, and stating that they don't participate in surveys.

Table 7: Reasons for Non-participation

Reason	New Patient Lung Clinic % (frequency) n = 25	Follow-up Lung Clinic % (frequency) n = 64	Total % (frequency) n = 89
Not interested	28.0 (7)	53.1 (34)	46.1 (41)
Missed	20.0 (5)	12.5 (8)	14.6 (13)
Too ill	12.0 (3)	14.1 (9)	13.5 (12)
Too preoccupied	16.0 (4)	4.7 (3)	7.9 (7)
Doesn't do questionnaires	0	4.7 (3)	3.4 (3)
Participant→non-participant (unable to reach)	0	4.7 (3)	3.4 (3)
Not yet ready	12.0 (3)	0	3.4 (3)
Too upset	4.0 (1)	1.6 (1)	2.2 (2)
Cannot contribute	0	3.1 (2)	2.2 (2)
Broken glasses	4.0 (1)	0	1.1 (1)
Blind	0	1.6 (1)	1.1 (1)
Deaf	4.0 (1)	0	1.1 (1)

Non-respondent Data

Non-responders were those patients that agreed to participate but did not return the completed questionnaires. Overall, 40 patients (19%) did not return the questionnaires (Table 6). During the reminder phone call, some patients provided explanations as to why they would not return the questionnaires. Of those that did not return the questionnaires, 13% and 28% of the NPLC and FULC patients respectively were too ill, and 20% and 28% of the NPLC and FULC patients respectively had died. The reason for not returning the questionnaires was not known for one-third of the non-responders.

Participant Characteristics

The demographic characteristics of the participants are described below. There were no statistically significant differences between the NPLC and the FULC patients (Table 8). Clinical differences are discussed.

Table 8: Demographic Characteristics of the Participants

Characteristic	New Patient Lung Clinic % (frequency) n = 50	Follow-up Lung Clinic % (frequency) n = 126	Total % (frequency) n = 176	P-values
Age:				0.2526
Median	65	66	66	
25 th , 75 th percentiles	57, 70	59, 73	58, 72	
Range	37 – 81	35 – 83	35 – 83	
Age categories:				0.450
Less than or equal to 60 years	38.0 (19)	30.2 (38)	32.4 (57)	
61 – 69 years	34.0 (17)	32.5 (41)	33.0 (58)	
Greater than or equal to 70 years	28.0 (14)	37.3 (47)	34.7 (61)	
Gender:				0.101
Male	72.0 (36)	58.7 (74)	62.5 (110)	
Female	28.0 (14)	41.3 (52)	37.5 (66)	
Marital status:				0.382
Single/never married	4.0 (2)	2.4 (3)	2.8 (5)	
Married	60.0 (30)	66.7 (84)	65.8 (114)	
Common-law/live with significant other	8.0 (4)	2.4 (3)	4.0 (7)	
Separated	2.0 (1)	0.8 (1)	1.1 (2)	
Divorced	12.0 (6)	9.5 (12)	10.2 (18)	
Widowed	14.0 (7)	18.3 (23)	17.0 (30)	
Highest level of education:				0.967
No schooling	0	2.4 (2)	1.1 (2)	
Elementary	20.0 (10)	14.3 (18)	15.9 (28)	
High school/secondary	50.0 (25)	50.0 (63)	50.0 (88)	
Community college/technical college	16.0 (8)	19.0 (24)	18.2 (32)	
University/teacher's college	6.0 (3)	5.6 (7)	5.7 (10)	
Graduate university degree	4.0 (2)	3.2 (4)	3.4 (6)	
Other	4.0 (2)	4.8 (6)	4.5 (8)	

(Table 8 continued)

Prior employment status:				0.916
Full-time employment	30.0 (15)	31.7 (40)	31.3 (55)	
Part-time/casual employment	6.0 (3)	4.0 (5)	4.5 (8)	
Household duties	6.0 (3)	8.7 (11)	8.0 (14)	
Student	0	0	0	
Retired	42.0 (21)	43.7 (55)	43.2 (76)	
Semi-retired	10.0 (5)	5.6 (7)	6.8 (12)	
Looking for work	0	0	0	
Medical leave/disability	2.0 (1)	2.4 (3)	2.3 (4)	
Other	4.0 (2)	3.2 (4)	3.4 (6)	
Current employment status:				0.320
Full-time	16.0 (8)	7.9 (10)	10.2 (18)	
Part-time/casual	0	1.6 (2)	1.1 (2)	
Household	4.0 (2)	8.7 (11)	7.4 (13)	
Student	0	0	0	
Retired	48.0 (24)	55.6 (70)	53.4 (94)	
Semi-retired	8.0 (4)	3.2 (4)	4.5 (8)	
Looking for work	0	2.4 (3)	1.7 (3)	
Medical leave/disability	20.0 (10)	14.3 (18)	15.9 (28)	
Other	4.0 (2)	2.4 (3)	2.8 (5)	
Place of residence:				0.279
Urban	70.0 (35)	77.8 (98)	75.6 (133)	
Non-urban	30.0 (15)	22.2 (28)	24.4 (43)	
Distance travelled to come to clinic:				0.156
Less than 25km	56.0 (28)	59.5 (75)	58.5 (103)	
25-50 km	6.0 (3)	12.7 (16)	10.8 (19)	
51-100 km	4.0 (2)	5.6 (7)	5.1 (9)	
>100 km	34.0 (17)	18.3 (23)	22.7 (40)	
Currently receiving care by an RN in the home:				0.230
Yes	10.0 (5)	16.7 (21)	14.8 (26)	
No	90.0 (45)	80.2 (101)	83.0 (146)	
Current living arrangement: *				0.220
Alone	18.0 (9)	23.0 (29)	21.6 (38)	
Spouse/significant other	68.0 (34)	67.5 (85)	67.6 (119)	
Son/daughter	8.0 (4)	5.6 (7)	6.3 (11)	
Friend	2.0 (1)	0	0.6 (1)	
Other	4.0 (2)	0.7 (1)	1.8 (3)	

(Table 8 continued)

Current yearly gross family income:				0.699
<\$20,000	26.0 (13)	31.7 (40)	30.1 (53)	
\$20,000 or more	64.0 (32)	58.7 (74)	60.2 (106)	
No income	0	2.4 (3)	1.7 (3)	
Don't know	4.0 (2)	3.2 (4)	3.4 (6)	
Did not respond	6.0 (3)	4.0 (5)	4.5 (8)	

* Total is greater than 100% as some patients live with more than one other person.

The median age of participants was 66 years. By age category, 38% of the NPLC patients were 60 years and under compared to 30% of the FULC patients. This was almost exactly reversed in the 70 years and older age category. Seventy-two percent of the NPLC patients versus 59% of the FULC patients were male. Most patients were married (66%) and had at least a high school education (82%). Inquiries were also made in regards to the patient's home situation. Almost 80% of patients lived with at least one person while one-fifth of patients lived alone. Ten percent of the NPLC patients currently had a Registered Nurse providing at least some care in their homes compared to 17% of the FULC patients.

Prior to diagnosis with lung cancer, approximately 31% of the patients were employed full-time and 43% were retired. At the time of the clinic visit, ten percent worked full-time and over 50% were retired. Additionally, the percentage of patients on medical leave or disability increased seven-fold following diagnosis with lung cancer. Reasons for change in employment status was not ascertained, but may be a result of the illness or a conscious change in lifestyle after diagnosis with a potentially life-threatening illness. Sixty percent of patients reported a gross family income in excess of \$20,000 per year.

Distance travelled to the clinic was assessed. Fifty-nine percent of the patients travelled less than 25 kilometers while 23% travelled over 100 kilometres for their clinic appointment. The percentage of patients travelling more than 100 kilometres to attend clinic was half in the FULC patient group than the NPLC patient group. This may be a conscious decision by patients to live in a city or town closer to Alberta Cancer Board services and resources following their diagnosis with lung cancer. Additionally, some follow-up patients are monitored solely in the community and not seen by a TBCC oncologist. While the needs of the community-followed patients were not assessed, it is possible that some types of needs can be met in a clinic and/or community setting. Three-quarters of the patients lived in an urban setting. However, when comparing the two clinics, fewer FULC patients lived in a non-urban setting than NPLC patients.

Illness characteristics of the two groups of patients were compared (Table 9). The median number of months since diagnosis was significantly different: one month for the NPLC patients (range 0 – 43 months) compared to 12 months for the FULC patients (range 0 – 199 months). Given the wide range of the number of months from one's diagnosis until attending the NPLC, it seems that many patients were monitored by their family doctor prior to being referred to the TBCC. Possible explanations for this delay may relate to factors that contraindicated treatment, such as older age or a later stage of cancer upon diagnosis, precluding treatment until symptomatic relief was necessary.

Table 9: Illness Characteristics of the Participants

Characteristic	New Patient Lung Clinic % (frequency) n = 50	Follow-up Lung Clinic % (frequency) n = 126	Total % (frequency) n = 176	P-value
Time since diagnosis:				
Median	1	12	7	<0.0001
25 th and 75 th percentiles	1, 3	6, 22	3, 20	
Range	0 – 43	0 – 199	0 – 199	
Type of lung cancer:				0.823
NSCLC	78.0 (39)	81.7 (103)	80.7 (142)	
SCLC	14.0 (7)	13.5 (7)	13.6 (24)	
Other lung cancer	2.0 (1)	4.8 (6)	4.0 (7)	
Missing information	6.0 (3)	0	1.7 (3)	
Stage of lung cancer:				
NSCLC:	(of 39)	(of 103)	(of 142)	
Early	7.7 (3)	21.4 (22)	17.6 (25)	
Locally advanced	41.0 (16)	44.7 (46)	43.7 (62)	
Advanced	15.4 (6)	20.4 (21)	19.0 (27)	
Unable to determine	12.8 (5)	1.9 (2)	4.9 (7)	
Not written	23.1 (9)	11.7 (12)	14.8 (21)	
SCLC:	(of 7)	(of 17)	(of 24)	
Limited	57.1 (4)	76.5 (13)	70.8 (17)	
Extensive	28.6 (2)	23.5 (4)	25.0 (6)	
Not written	14.3 (1)	0	4.2 (1)	
Presence of metastases:				0.426
No	36.0 (18)	40.5 (51)	39.2 (69)	
Yes	48.0 (24)	51.6 (65)	50.6 (89)	
Not confirmed but suspected	12.0 (6)	6.3 (8)	8.0 (14)	
Not written	4.0 (2)	1.6 (2)	2.3 (4)	
Current state of remission:				<0.001
No	82.0 (41)	40.5 (51)	52.3 (92)	
Yes	12.0 (6)	52.4 (66)	40.9 (72)	
Not confirmed	0	3.2 (4)	2.3 (4)	
Too soon after treatment to know	2.0 (1)	0.8 (1)	1.2 (2)	
Not written	4.0 (2)	3.2 (4)	3.4 (6)	
Disease severity				0.837
Lower	38.8 (19)	40.5 (51)	40.0 (70)	
Higher	61.2 (30)	59.5 (75)	60.0 (105)	
Treatment intent:				0.004
Curative	40.0 (20)	37.3 (47)	38.1 (67)	
Palliative	40.0 (20)	59.5 (75)	54.0 (95)	
Not yet determined	8.0 (4)	0	2.3 (4)	
Unknown	4.0 (2)	1.6 (2)	2.3 (4)	
Not written	8.0 (4)	1.6 (2)	3.4 (6)	

(Table 9 continued)

Prior treatment(s):*				
Radical radiotherapy	4.0 (2)	39.7 (50)	29.5 (52)	<0.001
Chemotherapy	12.0 (6)	31.7 (40)	26.1 (46)	0.008
Palliative radiotherapy	0	29.4 (37)	21.0 (37)	<0.001
Surgery	26.0 (13)	17.5 (22)	19.9 (35)	0.178
Have not started treatment	56.0 (28)	4.0 (5)	18.8 (33)	<0.001
Treatment was not pursued	6.0 (3)	10.3 (13)	9.1 (16)	0.561
Other	0	8.7 (11)	6.3 (11)	0.036
Treatment(s) used in the last month: *				
Treatment has been completed	10.0 (5)	75.4 (95)	56.8 (100)	<0.001
Have not started treatment	66.0 (33)	8.7 (11)	25.0 (44)	<0.001
Treatment was not pursued	6.0 (3)	8.7 (11)	8.0 (14)	0.759
Chemotherapy	6.0 (3)	3.2 (4)	4.0 (7)	0.408
Surgery	10.0 (5)	0	2.8 (5)	0.002
Other	2.0 (1)	1.6 (2)	1.7 (3)	1.000
Palliative radiotherapy	0	0.8 (1)	0.6 (1)	1.000
Radical radiotherapy	0	0	0	
Diagnosis of another cancer (prior to or after lung cancer diagnosis):				
Yes	25.0 (12)	15.9 (20)	18.4 (32)	0.165
Last hospital admission for lung cancer:				
Within last month	19.2 (9)	4.9 (6)	8.9 (15)	<0.001
1 – 12 months ago	14.9 (7)	33.6 (41)	28.4 (48)	
>13 months ago	6.4 (3)	19.7 (24)	16.0 (27)	
Never	59.6 (28)	41.8 (51)	46.8 (79)	

(Table 9 continued)

Complementary or alternative therapies used on a regular basis: *				
Use of any therapy	40.0 (20)	54.0 (68)	50.0 (88)	0.095
Vitamins and minerals	20.0 (10)	34.4 (43)	30.3 (53)	0.061
Herbal/natural therapies	16.0 (8)	19.2 (24)	18.3 (32)	0.621
Other	8.0 (4)	19.2 (24)	16.0 (28)	0.073
Traditional/cultural health practices	6.0 (3)	11.2 (14)	9.7 (17)	0.402
Mind-body therapies	6.0 (3)	8.8 (11)	8.0 (14)	0.760
Body therapies	8.0 (4)	4.0 (5)	5.1 (9)	0.278
Drugs	0	6.4 (8)	4.6 (8)	0.107
Energy therapies	0	5.6 (7)	4.0 (7)	0.194
Immune therapies	2.0 (1)	1.6 (2)	1.7 (3)	1.000
Dietary therapies	0	0	0	

* Totals are greater than 100% as some patients had/used more than one treatment

There was no difference between the clinics in the distribution of SCLC or NSCLC types of cancer. Diagnoses of NSCLC were more common than SCLC diagnoses. In the NPLC, most patients had locally advanced disease and almost half had metastases. The majority of NPLC patients were not in remission (82%) and were considered to have high disease severity (61%). Equal percentages of patients were considered curative versus palliative. The large number of patients that were not in remission at the time of their visit to the NPLC reflects the fact that most patients have not started treatment prior to their visit.

In the FULC, 75% of patients had limited, early, or locally advanced lung cancers. Two factors may be responsible for this higher percentage compared to the NPLC patients. First, at the time of the NPLC visit, many patients would not yet have had a complete work-up to confirm the stage of disease. Second, patients with early disease are more likely to survive and attend the FULC clinic than patients with more advanced

disease. One-half of the FULC patients were in remission and one-half had metastases. Sixty percent of patients had a higher disease severity and 60% were considered palliative. Less than 20% of the patients had had a diagnosis with another cancer (excluding non-melanoma skin cancers and cancer of the cervix in-situ) prior to or after their lung cancer diagnosis.

More NPLC than FULC patients had had a recent hospital admission (20% versus 5% respectively). However, 60% of the NPLC patients and 42% of FULC patients had never been admitted for lung cancer related care. This reflects the outpatient nature of the diagnosis, treatment, and follow-up of lung cancer patients. It follows that hospitalizations related to lung cancer are likely related to complications or serious adverse events.

In terms of treatment(s) ever received, 56% of NPLC patients had not started treatment prior to attending the clinic. But, 26% of NPLC patients had had surgery. This occurs when newly diagnosed patients are referred first to a surgeon and the post-operative NPLC visit serves as an opportunity to determine if further treatment is warranted. FULC patients had had a variety of treatments, including surgery (18%), chemotherapy (32%), and radical radiotherapy (40%). A further 29% had had palliative radiotherapy. Three-quarters of the FULC patients did not have treatment within the past month because it had been completed. This reflects clinic procedure in which, for example, patients are seen six weeks following radiation in order to allow the radiated area time to heal prior to assessment by the clinic staff.

