Title
The lung cancer patient's perception of dyspnea

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Publication Date
1984

The Lung Cancer Patient's Perception of Dyspnea

by

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THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

[redacted]

Date SEP . 9 1984 University Librarian

Degree Conferred: . . . .

The Lung Cancer Patient's Perception of Dyspnea

Mary L. Brown

Abstract

Dyspnea, or breathlessness, is a common symptom reported by patients with lung cancer. A convenience sample of thirty lung cancer patients experiencing dyspnea were interviewed twice over a two-month interval. The purposes of this study were to elicit descriptions of the sensation of dyspnea and to determine strategies used to cope with it in patients with lung cancer. A dyspnea visual analogue scale, the Karnofsky Performance Scale, and the American Thoracic Society Grade of Breathlessness Scale were used to quantify the relationship between the degree of breathlessness and the activity restriction imposed by the symptom. Interviews were thematically analyzed to determine patterns in the sensation of dyspnea, adaptive strategies, and adjustments in activities of daily living.

Subjects in this sample described a typical pattern for their dyspneic episodes. These were characteristically of gradual onset, plateaued, and then subsided. Dyspnea was usually precipitated by activity or an emotional event. Subjects with lung cancer rated their mean usual dyspnea as 39.54 and worst dyspnea as 76.43 on the visual analogue scale indicating significant dyspnea. All subjects said they felt extreme fatigue and experienced loss of concentration and memory when short of breath.

There was a significant correlation between the two activity scales, the Karnofsky Scale and the Grade of Breathlessness Scale. Additionally, the scores on these scales correlated significantly with the level of usual daily dyspnea ($p < 0.001$). In general, the lung cancer subjects exhibited a pattern of social isolation, saying they didn't want to be with others except for a trusted partner. This isolation was attributed to the social stigma attached to cancer. Most felt frustrated with recurring shortness of breath and anger over the diagnosis.

Lung cancer subjects used few strategies for managing dyspnea. They stopped to rest during acute episodes and tried to avoid thinking about their breathing to cope on a daily basis. Further, cancer subjects were unlikely to be taught by health care professionals about ways to manage their breathlessness. These findings, most probably, are reflective of the short duration of dyspnea experienced within the rapid downhill trajectory of lung cancer. The degree of breathlessness did not change over the eight weeks in this sample. However, activity significantly decreased due to progressive weakness with advancing malignancy.

Dedication

This thesis is lovingly dedicated to my son, Travis. Though young, his sense of humor, innocence and childish wisdom have helped me put major life events into proper perspective.

Acknowledgements

I would like to thank the patients who participated in my study. Their time and disclosure of very personal information was especially appreciated.

I am especially indebted to Dr. Virginia K. Carrieri, my thesis chairperson. Her support, time, and encouragement over these long months provided me with the energy to complete this project.

I would like to thank Dr. Marylin Dodd for her efforts as a member of my thesis committee and as a teacher and colleague. Her special contribution to my masters degree will always be appreciated.

I think Dr. Susan Janson-Bjerklie for her careful critique of my thesis and for her participation as a member of my thesis committee.

Many thanks to Mark Hudas, whose assistance in data analysis aided the research process.

My family, friends and colleagues are acknowledged for their support and encouragement during my graduate studies. I am especially indebted to my parents who provided me with a competitive spirit, and a notion that educational accomplishments were within my grasp.

I also thank the American Cancer Society for financial assistance during my graduate education.

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Chapter 1

Introduction

With dramatic progress having been made in the treatment of the hematopoetic malignancies, attention is now being focused on solid tumors that have traditionally been difficult to control. Cancers of the lung, breast and colon continue to predominate in our culture, and clinicians and researchers are working to develop new treatment programs that can alter rather dismal survival statistics. Concurrently, specific nursing research is necessary to define patient problems, develop and evaluate appropriate nursing interventions, relate these interventions to a conceptual framework, and further establish the role of the nurse in cancer care.

Lung cancer is the leading cause of cancer deaths in men, and it is projected that during this decade it will overtake breast cancer as the leading cause of cancer deaths in women. In the last thirty years no improvement has been made in the five year survival statistics of 10% (Livingston, 1982). These facts make the lung cancer patient a major health care consumer in the United States and a deserving recipient of time and effort from the cancer nurse researcher.

Physical and psychological adjustment to the diagnosis and course of lung cancer can be difficult for patient and family. Symptoms can be debilitating and disturbing. One of these symptoms, dyspnea, or shortness of breath, has been described as a symptom in other chronic diseases of the lung. Dyspnea may be present before the malignant diagnosis is actually made, or it may develop at any point during the illness. No documented nursing research exists on the experience of dyspnea in lung cancer patients. This study explores the dyspnea phenomenon and is an initial effort to establish a body of knowledge based on descriptions, trends, adaptation and patterns of the lung cancer patient's dyspnea experience.

The symptom of dyspnea is prevalent in many disease states and its impact on the lives of the patients experiencing it can be significant. It is a common phenomenon, and is clearly a human response to many actual or potential health problems that the American Nurses Association Social Policy Statement has defined as the basis for nursing (ANA, 1980). Given this validation for practice, nursing interventions developed from investigating the cancer patient's dyspnea experience could potentially enhance patient comfort and adaptation to the disease process.

In its effort to provide specific Outcome Standards for Cancer Nursing Practice, the Oncology Nursing Society (1979) included a Ventilation Standard, which can assist the nurse in planning care for the lung cancer patient who is short of breath. The standard includes the patient and family as the unit of care. It further indicates that following appropriate nursing intervention, the patient and family should be able to recognize factors that could impair ventilatory function and utilize measures that would provide optimum ventilatory capacity (ONS, 1979). The rationale recognizes the causes of ventilatory dysfunction. Also discussed is the psychological impact of respiratory distress and the limitations impaired ventilation can cause. Recognition that modifications in environment, mechanics and activity can improve respiratory function concludes the rationale section (ONS, 1979). The outcome criteria include energy conservation, reduction of pulmonary irritants, and awareness that extremes in the environment can influence respiratory function and utilization of oxygen. Airway maintenance, reasons for altered ventilation, and development of a plan for managing an altered airway are considered. The guidelines delineated in this standard can be utilized as an initial framework for the comprehensive care of the patient and family. They can assist the patient, family and nurse in dealing with the events surrounding the dyspnea experience. (See Appendix A.)

More specific information to aid in the care of the cancer patient with respiratory system dysfunction has been provided by the Clinical Practice Committee of the Oncology Nursing Society, who published "Guidelines for Nursing Care of Patients with Altered Ventilation" (Krzysko, Erdel, Greiner, & Lawrance, 1983). These guidelines defined the cancer population at risk and presented outcome expectations and management information based on the patient problem definition of potentially impaired, impaired and severely impaired gas exchange (Krzysko et al., 1983). (See Appendix B.) This format provides a systematic approach, giving the nurse direction and a plan for implementing general and individualized patient care.

The standard and guidelines were carefully conceived and developed in response to a need identified by the cancer nursing community. They illustrate the concern expressed by nursing leaders, who recognize the necessity to develop theory based conceptual categorizations and descriptions prior to the creation of logical propositions and responses (Chinn & Jacobs, 1983; Donaldson & Crowley, 1978). Marino (1981) points out the need for longitudinal research to establish interventions. Derdiarian (1981) suggests that careful assessments, documented observations, and appropriate tools must be formulated to address the psychosocial and physical problems of cancer patients, and that interventions must be based on methodical practice with a theoretical framework. Detailed information about the experience of dyspnea from this study can be used to develop nursing interventions for other cancer patients with dyspnea.

Purpose

The primary purpose of this study was to obtain descriptions of the sensation of dyspnea from a sample of lung cancer patients. Other objectives were to determine adaptive strategies used by this sample to cope with dyspnea, and to determine if a relationship existed between a scale used to measure dyspnea in pulmonary patients and a scale used to measure overall level of activity in cancer patients.

Research Questions

The specific questions addressed in this study were: (1) how does the lung cancer patient describe the nature of dyspnea, (2) what factors does the patient perceive to influence the dyspnea, and (3) what is the relationship between the Karnofsky Performance Scale and the American Thoracic Society Grade of Breathlessness Scale in lung cancer patients?

Chapter 2

Review of Literature and Conceptual Framework

Dyspnea: The Mechanism

Dyspnea is difficult, labored and uncomfortable breathing. The sensation is subjective and involves the patient's perception and reaction to the sensation (Comroe, 1966, 1974). It is sensory, totally perceived, interpreted and rated by the individual experiencing it (Widimsky, 1979). The degree of physical alteration may or may not reflect the subjective interpretation, and objective measurement may not correlate with the subjective feeling. On one end of the continuum are patients who may describe severe dyspnea, and demonstrate minor pathophysiological alterations. At the other extreme, are patients describing minimal dyspnea and demonstrating marked change in pulmonary function. Widimsky (1979) supports this statement following a review of dyspnea in a wide variety of disease states. In his view, pulmonary function disturbances differ according to disease and no one measurement of lung function can be accepted as an exact definition of respiratory capacity.