Half the patients reported using at least one complementary or alternative medicine (CAM) on a regular basis, 40% from the NPLC and 54% from the FULC. One-

third of patients used a vitamin and mineral therapy. Almost 20% reported use of herbal or natural therapies. Six percent of FULC patients used alternative drugs and six percent used energy therapies, while none of the NPLC patients reported their use. The most commonly used treatments were megavitamin therapy (14% from the NPLC and 19% from the FULC), Vitamin B (12% from the NPLC and 16% from the FULC), and shark cartilage (6% from the NPLC and 12% from the FULC). It was surprising to note that there were no significant differences in CAM use between the two groups. With its more recent popularity, it was expected that the use of CAMs among FULC patients would be greater than among NPLC patients. Patients were asked to identify CAMs used on a “regular basis,” but this term was not defined. As a result, differing interpretations of “regular” use may have been made. Duration of use was also not assessed; assessment of this variable may provide the most accurate reflection of CAM use.

Comparison of Participants, Non-participants and Non-respondents

Participants, non-participants, and non-respondents were compared to determine the generalizability of the results to the clinic population (Table 10). There were no statistically significant differences between the three groups based on age, gender, time since diagnosis, and presence or absence of metastases variables. There were slightly more males among the participants than the other groups.

Table 10: Comparison of Participants, Non-participants and Non-respondents

Characteristic	Participants % (frequency) n = 176	Non-participants % (frequency) n = 89	Non-respondents % (frequency) n = 40	P-value
Age:				0.125
Mean	65 years	68 years	66 years	
SD	9.54	10.80	11.93	
Median	66 years	70 years	67 years	
25 th , 75 th percentiles	58, 72	62, 76	58.5, 76	
Range	35 – 83	25 – 97	38 – 88	
Gender:				0.237
Male	62.5 (110)	51.7 (46)	57.5 (23)	
Female	37.5 (66)	48.3 (43)	42.5 (17)	
Place of residence:		N/a		0.940
Urban	75.6 (133)		75.0 (30)	
Non-urban	24.4 (43)		25.0 (10)	
Time since diagnosis:				0.2662
Median	7 months	8 months	6 months	
25 th , 75 th percentiles	3, 20	1, 34	1, 14.5	
Range	0 – 199	0 – 210	0 – 61	
Type of lung cancer:		N/a		0.509
NSCLC	82.1 (142)		82.5 (33)	
SCLC	13.9 (24)		10.0 (4)	
Other	4.1 (7)		7.5 (3)	
Presence of metastases:				0.097
Yes	51.7 (89)	45.7 (37)	66.7 (26)	
Treatment intent:		N/a		0.168
Curative	39.4 (67)		25.0 (10)	
Palliative	55.9 (95)		70.0 (28)	
Not yet determined	2.4 (4)		5.0 (2)	
Unknown	2.4 (4)		0	
Disease severity:		N/a		0.141
Lower	40.0 (70)		27.5 (11)	
Higher	60.0 (105)		72.5 (29)	

The participants and non-respondents were also compared on several other variables to determine if there was a difference that may account for response differences (Table 10). Again, no significant differences were noted between the two groups. Non-respondents had higher percentages of palliative patients (70% versus 56%) and of patients with a higher disease severity (73% versus 60%) than participants. While the

differences were not statistically significant, they are clinically significant. Patients' current health status may have been a contributing factor resulting in not returning the questionnaires.

Based on these analyses, the three groups are comparable on these demographic variables, and the participants and non-respondents are similar based upon the illness variables. The results of this study can be generalized to both non-participants and non-respondents.

Comparison of Participants to Alberta Cancer Registry Data

The participants were compared to all Alberta lung cancer patients to determine the generalizability of the results to the population of patients with lung cancer in Alberta (Table 11). The average age among participants was 65 years (SD=9.6) and 67 years among Alberta lung cancer patients (SD=11.2, $p=0.0181$). There were more males among the participants (63%) than the Alberta patients (56%), but the difference was not significant. The majority of patients had NSCLC (82% of participants versus 86% of Alberta patients) and 14% in each group had SCLC ($p<0.001$).

Table 11: Comparison of Participants to Alberta Lung Cancer Patients

Characteristic	Participants % (frequency) n = 176	Alberta Lung Cancer Patients % (frequency) n = 3833	P-value
Age: *			0.0181
Mean	65.0 years	66.8	
SD	9.6	11.2	
Range	35 – 83	18 – 97	
Type of lung cancer:			<0.001
NSCLC	82.1 (142)	85.6 (2820)	
SCLC	13.9 (24)	14.2 (467)	
Other lung cancer	4.1 (7)	0.2 (7)	
Time since diagnosis: +			<0.0001
Median	7 months	59 months	
25 th , 75 th percentiles	3, 20	22, 125	
Range	0 – 199	0 – 690	
Gender:			0.086
Male	62.5 (110)	55.9 (2144)	
Female	37.5 (66)	44.1 (1689)	
Place of residence:			<0.001
Urban	75.6 (133)	61.3 (2292)	
Non-urban	24.4 (43)	38.8 (1450)	

* Age for Alberta lung cancer patients alive as of January 1, 1998 (n = 2003).

+ Time since diagnosis for Alberta lung cancer patients alive as of January 1, 1998 (n = 1665).

The time since diagnosis was also significantly different ($p < 0.0001$), with a median time of seven months for participants (range 0 – 199 months) and 59 months for the Alberta population (range 0 – 690 months). A significant difference was also noted by place of residence ($p < 0.001$), with three-quarters of participants and 61% of Alberta patients living in an urban setting.

The differences in age and time since diagnosis between the participants and the Alberta lung cancer patients may be explained by understanding the data source. The Alberta Cancer Registry tracks all diagnoses of cancer. However, follow-up data may not be complete and therefore must be interpreted cautiously. For example, alive status (coded as alive or deceased) may not be correct as many patients die outside of Alberta and are not captured by the registry. Prior to analysis, all patients over the age of 100

were removed from the data file, assuming that these people were dead. However, younger patients that died and have not been recorded as such on the registry may have affected both the age and time since diagnosis variables, resulting in higher averages and wider ranges among the Alberta population. Also, place of residence is coded only at the time of diagnosis and, therefore, does not reflect subsequent address changes.

Given that the differences in demographic and illness characteristics between the two groups are small and reasonable explanations can be given for the differences, the results may be cautiously generalized to the Alberta lung cancer population.

Analyses of Unmet Needs and Quality of Life Data

Treatment of Missing Data

Missing data were assessed to determine the quality of the data. For the CNQ, there was very little missing data. There were a total of 36 cases in which a patient missed a whole page. There were a total of 220 missed items for questions 1 to 53, with a maximum of nine patients missing a given item. When calculating the mean scores of a given domain, a maximum of five patients were eliminated due to insufficient data to calculate the domain score. Again, this represents only a small fraction of the total cases. Overall, only 2.4% of responses were missing.

For the quality of life questionnaires, missing data on a given dimension was also very low. For the QLQ-C30, zero to four patients were eliminated from the analysis of a particular dimension. For the QLQ-LC13, a maximum of four patients were eliminated from the analyses of a given scale or item, except for the item related to pain to another part of the body which was responded to by only 149 patients.

Unmet Needs Analyses

The prevalence of need by domain was assessed as some versus no need. The percentage of patients with some need reflects the actual percentage of patients that indicated need (low, moderate, or high) for at least one item.

In rank order, the domains of need from highest to lowest for the entire group were: physical and daily living, psychological, health information, patient care and support, and interpersonal communication (Table 12). The differences in need by domain between the clinics were not statistically significant. Except for physical and daily living needs, a greater percentage of NPLC patients than FULC patients indicated they had some need in each domain. The percentage of FULC patients indicating some need in the physical and daily living domain may reflect their declining health and subsequent need for assistance. Yet, 80% of NPLC patients indicated some need in this domain, suggesting they may have had some physical changes or may expect some physical changes in the future.

Table 12: Prevalence of Some Need (Versus No Need) by Domain

Domain	Total - Patients With Some Need (%)	NPLC Patients With Some Need (%)	FULC Patients With Some Need (%)	P-value
Physical and daily living	86.71	80.00	89.43	0.098
Psychological	83.33	86.00	82.26	0.549
Health information	76.61	81.63	74.59	0.325
Patient care and support	61.49	64.00	60.48	0.666
Interpersonal Communication	40.94	44.90	39.34	0.504

For the NPLC, the highest needs were in the psychological domain (86%) whereas for the FULC it was physical and daily living needs (89%). Interpersonal

communication needs were least likely to be reported for both clinic groups: 45% by the NPLC patients and 39% by the FULC patients. It is important to note that despite the large numbers of patients indicating some need, the average scores for each domain were low, as will be reported later.

In terms of individual need items, needs related to fears about the cancer spreading or returning, fears about further physical disability or deterioration, being fully informed about remission, and coping with not being able to do things you used to do were the most prevalent need items (Table 13). It is concerning to note that at least 50% of patients indicated some need for the top 20 ranked items. This suggests that there are many areas in which interventions can be aimed in order to meet some of these needs. All but one of these needs were from the physical and daily living, psychological, or health information domains.

Table 13: Need Items and Frequency of Need

Need Item	Patients Indicating Some Need for the Item (%)	Overall Rank Of Patients Indicating Some Need	Of Patients With Some Need, Percent Indicating Moderate or High Need (%)	Rank of Patients Indicating Moderate or High Need	Domain of Need
Dealing with fears about the cancer spreading or returning	66.9	1	60.9	12	Psychological
Coping with fears about further physical disability or deterioration	63.0	2	49.5	32	Psychological
To be fully informed about cancer remission	62.0	3	75.7	4	Health information
Coping with frustration at not being able to do the things you used to do	61.5	4	55.1	25	Physical and daily living
Coping with fears about the pain and suffering you might experience	59.8	5	58.7	15	Psychological
To be fully informed about things you can do to help yourself to get well	59.3	6	72.5	6	Health information
Dealing with shortness of breath/ breathlessness	57.7	7	64.6	11	Physical and daily living
Dealing with lack of energy and tiredness	57.3	8	59.2	14	Physical and daily living
Dealing with feeling down or depressed	56.3	9	33.7	51	Psychological
Coping with an uncertain future	56.1	10	51.5	29	Psychological
To be fully informed about the possible effects of the cancer on the length of your life	55.3	11	77.7	3	Health information
Dealing with anxiety or stress	54.9	12	47.4	35	Psychological
To be fully informed about your test results as soon as possible	53.8	13	80.4	2	Health information
Dealing with concerns about your family's fears and worries	53.8	13	56.5	21	None
Coping with fears about losing your independence	52.9	15	53.8	28	Physical and daily living

(Table 13 continued)

Coping with keeping up with work around the home	52.3	16	56.7	20	Physical and daily living
Working through your feelings about death and dying	50.9	17	42.0	46	Psychological
To be fully informed about the odds of treatment success	50.6	18	82.6	1	Health information
To be given written information about ways of managing your illness and side-effects at home	50.3	19	57.5	17	Health information
Coping with worry that the cancer is beyond your control	50.3	19	43.7	43	Psychological
To be fully informed about support groups in your area	49.4	21	46.4	36	Health information
For your cancer specialist to write down all of the important points that he/she tells you	49.1	22	59.5	13	Health information
Coping with feeling bored and/or useless	47.4	23	39.0	49	Physical and daily living
Coping with the disruption to your usual routine and/or changes in your lifestyle	47.1	24	48.8	34	None
To be given a full explanation for every test and treatment procedure you go through	46.2	25	57.0	19	Health information
To be fully informed about benefits and side-effects of treatment or surgery before you agree to have it	45.6	26	74.4	5	Health information
To have the opportunity to talk to someone who understands and has been through a similar experience	45.6	26	42.3	45	None
Dealing with concerns about your family's ability to cope with caring for you	45.3	28	54.5	26	None
Coping with waiting for long periods of time for clinic appointments	45.1	29	65.8	9	Patient care and support

(Table 13 continued)

Dealing with concerns about your financial situation	45.0	30	64.9	10	None
Coping with disturbed sleep	44.8	31	50.6	31	Physical and daily living
Learning to feel in control of your situation	44.3	32	44.2	40	Psychological
Coping with anxiety about having treatment or surgery	42.5	33	51.4	30	Psychological
Trying to find meaning in this experience	42.3	34	35.2	50	Psychological
Coping with feeling unwell a lot of the time	41.0	35	43.7	43	Physical and daily living
Coping with overwhelming feelings of sadness or grief	40.2	36	31.4	53	Psychological
Dealing with anger and confusion about why this has happened to you	40.1	37	42.0	46	Psychological
Trying not to worry and/or to maintain a positive outlook	40.0	38	44.1	41	Psychological
For your cancer specialist to convey a positive sense of hope to you and your family	38.0	39	66.2	8	None
Accepting changes in your appearance and self-image	37.9	40	43.9	42	Psychological
For your cancer specialist to acknowledge (and show sensitivity to) your feelings and emotional needs	37.2	41	68.8	7	Patient care and support
To be reassured that your physical and emotional responses are normal	36.4	42	58.7	15	Patient care and support
Coping with changes in other people's attitudes and behavior towards you	35.9	43	32.8	52	Interpersonal communication
Dealing with pain	35.3	44	49.2	33	Physical and daily living
Learning to make the most of your time	34.7	45	44.8	38	Psychological
Coping with concerns about getting to and from the hospital	30.0	46	45.1	37	None

(Table 13 continued)

For nurses to acknowledge (and show sensitivity to) your feelings and emotional needs	28.7	47	57.1	18	Patient care and support
For nurses to attend promptly to your physical needs	28.4	48	56.3	23	Patient care and support
To have more choice about which cancer specialist you see and which hospital you attend	27.2	49	55.3	24	Patient care and support
Coping with awkwardness in talking with others about the cancer	26.3	50	44.4	39	Interpersonal communication
To be allowed to have family and friends with you in hospital whenever you want	22.4	51	56.4	22	Patient care and support
To have your rights for privacy fully protected when you're at the clinic or hospital	20.2	52	54.3	27	Patient care and support
Dealing with nausea and/or vomiting	18.5	53	40.6	48	Physical and daily living

In contrast to the presence or absence of need, the magnitude of need reflects the percentage of patients with some need that ranked the item as a moderate or high need for help. This may be more clinically important than the percentages of patients indicating some need for each item. Of the top 20 need items with the highest magnitude, nine were related to health information needs. Being fully informed about the odds of treatment success and about test results as soon as possible were each of some need to half of the participants, and were a moderate or high need for help for over 80% of those indicating some need.

In terms of the overall domain averages, health information needs were highest in all analyses among all comparison groups, followed by physical and daily living or

psychological needs. No statistically significant differences were noted in the subgroup analyses of clinic, sex, age, or place of residence, but clinically significant differences will be discussed. Scores could range from 0 to 100, but scores were not very high, with average need scores ranging from nine to 42. Average domain scores have not been reported by Lattimore-Foot (5) or Sanson-Fisher et al. (48), limiting our understanding and interpretation of the data beyond this study. Although health information needs were highest, they were still relatively low. Additionally, interpersonal communication needs were consistently the lowest ranked need and patient care and support need scores were only slightly higher.

The interpersonal communication domain is comprised of only two items. There are at least two possible explanations as to why the scores in this domain are consistently lowest. First, patients may not have interpersonal communication needs. Alternatively, the two items of the domain may not accurately reflect patients' interpersonal communication needs, resulting in the perception that there are few needs. This is one area that requires further exploration to ensure we are adequately assessing this domain.

Table 14 shows the mean scores for each domain of need by clinic and for the entire sample. Average scores for the NPLC ranged from 14.61 (95% CI 8.70 – 20.52) for interpersonal communication needs to 40.25 (95% CI 30.32 – 50.16) for health information needs. The ranking of domains was similar for the FULC but the patients' scores were higher for the physical and daily living domain rather than the psychological domain. The average scores of the FULC patients for three of the five domains were slightly lower than the NPLC average scores.

Table 14: Average Unmet Need Scores by Clinic

Domain	Total Mean Score (95% CI)	NPLC Mean Score (95% CI)	FULC Mean Score (95% CI)	P-value
Health information	36.73 (31.68 – 41.77)	40.25 (30.32 – 50.16)	35.31 (29.41 – 41.22)	0.3842
Physical and daily living	27.20 (23.61 – 30.78)	23.45 (17.33 – 29.57)	28.72 (24.31 – 33.13)	0.1893
Psychological	26.73 (22.97 – 30.48)	29.07 (22.16 – 35.98)	25.78 (21.26 – 30.30)	0.4356
Patient care and support	19.47 (15.77 – 23.16)	19.73 (13.16 – 26.30)	19.36 (14.85 – 23.87)	0.9289
Interpersonal communication	14.99 (11.60 – 18.39)	14.61 (8.70 – 20.52)	15.14 (10.98 – 19.32)	0.8880

Domain scores by sex are displayed in Table 15. Males demonstrated lower interpersonal communication needs (13.75, 95% CI 9.65 – 17.85) compared to females (17.19, 95% CI 11.11 – 23.26). Highest needs were noted in the health information domain, with averages of 37.91 for men (95% CI 31.22 – 44.60) and 34.74 for females (95% CI 27.03 – 42.46). However, there were only small differences in need by gender. It may be that the services available are not specific to males or females. A difference was expected since more males have lung cancer than females, and therefore services may be targeted to a male audience, resulting in unmet needs among the females. However, there is no indication that this is a problem.

Table 15: Average Unmet Need Scores by Sex

Domain	Mean Score for Males (95% CI)	Mean Score for Females (95% CI)	P-value
Health information	37.91 (31.22 – 44.60)	34.75 (27.03 – 42.46)	0.5500
Physical and daily living	26.88 (22.37 – 31.38)	27.73 (21.65 – 33.80)	0.8212
Psychological	26.01 (21.22 – 30.80)	27.95 (21.77 – 34.13)	0.6234
Patient care and support	20.88 (16.14 – 25.62)	17.10 (11.09 – 23.11)	0.3302
Interpersonal communication	13.75 (9.65 – 17.85)	17.19 (11.11 – 23.26)	0.3372

Differences in needs according to age were also examined (Table 16). The mean score for health information needs was highest among all three age groups, followed by psychological or physical and daily living needs. Psychological needs were significantly different between patients 60 years and younger and patients 70 years and older ($p=0.005$). The average score for interpersonal communication needs was lower for patients 70 years and older compared to the younger age groups, but the difference was not significant. A possible explanation is that at an older age, patients may be more accepting of their diagnosis and changes in needs than younger patients.

Table 16: Average Unmet Need Scores by Age Category

Domain	Mean Score for Patients 60 Years and Younger (95% CI)	Mean Score for Patients 61 – 69 Years (95% CI)	Mean Score for Patients 70 Years and Older (95% CI)	P-value
Health information	38.00 (28.85 – 47.15)	38.13 (28.86 – 47.40)	34.12 (25.84 – 42.41)	0.721
Psychological	33.32 (25.85 – 40.78)	28.27 (21.09 – 35.45)	18.84 (14.57 – 23.11)	<0.001 *
Physical and daily living	28.01 (21.61 – 34.41)	26.53 (20.18 – 32.88)	27.08 (20.82 – 33.33)	0.997
Interpersonal communication	19.57 (12.89 – 26.26)	16.06 (10.05 – 22.07)	9.47 (4.61 – 14.33)	0.070
Patient care and support	19.06 (12.31 – 25.81)	20.58 (13.99 – 27.17)	18.77 (12.52 – 25.02)	0.901

* Significant difference between patients 60 years and younger and patients 70 years and older ($p=0.005$)

Place of residence was examined by comparing the needs of urban and non-urban patients. Surprisingly, urban patients had higher needs than their non-urban counterparts in all domains (Table 17). Most strikingly, the average score for the health information needs of the urban patients was 38.57 (95% CI 32.68 – 44.46) compared to 30.06 for the non-urban patients (95% CI 21.14 – 40.99). Lowest needs were reported in the interpersonal communication domain, an average of 15.75 for urban patients (95% CI 11.67 – 19.82) and 12.69 for the non-urban patients (95% CI 6.64 – 18.73). The non-urban confidence intervals were wider, indicating more variability in need than the urban patients. This may be a result of fewer non-urban patients than urban patients in the sample. Again while clinical differences were noted, none of the differences were statistically significant. Non-urban patients may have lower expectations (e.g. level or quality of care) and, therefore, have lower needs than their urban counterparts. Further analyses could look at the size (by population) of a city or town as another indication of differences in need by place of residence.

Table 17: Average Unmet Need Scores by Place of Residence

Domain	Urban Patient Mean Score (95% CI)	Non-urban Patient Mean Score (95% CI)	P-value
Health information	38.57 (32.68 – 44.46)	30.06 (21.14 – 40.99)	0.2067
Physical and daily living	28.16 (23.89 – 32.42)	22.20 (17.60 – 30.80)	0.3516
Psychological	27.25 (22.87 – 31.64)	25.12 (17.62 – 32.63)	0.6302
Patient care and support	20.53 (16.07 – 24.98)	16.24 (9.77 – 22.70)	0.3242
Interpersonal communication	15.75 (11.67 – 19.82)	12.69 (6.64 – 18.73)	0.4446

A crude measure of disease severity was used to assess differences in need (Table 18). Patients with a lower severity of disease had lower health information needs (28.48, 95% CI 21.00 – 35.95, $p=0.0096$), psychological needs (21.45, 95% CI 16.02 – 27.88, $p=0.0261$), and patient care and support needs (14.24, 95% CI 8.97 – 19.50, $p=0.0283$) compared to the higher severity group. No significant differences were noted in terms of physical and daily living or interpersonal communication needs. This suggests that some disease variables may affect patients' needs but further research is required.

Table 18: Average Unmet Need Scores by Disease Severity

Domain	Lower Severity Mean Score (95% CI)	Higher Severity Mean Score (95% CI)	P-value
Health information	28.48 (21.00 – 35.95)	41.97 (35.26 – 48.67)	0.0096
Physical and daily living	25.40 (19.65 – 31.16)	28.40 (23.71 – 33.09)	0.4218
Psychological	21.45 (16.02 – 27.88)	30.06 (24.97 – 35.16)	0.0261
Patient care and support	14.24 (8.97 – 19.50)	22.60 (17.58 – 27.62)	0.0283
Interpersonal communication	12.55 (7.26 – 17.83)	16.16 (11.76 – 20.55)	0.2989

Given that there were few statistically significant differences in unmet need by clinic, gender, place of residence, age category, and disease severity, further analyses of the unmet needs of the entire sample was justified.

Needs related to the access to services and resources provided insight into the need for improved services, as well as the need for further assessment of individual services. For any given service or resource item, less than 40% of the patients expressed an unmet need (Table 19). Among those who had some need, most patients expressed a low or moderate need. Important needs were for parking (39%), respiratory therapy (37%), financial assistance (37%), and drop-in counselling and support (36%). Interestingly, these needs were met or not applicable for over 60% of the patients. It is significant that 21% of the patients had a moderate or high need for financial assistance.

Table 19: Items of Need for Access to Services or Resources

Service or Resource	No Need – N/A % (n)	No Need – Already Met % (n)	Low Need % (n)	Moderate Need % (n)	High Need % (n)	Patients Indicating Some Need %
Easy parking	31.6 (53)	29.8 (50)	12.5 (21)	13.1 (22)	13.1 (22)	38.7
Respiratory therapy	44.2 (73)	18.8 (31)	17.0 (28)	11.5 (19)	8.5 (14)	37.0
Financial assistance	51.2 (85)	12.1 (20)	15.7 (26)	10.8 (18)	10.2 (17)	36.7
Drop-in counselling/ support	44.9 (74)	19.4 (32)	22.4 (37)	7.3 (12)	6.1 (10)	35.8
Telephone support	44.2 (73)	23.0 (38)	19.4 (32)	6.1 (10)	7.3 (12)	32.8
Brochures about services/benefits	25.3 (43)	44.1 (75)	10.6 (18)	14.1 (24)	5.9 (10)	30.6
Relaxation classes	53.9 (89)	16.4 (27)	15.2 (25)	9.1 (15)	5.5 (9)	29.8
Pain clinic	53.9 (89)	17.6 (29)	15.2 (25)	7.9 (13)	5.5 (9)	28.6
Palliative care	60.3 (97)	13.7 (22)	14.9 (24)	6.2 (10)	5.0 (8)	26.1
Library	42.9 (72)	32.1 (54)	16.1 (27)	6.0 (10)	3.0 (5)	25.1
Home nursing	55.2 (91)	20.0 (33)	14.6 (24)	6.1 (10)	4.2 (7)	24.9
Transportation to/ from clinic	53.0 (89)	26.8 (45)	10.7 (18)	6.0 (10)	3.6 (6)	20.3
Food and drink	51.2 (86)	33.3 (56)	10.1 (17)	3.6 (6)	1.8 (3)	15.5
Advice/supply wigs	70.1 (115)	14.6 (24)	9.2 (15)	2.4 (4)	3.7 (6)	15.3
Care for family at clinic	73.9 (119)	18.6 (30)	2.5 (4)	2.5 (4)	2.5 (4)	7.5

The need for help from support persons was also assessed by individual items.

Few patients reported a need for help from support persons (Table 20). Patients indicated the strongest unmet needs for help or support from health care professionals: 36% from their cancer specialist, 28% from a family doctor, and 21% from the clinic nurse(s).

Approximately 40% of patients indicated that needs from these professionals were already met. Responses to the items of need for help or support from support persons suggests that health care professionals have an important role in this area but that patient expectations are not being met. This was true for the three specialties that are most involved in lung cancer patient's care. Most strikingly, 15% of patients had a high need for support from their cancer specialist, reflecting patients' desire for their support.

Table 20: Items of Need for Help or Support From Support Persons

Category of Support	Need for Help or Support From This Person	No Need – N/A % (n)	No Need – Already Met % (n)	Low Need % (n)	Moderate Need % (n)	High Need % (n)	Patients Indicating Some Need %
Health professional	Cancer specialist	19.9 (34)	44.4 (76)	10.5 (18)	10.5 (18)	14.6 (25)	35.6
	Family doctor	31.0 (53)	41.5 (71)	9.9 (17)	11.7 (20)	5.9 (10)	27.5
	Clinic nurse(s)	40.0 (66)	38.8 (64)	10.9 (18)	7.9 (13)	2.4 (4)	21.2
	Home help worker	63.8 (104)	17.2 (28)	9.2 (15)	7.4 (12)	2.5 (4)	19.1
	Naturopath	69.4 (109)	12.1 (19)	10.2 (16)	5.1 (8)	3.2 (5)	18.5
	Dietitian	70.6 (113)	12.5 (20)	11.9 (19)	4.4 (7)	0.6 (1)	16.9
	Psychologist	71.3 (114)	13.1 (21)	10.0 (16)	4.4 (7)	1.3 (2)	15.7
	Clergy	59.6 (99)	25.3 (42)	9.0 (15)	1.8 (3)	4.2 (7)	15.0
	Social worker	73.1 (117)	13.1 (21)	10.0 (16)	2.5 (4)	1.3 (2)	13.8
	Home care nurse	70.8 (114)	16.2 (26)	6.2 (10)	3.7 (6)	3.1 (5)	13.0
	Pharmacist	61.6 (101)	28.1 (46)	6.1 (10)	1.8 (3)	2.4 (4)	10.3
	Palliative care worker	81.1 (129)	8.8 (14)	6.3 (10)	3.1 (5)	0.6 (1)	10.0
	Physiotherapist	80.5 (128)	11.3 (18)	4.4 (7)	2.5 (4)	1.3 (2)	8.2
Family and Friends	Children	40.4 (67)	41.0 (68)	6.0 (10)	9.0 (15)	3.6 (6)	18.6
	Friends	37.7 (64)	45.3 (77)	9.4 (16)	5.9 (10)	1.8 (3)	17.1
	Extended family	43.8 (71)	40.1 (65)	8.6 (14)	4.3 (7)	3.1 (5)	16.0
	Spouse/partner	43.3 (71)	42.1 (69)	3.1 (5)	4.9 (8)	6.7 (11)	14.7
	Workmates	77.1 (121)	15.3 (24)	3.2 (5)	2.6 (4)	1.9 (3)	7.7
	Boss	77.6 (121)	15.4 (24)	1.3 (2)	1.9 (3)	3.9 (6)	7.1
	Parent(s)	84.6 (121)	10.5 (15)	2.1 (3)	2.8 (4)	0	4.9
Volunteer	Volunteer support visitor	77.5 (124)	6.9 (11)	8.8 (14)	3.1 (5)	3.8 (6)	15.7
	Wig specialist	86.4 (140)	4.3 (7)	4.9 (8)	0.6 (1)	3.7 (6)	9.2
	Meals on Wheels worker	86.0 (135)	5.7 (9)	7.0 (11)	1.3 (2)	0	8.3

Help or support from a spouse or partner was needed for 15% of patients, while 42% indicated the need was already met. Needs for support from immediate and extended family and friends were also important to patients. Conversely, family and friends may have needs related to how to support their family member. It would be important in future research to determine the needs of family members as well.

Quality of Life Analyses

EORTC QLQ-C30 Analyses

Assessment of QOL using the EORTC core module questionnaire included comparisons by clinic, sex, age, place of residence, and disease severity. No statistically significant differences were noted between the subgroups, but clinical differences are presented in this section.

In terms of interpreting QOL data, a higher score in the functioning scales and quality of life scale indicates a better level of functioning. A higher score in the symptom scales and items represents a higher level of symptoms. In Aaronson et al.'s study (1), average functioning scale scores ranged from 56 to 84, while the symptom scores ranged from 4 to 41. The global QOL scale score was 57. These scores were of patients with nonresectable lung cancer for whom chemotherapy or radiation was indicated, but patients had not yet started treatment.

Table 21 shows the mean scores for each quality of life dimension by clinic. There were no statistically significant differences between the two clinic groups in the cognitive, emotional, social functioning, and role dimensions, or on the global health status/QOL scale. A significant difference was noted between the NPLC patients (73.07, 95% CI 66.45 – 79.69) and the FULC patients (64.96 95% CI 60.78 – 69.13) in the physical functioning dimension ($p=0.0411$). This reflects what is seen clinically in which patients experience a general deterioration over time due to the lung cancer. The moderately high functioning scores demonstrate that the patients generally have a good functional QOL.

Table 21: Average Core Quality of Life (EORTC QLQ-C30) Dimension Scores by Clinic

Dimension	Total Mean Score (95% CI)	NPLC Mean Score (95% CI)	FULC Mean Score (95% CI)	P-value
Cognitive functioning	79.79 (76.35 – 83.23)	80.67 (74.22 – 87.11)	79.44 (75.31 – 83.56)	0.7502
Emotional functioning	72.06 (68.87 – 75.25)	69.22 (63.65 – 74.79)	73.21 (69.31 – 77.11)	0.2656
Social functioning	67.62 (62.98 – 72.27)	68.00 (58.39 – 77.61)	67.47 (62.15 – 72.80)	0.9196
Physical functioning	67.26 (63.72 – 70.80)	73.07 (66.45 – 79.69)	64.96 (60.78 – 69.13)	0.0411
Role functioning	63.35 (58.46 – 68.25)	66.00 (57.18 – 74.82)	62.30 (56.36 – 68.24)	0.5028
Global health status/QOL	42.62 (39.41 – 45.84)	40.50 (34.74 – 46.26)	43.48 (39.58 – 47.39)	0.4090
Dyspnea	44.57 (39.61 – 49.53)	40.67 (32.05 – 49.29)	46.13 (40.05 – 52.21)	0.3272
Fatigue	41.54 (37.68 – 45.40)	41.33 (33.11 – 49.55)	41.62 (37.25 – 45.99)	0.9470
Insomnia	34.28 (29.68 – 38.88)	40.00 (30.62 – 49.38)	32.01 (26.73 – 37.29)	0.1228
Appetite loss	26.14 (21.58 – 30.69)	32.00 (22.63 – 41.37)	23.81 (18.61 – 20.01)	0.1099
Financial difficulties	25.05 (20.07 – 30.03)	20.00 (10.24 – 29.76)	27.10 (21.28 – 32.92)	0.2028
Pain	24.91 (21.00 – 28.81)	21.33 (14.17 – 28.50)	26.32 (21.63 – 31.01)	0.2566
Constipation	23.37 (19.07 – 27.67)	21.33 (13.74 – 28.93)	24.19 (18.94 – 29.45)	0.5538
Nausea and vomiting	7.67 (5.27 – 10.07)	9.67 (3.84 – 15.49)	6.88 (4.41 – 9.35)	0.3803
Diarrhea	7.13 (4.63 – 9.63)	6.80 (1.64 – 11.97)	7.26 (4.37 – 10.14)	0.8721

Overall, the mean QOL score was 42.62 (95% CI 39.41 – 45.84). Patients reported few difficulties with nausea and vomiting and diarrhea, symptoms not frequently associated with lung cancer. Dyspnea (44.57, 95% CI 39.61 – 49.53) and fatigue (41.54, 95% CI 37.68 – 45.40) were the symptoms reported most commonly. These results suggest that the symptoms experienced may negatively affect their QOL.

By sex, there were no significant differences in QOL dimension scores or the global health status/QOL scale score (Table 22). Females reported greater social

functioning (71.97, 95% CI 64.85 – 79.09) and role functioning (67.42, 95% CI 59.84 – 75.01). Males reported greater dyspnea (48.48, 95% CI 42.12 – 54.85) than females (37.95, 95% CI 30.10 – 45.79, $p=0.0425$). Males reported higher symptoms except for insomnia and pain, and women also had higher financial difficulty scores.