Dyspnea is most frequently observed in primary pulmonary disease, heart disease, and neuromuscular disorders affecting respiratory muscles. It can also occur with pregnancy, obesity, and in particular psychological conditions characterized by anxiety.

Though the physical mechanisms of dyspnea are poorly understood, several authors have advanced theories relating to breathlessness.

Rappaport (1971) defined two types of pulmonary disease in which dyspnea can occur: those respiratory diseases associated with increased ventilation and those associated with increased resistance to breathing. Widimsky (1979) elaborates by classifying dyspnea into three categories: dyspnea occurring during hyperventilation due to insufficient oxygen saturation of arterial blood; dyspnea occurring in relative states of hyperventilation caused by the restriction of the actual breathing area; and dyspnea occurring when ventilation is disturbed by mechanical forces.

Generally speaking, however, most theories about dyspnea fall into four major categories. Those categories are: (1) stimulation of afferent intrapulmonary receptors, (2) increased sensitivity to changes in ventilation perceived via central nervous system mechanisms, (3) reduced ventilatory capacity or breathing reserve, and (4) stimulation of neural receptors in the skeletal joints and muscles or tendons of the intercostal and diaphragmatic musculature (Howell & Campbell, 1966; Widdicome, 1971).

Research focusing on neural impulses has categorized intrapulmonary receptors into three major groups: pulmonary stretch receptors (tonically active, slowly adapting) which increase the rate of breathing; irritant receptors (rapidly adapting) that respond to irritants, asphyxia, hypercapnia and pulmonary congestion; and "J" receptors (activated by interstitial distortion) which may contribute to the dyspnea sensation in certain clinical situations in patients with pulmonary edema, congestive heart failure, embolism and pneumonia (Guz, Noble, Eisele, & Trenchard, 1970; Widdicome, 1979).

Central nervous system mechanisms and increased subjective sensitivity to changes in ventilation and their relationship to dyspnea have also been investigated. Frankstein (1970) has proposed that the disturbance of nerve potentials in the cerebral cortex by hypoxemia causes increased reflex discharge in the pyramidal tracts that conduct impulses from the cerebral cortex to the respiratory muscles. He carried this hypothesis further by stating that the resulting weakness of respiratory muscles creates a perceived discrepancy between increased effort to breathe and inadequate muscle contractions leading to the sensation of dyspnea. Central nervous system mechanisms to explain dyspnea are not easily tested in humans, and animals cannot report subjective sensations, so the above theory and others relating to a central nervous system component for dyspnea remain subject to conjecture.

Theories suggesting that the dyspneic sensation comes from a reduction in ventilatory capacity or breathing reserve have also been suggested (Cournand & Richards, 1941). Objections to this theory revolve around the fact that normal subjects can increase ventilation and decrease breathing reserve without becoming dyspneic.

The stimulation of muscle and joint receptors causing dyspnea is the fourth viewpoint. Into this category fall the studies by Campbell and Howell (1966) that have advanced the "length-tension inappropriateness theory." This theory states that the significant factor in the perception of dyspnea is the relationship of the pressure (tension) generated by respiratory muscles and the tidal volume (change of length) that can result. Misalignment of fibers in the muscle spindles of the intercostal muscles result from a disparity between tension in the muscle and change in the length. The spindles, functioning as neural integrators, transmit signals which create an awareness of breathing, bringing it to a conscious level. This theory, now called "mechanical inappropriateness" is considered the most plausible explanation of dyspnea since it reflects the complex nature of the phenomenon and has its base in the sensed difference between the performance of the respiratory apparatus and a drive to breathe (Campbell, 1974).

Burki (1980) purports that the dyspnea sensation comes from an awareness of change between central respiratory drive and respiratory pump output. This author discusses several other theories, but supports the "mechanical inappropriateness" theory as the most viable in explaining the dyspnea phenomenon.

Lung Cancer and Dyspnea

The National Cancer Institute has projected that in 1984 the incidence of lung cancer will be 22 percent of all cancers in men and ten percent of all cancers in women (Silverberg, 1984). The 1984 projection for deaths attributed to lung cancer are proposed to be 35 percent of all cancer deaths in men and 18 percent of all cancer deaths in women (Silverberg, 1984). These figures suggest that the incidence of lung cancer is increasing more rapidly than any other malignancy in both males and females (Greco & Hande, 1982).

Several etiologic factors have been implicated in the development of lung cancer, most notably the inhalation of cigarette smoke (Greco & Hande, 1982; Van Houtte, Salazar, Phillips, & Asbury, 1983).

Tobacco smoke contains a complex mixture of physical and chemical tumor initiators and cocarcinogens, and it is well known that the risk of developing lung cancer is proportional to the number of cigarettes smoked (Hande & Greco, 1982; Van Houtte et al., 1983). Even though these factors have been widely publicized in the lay press, there has been no reduction in cigarette consumption in this country. Other factors such as atmospheric pollution and occupational exposure to uranium, asbestos, arsenic, nickel, vinyl chloride, iron-oxide and chromium have been documented as contributing agents in the development of carcinoma of the lung (Chaffin & Reininger, 1981; Holmes, Sarna, & Petrovich, 1980; Livingston, 1982; Ruckdeschel, 1981; Van Houtte et al., 1983).

The natural history of lung cancer begins with exposure to any one or a combination of the carcinogens previously discussed, producing a preclinical phase that may last several years (Cohen, 1982; Minna, Higgins, & Glatstein, 1982). During this phase, atypical cellularity from cytologic changes in the host can be seen in sputum, with eventual progression to carcinoma in situ. Prolonged and repetitive injury to bronchial epithelium will eventually lead to frank invasion and symptom expression (Cohen, 1982; Minna et al., 1982).

About ninety to ninety-five percent of all pulmonary neoplasms arise in bronchial or bronchioalveolar epithelium or from bronchial mucous glands yielding nearly a dozen histologic types under the broad heading of lung cancer (Cohen, 1982; Jett, Cortese, & Fontana, 1983; Minna et al., 1982, 1982). Various cell types have different natural histories and different responses to therapy making correct histologic diagnosis imperative to treatment planning and prognosis prediction. Ninety percent of these belong to four major categories. These cell types, incidence and metastatic patterns are summarized in Table 1.

Clinical manifestations of lung cancer depend upon the location and size of the primary tumor and presence or absence of distant metastases. Occasionally, small, localized asymptomatic lesions may not be early stage tumors, but can be surgically resected and yield improved patient survival statistics (Jett et al., 1983). Unfortunately, at the time of diagnosis, many lung cancers are far along in their natural course, since most have been present for long periods of time, and many will have already spread to regional or distant lymph nodes or distant metastatic sites. Most authors agree that at least ninety percent of patients with lung cancer are symptomatic at diagnosis (Livingston, 1982; Martini, 1978; Minna et al., 1982; Sarna et al., 1980).

Health care providers can assist in detecting lung cancer in three specific situations. In the first instance, a patient may have a negative chest X-ray, but have positive sputum cytology. This is a characteristic presentation of epidermoid carcinoma. Secondly, an asymptomatic patient may have an abnormal chest X-ray (often seen with adenocarcinoma or large cell anaplastic tumors) and thirdly, the development of a new respiratory symptom or change in an old respiratory symptom may cause an individual to seek medical attention, as in oat cell carcinoma (Cohen, 1982). A combination of any of these situations could also exist (Cohen, 1982).

The specific type of primary tumor will influence the symptoms

Table 1

Major Histologies, Incidence and Primary Metastatic Sites for Bronchogenic Cancer

Histology		Incidence	Primary Area of Metastases
I.	Epidermoid Carcinoma (Squamous Cell)	30%	Bronchial lumen (produces obstruction with associated pneumonilitis
II.	Small Cell Anaplastic Carcinoma (Oat Cell)	20-25%	Regional lymph nodes, liver, adrenal glands, bone, CNS, bone marrow (usually disseminated at diagnosis)
III.	Adenocarcinoma	30-35%	Other lung, liver, bone, kidney, central nervous system
IV.	Large Cell Anaplastic Carcinoma	10-15%	Mediastinal lymph nodes, pleura, adrenal glands, CNS, bone marrow

and physical manifestations of lung cancer. Complications related to extension into the mediastinum, metastasis to distant locations, ectopic hormone production by some tumors, and the occurrence of paraneoplastic symptoms can also be present (Cohen, 1982; Minna et al., 1982).