Table 22: Average Core Quality of Life (EORTC QLQ-C30) Dimension Scores by Sex

Dimension	Mean Score of Males (95% CI)	Mean Score of Females (95% CI)	P-value
Cognitive functioning	80.40 (76.37 – 84.43)	78.79 (72.42 – 85.16)	0.6546
Emotional functioning	73.51 (69.34 – 77.67)	69.70 (64.68 – 74.71)	0.2536
Physical functioning	67.59 (62.94 – 72.23)	66.72 (61.16 – 72.28)	0.8154
Social functioning	64.97 (58.85 – 71.08)	71.97 (64.85 – 79.09)	0.1492
Role functioning	60.91 (54.49 – 67.33)	67.42 (59.84 – 75.01)	0.2044
Global health status/QOL	43.52 (39.50 – 47.53)	41.16 (35.69 – 46.63)	0.4841
Dyspnea	48.48 (42.12 – 54.85)	37.95 (30.10 – 45.79)	0.0425
Fatigue	44.09 (39.13 – 49.05)	37.29 (31.14 – 43.44)	0.0922
Insomnia	33.03 (27.28 – 38.79)	36.36 (28.53 – 44.20)	0.4907
Appetite loss	28.48 (22.34 – 34.63)	22.22 (15.58 – 28.86)	0.1900
Constipation	25.62 (19.94 – 31.29)	19.70 (13.11 – 26.28)	0.1879
Pain	23.64 (18.97 – 28.30)	27.02 (19.95 – 34.09)	0.4092
Financial difficulties	23.46 (17.29 – 29.62)	27.69 (19.11 – 36.28)	0.4176
Diarrhea	8.10 (4.50 – 11.70)	5.56 (2.48 – 8.63)	0.2870
Nausea and vomiting	7.88 (4.67 – 11.09)	7.32 (3.72 – 10.93)	0.8256

For all age categories, mean scores for cognitive functioning were highest (Table 23). Physical functioning decreased with increasing age. While the difference was not significant, it may be a result of age-related body changes rather than changes in physical

functioning related to lung cancer. For cognitive, emotional, and social functioning, the youngest age group had the lowest levels. This may reflect a greater difficulty in adjusting to illness by the younger patients. The youngest age group had significantly higher financial difficulty scores (41.07, 95% CI 31.00 – 51.14) than the older age groups ($p = 0.001$). It may be that younger patients who are more likely to need employment are unable to maintain their previous employment status and are affected financially.

Table 23: Average Core Quality of Life (EORTC QLQ-C30) Dimension Scores by Age Category

Dimension	Mean Score for Patients 60 Years and Younger (95% CI)	Mean Score for Patients 61 – 69 Years (95% CI)	Mean Score for Patients 70 Years and Older (95% CI)	P-value
Cognitive functioning	75.44 (68.49 – 82.39)	82.75 (76.22 – 89.27)	81.11 (76.66 – 85.56)	0.005 *
Physical functioning	70.76 (65.09 – 76.43)	68.95 (63.08 – 74.83)	62.27 (55.40 – 69.13)	0.219
Emotional functioning	66.81 (60.93 – 72.70)	73.44 (68.09 – 78.80)	75.74 (70.35 – 81.14)	0.773
Role functioning	61.70 (52.81 – 70.58)	69.49 (61.67 – 77.32)	58.89 (49.94 – 67.84)	0.534
Social functioning	57.89 (49.37 – 66.42)	72.81 (65.35 – 80.26)	71.94 (63.96 – 79.93)	0.595
Global health status/QOL	39.91 (34.65 – 45.18)	40.64 (34.82 – 46.46)	47.08 (41.36 – 52.81)	0.662
Dyspnea	41.52 (32.63 – 50.41)	43.50 (34.93 – 52.08)	48.59 (39.85 – 57.32)	0.987
Fatigue	41.13 (34.61 – 47.65)	40.96 (33.50 – 48.43)	42.50 (36.10 – 48.90)	0.416
Financial difficulties	41.07 (31.00 – 51.14)	18.71 (10.69 – 26.73)	16.11 (9.48 – 22.74)	0.015+
Insomnia	38.01 (29.42 – 46.61)	37.29 (29.05 – 45.53)	27.78 (20.48 – 35.07)	0.547
Pain	26.32 (19.90 – 32.73)	23.16 (15.47 – 30.86)	25.28 (18.81 – 31.74)	0.261
Appetite loss	26.32 (18.35 – 34.29)	27.12 (18.51 – 35.73)	25.00 (17.46 – 32.54)	0.612
Constipation	20.47 (14.05 – 26.89)	23.98 (16.18 – 31.77)	25.56 (17.26 – 33.85)	0.103
Diarrhea	7.02 (2.68 – 11.36)	6.55 (2.97 – 10.13)	7.78 (2.67 – 12.88)	0.015*
Nausea and vomiting	5.56 (1.79 – 9.32)	6.78 (2.35 – 11.21)	10.56 (6.22 – 14.89)	0.338

* No significant difference when Bonferroni multiple-comparison test used

+ Significant difference between patients 60 years and younger with patients 61 – 69 years ($p=0.001$) and patients 70 years and older ($p<0.001$)

Urban versus non-urban residence was not a factor in the functioning or quality of life scores (Table 24). While functioning scores between the groups were very similar, non-urban patients had greater physical functioning scores (71.47, 95% CI 64.44 – 78.51) than urban patients (65.90, 95% CI 61.78 – 70.02). Urban patients reported significantly more nausea and vomiting (9.02, 95% CI 5.96 – 12.08) than non-urban patients (3.49,

95% CI 1.10 – 5.88, $p=0.0051$), although the actual number of patients experiencing nausea and vomiting was very small. Urban patients had higher symptom scores except for insomnia and financial difficulties.

Table 24: Average Core Quality of Life (EORTC QLQ-C30) Dimension Scores by Place of Residence

Dimension	Mean Score for Urban Patients (95% CI)	Mean Score for Non-Urban Patients (95% CI)	P-value
Cognitive functioning	80.28 (76.54 – 84.02)	78.29 (70.03 – 86.56)	0.6245
Emotional functioning	72.67 (69.24 – 76.09)	70.22 (62.36 – 78.08)	0.5680
Social functioning	67.18 (61.70 – 72.65)	68.99 (60.00 – 77.99)	0.7401
Physical functioning	65.90 (61.78 – 70.02)	71.47 (64.44 – 78.51)	0.1826
Role functioning	62.53 (56.84 – 68.22)	65.89 (55.95 – 75.84)	0.5620
Global health status/QOL	43.83 (39.86 – 47.80)	38.95 (34.12 – 43.79)	0.1219
Dyspnea	45.45 (39.55 – 51.36)	41.86 (32.61 – 51.12)	0.5397
Fatigue	41.48 (37.05 – 45.91)	41.73 (33.55 – 49.92)	0.9559
Insomnia	32.33 (27.31 – 37.35)	40.31 (29.44 – 51.18)	0.1421
Appetite loss	26.82 (21.48 – 32.15)	24.03 (14.99 – 33.08)	0.6056
Pain	24.81 (20.55 – 29.07)	25.19 (15.80 – 34.58)	0.9342
Constipation	24.43 (19.23 – 29.62)	20.16 (12.68 – 27.63)	0.3989
Financial difficulties	23.85 (17.81 – 29.88)	28.68 (20.13 – 37.23)	0.4088
Nausea and vomiting	9.02 (5.96 – 12.08)	3.49 (1.10 – 5.88)	0.0051
Diarrhea	7.44 (4.36 – 10.51)	6.20 (2.16 – 10.24)	0.6274

By disease severity, there were no significant differences in the needs scores between the two groups (Table 25). Those with a higher disease severity reported slightly

better physical functioning (68.63, 95% CI 64.07 – 73.20) and role functioning (64.92, 95% CI 58.60 – 71.24) than the lower severity group. One would expect patients with greater disease severity to have poorer QOL. But, this finding may suggest that the disease severity category does not reflect the appropriate variables. Global health status/QOL scores and confidence intervals were very similar. Although the scores were again very similar between groups, the higher severity patients had more symptoms of insomnia, financial difficulties, constipation, and nausea and vomiting.

Table 25: Average Core Quality of Life (EORTC QLQ-C30) Dimension Scores by Disease Severity

Dimension	Lower Severity Mean Score (95% CI)	Higher Severity Mean Score (95% CI)	P-value
Cognitive functioning	79.47 (74.06 – 84.88)	79.81 (75.25 – 84.36)	0.9247
Emotional functioning	72.46 (67.26 – 77.66)	72.01 (67.89 – 76.13)	0.8911
Social functioning	67.87 (59.95 – 75.80)	67.63 (61.81 – 73.44)	0.9595
Physical functioning	64.92 (59.16 – 70.68)	68.63 (64.07 – 73.20)	0.3137
Role functioning	60.95 (52.95 – 68.95)	64.92 (58.60 – 71.24)	0.4373
Global health status/QOL	42.39 (37.34 – 47.45)	42.87 (38.60 – 47.14)	0.8870
Dyspnea	46.38 (38.58 – 54.17)	43.81 (37.28 – 50.34)	0.6189
Fatigue	42.22 (36.10 – 48.35)	41.16 (36.10 – 46.26)	0.7928
Insomnia	32.86 (25.63 – 40.08)	34.92 (28.83 – 41.01)	0.6669
Appetite loss	26.19 (18.79 – 33.59)	26.35 (20.44 – 32.26)	0.9733
Pain	24.52 (18.15 – 30.90)	25.08 (20.02 – 30.14)	0.8916
Financial difficulties	23.53 (15.28 – 31.78)	26.28 (19.92 – 32.65)	0.5966
Constipation	21.74 (14.90 – 28.58)	24.68 (19.04 – 30.32)	0.5117
Diarrhea	7.73 (3.36 – 12.10)	6.80 (3.72 – 9.87)	0.7209
Nausea and vomiting	5.48 (2.71 – 8.24)	9.21 (5.63 – 12.78)	0.1030

Overall, there were few differences in the core QOL dimension scores by clinic, gender, place of residence, age category, and disease severity. Analyses of the combined sample was therefore indicated.

EORTC QOL-LC13 Analyses

The analyses of the lung cancer module scales and items by clinic are summarized in Table 26. Overall, coughing and dyspnea were the symptoms reported most frequently. Scores were less than 30 for any of the other symptoms. Hemoptysis was experienced by significantly more NPLC patients (9.33, 95% CI 4.26 – 14.41) than FULC patients (11.85, 95% CI 0.50 – 3.20, $p=0.0060$). The higher score among NPLC patients may be attributable to those whose disease was diagnosed based on the presence of this symptom or patients that have been referred to the NPLC later in the disease course for possible radiation due to hemoptysis. FULC patients reported statistically significant higher pain in other parts (31.45, 95% CI 24.89 – 38.01) than NPLC patients (18.70, 95% CI 12.02 – 25.37, $p=0.0074$).

Table 26: Average Lung Cancer Quality of Life (EORTC QLQ-LC13) Dimension Scores by Clinic

Dimension	Total Mean Score (95% CI)	NPLC Mean Score (95% CI)	FULC Mean Score (95% CI)	P-value
Coughing	40.00 (36.12 – 43.88)	38.10 (31.33 – 44.87)	40.74 (35.99 – 45.49)	0.5474
Dyspnea	35.94 (32.24 – 39.63)	35.78 (29.05 – 42.51)	36.00 (31.52 – 40.48)	0.9574
Pain in other parts	27.89 (22.76 – 33.02)	18.70 (12.02 – 25.37)	31.45 (24.89 – 38.01)	0.0074
Pain in chest	21.33 (17.59 – 25.07)	19.33 (13.25 – 25.41)	22.13 (17.46 – 26.81)	0.5058
Pain in arm or shoulder	20.35 (16.42 – 24.28)	22.67 (15.15 – 30.19)	19.40 (14.74 – 24.06)	0.4577
Peripheral neuropathy	15.15 (11.60 – 18.70)	16.00 (8.53 – 23.47)	14.81 (10.77 – 18.86)	0.7672
Alopecia	15.05 (10.53 – 19.56)	18.67 (8.69 – 28.64)	13.60 (8.62 – 18.58)	0.3183
Dysphagia	9.14 (6.15 – 12.13)	7.33 (0.62 – 14.04)	9.87 (6.60 – 13.14)	0.4985
Sore mouth	8.09 (5.29 – 10.89)	10.00 (3.58 – 16.42)	7.32 (4.31 – 10.32)	0.4505
Hemoptysis	3.98 (2.20 – 5.76)	9.33 (4.26 – 14.41)	1.85 (0.50 – 3.20)	0.0060

There were no statistically significant differences for symptoms by sex (Table 27), age (Table 28), place of residence (Table 29), or disease severity (Table 30), with one exception. Males were more likely to report hemoptysis. There are several results that are clinically significant. Women and younger patients reported more alopecia than men and older patients. Patients 70 years and older reported more dyspnea than the younger age groups. This may also reflect age-related changes or the onset of other lung diseases affecting lung performance. As well, common symptoms of lung cancer, such as cough, dyspnea, and pain were scored higher than symptoms associated with treatment such as dysphagia, alopecia, and sore mouth.

Table 27: Average QLQ-LC13 Quality of Life Dimension Scores by Sex

Dimension	Mean Score of Males (95% CI)	Mean Score of Females (95% CI)	P-value
Coughing	41.59 (36.86 – 46.32)	37.37 (30.55 – 44.19)	0.3001
Dyspnea	37.72 (32.72 – 42.71)	33.00 (27.62 – 38.37)	0.2230
Pain in other parts	25.00 (19.07 – 30.93)	32.73 (23.15 – 42.30)	0.1503
Pain in chest	21.21 (16.64 – 25.79)	21.54 (14.94 – 28.14)	0.9339
Pain in arm or shoulder	20.68 (15.78 – 25.57)	19.79 (13.04 – 26.54)	0.8301
Peripheral neuropathy	15.15 (10.59 – 19.72)	15.15 (9.37 – 20.93)	1.0000
Alopecia	13.03 (7.83 – 18.23)	18.46 (9.94 – 26.98)	0.2802
Dysphagia	8.79 (4.82 – 12.76)	9.74 (5.19 – 14.30)	0.7614
Sore mouth	8.79 (5.00 – 12.57)	6.88 (2.84 – 10.91)	0.4929
Hemoptysis	5.45 (2.82 – 8.09)	1.52 (0.00 – 3.24)	0.0138

Table 28: Average QLQ-LC13 Quality of Life Dimension Scores by Age Category

Dimension	Mean Score for Patients 60 Years and Younger (95% CI)	Mean Score for Patients 61 – 69 Years (95% CI)	Mean Score for Patients 70 Years and Older (95% CI)	P-value
Coughing	36.26 (29.11 – 43.40)	41.38 (35.17 – 47.59)	42.22 (35.16 – 49.29)	0.489
Dyspnea	35.09 (29.41 – 40.76)	32.96 (26.90 – 39.02)	39.74 (32.20 – 47.27)	0.059
Pain in other parts	30.61 (20.68 – 40.55)	25.53 (17.57 – 33.49)	27.45 (18.32 – 36.58)	0.242
Peripheral neuropathy	20.47 (12.85 – 28.08)	10.73 (5.78 – 15.69)	14.44 (8.65 – 20.24)	0.007*
Pain in chest	20.24 (14.18 – 26.30)	21.47 (14.30 – 28.64)	22.22 (15.75 – 28.69)	0.346
Pain in arm or shoulder	20.00 (12.52 – 27.48)	21.05 (13.65 – 28.46)	20.00 (14.03 – 25.97)	0.290
Alopecia	16.96 (8.25 – 25.66)	15.52 (7.44 – 23.60)	12.78 (5.67 – 19.88)	0.409
Dysphagia	12.28 (6.34 – 18.22)	10.34 (4.61 – 16.08)	5.00 (1.17 – 8.83)	0.004 *
Sore mouth	8.19 (3.38 – 13.00)	7.02 (2.37 – 11.67)	9.04 (3.73 – 14.35)	0.485
Hemoptysis	4.09 (0.72 – 7.47)	3.95 (0.69 – 7.21)	3.89 (1.10 – 6.68)	0.403

* No significant difference when Bonferroni multiple-comparison test used

Table 29: Average QLQ-LC13 Quality of Life Dimension Scores by Place of Residence