The symptom of dyspnea often coexists with cough, wheezing and chest pain in centrally located obstructive tumors. A restrictive dyspneic process can result from bulky tumor or pleural effusion in peripheral pulmonary structures (Minna et al., 1982; Sarna et al., 1980). Dyspnea may also accompany sequellae of lung cancer such as superior vena cava syndrome, pneumonia or pneumonitis (Spross, 1979; Canellos, Cohen, & Posner, 1981). In summary, dyspnea will be seen either as a presenting symptom at initial examination, a treatable complication of lung cancer, or a sign of advancing tumor. If the dyspnea is related to infection or inflammation it can usually be reversed by appropriate antibiotic therapy. Dyspnea resulting from pleural effusions can be alleviated with therapeutic thoracentesis (Canellos et al., 1981). Though dyspnea is frequently mentioned in the lung cancer literature, few studies have actually documented its occurrence or attempted to quantify the sensation.

The most extensive study in observing high risk populations for lung cancer was the Philadelphia Pulmonary Neoplasm Research Project (PNRP) (Weiss, Boucot, & Seidman, 1982). This study involved data from 6136 men enrolled in a screening project from 1951 to 1955. Chest X-rays and interviews were completed every six months for ten years. Data from this study has been and still is being extensively reviewed.

Of the 205 cases of lung cancer identified, 84 were detected on the first visit and 121 on subsequent visits. This prospective study carefully observed the patients diagnosed during the study period and all other subjects were considered at risk. Smoking histories as well as symptoms were considered in the interview process, and although dyspnea was mentioned as a symptom in 40% of the 205 patients studied, no further information is given about its course or concern to patients (Weiss, Boucat, & Seidman, 1982). Several substudies were also undertaken during the investigation, and involved such topics as ventilatory function as related to smoking, and improved techniques needed to take repeated chest X-rays. The study did not screen any women, but at that time, lung cancer was not common in women. Certainly the information gained is generalizable to the male population and the study could be replicated. Numerous published reports have resulted from this study, and provide rich and extensive data about lung cancer risk factors. It is an impressive study and has yielded valuable information about lung cancer screening and detection, but little information about dyspnea.

Chaffin and Reininger (1981) followed 25 male patients with histologically confirmed bronchogenic cancer from 1976 and 1978. All patients were in one nursing home and only one achieved a five-year survival. Demographic and retrospective symptom data was collected on this sample, with 32% of the patients presenting initially with dyspnea at the time of diagnosis. No information about the pattern of dyspnea or its severity during the study period was reported. The data was presented within a theoretical discussion about bronchogenic cancer rather than a research format and should be viewed only from a descriptive perspective.

Dyspnea, as a presenting symptom, was found to be present in only eleven of 170 patients undergoing radical radiotherapy for cure in a 1980 study by Coy and Kennelly. Sixteen (9%) of the patients in this study were asymptomatic at presentation (considered by the investigators to be a large number) and dyspnea was ranked third behind hemoptysis and cough in symptom description. Again, only the presence of the dyspnea is reported, and no further information about its effect on the patients is described.

Sarna, Holmes and Petrovich (1980) reviewed presenting signs and symptoms of lung cancer and estimated that 40% of all patients with lung cancer will exhibit dyspnea at diagnosis. No other discussion is given about the symptom in their article.

Clearly the symptom of dyspnea is often present in obstructive and restrictive respiratory processes associated with lung cancer. It will usually appear gradually and may have been present in conjunction with other chronic diseases of the lung. Unless patients are specifically questioned about its presence and effects on their daily activities, dyspnea may only be added to the list of symptoms with no other effort made to quantify or explore its significance to these patients.

Lung Cancer Staging

Following appropriate diagnostic procedures, clinical staging of the tumor is done. The basic goal of the staging process is to separate and classify groups of patients with similar characteristics

(Feinstein & Wells, 1982).

Other purposes for staging include the rationale for treatment selection, estimation of probabilities of cure and survival, facilitation of communication about patient status, and comparison of results from different treatment series (Feinstein & Wells, 1982; Minna et al., 1982). Knowledge of cancer staging may be useful in interpreting symptomatology and assisting the nurse in developing appropriate interventions and plans for patient care.

While single staging systems exist for most malignancies, two systems exist for lung cancer since there are great biologic differences between non-small cell and small cell tumors, and poor correlation of these two classifications of tumor types existed utilizing only one system. The TNM system is currently being used for non-small cell tumors. This system denotes the size and extent of the primary tumor (T), regional lymph node involvement (N), and presence or absence of distant metastases (M) (Jett et al., 1983). These categories are then combined to define the specific stage of the disease which is designated as I, II, or III (Greco & Hande, 1982; Jett et al., 1982; Minna et al., 1982).

Since several studies determined that TNM factors were not prognostically useful for survival in small cell patients, a two stage system has been adopted for this disease. In this system, limited stage disease is defined as disease confined to one hemithorax and to regional lymph nodes and extensive disease is disease beyond this including distant metastases to lymph nodes, brain, liver, bone marrow, intra-abdominal and soft tissue (Greco & Hande, 1982; Jett et al., 1982; Minna et al., 1982).

The Psychological Component of Lung Cancer and Dyspnea

Several authors have suggested a psychological component in the dyspnea experienced by patients with obstructive lung disease, emphysema and asthma (Dudley, Glaser, Jorgenson, & Logan, 1980). In evaluating the psychological component of dyspnea, the lung cancer patient is at a distinct disadvantage. With possible pre-existing pulmonary disease already present, the newly diagnosed lung cancer patient may picture the tumor taking up space and develop a fear of being unable to receive a sufficient amount of air. Lung cancer may be "...perceived as 'punishment' for a lifetime of smoking..." and may further complicate the patient's emotional response to diagnosis (Ruckdeschel, 1982, p. 1).

Since the lung cancer patient must deal with the probability of a poor prognosis despite aggressive treatment (Livingston, 1982; Ruckdeschel, 1982), the nurse should carefully explore the patient's perception of the disease in relation to the symptom of dyspnea. Marino (1981) points out that cancer is perceived differently by different people and an informed listener can be helpful to the patient and family as they "...work to integrate this massive threat to their well-being" (p. 58). What illness means, and what defense mechanisms are manifested (denial, anger, grief, guilt) are also important factors for the nurse to consider. Fears of death, uncertainty of future, pain, or losing a body part or function, losing family or work, expensive medical care and alienation from others are of concern. Holland (1976) reports that gradual acceptance of the disease will result but that "...anxiety, insomnia, anorexia, inability to concentrate, and irritability is normal (following diagnosis)..." (p. 264). Dealing with misconceptions, investigating and mobilizing resources and encouraging action are appropriate professional activities (Derdiarian, 1981; Marino, 1981). The nurse must also be aware of maladaptive behaviors, with extreme responses of total denial, search for alternative therapies and fatalistic refusal to accept treatment as being possible (Holland, 1976).

While many cancer patients deal with exacerbations and remissions and the constant threat of recurrence after completion of a long course of treatment, the lung cancer patient will usually live with a relatively slow progression of the disease (Derdiarian, 1981; Marino, 1981). Certain paraneoplastic complications can be manifested in the lung cancer patient requiring hospitalization and causing additional stress to the patient and family. These complications can include ectopic hormone production, pleural effusion, pneumonia, superior vena cava syndrome and dyspnea (Cannellos, Cohen, & Posner, 1981). For the patient and family, understanding, support, acceptance of feelings and assurance that they will not be abandoned should be cornerstones for nursing interventions (Derdiarian, 1981). Consistency and continuity of care are of prime importance and nursing assessment should be consolidated and made available to all nurses caring for a particular patient and family through the illness.

Conceptual Framework

The conceptual framework for this study is based on chronic illness and the theories of Strauss and Glaser.

In their classic work on chronic illness, Strauss and Glaser (1975) utilize Mayo's definition of chronic illness. This definition states that chronic illness is any disease with one or more of the following characteristics: permanency, possible continued disability, irreversible pathophysiological changes, specialized preparation of the patient for rehabilitation and possible long periods of supervision, observation and/or care. Lawrence and Lawrence (1979) define chronic illness as "...a long-term condition characterized by slow, progressive decline in normal physiologic function which requires continuing medical therapy and nursing intervention" (p. 35).

Malignant disease in general and lung cancer more specifically, fit these definitions, though the longevity of the cancer patient (and particularly the lung cancer patient) may be shorter than the longevity of patients with other chronic diseases.

Gerson and Strauss (1975) further elaborate on the characteristics of chronic illness, by discussing the management (not cure) of these diseases. They reflect on the long-term nature of chronic illness, the usual uncertainty of the prognosis, and the emphasis on palliative therapy provided for this patient population. Patients with chronic disease usually have exacerbations and remissions of their illnesses, and may require treatment for multiple chronic diseases (Gerson & Strauss, 1975).

When compared to patients who may have a single, short illness, patients with chronic illness experience an intrusion upon their lives requiring an adjustment of home and work activities (Gerson & Strauss, 1975). The need for extensive use of ancillary services, struggles for authority among patients, health care workers and funding sources, and the expense of chronic illness complicate the picture. Primary care as a delivery system is generally the model utilized by patients with chronic illness. However, it is the contention of Gerson and Strauss (1975) that increased cost, conflict among physicians about responsibility, greater patient risk, and increased accounting and procedural review overhead lead to poorly treated chronically ill patients.

The magnitude of the chronic illness problem is overwhelming. Three out of four hospital beds are occupied by chronically ill patients, but the majority of the chronically ill and disabled live in the community (Garant, 1981; Goldsteim, Regnery, & Wellin, 1981). A dilemma for the chronically ill can arise from the perception of living in a limbo status, "...a crossroad between physical and emotional well-being, or 'health' and non-being or 'death'" (Garant, 1980, p. 2166). Waiting becomes a part of the chronically ill person's life, as one learns to depend upon others for help to perform activities and functions that used to be taken for granted. Priorities, values and what the individual considers important may change in the course of the illness. New structure and restrictions, limitations and loss of independence frequently result as a patient progresses through the chronic illness continuum.

In her discussion about cancer as a chronic disease, Garant (1981) proposes that although cancer has different connotations for different people, concerns fall into three negative and passive areas: losses, changes and responses. Since cancer patients often express feelings about control and coping, the nurse can utilize this information in planning critical interventions. Strauss and Glaser (1975) discuss the strengths and weaknesses in the health care system that can either assist or impede the chronically ill person. They suggest the addition of psychological and social knowledge to the data collected about an individual patient. They also believe that common social and psychological problems are shared by the chronically ill, and that understanding these common themes can assist health care professionals in managing these patients.

Figure 1 presents a visualization of the multiple problems of daily living that the person with chronic illness may encounter.

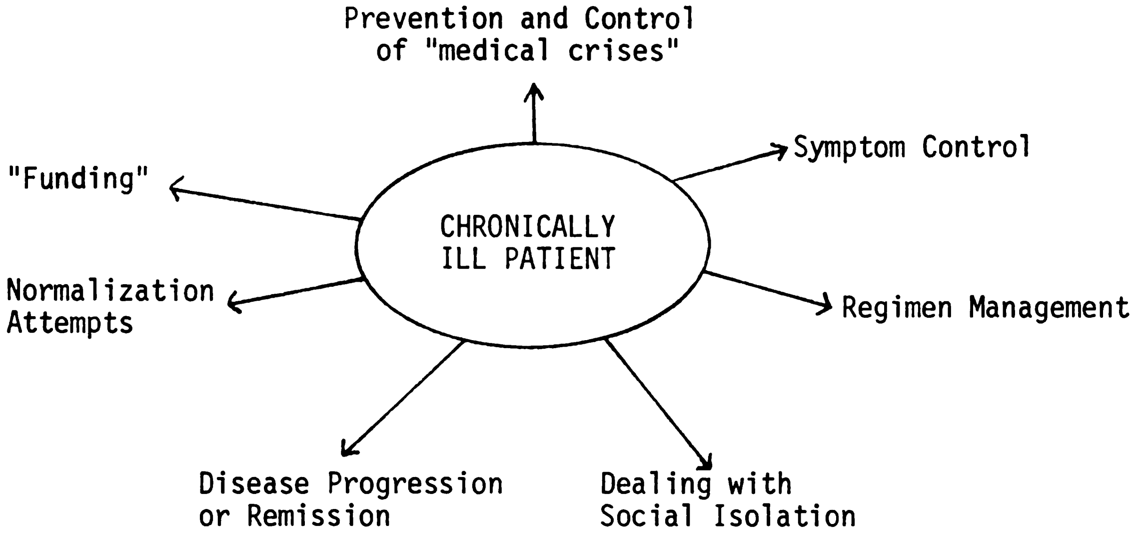


Figure 1. A summarization of physical and psychological problems experienced by the chronically ill. (Adapted from Strauss and Glaser, 1975, p. 7).

In applying this framework to the lung cancer patient experiencing dyspnea, the investigator proposes Figure 2.

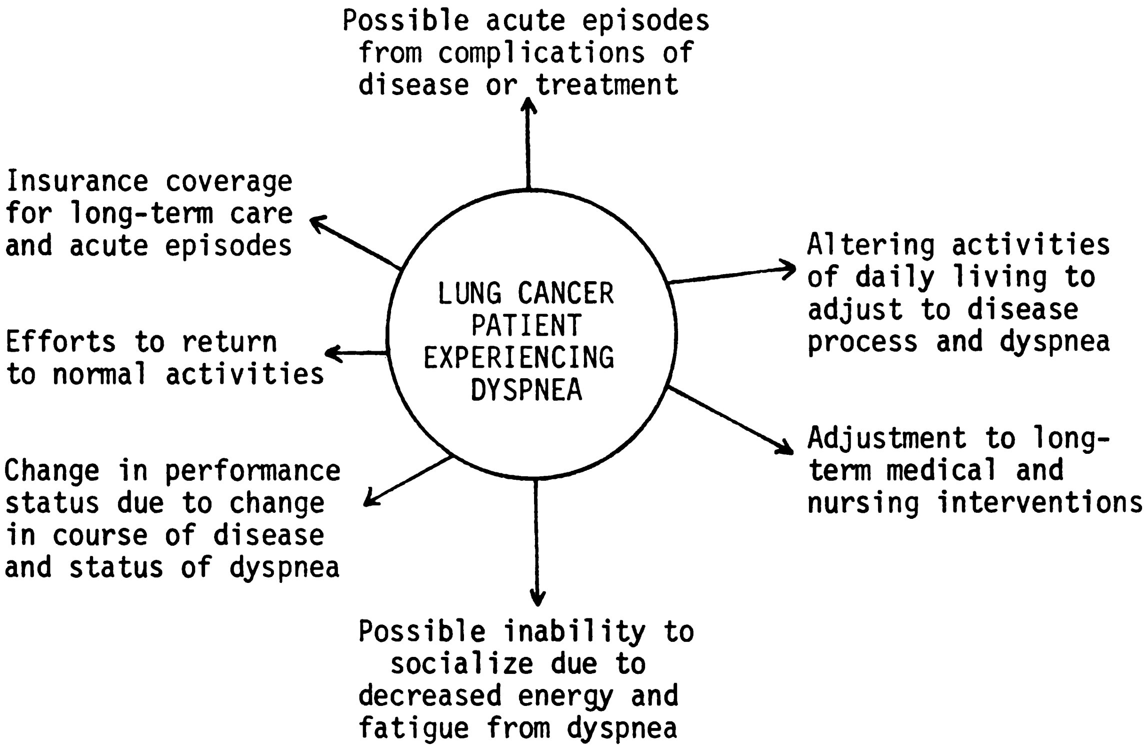


Figure 2. A visual summarization of problems that may be experienced by the lung cancer patient with dyspnea.

To manage these problems successfully, Strauss and Glaser (1975) suggest the development of "basic strategies". They recognize the necessity to utilize family and friends to assist with organizing "arrangements" and positive or negative "consequences" of these organizational efforts on patients and family. MacVicar and Archbold (1976) discuss the importance of evaluating the stress of chronic illness on the family. They believe there are other influences which could affect the family's ability to cope with the illness experience. These factors are: (1) the characteristics of the event; (2) the threat that might be perceived to relationships, status, and goals in the family; (3) available resources to the family; (4) same or similar situational experiences in the past.

MacVicar and Archbold (1976) suggest criteria formulated by Nagi that can enhance the Strauss-Glaser framework in developing the picture of the chronically ill person. These criteria include:

> The point in the life cycle at which the illness occurs.
> The type of onset--either gradual or very sudden, allowing no warning.
> The degree of pain, trauma, and threat to life.
> The nature and degree of limitations imposed upon the individual's capacity and level of functioning.
> The degree of visibility, disfigurement, or associated stigma.
> The type of treatment and care required and received.
> The state of underlying pathology--either eliminated or arrested; slowly or rapidly progressive.
> Prognosis and potential for restorative training.
> (p. 184)

Strauss and Glaser (1975) further identify trajectories for chronic illness. They note varying shapes of trajectories for different diseases and state that patient, family and health care provider may have different views of what the trajectory may be. In practically applying this concept to the lung cancer patient with dyspnea, the general physical condition of the patient, extent of disease, the patient's desires regarding treatment, the available systems of support, and the ever-pressing problem of efficacy of treatment will influence the trajectory of the illness. Generally, however, the trajectory is a progressive downward course with occasional plateaus.