Dimension	Mean Score for Urban Patients (95% CI)	Mean Score for Non-Urban Patients (95% CI)	P-value
Coughing	40.10 (35.55 – 44.65)	39.68 (31.99 – 47.37)	0.9280
Dyspnea	36.95 (32.53 – 41.38)	32.82 (26.14 – 39.49)	0.3432
Pain in other parts	27.73 (21.62 – 33.84)	28.33 (18.51 – 38.15)	0.9175
Pain in chest	21.97 (17.61 – 26.33)	19.38 (11.88 – 26.88)	0.5576
Pain in arm or shoulder	18.83 (14.36 – 23.30)	25.20 (16.79 – 33.61)	0.1732
Peripheral neuropathy	15.04 (10.91 – 19.17)	15.50 (8.30 – 22.71)	0.9117
Alopecia	15.04 (9.75 – 20.33)	15.08 (6.13 – 24.02)	0.9938
Dysphagia	9.60 (5.94 – 13.25)	7.75 (2.83 – 12.68)	0.5481
Sore mouth	9.16 (5.66 – 12.67)	4.76 (1.08 – 8.44)	0.0860
Hemoptysis	4.01 (1.89 – 6.13)	3.88 (0.55 – 7.20)	0.9492

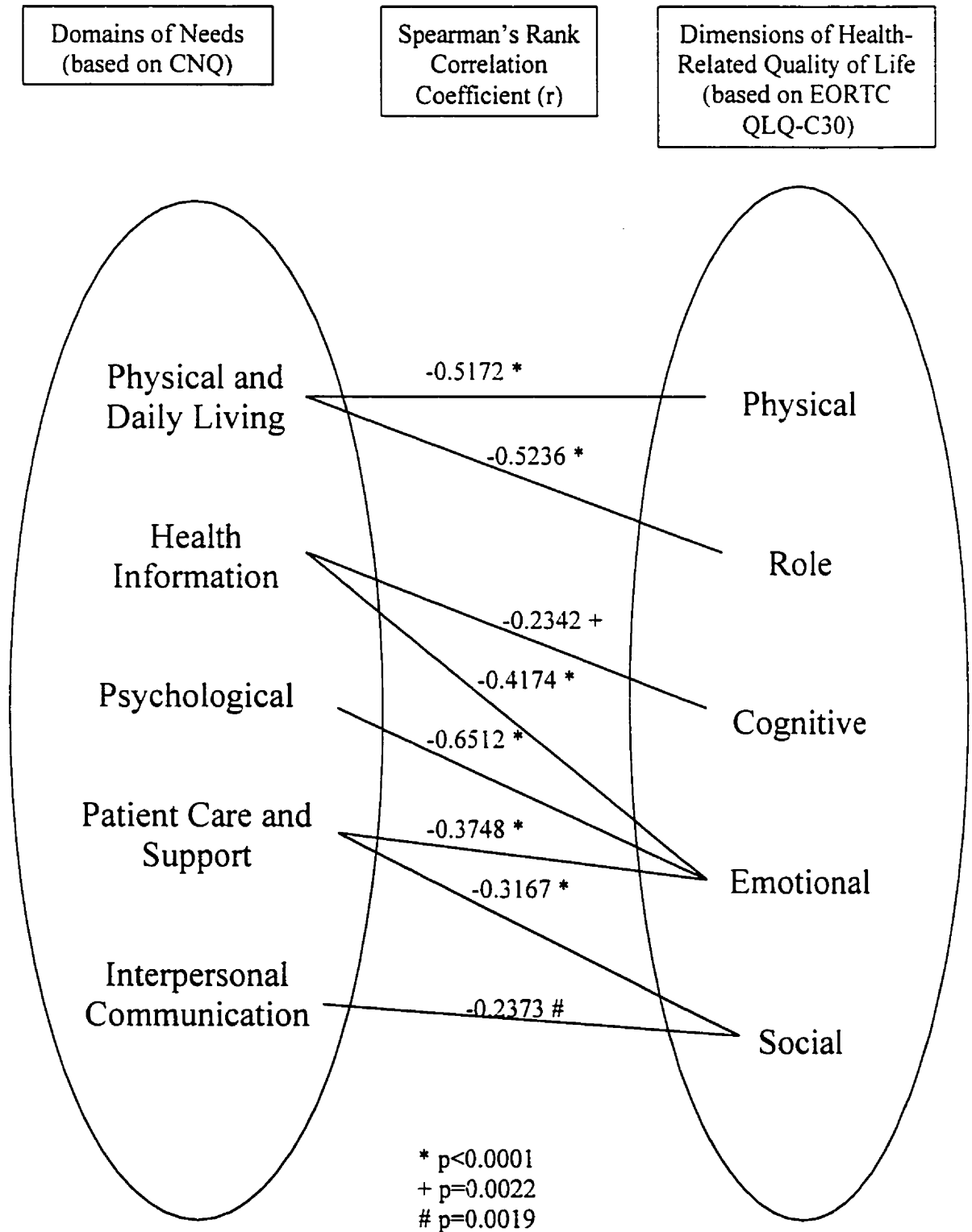
Table 30: Average QLQ-LC13 Quality of Life Dimension Scores by Disease Severity

Dimension	Lower Severity Mean Score (95% CI)	Higher Severity Mean Score (95% CI)	P-value
Dyspnea	37.52 (32.03 – 43.02)	35.13 (30.10 – 40.17)	0.5356
Coughing	36.67 (31.06 – 42.27)	42.31 (36.95 – 47.67)	0.1625
Pain in other parts	30.65 (22.35 – 38.94)	25.79 (19.12 – 32.47)	0.3605
Pain in chest	21.74 (15.94 – 27.54)	21.27 (16.28 – 26.26)	0.9043
Pain in arm or shoulder	19.81 (13.62 – 26.00)	20.59 (15.37 – 25.80)	0.8487
Alopecia	16.43 (9.21 – 23.64)	13.97 (8.05 – 19.89)	0.6024
Peripheral neuropathy	14.29 (8.78 – 19.79)	15.87 (11.13 – 20.61)	0.6681
Sore mouth	7.73 (2.94 – 12.52)	8.41 (4.91 – 11.91)	0.8146
Dysphagia	7.14 (2.68 – 11.61)	10.58 (6.51 – 14.64)	0.2698
Hemoptysis	3.81 (1.26 – 6.36)	4.13 (1.65 – 6.61)	0.8642

Analyses of the Relationship Between Unmet Needs and Quality of Life

Correlations between the domains of unmet needs and the associated dimensions of quality of life were determined based on the proposed conceptual framework (Figure 2) and the previously identified hypothesized relationships. Spearman's rank correlation coefficients ranged from -0.2342 to -0.6512 (Figure 5). This suggests, as expected, that there was an inverse relationship between one's QOL and unmet needs, where as needs increase, one's QOL decreases and vice-versa. The direction of the relationship cannot be determined from these correlations. However, these results indicate that only 5.5 to 42.4% of the variability can be explained by the observed associations based on the coefficient of determination (r^2).

Figure 5: Correlation Coefficients Between Unmet Need Domains and Quality of Life Dimensions



There were moderate negative correlations between psychological needs and emotional functioning ($r = -0.6512$, $p < 0.0001$), physical and daily living needs and role functioning ($r = -0.5236$, $p < 0.0001$), and physical and daily living needs and physical functioning ($r = -0.5172$, $p < 0.0001$). This type of analysis permits only limited interpretation. These correlations indicate only that these unmet need domains and QOL dimensions are related. Further research is needed to determine the direction of the relationship and if interventions would fulfill unmet needs or improve QOL.

The other relationships were suggestive of weak negative correlations. The weak relationship between the interpersonal communication domain and the social dimension of QOL may reflect that the items of the interpersonal communication domain make up only a part of the social functioning assessment. Cognitive functioning and health information needs also demonstrated a weak relationship. This proposed relationship was felt to be the weakest relationship because the cognitive functioning items focus on memory recall and concentration whereas the health information items relate to the provision of specific information.

While the relationships were not particularly strong, the results suggest that this QOL assessment measures a different concept than the unmet needs assessment. The associated p-values for each of the correlations between the unmet need domains and QOL dimensions indicate that the relationships are statistically significant and there is a rank association between the compared variables.

Chapter 4: Discussion

Overview of the Discussion

The discussion is presented in four sections. First, an overview of the findings and implications for clinical practice are presented and the results are compared to the literature. Second, the study's strengths and limitations are assessed. Third, the appropriateness of the tools used is assessed. Lastly, the directions for future research are discussed.

Overview of the Findings and Clinical Implications

Unmet needs were assessed using the CNQ. Needs were compared by clinic attended (NPLC versus FULC) and by subgroup (sex, age, place of residence, and disease severity). These comparisons were intended to get a sense of differences in need that may exist.

Comparisons of the two clinic groups were expected to show differences that reflect how patients progress through the disease trajectory. There were insufficient numbers of patients to consider differences by other variables, such as stage of disease or time since diagnosis. Instead, the clinic attended was expected to be a proxy measure for the time since diagnosis. Overall, there were few differences between the NPLC patients and the FULC patients. This allowed for combined analyses for the needs and QOL assessments. It is significant that the two groups are comparable as it suggests that interventions could be directed at both clinic groups rather than necessitating clinic-specific interventions. Not only is this less costly, but it is less resource intensive to provide interventions to a broader group of patients. However, comparison by clinic may not adequately compare patients by time since diagnosis since not all patients attended

clinic immediately upon diagnosis. The differences by clinic may actually reflect how and where services are delivered. Further assessment of this proxy measure for time since diagnosis is necessary to ensure the validity of this comparison.

There were no differences in unmet needs based on the subgroup comparisons. Differences were not found, suggesting that the needs of the population were relatively homogeneous. It may also mean that the instrument does not discriminate between the subgroups. However, the psychometric testing supports the use of this questionnaire. Researchers should merely continue to assess the possibility of subgroup differences when using this instrument.

Based on clinical experience, differences were expected within the subgroups. Differences by sex related to coping mechanisms and interpersonal relationships were anticipated. Needs did not differ between the males and females, therefore, there may be no actual difference. Alternatively, patient needs may have been resolved and the difference could lie in the mechanism used by males and females to resolve their needs.

Age differences were expected based on subjective observations in clinic where differences in communication patterns, desire for health information, and support systems were noted between patients less than 50 years old and those more than 75 years old. A significant difference was only noted in psychological needs between the youngest and oldest age groups. It is possible that the age tertiles used in this study were too wide to demonstrate the anticipated differences.

Urban versus non-urban place of residence could have impacted needs related to the availability of services and resources. A difference was not noted, suggesting that the services and resources currently available to non-urban patients are sufficient to meet

some needs. But, gaps that exist need to be filled by different means to meet the needs of both urban and non-urban patients. These results compare to those of Silveria and Winstead-Fry (39) who did not find a difference in needs between urban and rural patients.

The measure of disease severity was developed to gain a general understanding of a patient's condition at the time of clinic. It provides insight into a patient's disease state because it reflects both the disease stage and the presence or absence of metastases. As one would expect, patients with a higher disease severity had higher needs. It is not reasonable to draw many conclusions from these results since the measure of disease severity has not been tested. It does, however, suggest that a measure of disease severity warrants consideration in further studies.

Overall, physical and daily living and psychological needs were most prevalent among the patients. Health information needs were also high. In Foot and Sanson-Fisher's research (4), psychological and health information needs were most prevalent. All the scores in this study were higher than those in Foot and Sanson-Fisher's study (4), except in the health information domain. Foot and Sanson-Fisher (4) did not ascertain the needs of newly diagnosed patients which may have resulted in a lower prevalence of unmet needs in comparison to the prevalence found in this study. In the pilot study, the prevalence of need in all domains was less than in the main study, particularly for interpersonal communication and patient care and support needs. This was expected since only FULC patients were sampled in the pilot study.

In this study, the highest needs were noted in the health information domain, followed by the physical and daily living and psychological domains. Consistently, the

lowest scoring domains were for patient care and support and interpersonal communication needs. Comparisons cannot be made with other studies because the average domain scores were not reported in other studies that used the CNQ (4,5,48).

Health information needs were expected to be higher among NPLC, younger, non-urban, and higher severity patients. These needs were anticipated to be related to cognitive and emotional functioning as information may provide patients with insight into the effect of the disease upon their daily lives. NPLC patients had higher needs than FULC patients, reflecting the need for information among newly diagnosed patients. However, their cognitive and emotional functioning QOL scores were similar. This suggests that the presence of health information needs was not reflected in the associated dimensions of QOL. Needs of the oldest tertile of patients were slightly less than the younger tertiles, and the emotional functioning score of the oldest tertile was slightly higher. Younger patients may feel a greater sense of control with more knowledge than the older patients. Non-urban patients actually had lower needs than urban patients and no difference in the associated QOL dimensions. While it was expected that non-urban patients may have less access to information than urban patients, they may have a lower expectation for information resources than urban patients. Lastly, patients with a higher disease severity had significantly higher needs than lower severity patients, but no differences in their cognitive and emotional functioning scores. Patients may desire more information about their disease as it progresses, resulting in this difference in needs.

Patients with lung cancer may have physical changes related to decreased lung capacity, lower energy levels, pain, and general physical deterioration that may also be exacerbated by the effects of treatment(s). This may be more pronounced among FULC

patients than NPLC patients due to greater effects of the illness and/or treatment side effects over time. The data shows a small increase in physical and daily living needs by the FULC patients and that the physical and role functioning dimensions of FULC patients decreased. A similar trend was also expected for age. Older patients had lower physical functioning scores than younger patients. In terms of role functioning for QOL, the eldest group had the lowest score, but the middle age category had the highest role functioning. One might also have expected greater physical and daily living needs among older patients which is not seen in the data. One possible explanation is that older patients may expect age-related changes and, as a result, have fewer needs, yet the changes still affect their QOL.

Differences in psychological needs were expected by clinic, sex, gender, and disease severity. NPLC patients had slightly higher psychological needs and slightly lower emotional functioning than FULC patients. This was expected based on perceived differences in coping related to the time since diagnosis. However, there were very small differences in needs and QOL by sex, suggesting that sex may not play a role in coping with needs related to anxiety, anger, and depression. There was a downward trend in unmet needs in this domain by age category which could be a result of different coping mechanisms related to health and illness that may develop with age. This corresponds with the upward trend in emotional functioning by age category. Higher disease severity may result in increasing needs related to the emotional aspects of the illness. However, there was no corresponding decrease in emotional functioning with higher disease severity. Patients may not have the same expectations for their QOL in this dimension as their disease becomes more severe.

In terms of the relationship with QOL, the domains of need were the important units of analysis. While the needs of lung cancer patients as a group are central to this discussion and determining the need for resources, the needs of individuals are of utmost importance. Patients come to the clinics with varying backgrounds, experiences with the health care system, and experiences with illness and cancer. For the purpose of determining the need for services and interventions, patients are categorized. However, specific interventions will ultimately affect individuals and hopefully fulfill their needs.

Sanson-Fisher et al. (48) revised the CNQ and assessed the moderate or high unmet needs reported by cancer patients. Of the ten highest moderate or high unmet needs, only three were similar to those reported in this study. However, most of the ranked needs from Sanson-Fisher et al.'s study were among the ten highest unmet needs (based on some need) in this study. Sanson-Fisher et al.'s sample did not include patients diagnosed within the past three months, which may account for some of the differences.

The top three unmet need items expressed by patients in this study were fears of the cancer spreading or returning, fears of physical deterioration, and being fully informed about remissions. However, the needs in which patients indicated a moderate or high need for help were for dealing with pain, and to be fully informed about remission and test results as soon as possible. In Foot and Sanson-Fisher's study (4), items related to the health information and psychological domains had the highest needs (ranked as moderate or high need for help), including information about remission, test results as soon as possible, and things patients can do to get themselves well. These needs were echoed in Sanson-Fisher et al.'s study (48). The results of these three studies concur that information is a particularly strong need for patients that should be addressed.

It was interesting to note that while 59% of the participants indicated that coping with fears about the pain and suffering that may be experienced was a moderate or high need for help, only 34% of the patients in Lattimore-Foot's study (5) ranked it comparably. This may be related to the specific disease group used in this study compared to the generic sample used in Lattimore-Foot's study (5).

The QOL analyses failed to show a significant difference among any of the comparison groups. Dyspnea, coughing, fatigue, and insomnia had the highest morbidity. However, symptoms of pain and appetite loss scored moderately high. These symptoms are commonly reported by patients with lung cancer (2). As well, financial difficulties were also present and scored highly.

The results of this study suggest that there is a relationship between QOL and unmet needs, but the relationship is less striking than originally expected. The results indicated moderate negative correlations between the physical and daily living domain of need and both the physical and role dimensions of QOL, and between the psychological domain of need and the emotional dimension of QOL. These are the relationships that seem, at first glance, to be the most obvious relationships. The weaker relationships may reflect that the particular domain of unmet need only captures a part of what the corresponding dimension of QOL represents. As well, the EORTC emphasizes the physical dimension of QOL. Consequently, the four other functional dimensions were less thorough in their assessments. This may also have affected the relationships with the unmet need domains.