The "work" being done by the chronically ill patient/family must also be considered by the health care provider. Strauss, Fagerhaugh, Suczek, and Winer (1981) discuss in depth the "work" being done by patients in a technologized hospital. They further define this work as being all physical and psychological activities that are done to support the ill person. These activities may be done by the ill person or significant others. An example of physical work that might need to be done by the patient/family can center around planning, preparing and administering adequate nutritional support. Psychological work can be seen in the process of adjusting to being chronically ill.

This information can assist in evaluating the patient in any setting. Physical and psychological work already done by patients and families must be carefully considered. It is this author's contention that much time and effort could be saved if this information would be assimilated into the ongoing assessment process.

In thinking about the work being done by the lung cancer patient with dyspnea and his/her family, this author suggests Figure 3.

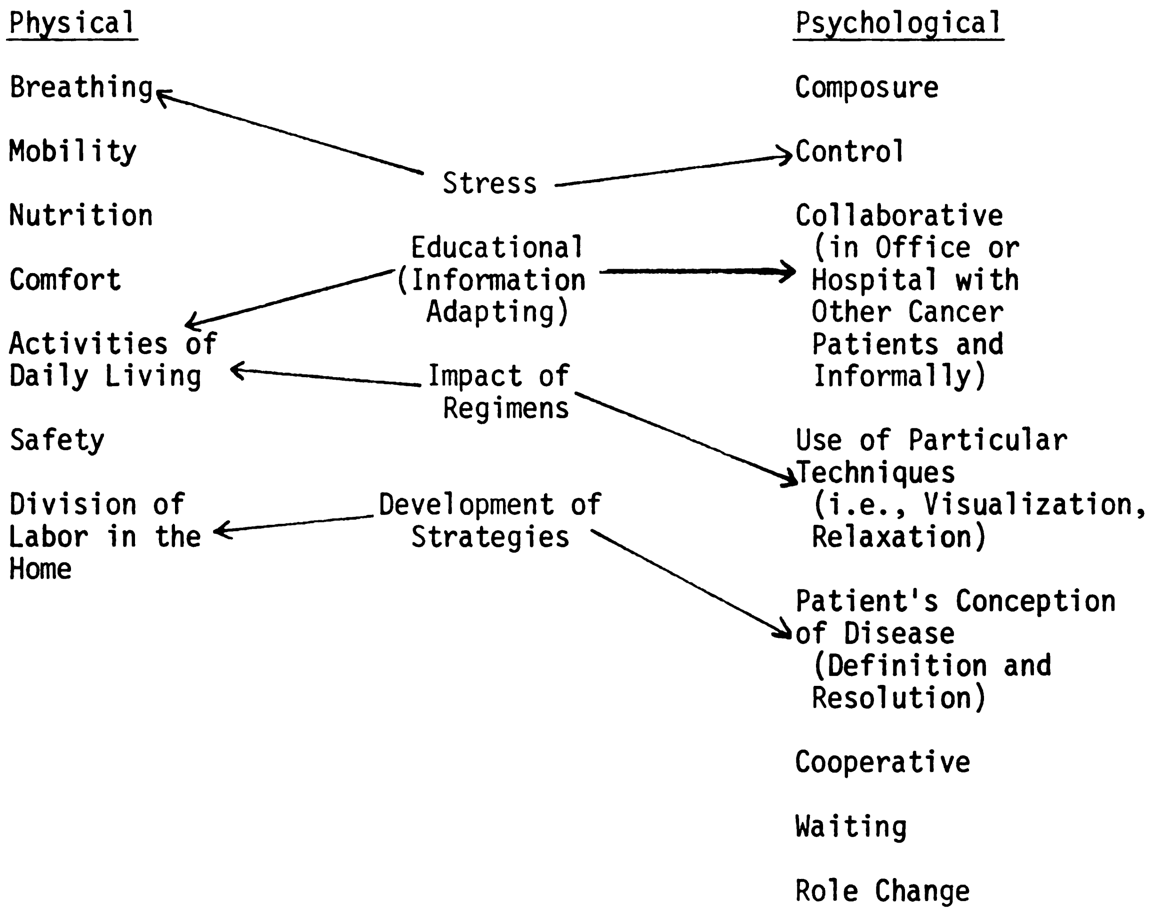


Figure 3. Physical and Psychological Work to be Done by the Lung Cancer Patient with Dyspnea

Evaluating any or all of this work can assist in responding to the needs of the chronically ill lung cancer patient with dyspnea.

In helping the cancer patient to adjust and adapt to chronic illness, goal-directed nursing activities can be formulated. People need to find meaning in their illness, and a "...human-to-human relationship between patient and nurse can assist in this process" (Garant, 1980, p. 2167). A therapeutic relationship, based on trust, the patient's agenda (not the nurse's), and a focus on the present can be of great value. Dealing with physical and psychological problems, and participation in care planning and decision making, can pose problems for the lung cancer patient with dyspnea who is working hard just to breathe. The need for an organized, systematic framework is of paramount importance for the nurse. Regular evaluation of the patient's quality of life, with time spent on adjusting to changes produced by the illness can guide in planning care.

Utilization of the information provided on chronic illness, cancer as a chronic disease, and a suggested framework can assist the nurse in determining what information the patient and family need to cope effectively with the illness. Priorities can then be determined, mutual goals set, and a plan of action can be implemented. With a focus on the patient and family, the nurse can then provide comprehensive nursing care as the patient and family work to cope with all that has, is and will happen.

Chapter 3

Methodology

Research Design

The research design for this longitudinal study was descriptive and correlational. A convenience sample of 30 lung cancer patients was interviewed twice over an eight week period. This design and sample selection method permitted provision of the description of dyspnea over time, since little prior knowledge of the symptom existed (Brink & Wood, 1978). A correlational design permitted a description about beginning relationships among variables rather than determination about a cause and effect relationship.

Definition of Terms

Dyspnea. The sensation of dyspnea is subjective and includes both the perception of labored breathing by the patient and the reaction to that sensation (Comroe, 1966, 1977).

Lung Cancer Patient. A person seeking medical and nursing care for a histologically established diagnosis of lung cancer.

Sampling Plan

Nature and Size

A convenience sample of 30 adult subjects, 17 male and 13 female, diagnosed with lung cancer and who had the complaint of shortness of breath, was obtained from four medical oncologists in private practice in a large urban metropolitan area and by referral from the medical oncology clinic in a nearby Veterans Administration Hospital.

Subject selection and data collection took place over a one year period.

The physicians informed the investigator of potential subjects and times of office appointments. Potential subjects were approached and interviewed by the investigator to determine eligibility and willingness to participate.

Human Subjects Assurance

Medical approval for access to office and Veterans Administration patients was granted in response to a letter of request sent by the investigator to the participating physicians (see Appendix C). The study protocol was reviewed and accepted by committees for Human Research at the University of California, San Francisco, and the Veterans Administration Hospital and Medical Center, Palo Alto, and the private practice physicians.

Each subject signed a Consent Form (see Appendix D) after being invited to participate and reviewing an "Explanation of Consent" form (see Appendix E) and the "Experimental Subject's Bill of Rights" (see Appendix F).

Code numbers were used on all data collection forms with names used only on informed consent forms. Code sheets were kept locked in the office of the investigator.

All patients who were approached agreed to participate in the study and met specified criteria prior to participation.

Criteria for Sample Selection

Criteria for the sample selection required that all patients:

a. Have a histologically confirmed diagnosis of lung cancer (histologies to include squamous or epidermoid carcinoma, large cell anaplastic carcinoma, small cell anaplastic carcinoma or oat cell carcinoma, adenocarcinoma).

b. Be experiencing dyspnea in the course of the lung cancer disease process. This was confirmed by patient and physician when the patient was approached to participate in the study.

c. Be oriented to time, person and place.

d. Be able to read and write the English language.

e. Have given informed consent.

f. Be 18 years or older.

Research Setting

Interviews were conducted either in an acute care hospital, the physician's office or in patient's homes. All patients resided in the Santa Clara Valley, and careful provision for privacy was made at the time of the interview. Efforts were made by the interviewer to provide a relaxed, unhurried environment and not to interfere with hospital, office or at-home routines.

Procedure

Following referral and subject consent to participate in the study, subjects were interviewed at Time 1 using the selected instruments, i.e., Dyspnea Interview Schedule, Dyspnea Descriptive Scale, and the American Thoracic Society Respiratory Disease Questionnaire. The interview lasted from 45 minutes to one and one-half hours depending upon the subject. The interviewer then assigned the patient an activity level score based on the Karnofsky Performance Scale, and verified this score with the patient's physician. Data regarding tissue cell type, classification, stage of disease, chemotherapy and radiation was collected from the patient's medical record.

Eight weeks following the initial interview, at Time 2, the subjects were contacted by the interviewer, either by phone or at the physician's office, and a meeting was scheduled. During the second interview, subjects were again asked questions regarding their perception of dyspnea utilizing selected instruments, i.e., Dyspnea Descriptive Scale, and the Five Level Breathlessness Scale from the American Thoracic Society Respiratory Disease Questionnaire. This interview lasted from ten to fifteen minutes. A second Karnofsky score was obtained utilizing the same procedure as in Time 1.

Instruments

Four data collection tools were used to obtain information regarding the dyspnea experience from the subjects.

The Respiratory Disease Questionnaire for Use With Adults and Children in Epidemiological Research (ATS Questionnaire) published by the American Thoracic Society was used to collect demographic and health history data (see Appendix G). Smoking histories, concurrent chest illnesses and respiratory symptoms are examples of information obtained from this questionnaire. Also included is the Grade of Breathlessness Scale, a five level scale of breathlessness which was used to measure functional disability resulting from shortness of breath. Additional information regarding insurance, chemotherapy, radiation therapy, tissue diagnosis, and stage of disease at diagnosis was added by the investigator.

The second instrument used was the Dyspnea Interview Schedule (see Appendix H). This semi-structured open-ended questionnaire was developed by Carrieri and Janson-Bjerklie (1983) and has been used in a large dyspnea study involving patients with asthma, COPD, and vascular disease. This instrument obtained information related to physical, environmental, emotional and social variables related to living with dyspnea. Examples of questions were: "Tell me about the last time you were short of breath. If you couldn't tell anybody you were short of breath, how would they know? What helps your shortness of breath go away? How does your shortness of breath affect your family? Have you ever had any classes or learned about your shortness of breath? Have you noticed any changes in your concentration and memory during your illness?"

The Dyspnea Visual Analogue Scale (DVAS) is a visual analogue scale developed by Carrieri and Janson-Bjerklie (1983) from those previously used to measure pain intensity (see Appendix I). This instrument is actually two visual analogue scales designed to measure the worst and usual breathlessness the subject experiences. It consists of two ten centimeter lines on a piece of paper marked in equal increments of 10 from zero to 100. At the extreme left are the words "No difficulty breathing"; at the center are the words "Moderate difficulty breathing"; and at the extreme right are the words "Unable to breathe." Subjects marked the numerical equivalent on the lines according to their perception of their worst and their usual dyspnea experienced.

The visual analogue scale as a measurement of sensations has been tested for validity in several pain evaluation studies. It was found to be accurate and valid and representative of the pain experience (Joyce, Zutshi, Hrubes, & Mason, 1975; Reville, 1983).

Carrieri and Janson-Bjerklie have found concurrent validity with the visual analogue scale and grade of breathlessness scale in their dyspnea study with pulmonary patients (1983).

The Karnofsky Performance Scale (KPS) was designed to measure patient activity and medical care requirements (Karnofsky, 1952). It has been used extensively to measure patient independence and generally assess cancer patients (see Appendix J). It was tested for reliability and validity and has been shown to be a "...global indicator of the functional status of patients with cancer..." (Yates, Chalmer, & McKegney, 1980, p. 2220). It is conceivable that this scale could be used to document functional status in patients with other chronic illnesses.

Limitations

Initially, a sample of lung cancer patients without other complicating illnesses were sought. Shortly after the data collection period had begun, it became clear that this would not be feasible. Several subjects reported concurrent pulmonary disease, making a pure lung cancer population impossible to obtain.

Other limitations were reflective of the study design. No control group was utilized, and patients were not randomly assigned. Since the study was retrospective in nature, patient recall was vital, and there was no available mechanism to accurately validate what was actually communicated by the patient.

Data Analysis

To analyze data, the t-test and Spearman correlation coefficient were used. The t-test analyzed matched scores at Time 1 and Time 2 from the Grade of Breathlessness Scale, Karnofsky Performance Scale, and the Dyspnea Visual Analogue Scale. The Spearman correlation coefficient measured relationships between variables using these same instruments. Frequency distributions for descriptive data were also obtained. Thematic analysis of the interviews completed the data analysis.

Chapter 4

Results

Sample Characteristics

Extensive demographic data was obtained from the 30 patients inteviewed at Time 1. In the eight week interval between Time 1 and Time 2, two patients expired, leaving a sample of 28 at Time 2.

Seventeen males and thirteen females were interviewed at Time 1 and fifteen males and thirteen females were interviewed at Time 2. At Time 1, 18 interviews were conducted in the physicians' offices, 11 in the patients' homes, and one in the hospital. At Time 2, 24 patients were seen in the physicians' offices and four were seen in the hospital. At the time of the initial interview, 28 were undergoing chemotherapy, and 17 had received radiation therapy.

In Table 2, specific information regarding age, sex, race, education, marital status, income and income source, and employment status is summarized. The mean age was 62.97 years, with a standard deviation of 7.17. The mean age and male to female ratio are representative of the national statistics available for lung cancer (Silverberg, 1984). All subjects were Caucasian, and the majority were Protestant and Catholic. The mean educational level of this sample (12.4 years in school), as well as the average income was moderately high. The living situations of the subjects revealed that all but two lived with spouse or spouse and other family. Twenty-seven subjects were retired demonstrating that many were past retirement age, and

Table 2

Characteristics of Subjects (N=30)

Characteristic		N	Percent
Age (years)	46-74		
Sex	Male	17	56.6
	Female	13	43.3
Years in School	8-18		
Marital Status	Married	28	93.3
	Widowed	1	3.3
	Single	1	3.3
Religion	Protestant	19	63.3
	Catholic	9	30.0
	Jewish	1	3.3
Living Situation	Alone	2	6.7
	With Spouse	23	76.6
	With Spouse and Family	5	16.6
Employment Status	Temporarily Unemployed	2	6.7
	Retired	27	90.0
	Other	1	3.3
Current Average Income	<$8,000	1	3.3
	<$15,000	1	3.3
	<$22,000	12	40.0
	<$29,000	5	16.6
	<$30,000 or greater	8	26.6
Income Source	Job by self or spouse	8	26.6
	Disability	2	6.7
	Social Security, Retirement, Investments	20	66.7

others either retired early or were medically retired.

Smoking histories were obtained and revealed extensive cigarette abuse (Table 3). Twenty-five patients had smoking histories, with nine still smoking at Time 1. Pack year histories ranged from 29 to 144, with a mean of 60.37, and a standard deviation of 36.27. Two patients were pipe smokers and one patient smoked cigars.

Lung cancer diagnoses included oat cell carcinoma, large cell carcinoma, adenocarcinoma, squamous cell carcinoma and mesothelioma. Although mesothelioma was not included in the original categories of lung cancers to be studied, two patients reported significant dyspnea as a result of this diagnosis, and were therefore included in the sample. Mesothelioma is a rare disease, and is seen in .2% of all lung cancer patients (Livingston, 1982). It has been noted more frequently, however, since patients exposed to asbestos in the 1940's are now manifesting the disease as they reach their seventh decade. The two patients in the sample had many similar characteristics. Both were exposed to asbestos during World War II, both were non-smokers, and both had presented at diagnosis with dyspnea related to pleural effusion.

Of the 20 patients with oat cell carcinoma, 19 were staged with extensive disease, and one with limited disease. All other patients were staged with Stage III disease. Frequencies of the malignant diagnoses can be seen in Table 3. The majority of the sample were also suffering from other pulmonary diseases and those that they reported were most troublesome to them are included in Table 3.