This is the first study to investigate the relationships between unmet needs and QOL. It will be important for future studies to compare findings with these results. The

direction of the relationship cannot be determined from the analyses used in this study. It seems logical that QOL would be affected by the presence or absence of needs. However, there are many other factors besides unmet needs that also affect QOL, such as hope and patient satisfaction, that may be more strongly correlated with QOL.

In some cases, patients did not seem to be aware of the services and resources that currently exist at the TBCC. It was not ascertained if patients wanted access to services or if they wanted enhanced services. For example, palliative care services were identified as a need. These services are offered through the Calgary Regional Health Authority, but patients may not have known of the service or they may have wanted additional help. While this questionnaire provided an overview of the need for services and resources, it is important to delve further into each individual service to determine the particularities of the need. As well, the patient may be reticent to seek help for a particular need. It will be important for staff to identify this feeling and find strategies to encourage patients to seek assistance.

Some of the differences noted by clinic may reflect the timing of the presentation of the information and the available services, rather than actual differences in needs inherent in the clinics. Many patients come to clinic and are overwhelmed by their diagnosis and information. Consequently, they may not recall the information. NPLC patients may, therefore, have had higher information needs due to information overload rather than an actual lack of health information services. Interestingly, Perez et al. (49) surveyed 148 women with metastatic breast cancer regarding an intervention aimed to provide patients with information. Patients were given written information and an evaluation form related to the acceptability and the adequacy of the information they had

been given. Over 60% of the patients stated they would have preferred to receive this information at diagnosis. In further studies, evaluation of the content and timing could be collected prospectively to allow for greater understanding of the intervention's acceptability.

It seems that a variety of strategies to inform patients are necessary. It is important that patients are able to access this information when they determine they need help to meet an unmet need. Determining the appropriate strategies will become easier as more research is done to predict which patients have needs and when these needs arise.

Given the general need for assistance with physical and daily living needs, interventions to meet this need may result in staffing implications. This could include providing actual physical help for patients at clinic, or it could also involve RNs and/or physiotherapy staff providing guidance, suggestions, and referrals to aid patients to cope better at home.

In terms of the psychological needs, there is a role for physicians, nurses, and other staff (e.g. psychologists, social workers, and clergy) to identify and meet these needs. When unmet needs are identified, staff from Psychosocial Resources, for example, may be able to provide suggestions and guidance to patients to meet some of these needs. The services offered through the TBCC may provide ongoing, intermittent, or once only care, depending on the individual's needs.

In the current health care system there are fiscal restraints affecting the development of new programs. This also means that the need for existing programs and personnel has to be justified. This needs assessment can provide some justification for these services and resources based on patients' identified needs. Evaluations of the

resources that are currently available at the TBCC and in the community should be conducted. These evaluations would see if the services and resources truly meet patient needs. This would also provide the opportunity to make improvements to ensure the maximum benefit from a program.

The functioning scores for QOL were similar to those of pre-treatment patients in Aaronson et al.'s study (1). However, patients in this study reported worse global health/QOL than the EORTC Study Group's sample, in which the mean score prior to treatment was 57. The lower QOL score may reflect the poorer QOL of the overall lung cancer population rather than only of those about to start treatment. This study's symptom scores were very similar to those from the EORTC Study Group. However, the financial impact item score was more than double that of the EORTC Study Group. The higher score may reflect the increasing financial burden imposed by the illness.

Measurement of quality of life can be considered a type of validation of the CNQ. This is because aspects of HRQL are included in the assessment of needs. This was validated by the correlations of the subscales of the EORTC with the appropriate domains of the CNQ, as described previously. The correlations suggest that while each survey measures a different construct, there is an inverse relationship between the constructs.

Both the pilot and main studies add to a body of knowledge related to unmet needs by providing evidence of the CNQ's usefulness, adding further refinements to the tool, and demonstrating the relationships between unmet needs and quality of life.

Strengths and Limitations of the Study

Strengths

A tool such as the CNQ, that is easily administered and appropriate for use in clinical practice, may be valuable to help identify and triage patients needs. Health care professionals can refer patients to community resources to meet patients' needs in order to initiate action and to improve patient outcomes. With future use, the identification of unmet needs may be used to improve both patient care and lung cancer patients' experiences with their illness and the health care system.

A major strength of this study is the demonstrated validity and reliability of the CNQ from the pilot study that corresponds to the psychometric properties determined by Foot and Sanson-Fisher (4) with a generic cancer patient population in Australia. The results of the pilot study demonstrated that the research methods were feasible to meet the objectives of the main study. It also enabled the researcher to make minor changes to the methodology to facilitate the main study.

This study specifically addressed the needs of outpatients with lung cancer. This group of patients is becoming increasingly large. With the restructuring of health care, less inpatient care is provided, resulting in more patients being cared for at home. Diagnosis, treatment, and follow-up for lung cancer are done almost entirely on an outpatient basis. As a result, clinicians need to focus their interventions to meet the needs of outpatients so that they may cope in their home environment. As well, needs of outpatients may be different than the needs of inpatients and this study serves to highlight the needs of outpatients.

Overall, recruitment from the two clinics was successful and the follow-up strategies helped ensure a high response rate. Support for both the pilot and main studies

was gained by explaining the study to the clinic staff and physicians prior to data collection. Support was reinforced when the researcher demonstrated that the recruitment procedure involved minimal disruption in an already busy clinic. Additionally, the opportunity to get phone consent for the main study further reduced the chance of disrupting the clinic. The assessment of the unmet needs of newly diagnosed patients was also a strength of this study because they have been excluded from other surveys using the CNQ due to ethical concerns of their vulnerability. The inclusion of newly diagnosed patients will ultimately ensure that their needs are considered and may improve their access to health care services.

Selection bias in the sample may have resulted if consenting patients differed from non-participants. However, given the comparisons based on age, gender, time since diagnosis, and the presence or absence of metastases, the non-participants were not significantly different from the participants. Therefore, selection bias is not a concern.

Comparisons of the demographic and illness data of the participants, non-participants, and non-respondents confirmed that the participants are representative of the clinic patients, and, therefore, the findings are generalizable to all lung cancer patients attending the TBCC clinics. The results may also be cautiously generalized to the population of Alberta lung cancer patients. The statistically significant differences noted between the participants and the Alberta lung cancer patients seem to be related to the sample size of the participants in comparison to the much larger Alberta lung cancer population, rather than actual differences in the two groups.

A common problem with surveys is a low response rate. However, both the pilot and the main studies had satisfactory response rates. This was most likely due to the

rigorous follow-up. Additionally, this population may have been particularly motivated to participate in such a survey given that the targeted patient population was very specific and there have been few psychosocial studies pertaining specifically to lung cancer patients. As a result, patients may have had a strong interest in the topic and its results.

As in all self-administered surveys, one is not able to control for the completeness of the responses or misunderstanding of the questions. However, patients were encouraged to contact the researcher by phone with any questions or problems, and the follow-up phone call clarified problems following completion of the questionnaires. Respondent burden and the potential for missing data in the CNQ were pre-identified concerns due to the length of the questionnaire and the frailness of the patient population. As well, the length of the questionnaire raised the possibility of inadvertently skipping a page. However, the questionnaires for both the pilot and main studies were generally completed thoroughly. The majority of missed pages were for questions 54 (access to services and resources) and 55 (access to support persons). This may reflect patients' greater willingness to complete the need items rather than the access to people, services, and resources questions. This may also reflect the fatigue level of patients given that the amount of missing data increased as the questionnaire went on. Overall, there was very little missing data and only one follow-up phone call leading to rejection of one inpatient's questionnaires, therefore, it is believed that the quality of the data was very high.

A particular effort was made to minimize any social response bias introduced by study personnel or from the clinic setting. Patients were asked to complete the questionnaires at home rather than at the clinic. Additionally, when the follow-up call

was made, questionnaire responses were not clarified with respondents. This was done to prevent patients from selecting or changing their responses based on perceived influence from the researcher. As a result, the results of this study provide an indication of the acceptability of the CNQ in clinical practice.

One major strength of the design was that the researcher had the opportunity to meet with patients in the clinic and see how their illness affects their lives in ways not captured by a questionnaire. This resulted in minor modifications in the main study methodology. Most importantly, this provided a context to understand patients' experiences: a reminder of the individuality of patients and the importance of allowing patients time to tell their story.

Limitations

Three identifiable groups of patients were not accessed for this study. First, some patients died prior to their first clinic appointment. While this would involve a small number of patients, these patients may have had very specific and very high needs. Second, patients who did not speak or read English were not included. This English literacy prerequisite may have also biased the sample. This highlights a weakness of this type of survey: their needs were not represented, and further, access to resources may be limited for non-English speaking patients. As a result, it seems probable that non-English patients would have more and/or higher needs than the patients that participated. Further studies should consider language and related factors in their needs assessments. Third, the needs of patients currently receiving treatment were not assessed. This results in a significant gap in our knowledge of patients' needs at this particular point along the illness trajectory.

The results of this study have raised some questions regarding the completeness of the CNQ and, more particularly, of the interpersonal communication domain, despite its face and content validity. The broader applicability of this domain may have been overlooked by the researcher, content experts, and patients due to the breadth of the entire CNQ. A more specific review of this domain may clarify the need for additional items. In fact, Bonevski et al. (50) recently revised the CNQ and eliminated the interpersonal communication domain and one of its two items was retained without being associated with a specific domain.

Another deficit in the CNQ is the absence of items relating to patient's sexual and spiritual needs, and financial needs are not assessed in depth. These assessments should be added or strengthened to ensure the comprehensiveness of the questionnaire. Bonevski et al. (50) have included a sexuality domain in their revised CNQ.

Appropriateness of the Tools

Cancer Needs Questionnaire

Overall, the CNQ has the potential to be a widely used tool to assess patient needs. Several minor changes to the questionnaire would be helpful for further use. First, the instructions need to note that not all questions will pertain to all patients and that the "no need- never a problem" selection may be most appropriate. Second, this selection should explicitly state that it also refers to a "not applicable" response. Further testing of the tool and possibly adding items may also strengthen its comprehensiveness.

With the CNQ's demonstrated psychometric properties, it has the potential to be used in more research and eventually in clinical practice. In order to maintain consistency in its application, a manual for the use of the CNQ needs to be developed to ensure that

studies can be replicated and that information is collected similarly. A manual for the CNQ should include definitions related to unmet needs, a description of the domains, the target patient population, validity and reliability data, and methods to handle missing data. Additionally, average item and domain scores should be included as reference scores to facilitate future comparisons.

EORTC QLQ-C30 and QLQ-LC13

The EORTC QOL questionnaires were appropriate for use because of their broad conceptualization of the dimensions of QOL. However, as previously mentioned, the use of a QOL tool intended for use in clinical trials rather than a tool used in psychosocial studies may have resulted in an overemphasis upon the physical dimension of QOL. Further studies may use a different QOL tool that meets the criteria for selection of a QOL tool, as described in Chapter 1.

Directions for Further Research

This study has provided a foundation for further research pertaining to unmet needs. Further research could continue to examine the unmet needs of this and other cancer patient populations and to assess the relationship between QOL and unmet needs.

Patients were aware that they would not benefit personally from participating in this study given that its intent was to identify needs rather than to initiate interventions to meet these needs. Ethically, further research must evaluate interventions intended to meet needs to ensure that patients ultimately benefit from improved care.

The completeness of the interpersonal communication domain of unmet needs should be addressed and improvements made, if deemed necessary. As previously mentioned, sexuality and spirituality needs are not addressed in the CNQ and may be

important for other diagnostic groups. Spiritual and sexual items were included in Lattimore-Foot's pilot version of the CNQ (5). However, they were removed as they were either non-discriminative or less reliable than the items maintained in the CNQ. In Bonevski et al.'s most recent study (50), sexual needs were again included. If changes were made to the CNQ, it would be important to do further factor analyses of the CNQ items. This would ensure that the groupings of items are appropriate and would validate the original factor analysis. Additionally, it would indicate if some of the items not currently associated with a domain should be included in a particular domain.

The results suggest that meeting the health information needs of outpatients with lung cancer is a priority. While normally small pilot projects would be conducted to evaluate interventions intended to meet specific needs, there are currently many information resources available to patients. Instead, the timing of the presentation of information may need to be evaluated.

There are several possibilities of further study related to needs. A longitudinal study of the needs of outpatients with lung cancer could identify differences prior to, during, and following treatment. Inclusion of an assessment of QOL and the appropriate analyses could corroborate or refute the weak to moderate relationships between QOL and unmet needs as found in this study. The responsiveness of the unmet needs assessment to changes in patient condition needs to be determined. As well, the stability or transience of needs over time should be assessed to ensure that there is sufficient time to implement an intervention. The pilot study showed that needs do not change in a two-week period. This is important since this may allow sufficient time for an intervention to be implemented. Future studies will need to determine details regarding the interpretation

of unmet need scores. This would include establishing clinically significant differences in scores.

Predictors of unmet need will be an important area for future consideration because prevention can then become the focus of interventions. Multiple regression can be used to determine predictors of unmet need. As well, clinical trials to assess particular interventions would help determine their appropriateness based on a measurement of needs prior to and after an intervention. With further research into the needs of other diagnostic groups, these interventions may eventually be applied more broadly to meet the needs of many cancer patients.

Siegel et al. (51) conducted an intervention study to meet oncology patient needs for practical assistance, such as personal care, transportation, and paying medical bills. A computerized telephone survey was used to determine patient needs. A social worker called those patients that identified needs to deliver services to meet those needs. A similar intervention study could be tested with this sample.

As interventions are used to meet unmet needs, outcomes must be evaluated. While the relationship with QOL may not be strong, fulfillment of needs could potentially improve patient satisfaction, decrease symptoms, and/or improve compliance with treatment and follow-up.

These results clearly show the needs of outpatients with lung cancer. We need to continue to assess possible differences in need by patient subgroups. This will help to determine if there are subgroups of patients at risk. In further research, the needs of other diagnostic groups and other patient subgroups (e.g. inpatients, palliative patients, and patients currently receiving treatment) need to be assessed. This will help determine if the

instrument is sensitive to the broad range of illness experiences that patients may face. However, there are certain patient subgroups whose needs cannot be assessed, such as patients that are too ill or frail, emotionally vulnerable, or unwilling to participate. A proxy assessment could be used. That does introduce biases inherent in the subjective nature of unmet needs assessments, but a proxy assessment may be the best option to determine the needs of subgroups that may not otherwise be known.

It will be important to determine if unmet needs differ by level of education, type of illness, or duration of illness. Additionally, needs of patients experiencing a recurrence of the disease may be different, as suggested by Dudgeon et al. (37). While no differences were found in Dudgeon et al.'s study (37), knowledge level and/or physical deterioration could potentially affect needs and should be considered in further studies. This would be important to determine because the type and the timing of the intervention could be specific to the group of patients being assessed.

Frequency of administration of the CNQ needs to be determined. Administration should be regular enough that needs are adequately assessed and that interventions can be implemented, but not so frequently that patients feel burdened. As well, compliance with completion may decrease if administered too frequently.

One must exercise caution with the use of the CNQ. The possibility of health care providers labeling patients as "needy" was identified as a concern by Lattimore-Foot (5). Hopefully educating clinicians of the purpose of this assessment and eventually demonstrating how needs can be met with certain interventions will ensure that this does not occur.

This research did not delve into the needs of family members. This was a conscious decision in order to narrow the scope of this study. But the needs of families should also be researched to ensure that services and resources also meet their needs.

The researcher found that the study design of the main study had almost exhausted the available follow-up patients. This resulted in a smaller FULC sample size than originally intended. But this provides useful methodological information for further studies of this nature. Otherwise, the methods used in this study were very successful and are replicable.

Conclusion

There is a small but growing body of literature related to the unmet needs of cancer patients. This study has improved our understanding of the unmet needs of a specific diagnostic group. Identification of the needs of outpatients with lung cancer is the first step towards the goal to fulfill patients' unmet needs. In order to fill the gaps in care and support for cancer patients, physical and psychosocial needs must be identified. Ultimately, assessments of patients' needs are intended to improve their experiences with their illness.

This study found that lung cancer patients' unmet needs were predominately from the health information, physical and daily living, and psychological domains. The average domain scores were low, but the majority of patients reported some need in those domains. While the relationship between unmet needs and quality of life is not strong, it remains to be seen if any interventions intended to fulfill unmet needs would improve patients' quality of life, satisfaction with care, nursing practice, and ultimately, patient

care. This study helps to provide a foundation for further research into the needs of cancer patients.

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Appendix 1: Consent Form



TOM BAKER CANCER CENTRE SOUTHERN ALBERTA CANCER PROGRAM

Determining the Unmet Needs of Outpatients with Lung Cancer and the Relationship Between Unmet Needs and Quality of Life

Principal Investigators: H. S. Campbell, R.N., Ph.D., U. Dawe, R.N., Ph.D. and R. Brant, Ph.D.
Co-investigator: Janine Davies, R.N., B.N.

Consent Form

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

The purpose of this study is to identify the unmet needs of outpatients diagnosed with lung cancer, and determine if unmet needs are related to patients' quality of life. The unmet needs questions will relate to psychological needs (related to anxiety, anger, and depression), health information needs (related to needs for information about the disease, treatment, and prognosis), physical and daily living needs (related to coping with physical symptoms and side-effects, loss of independence, and activities of daily living), patient care and support needs (related to staff sensitivity to both physical and emotional needs, privacy and choice of specialists), and interpersonal needs (related to awkwardness in talking and relating to others). The two quality of life questionnaires relate to your functioning in everyday life and the presence of symptoms. The use of these questionnaires may eventually help improve patient care and services provided for patients. The researcher will access your health records charts to get basic information about your diagnosis and treatment(s). There may be no direct benefits to participants in this study. The information may be used for other analyses at a later date.

Your participation in this study would involve the completion of three questionnaires at home in the next 2-3 days. The time required to complete the questionnaires is approximately 50 minutes. A brief (5 minute) follow-up phone call will follow in which you may discuss your results with the researcher. There will be no cost associated with this study: a reply-paid envelope will be given to you to return the questionnaire.

Your participation in this study is voluntary- there will be no penalty to refuse to participate. There will be no health risks resulting from participation or refusal to participate in the research.

Confidentiality

You will be assigned a number for use on the questionnaire. Information linking your identity with your assigned number will be kept in a locked cabinet and used only by study personnel. No record bearing your name will be provided to anyone else except the investigators involved in this study. You will not be identified as an individual in any report coming from this study.

Page 1 of 2 June 1999 initials _____

All material and data obtained from this study will be stored and may be used for future analysis without obtaining further consent from you. However, each study arising as a result of information obtained in this study will be submitted for ethical approval.

In the event that you suffer injury as a result of participating in this research, no compensation will be provided for you by the University of Calgary, the Alberta Cancer Board, or the researchers, Janine Davies, Dr. H. S. Campbell, Dr. U. Dawe or Dr. R. Brant. You still have all your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Janine Davies at 220-5984.

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at 403-220-7990.

Participant's Name

Participant's Signature

Date

Investigator and/or Delegate's Name

Investigator and/or Delegate's Signature

Date

Witness' Name

Witness' Signature

Date

A copy of this consent form has been given to you to keep for your records and reference.

Appendix 2: Lung Cancer Information Questionnaire

Clinic review _____ Chart reviewed post-clinic _____ ID# _____

1

LUNG CANCER INFORMATION QUESTIONNAIRE

- 1 Diagnosis of lung cancer:
 Month _____ Day _____ Year _____

- 2 Type of lung cancer:
 ☐ SCLC¹ ☐ NSCLC² ☐ Other³ _____
 ☐ Oat cell¹ ☐ Squamous²
 ☐ Anaplastic¹ ☐ Adenocarcinoma²
 ☐ Large cell²

- 3 Stage of lung cancer: T _____ N _____ M _____
 NSCLC SCLC
 ☐ early stage (stage I and II)¹ ☐ limited⁴ ☐ Other type of cancer⁰
 ☐ locally advanced (stage IIIA and IIIB)² ☐ extensive⁵
 ☐ advanced (stage IV)³
 ☐ not written⁶ ☐ not written⁸
 ☐ unable to determine⁷ ☐ unable to determine⁹

- 4 Has the lung cancer metastasized?
 ☐ Yes¹ ☐ No² ☐ Not confirmed but suspected⁴
 If yes, list the other areas that have been affected:

- 5 Is the lung cancer currently in a state of remission (ie. stopped growing/diminishing/stable/on hold)?
 ☐ Yes¹ ☐ No² ☐ Not confirmed³ ☐ Too soon after treatment to know⁴

- 6 Which of the following surgery or treatments for the lung cancer have ever been used?
 (Check all that apply)
 ☐ Chemotherapy
 ☐ Radical radiotherapy
 ☐ Palliative radiotherapy
 ☐ Surgery
 ☐ Hormone treatment
 ☐ Treatment was not pursued
 ☐ Have not started treatment
 ☐ Other: _____

Appendix 3: Non-participant Survey

Date (mm/dd/yy) _____

NP ID# _____

CNQ NON-PARTICIPANT SURVEY



1. Why did you choose not to participate in this survey?
 - ☐ I never participate in studies¹
 - ☐ I am too sick at this time²
 - ☐ I have already completed too many questionnaires³
 - ☐ The questionnaires are too long⁴
 - ☐ Other (please specify)⁵ _____
2. When were you first told of your lung cancer?
 Month _____ Day _____ Year _____
3. Has the cancer since spread to any other areas of your body?
 - ☐ Yes¹
 - ☐ No²
 - ☐ Don't know³
 - ☐ Not confirmed but suspected⁴
4. When were you born?
 Month _____ Day _____ Year _____
5. Are you...?
 - ☐ Male¹
 - ☐ Female²
6. Which of the following medical treatments for the cancer have you received during the last month? (Check all that apply)
 - ☐ Surgery
 - ☐ Chemotherapy (via drip or tablets)
 - ☐ Radiotherapy (intended to cure)
 - ☐ Palliative radiation (intended to control symptoms)
 - ☐ Hormone therapy
 - ☐ No treatment because:
 - ↳ ☐ Treatment has been completed
 - ↳ ☐ Treatment is not being pursued
 - ↳ ☐ Treatment has not been started
 - ☐ Other (please state in space below)

Appendix 4: Cancer Needs Questionnaire

JD (1)

 $CL_{(2)} \quad C/T$

ID# _____

Date Issued: _____

Date Completed: _____

CANCER NEEDS QUESTIONNAIRE

You have agreed to participate in this survey to identify the unmet needs of patients with lung cancer. There is a list of items relating to different types of issues or needs that you may have faced as a result of having cancer. Do not be concerned if you believe there may not be a solution to your problem -- it is our responsibility to plan services, if possible, that will best meet your needs.

It is important that you, the patient, complete the questionnaires. Your responses will be kept confidential.

If you have any comments, you may write them directly on the questionnaires.

Please return the questionnaires in the stamped self-addressed envelope. If you have any questions or concerns, please call Janine Davies at (403) 220-5984. Thank you for your participation!

CANCER NEEDS QUESTIONNAIRE

1

INSTRUCTIONS FOR COMPLETING QUESTIONS 1-53

For each item, circle the ONE number that best indicates your current level of need for help.

When you circle the score:	Your <u>current</u> level of need for <u>help</u> is:	Which means:
1	None- Never a Problem	This item has <u>never been a problem</u> for you as a result of having lung cancer and you do not require help.
2	Already Satisfied	You have had this problem but it is no longer a problem, so you do not require help.
3	Low	The item is of <u>minor</u> concern, causing only minimal physical, mental, emotional or social discomfort to you. This need is not being met.
4	Moderate	The item causes you <u>some</u> concern or discomfort. This need is not being met.
5	High	The item is of <u>major</u> concern or importance to you. This need is not being met.

EXAMPLE

What is your <u>current</u> level of need for <u>help</u> : (Please circle one score)	NO NEED		SOME NEED		
	None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
1. Dealing with nausea and/or vomiting	1	2	3	4	5
2. Dealing with fears about the cancer spreading	1	2	3	4	5
3. To be given more information about the side-effects of your treatment	1	2	3	4	5

In the above example, if you put circles where we have it means that:

Question #1: A score of 1 (None- Never a Problem) indicates that you have never experienced nausea or vomiting as a result of the cancer or its treatment. This item therefore is not and has not been a problem, and you do not need any help.

Question #2: A score of 5 (High Need) indicates that dealing with fears about cancer spreading is an issue of major concern with which you have a high need for help.

Question #3: A score of 2 (Already Satisfied) indicates that you are already satisfied with the amount of information you have been given about the side-effects of your treatment, and therefore you do not need any additional help.

CANCER NEEDS QUESTIONNAIRE

2

What is your current level of need for help?

	Issue of Need (Please circle one score)	NO NEED		SOME NEED		
		None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
1.	Dealing with pain	1	2	3	4	5
2.	Dealing with lack of energy and tiredness	1	2	3	4	5
3.	Dealing with nausea and/or vomiting	1	2	3	4	5
4.	Coping with feeling unwell a lot of the time	1	2	3	4	5
5.	Coping with disturbed sleep	1	2	3	4	5
6.	Coping with keeping up with work around the home	1	2	3	4	5
7.	Coping with frustration at not being able to do the things you used to do	1	2	3	4	5
8.	Coping with fears about losing your independence	1	2	3	4	5
9.	Dealing with anger and confusion about why this has happened to you	1	2	3	4	5
10.	Coping with feeling bored and/or useless	1	2	3	4	5
11.	Dealing with anxiety or stress	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

3

	Issue of Need <i>(Please circle one score)</i>	NO NEED		SOME NEED		
		None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
12.	Dealing with feeling down or depressed	1	2	3	4	5
13.	Coping with overwhelming feelings of sadness or grief	1	2	3	4	5
14.	Dealing with fears about the cancer spreading or returning	1	2	3	4	5
15.	Coping with fears about the pain and suffering you might experience	1	2	3	4	5
16.	Coping with anxiety about having treatment or surgery	1	2	3	4	5
17.	Coping with fears about further physical disability or deterioration	1	2	3	4	5
18.	Accepting the changes in your appearance and self-image	1	2	3	4	5
19.	Coping with worry that the cancer is beyond your control	1	2	3	4	5
20.	Coping with an uncertain future	1	2	3	4	5
21.	Working through your feelings about death and dying	1	2	3	4	5
22.	Learning to feel in control of your situation	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

4

Issue of Need (Please circle one score)		NO NEED		SOME NEED		
		None- a Problem	Never Satisfied	Low Need	Moderate Need	High Need
23.	Learning to make the most of your time	1	2	3	4	5
24.	Trying not to worry and/or to maintain a positive outlook	1	2	3	4	5
25.	Trying to find meaning in this experience	1	2	3	4	5
26.	Coping with the disruption to your usual routine and/or changes in your lifestyle	1	2	3	4	5
27.	Coping with awkwardness in talking with others about the cancer	1	2	3	4	5
28.	Coping with changes in other people's attitudes and behavior towards you	1	2	3	4	5
29.	Dealing with concerns about your family's fears and worries	1	2	3	4	5
30.	Dealing with concerns about your family's ability to cope with caring for you	1	2	3	4	5
31.	Dealing with concerns about your financial situation	1	2	3	4	5
32.	Coping with concerns about getting to and from the hospital	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

5

Issue of Need (Please circle one score)	NO NEED		SOME NEED		
	None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
33. Coping with waiting for long periods of time for clinic appointments	1	2	3	4	5
34. To be allowed to have family or friends with you in hospital whenever you want	1	2	3	4	5
35. To have your rights for privacy more fully protected when you're at the clinic or hospital	1	2	3	4	5
36. To have more choice about which cancer specialist you see and which hospital you attend	1	2	3	4	5
37. To be reassured by your doctor(s) that your physical and emotional responses are normal	1	2	3	4	5
38. For nurses to attend promptly to your physical needs in hospital	1	2	3	4	5
39. For <u>nurses</u> to acknowledge (and show sensitivity to) your feelings and emotional needs	1	2	3	4	5
40. For your <u>cancer specialist</u> to acknowledge (and show sensitivity to) your feelings and emotional needs	1	2	3	4	5
41. For your cancer specialist to convey a positive sense of hope to you and your family	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

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Issue of Need (Please circle one score)		NO NEED		SOME NEED		
		None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
42.	To have the opportunity to talk to someone who understands and has been through a similar experience	1	2	3	4	5
43.	For your cancer specialist to <u>write down</u> all of the important points that he/she tells you	1	2	3	4	5
44.	To be given written information about ways of managing your illness and side-effects at home	1	2	3	4	5
45.	To be given a full explanation for <u>every</u> test and treatment procedure you go through	1	2	3	4	5
46.	To be fully informed about all of the benefits and side-effects of treatment or surgery <u>before</u> you agree to have it	1	2	3	4	5
47.	To be fully informed about the odds of treatment success	1	2	3	4	5
48.	To be fully informed about your test results <u>as soon as possible</u>	1	2	3	4	5
49.	To be fully informed about the <u>possible</u> effects of the cancer on the length of your life	1	2	3	4	5
50.	To be fully informed about cancer remission	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

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Issue of Need (Please circle one score)		NO NEED		SOME NEED		
		None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
51.	To be fully informed about things you can do to help yourself to get well	1	2	3	4	5
52.	To be fully informed about support groups in your area	1	2	3	4	5
53.	Dealing with shortness of breath / breathlessness	1	2	3	4	5
	Other unmet needs (please specify): _____ _____	1	2	3	4	5

Question 54 on next page

CANCER NEEDS QUESTIONNAIRE

8

54.

INSTRUCTIONS FOR COMPLETING QUESTION 54
 related to access to services and resources

When you circle the score:	Your <u>current</u> level of need for <u>easy</u> access to the service or resource is:	Which means:
1	None- Never a Problem	Never a problem for me <u>OR</u> not interested in having access to this service or resource.
2	Already Satisfied	Already fully satisfied with access to this service or resource. The need is being met.
3	Low	Low desire for access to this service. The need is not being met.
4	Moderate	Moderate desire for access. The need is not being met.
5	High	Strong desire for access. The need is not being met.

What is your <u>current</u> level of need for <u>easy</u> access to the following services and resources: (Please circle one score)		NO NEED		SOME NEED		
		None- Never a Problem	Already Satisfied	Low Need	Moderate Need	High Need
A.	Food and drink facilities in or near clinic waiting room	1	2	3	4	5
B.	Easy car parking at the clinic	1	2	3	4	5
C.	Transportation to and from the clinic	1	2	3	4	5
D.	Care for an ailing spouse or family member at the clinic	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

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What is your <u>current</u> level of need for <u>easy access to the following services and resources:</u> (Please circle one score)		NO NEED		SOME NEED		
		None - a Problem	Never Satisfied	Low Need	Moderate Need	High Need
E.	Brochures about services and benefits for cancer patients	1	2	3	4	5
F.	Advice regarding wigs / supply of wigs	1	2	3	4	5
G.	Library of books and videos about cancer and related issues	1	2	3	4	5
H.	Relaxation classes	1	2	3	4	5
I.	Drop-in counselling & support service	1	2	3	4	5
J.	24 hour telephone support & cancer advisory service	1	2	3	4	5
K.	Home nursing service	1	2	3	4	5
L.	Palliative care / hospice care / respite care	1	2	3	4	5
M.	Financial assistance for travel, treatment and equipment expenses	1	2	3	4	5
N.	Pain clinic	1	2	3	4	5
O.	Respiratory therapy	1	2	3	4	5
P.	Other services or resources you may need (please specify):	1	2	3	4	5

Question 55 on next page

CANCER NEEDS QUESTIONNAIRE

10

55.