Patients reported extensive pulmonary symptomatology including

Table 3

Smoking Histories, Lung Cancer Data,
Other Pulmonary Data (N=30)

Characteristic		N	Percent
Smoking History			
Smokers		25	83.3
Smokers at Time 1		9	30.0
Pack Years	29-144		
Age Started Smoking	12-25		
Age Stopped Smoking	50-74		
Inhaled Smoke from Cigarettes	No	1	3.3
	Moderately	14	46.7
	Deeply	10	33.3
Pipe Smokers		2	6.7
Cigar Smokers		1	3.3
Lung Cancer Diagnosis			
Oat Cell		20	66.7
Large Cell		2	6.7
Adenocarcinoma		2	6.7
Squamous Cell		4	13.3
Mesothelioma		2	6.7
Lung Cancer Staging			
Oat Cell			
Extensive		19	63.3
Limited		1	3.3
All Others			
Stage III		10	33.3
Other Pulmonary Diagnoses			
Pneumonia		22	73.3
Emphysema		18	60.6
Bronchitis		16	53.3
Chronic Bronchitis		10	33.3
Allergies		10	33.3
Asthma		7	23.3
Pulmonary Disease Most Troublesome at Time 1			
Emphysema		13	43.3
Chronic Bronchitis		6	20.0
Lung Cancer		6	20.0
Asthma		3	10.0
COPD		1	3.3

Table 3 (continued)

Characteristic	N	Percent
Other Pulmonary Symptomatology		
Cough	24	80.0
Mucous	13	43.3
Wheeze		
With Cold	13	43.3
Without Cold	13	43.3
Pulmonary Medicines Used		
Steroids		
Oral	12	40.0
Inhaled	2	6.7
Bronchodilators	8	26.6
Home Oxygen		
Continuous	6	20.0
Intermitant	5	16.6
Dust and Chemical Exposure		
Dusty Job Greater Than One Year	13	43.3
Chemical Exposure	6	20.0

cough, wheeze, and mucous production. Twenty-four (80%) had cough, 13 (43.3%) reported mucous production, 13 (43.3%) had wheezing with a cold and 13 (43.3%) reported wheezing without a cold. Medications used for pulmonary symptoms were steroids, bronchodilators and oxygen. Twelve patients reported using steroids, eight used bronchodilators and 11 used oxygen, either intermittantly or continuously. It is not known if the steroids prescribed were part of a chemotherapy regimen or for other pulmonary disease. The use of bronchodilators and home oxygen by eight and 11 patients respectively, further indicates the need for specific interventions for a large number of patients in the sample.

It is interesting to note that 63.3% of the patients had occupational exposures to dust and chemicals. Thirteen patients had worked in a dusty job for greater than one year. Two reported mild dust exposure, eight had moderate dust exposure, and three believed they had severe dust exposure. Six patients had been exposed to chemicals in a variety of settings. One had mild exposure, four moderate exposure, and one severe exposure.

Severity of Dyspnea and Activity Level

At Time 1, 93.3% of the subjects had grades of breathlessness of 3, 4, and 5 as rated by the ATS Grade of Breathlessness Scale. At Time 2, 80% had similar scores, indicating severe dyspnea for this sample. The mean grade of breathlessness for the total sample at Time 1 was 3.64, and the mean at Time 2 was 3.50 (Table 4). Almost 37% of the sample (36.7%) had to stop for breath when walking on the level at their own pace, while 23.3% were too breathless to leave

Table 4

Frequency of Subjects in
Each Grade of Breathlessness for
Time 1 and Time 2

Grade	T_1 n=30	T_2 n=28
0 = No shortness of breath	0	0
1 = Shortness of breath hurrying on the level or walking up a slight hill	1 (3.3%)	3 (10.0%)
2 = Walk slower than others of the same age on the level because of breathlessness	1 (3.3%)	1 (3.3%)
3 = Stop for breath when walking on the level at own pace	11 (36.7%)	9 (30.0)
4 = Stop for breath after walking about 100 yards (or after a few minutes) on the level	10 (33.3%)	9 (30.0%)
5 = Too breathless to leave the house or breathless when dressing	7 (23.3%)	6 (20.0%)

their own house. There was no significant difference between Time 1 and Time 2 in the Grade of Breathlessness Scale (T=.89 N.S. Table 5).

The mean usual dyspnea score on the DVAS was 39.54 at Time 1 and 40.71 at Time 2 (T=.65 N.S.). The mean worst dyspnea score was 76.43 at Time 1 and 78.93 at Time 2. Although there was a slight increase in dyspnea from Time 1 to Time 2, this increase was not statistically significant.

The Karnofsky Index at Time 1 was 78.57 and 63.92 at Time 2. This difference was statistically significant at the .001 level of significance (T=3.55). This decrease demonstrates a significant decline in activity level for this sample from Time 1 to Time 2.

Relationships Between Dyspnea and Activity Scales

The Spearman correlation coefficient was used to answer the research question of whether there was a relationship between the two activity scales (Karnofsky and Grade of Breathlessness). As expected and listed in Table 6, there was a significant moderate correlation between these two scales (T_1=r=.59, p=.001; T_2=r=.56; p=.002). There was a strong correlation between the two instruments used to measure dyspnea, the Grade of Breathlessness Scale and the Dyspnea Visual Analogue Scale at Time 1 (worst dyspnea r=.71, p=.001; usual dyspnea r=.73, p=.001). Although significant, this correlation was only moderate at Time 2 (worst dyspnea r=.55, p=.002; usual dyspnea r=.56, p=.002).

In this sample, there was a moderate relationship between the Karnofsky Performance Scale, a measure of activity, and perceived level of shortness of breath. At Time 1, the Karnofsky Performance

Table 5

T test for the Five Level Grade of Breathlessness Scale, Karnofsky Performance Scale, and the Dyspnea Visual Analogue Scale

	Mean	S.D.	Mean (Difference)	Standard Deviation	T Value	2-Tail Probability
Grade of Breathlessness	T_1 3.64	.99	.14	.85	.89	.38
	T_2 3.50	1.2				
Karnofsky	T_1 68.57	9.71	4.64	6.93	3.55	.001
	T_2 63.92	10.66				
Dyspnea Worst	T_1 76.43	17.04	2.50	1.32	1.89	.070
	T_2 78.93	16.85				
Dyspnea Usual	T_1 39.54	18.16	1.18	9.60	.65	.522
	T_2 40.71	18.24				

Scale was moderately correlated with both usual (r=.48, p=.007) and worst dyspnea (5=.50, p=.005). At Time 2, these moderate correlations were still evident (usual-r=.41, p=.03; worst-r=.52, p=.004). The correlation coefficients can be seen summarized in Table 6.

Analysis of Interviews

The interviews were thematically analyzed by the investigator. Descriptions about the sensation, precipitating events, prodromal indicators, patterns of dyspnea, and behaviors others may observe during a dyspneic episode were categorized. Strategies for managing the dyspnea, patient education and effect on activities of daily living were identified.

The Sensation of Dyspnea

In actually describing the dyspnea sensation, all 30 subjects used the term "short of breath." Ninety-seven percent (n=29) of them also used the words "difficulty breathing," "hard to move air," and "tired or fatigue" as descriptors for their dyspnea. Sixty-three percent (n=19) identified not getting enough air or a feeling of suffocation as the most appropriate description for their dyspnea. It is interesting to note that only 47% (n=14) used the word "tightness" and 7% (n-2), used the words "filling up or drowning" to describe their shortness of breath.

The chest in general was described by 96.7% (n=29) as the location for their sensation. Other physical sensations noted were poor concentration (n=26), loss of appetite (n=22), loss of memory (n=13), smothering (n=6), sweating (n=5). Patients also described emotions felt during the dyspneic episodes with the terms anger, helplessness,

Table 6

Spearman Correlation Coefficients

	Time 1		Time 2	
	r	p	r	p
Karnofsky with Grade of Breathlessness	.59	.001	.56	.002
Karnofsky with Ususal Dyspnea	.48	.007	.41	.03
Karnofsky with Worst Dyspnea	.50	.005	.52	.004
Grade of Breathlessness with Worst Dyspnea	.71	.001	.55	.002
Grade of Breathlessness with Usual Dyspnea	.73	.001	.56	.002
Dyspnea Usual with Dyspnea Worst	.77	.001	.65	.001

depression, loss of strength, agitation, anxiety, nervousness and fear.

In discussing his dyspnea, one man stated: "The shortness of breath never goes away. It is not always bothersome, but it is always waiting for me. It is a big problem both psychologically and physically. It is a very discouraging aspect of this disease--the sharpest reminder of mortality."

For one woman, her shortness of breath was the first symptom of her lung cancer. At the time of the interview she stated that she had dyspnea with any activity, and that she no longer liked being alone, which had previously been a pleasant experience. She had previously been very active and independent, and was now dependent on family for most of her needs. In describing how her body felt during a dyspneic event, she stated: "My body feels very tired, and I know I must slow down. I don't like feeling tired, and I know I don't like being short of breath. It's very limiting."

Precipitants and Prodromal Indicators

Physical Precipitants

Physical activities were frequent precipitating factors for the subjects. Many stated that any physical activity caused dyspnea. Mechanical behaviors such as crying, laughing and smoking were also mentioned as triggering shortness of breath. Environment contributed to the dyspnea, and patients mentioned wind, bad weather, pollens in the air, crowded places and smoke as causing dyspnea.