INSTRUCTIONS FOR COMPLETING QUESTION 55		
What is your current level of need for help or support with issues related to your lung cancer from the following persons?		
When you circle the score:	Your current level of need for the help or support with issues related to your lung cancer from the following persons is:	Which means:
1	None - Never is a problem	Never a problem for me OR not interested in OR have not considered obtaining help from this person
2	Already Satisfied	Already fully satisfied with the help or support given by this person
3	Low	Low desire for more help or support from this person
4	Moderate	Moderate desire for more help or support from this person
5	High	Strong desire for more help or support from this person

What is your current level of need for help or support with issues related to your lung cancer from the following persons:		NO NEED		SOME NEED		
(Please circle one score)		None - Never is a Problem	Already Satisfied	Low Need	Moderate Need	High Need
A.	Your husband or wife or partner	1	2	3	4	5
B.	Your parent(s)	1	2	3	4	5
C.	Your children	1	2	3	4	5
D.	Your extended family	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

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What is your <u>current</u> level of need for help or support with issues related to your lung cancer from the following persons: (Please circle one score)		NO NEED		SOME NEED		
		None- a Problem	Never Already Satisfied	Low Need	Moderate Need	High Need
E.	Your friends	1	2	3	4	5
F.	Your boss	1	2	3	4	5
G.	Your workmates	1	2	3	4	5
H.	Home help worker (nursing assistant, house cleaner, etc.)	1	2	3	4	5
I.	Meals on Wheels worker	1	2	3	4	5
J.	Dietitian or nutritionist	1	2	3	4	5
K.	Alternative therapy provider or herbalist or naturopath	1	2	3	4	5
L.	Wig specialist	1	2	3	4	5
M.	Pharmacist	1	2	3	4	5
N.	Physiotherapist	1	2	3	4	5
O.	Palliative care worker	1	2	3	4	5
P.	Home care or community nurse	1	2	3	4	5
Q.	Your family doctor (GP)	1	2	3	4	5

CANCER NEEDS QUESTIONNAIRE

12

What is your <u>current</u> level of need for help or support with issues related to your lung cancer from the following persons: (Please circle one score)		NO NEED		SOME NEED		
		None- a Problem	Never Satisfied	Low Need	Moderate Need	High Need
R.	Your cancer specialist	1	2	3	4	5
S.	Clergy, minister, spiritual counsellor	1	2	3	4	5
T.	A volunteer support visitor	1	2	3	4	5
U.	Social worker	1	2	3	4	5
V.	Psychologist or counsellor	1	2	3	4	5
W.	Clinic nurse(s)	1	2	3	4	5
X.	Other support persons (please specify): _____ _____ _____	1	2	3	4	5

Question 56 on next page

CANCER NEEDS QUESTIONNAIRE

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In the following section, we would like to ask you some questions about your disease.
Please "X" the appropriate circle.

56. When were you first told you have lung cancer? (Please be as specific as possible.)

Year _____ Month _____

57. Has the lung cancer spread to any other areas of your body?

☐ Yes¹ ☐ No² ☐ Don't know³

↳ Please list below the other areas of your body that have been affected:

58. Has your doctor indicated to you that the lung cancer is currently in a state of remission (ie. stopped growing / diminishing / stable / on hold)?

☐ Yes¹ ☐ No² ☐ Not confirmed³ ☐ I don't know⁴

59. Which of the following surgery or treatments for the cancer have you ever received?
(Check all that apply)

- ☐ Chemotherapy (via drip or tablets)
☐ Radical radiotherapy (radiation treatment aimed to cure)
☐ Palliative radiation (radiation treatment aimed to reduce symptoms)
☐ Surgery (this does not include a biopsy)
☐ Hormone treatment
☐ Treatment was not pursued
☐ I have not started treatment yet
☐ Other (please state in space below):

CANCER NEEDS QUESTIONNAIRE

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60. Which of the following medical treatments for the lung cancer have you received during the last month? (Check all that apply)

- ☐ Surgery
☐ Chemotherapy (via drip or tablets)
☐ Radical radiotherapy (radiation treatment aimed to cure)
☐ Palliative radiation (radiation treatment aimed to reduce symptoms)
☐ Hormone therapy
☐ No treatment because:
 ↳ ☐ Treatment has been completed
 ↳ ☐ Treatment is not being pursued
 ↳ ☐ I have not yet started treatment
☐ Other (please state in space below):

61. Which of the following therapies (alternative therapies) do you do for yourself on a regular basis for your lung cancer? (Check all that apply)

- | | |
|---|---|
| <input type="radio"/> Megavitamin therapy | <input type="radio"/> Hoxsey method |
| <input type="radio"/> Vitamin B | <input type="radio"/> Shark cartilage |
| <input type="radio"/> Betacarotene | <input type="radio"/> Imagery |
| <input type="radio"/> Chiropractic | <input type="radio"/> Meditation |
| <input type="radio"/> Massage | <input type="radio"/> Chinese medicine |
| <input type="radio"/> Echinacea | <input type="radio"/> Chelation therapy |
| <input type="radio"/> Essiac | <input type="radio"/> Co-enzyme Q10 |
| <input type="radio"/> Metabolic therapy | <input type="radio"/> Laetrile |
| <input type="radio"/> Immuno-augmentative therapy | <input type="radio"/> Acupuncture |
| <input type="radio"/> Spiritual healing | <input type="radio"/> Healing touch |
| <input type="radio"/> Reiki | <input type="radio"/> Other (please specify): |
- _____

62. Have you ever been diagnosed with any type of cancer before (eg. skin, breast or prostate cancer)?

☐ Yes¹ ☐ No²

↳ If yes, please specify:

Type of cancer _____ Year of diagnosis _____

Type of cancer _____ Year of diagnosis _____

CANCER NEEDS QUESTIONNAIRE

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63. When was the last time that you were admitted to hospital and stayed overnight to receive treatment or surgery for lung cancer?

- ☐ Within the last month¹
☐ 13 - 24 months ago⁵
☐ 1 - 3 months ago²
☐ 25 - 36 months ago⁶
☐ 4 - 6 months ago³
☐ More than 3 years ago⁷
☐ 7 - 12 months ago⁴
☐ Never admitted to hospital overnight for lung cancer-related care⁸

In the following section, we would like to get some information about you in order to understand the characteristics of people that participate in this survey.
Please complete the following questions. Thank you.

64. When were you born?
Month _____ Day _____ Year _____

65. Are you...?
☐ Male¹
☐ Female²

66. What is your current marital status?
☐ Single / Never Married¹
☐ Separated⁴
☐ Married²
☐ Divorced⁵
☐ Common-law / live with significant other³
☐ Widowed⁶

67. What is the highest level of education that you have completed?
☐ No schooling¹
☐ University or teacher's college / undergraduate degree⁵
☐ Elementary²
☐ Graduate university degree⁶
☐ High school/secondary³
☐ Other (please specify below):⁷
☐ Community college/technical college⁴
-

68. Which of the following best describes your employment situation before you developed cancer?
(Please check one only)

- ☐ Full-time employment¹
☐ Semi-retired⁶
☐ Part-time employment/casual²
☐ Looking for work⁷
☐ Household duties³
☐ Medical leave / disability⁸
☐ Student⁴
☐ Other (please specify below):⁹
☐ Retired⁵
-

CANCER NEEDS QUESTIONNAIRE

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69. What is your current work situation?*(Please check one only)*

- | | |
|--|--|
| <input type="radio"/> Full-time employment ¹ | <input type="radio"/> Semi-retired ⁶ |
| <input type="radio"/> Part-time employment/casual ² | <input type="radio"/> Looking for work ⁷ |
| <input type="radio"/> Household duties ³ | <input type="radio"/> Medical leave / disability ⁸ |
| <input type="radio"/> Student ⁴ | <input type="radio"/> Other (please specify below): ⁹ |
| <input type="radio"/> Retired ⁵ | _____ |

70. What is your usual occupation?

(Note: If retired or on medical leave or disability, please state your usual occupation before giving up work)

71. How far have you travelled to come to clinic?

- | | |
|---|--|
| <input type="radio"/> Less than 25 km (less than 17 miles) ¹ | <input type="radio"/> 51 - 100 km (34 - 66 miles) ³ |
| <input type="radio"/> 25 - 50 km (17 - 33 miles) ² | <input type="radio"/> More than 100 km (more than 66 miles) ⁴ |

72. How many children (aged under 18 years) currently live in your household?

73. Including yourself, how many adults (aged 18 years or over) currently live in your household?

74. Do you currently receive care by a Registered Nurse (RN) who comes to your home (eg. Homecare)?

- | | |
|--|---------------------------------------|
| <input type="radio"/> Yes ¹ | <input type="radio"/> No ² |
|--|---------------------------------------|

75. With whom do you currently live? *(Please check all that apply.)*

- | | |
|---|--|
| <input type="radio"/> I live alone ¹ | <input type="radio"/> Friend ⁴ |
| <input type="radio"/> Spouse / significant other ² | <input type="radio"/> Other (please specify below): ⁵ |
| <input type="radio"/> Son or daughter ³ | _____ |

CANCER NEEDS QUESTIONNAIRE

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The following question is to help us compare the needs of people with different incomes.

76. What is your current yearly gross family income (i.e. before taxes and deductions)?
- | | | |
|---|---|---|
| <input type="radio"/> Less than \$20,000 ⁵ | → <input type="radio"/> Less than \$10,000 ¹ | → <input type="radio"/> Less than \$5,000 |
| | | → <input type="radio"/> \$5,000 or more |
| | → <input type="radio"/> \$10,000 or more ² | → <input type="radio"/> Less than \$15,000 |
| | | → <input type="radio"/> \$15,000 or more |
| <input type="radio"/> \$20,000 or more ⁶ | → <input type="radio"/> Less than \$40,000 ³ | → <input type="radio"/> Less than \$30,000 |
| | | → <input type="radio"/> \$30,000 or more |
| | → <input type="radio"/> \$40,000 or more ⁴ | → <input type="radio"/> Less than \$60,000 |
| | | → <input type="radio"/> \$60,000 - \$79,999 |
| | | → <input type="radio"/> \$80,000 or more |
| <input type="radio"/> No income ⁷ | | |
| <input type="radio"/> Don't know ⁸ | | |

Thank you very much for completing this questionnaire!

Once you have completed the questionnaires, please mail them in the self-addressed envelope.

If you have misplaced the envelope, please return this questionnaire to: **Janine Davies, c/o Department of Community Health Sciences, 3330 Hospital Dr. NW, Calgary, AB T2N 4N1.**

A follow-up phone call will follow in the next two weeks. Please provide your phone number:

Phone: _____

If you have any questions, concerns, or wish follow-up, please contact Janine at (403) 220-5984.

**Appendix 5: Cancer Needs Questionnaire Item Numbers by Domain of
Unmet Need**

Domain 1: Psychological need domain (16 items)

9, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25

Domain 2: Health information (10 items)

43, 44, 45, 46, 47, 48, 49, 50, 51, 52

Domain 3: Physical and daily living (10 items)

1, 2, 3, 4, 5, 6, 7, 8, 10, 53

Domain 4: Patient care and support (8 items)

33, 34, 35, 36, 37, 38, 39, 40

Domain 5: Interpersonal communication (2 items)

27, 28

Items 26, 29, 30, 31, 32, 41, 42 have no primary loading factor (domain).

Appendix 6: List of Content Experts

Lesley Degnar, RN Ph.D.
Director, Cancer Nursing Research Group
St. Boniface General Hospital Research Centre
Winnipeg, MB

Marg Fitch, RN Ph.D.
Head, Oncology Nursing
Toronto-Sunnybrook Regional Cancer Centre
Toronto, ON

Carolyn Gotay, Ph.D.
Associate Researcher
Cancer Research Centre of Hawaii
University of Hawaii at Manoa
Honolulu, HI

Karin Olson, RN Ph.D.
Coordinator, Nursing Research
Cross Cancer Institute
Edmonton, AB

Appendix 7: EORTC QLQ-C30



QUALITY OF LIFE QUESTIONNAIRE

ID # _____

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

--	--	--	--	--

Your birthdate (Day, Month, Year):

--	--	--	--	--	--	--	--	--	--

Today's date (Day, Month, Year):

31									
----	--	--	--	--	--	--	--	--	--

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week:				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4

Please go on to the next page

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

Please go on to the next page

Appendix 8: EORTC QLQ-LC13

ENGLISH

**EORTC QLQ - LC13**

Patients sometimes report that they have the following symptoms. Please indicate the extent to which you have experienced these symptoms during the past week.

During the past week :	Not at All	A Little	Quite a Bit	Very Much
31. How much did you cough?	1	2	3	4
32. Did you cough blood?	1	2	3	4
33. Were you short of breath when you rested?	1	2	3	4
34. Were you short of breath when you walked?	1	2	3	4
35. Were you short of breath when you climbed stairs?	1	2	3	4
36. Have you had a sore mouth or tongue?	1	2	3	4
37. Have you had trouble swallowing?	1	2	3	4
38. Have you had tingling hands or feet?	1	2	3	4
39. Have you had hair loss?	1	2	3	4
40. Have you had pain in your chest?	1	2	3	4
41. Have you had pain in your arm or shoulder?	1	2	3	4
42. Have you had pain in other parts of your body?	1	2	3	4
If yes, where				
43. Did you take any medicine for pain?				
1 No 2 Yes				
If yes, how much did it help?	1	2	3	4

Appendix 9: Transformation Formulas of CNQ Unmet Need Scores to a Linear Scale

Based on a linear scale of 0 to 100, scores for each item were transformed according to the developers instructions (5) as follows:

no need (both “not applicable” and “already satisfied”) = 0,

“low need” = 33.3,

“moderate need” = 66.6, and

“high need” = 99.9.

Appendix 10: Conversion Formulas of EORTC Data to a Linear Scale

The following formulas were used to transform the quality of life scores to a 0 to 100 scale, based on the following instructions by (1).

To calculate the raw score:

$$RS = (I_1 + I_2 + \dots + I_n) / n$$

Where: I = score selected by the patient for that particular item.

To apply the linear transformation:

Functional scales (physical, role, emotional, cognitive and social):

$$S = \{ 1 - (RS - 1) / \text{range} \} \times 100$$

Symptom scales (fatigue, nausea and vomiting, and pain), symptom items (dyspnoea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties), Global Health Status/QOL scale, and QLQ-LC13 items *:

$$S = \{ (RS - 1) / \text{range} \} \times 100$$

Where: S = scale score
 RS = raw score
 Range = difference between minimum and maximum possible values of the RS

- * Items 33, 34 and 35 of the QLQ-LC13 refer to dyspnea. All items should be answered to obtain a scale score. However, given that not all patients may climb stairs (item 35), if the score for item 35 is missing, then items 33 and 34 are to be used as single item measures.

Appendix 11: Letters of Permission

Letter 1: Use of the Cancer Needs Questionnaire

Letter 2: Use of the EORTC QLQ-C30 and EORTC QLQ-LC13

34 Andrew Road
Valentine NSW 2280
AUSTRALIA

16th December, 1998

Dear Janine,

Thank you for your correspondence, in which you requested permission to use the CPNQ in your post-graduate work.

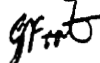
I would be very pleased for you to employ the questionnaire for your research work, Janine. It sounds like an ambitious undertaking!

I do, however, alert you to the fact that the title of the instrument is now the CNQ (Cancer Needs Questionnaire - changed in order to avoid the politically insensitive "cancer patient" title). I also hope that you have access to my PhD thesis, as this provides the most up-to-date data regarding the instrument. I have so far had very little success in getting our Australian research recognised by publishers in any other part of the world! Perhaps you will have more luck in this regard!

Finally, I do apologise for the delay in responding to your correspondence. I am no longer employed by the University of Newcastle, and I have only just received your letter. If you wish to contact me regarding your research in the future, I'd suggest you write to the above address. (I unfortunately do not have access to email technology at my present workplace). I would be happy to assist in any way I can.

Best wishes with it all. I admire your vision!

Kind regards,



Glenda Lattimore-Foot



International Association under Belgian Law

EORTC QLQ-C30 USER'S AGREEMENT

The EORTC Quality of Life Study Group grants permission to Ms. Janine Davies to employ the EORTC QLQ-C30 in an academic quality of life study entitled: *"Identifying the Needs of Outpatient Lung Cancer Patients and Determining the Relationship of Unmet Needs to Quality of Life"*.

The Study Group will supply Ms. Janine Davies, with: (1) the QLQ-C30 in the currently available languages; and (2) the standard algorithms for scoring the QLQ-C30. Use of the EORTC QLQ-C30 in the above-mentioned investigation is subject to the following conditions:

1. Ms. Janine Davies confirms that this study is being conducted without direct or indirect sponsorship or support from pharmaceutical, medical appliance or related, for-profit health care industries.
2. Ms. Janine Davies will not modify, abridge, condense, translate, adapt or transform the QLQ-C30 or the basic scoring algorithms in any manner or form, including but not limited to any minor or significant change in wording or organization of the QLQ-C30.
3. Ms. Janine Davies will not reproduce the QLQ-C30 or the basic scoring algorithms except for the limited purpose of generating sufficient copies for its own use and shall in no event distribute copies of the QLQ-C30 to third parties by sale, rental, lease, lending, or any other means. Reproduction of the QLQ-C30 as part of any publication is strictly prohibited.
4. Analysis and reporting of QLQ-C30 data by Ms. Janine Davies should follow the written guidelines for scoring of the QLQ-C30 as provided by the EORTC Study Group on Quality of Life.
5. This agreement holds for the above mentioned study only. Use of the QLQ-C30 in any additional studies of Ms. Janine Davies will require a separate agreement.

Signed and dated by:

12 November 1998
Karen West
EORTC Quality of Life Group

Signed and dated by:

99-01-12

Ms. Janine Davies
University of Calgary