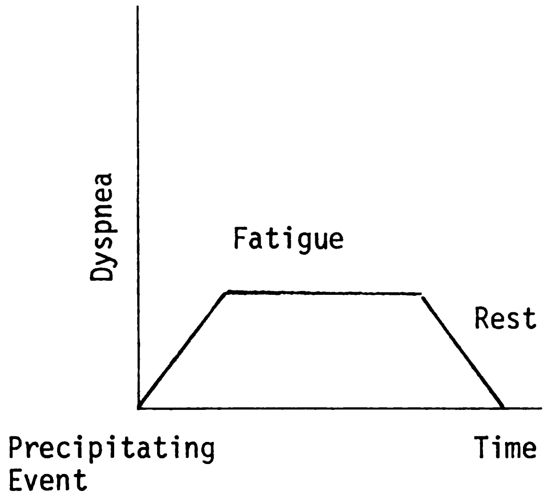
Emotional Responses as Precipitants

The emotional component of the dyspnea experience in this sample can also be seen in the responses given to interview questions about precipitants causing shortness of breath.

Subjects described stress about not being able to work, frustration about their overall situation and anything causing excitement as precipitants causing dyspnea. One subject stated he became short of breath when thinking about the death of his son, which had occurred the previous year. Minor disagreements with spouses, anxieties caused by family and friends and concerns about the future were also described as precipitating shortness of breath. Several subjects discussed some fear about the extent of the tumor, its location, and their inability to change its course as causing some dyspnea.

Patterns

Subjects reported specific patterns and durations for the dyspnea. Thirteen (43.3%) stated that an episode lasted less than ten minutes, 13 also reported episodes lasting less than 30 minutes. Two (6.7%) reported variable time limits and two had episodes lasting several hours. Although the length of the dyspnea pattern varied, the picture was relatively consistent. Patients described the precipitating event (either emotional or physical), a gradual increase in dyspnea, a plateau (during which time most patients experienced fatigue), and a subsiding of the dyspnea following rest. Figure 4 visually describes the dyspnea pattern.



Duration of Episode

Less than 10 minutes	n=13 (43.3%)
Less than 30 minutes	n=13 (43.3%)
Variable	n= 4 (13.3%)

Figure 4: The Dyspnea Pattern

Behaviors Others Would Observe

The most frequent behaviors patients described that others would observe were resting more (100%), slower in activity (97%), loss of appetite (74%), hard breathing (57%), rapid breathing (53%). Those behaviors that would seem more common in pulmonary patients, such as wheezing (20%), coughing (10%), pursed lip breathing (3%) were not identified as frequently by this sample of patients. Only 10% of the subjects said they did not think others would notice their shortness of breath (Table 7).

Table 7

Behaviors Others Would Observe (N=30)

Behavior	N	Percent
Rest More	30	100
Slower in Activity	29	96.7
Loss of Appetite	22	73.7
Hard Breathing, Heavy Panting	17	53.3
Rapid Breathing	16	53.3

These behaviors were of concern to several patients who felt that others should not be subjected to the distresses and problems of their disease. Several subjects stated that they did not want to burden others, and that their shortness of breath was another symptom they felt they must cope with by themselves.

Strategies for Managing Dyspnea

A total of 70 strategies were described by this sample of lung cancer patients. The number of strategies used by an individual patient ranged from seven to 26 with the mean being 13.53. Little gender difference was seen in mean numbers of strategies used, with males using a slightly higher number of strategies (13.82) than females (13.15).

The strategies were categorized into short-term physical strategies used to manage an acute dyspneic episode and long-term lifestyle changes. A miscellaneous category of "other behaviors" can also be listed as those used in long-term planning, and these were used by only a few patients.

The most frequent short term strategies for acute shortness of breath were changes in position and activity, including lying down (60%), moving slower (43%), changes in position (47%).

The majority of strategies were long-term changes in activities of daily living, lifestyle or attitude. Almost all of these subjects (97%) stated they had decreased or modified their activities because of their shortness of breath. This modification included advanced planning of activities and change in time of activities.

Most subjects had transferred activities of daily living or required assistance from family, friends or hired help. Changes in activities of daily living included changes in bathing (73.3%), eating (66.7%), dressing and grooming (56.7%). Twenty percent of the subjects used breathing strategies with activities to decrease shortness of breath. Seven percent described home remedies and 14% stated they avoided precipitants. All strategies are summarized in Table 8.

In describing emotional strategies used to cope with their dyspnea, patients generally tried to be positive (50%) and accept the situation (76%). Fifty-three percent avoided being alone, and 80% responded that they had socially isolated themselves from friends and outside contacts. Spouse and family were generally those with whom the patient spent time.

In discussing his dyspnea, one man reflected that although his shortness of breath was limiting, he had learned to live with it. He believed it was actually somewhat better since beginning chemotherapy a few months prior to the interview. He also believed that his shortness

Table 8

Strategies Exhibited to Cope With Dyspnea

Strategy	N	Percent
I. Long Term Strategies		
A. Activities of Daily Living		
1. Assistance or transfer of ADL's to family, friends, hired help	22	73.3
2. Changes in bathing	22	73.3
3. Changes in eating	20	66.7
4. Changes in dressing, grooming	17	56.7
5. Living arrangement change	2	6.7
B. General Activities		
1. Advanced planning of activities	29	97.6
2. Change in time of activities	29	97.6
3. Planned decrease or modified activities	29	97.6
C. Other Behaviors		
1. Breathing strategies (pattern with activities)	6	20.0
2. Avoid precipitants	5	16.7
3. Home remedies	2	6.7
4. Increased exercise	2	6.7
5. Increased ventilation (taking deep breaths)	2	6.7
6. Diversional activities	1	3.3
7. Protective behaviors	1	3.3
8. Relaxation techniques	1	3.3
D. Social Isolation	24	80.0
E. Emotional Strategies		
1. Accepts situation	23	76.6
2. Avoids being alone	16	53.3
3. Good attitude, stay in good frame of mind	15	50.0
4. Prayer, meditation	7	23.3
5. Doesn't think about it	4	13.3
6. Eliminates stress	3	10.0
7. Conscious attempt to be calm	2	6.7
8. Affection from families	1	3.3

Table 8 (continued)

Strategy	N	Percent
II. Short Term Strategies		
A. Physical Strategies	18	60.0
2. Positioning	14	46.7
3. Move slower	13	43.3
4. Use of an inhaler	4	13.3
5. Posture	3	10.0
6. Medicines	2	6.7
7. Pursed lip breathing	2	6.7

of breath and general debilitation made his life more difficult and it was harder to do things for himself. This same patient stated that talking about his shortness of breath made it easier for him to cope with it. He believed that although his wife and daughter were nervous and uncomfortable about it, they were also tired of discussing it. He hoped they would try to understand why he needed to talk about it, both for himself and for them.

A well-educated patient described himself as having more shortness of breath when anxious. In his words he said, "I find myself becoming aggravated in situations that would have never bothered me before. I become angry more quickly which increases the shortness of breath, and then I have to make a conscious effort to relax. I guess you could say I have flahses of temper, and I've asked my family and friends to be aware that this is going on, and that sometimes I get short of breath."

A woman, newly diagnosed with lung cancer, remarked "I became more short of breath after learning about my diagnosis. I guess it's fear and I try to talk to myself to relax. I try to cover it up, but my family knows. I just look for a place to sit when I feel myself getting short of breath." This patient described herself as previously very sedentary. She stated that although she had been inactive previously, she didn't like the fact that now her inactivity was forced.

Patient Education

When asked what they had been taught about their shortness of breath, or who had taught them, only 10% of the patients had received any education by health professionals. These three subjects had attended a formal class in a pulmonary rehabilitation program. All of the other subjects denied receiving any information about their shortness of breath and stated that what strategies they had learned to cope with the dyspnea were self-taught.

No patient identified any useful strategies that had been taught by nurses, clearly demonstrating the need for improved nursing interventions in this area. This data is summarized in Table 9.

Table 9

Patient Education

Source of Education	N	Percent
Taught self	17	56.6
Taught by M.D.	3	10.0
Taught by other health professionals in formal class	3	10.0
Taught by R.N.	0	00.0

Chapter 5

Discussion

The findings of this study demonstrate that dyspnea is a significant problem for some patients with lung cancer. The results of this study should provide empirical information that can be added to the existing body of knowledge about the nature of the lung cancer patient's experience with dyspnea. The results also show that the severity of dyspnea for patients in the study was considerable.

The Sensation of Dyspnea

In answering questions about the nature of dyspnea, some similarities were evident. These similarities involved specific terms used by patients to describe their dyspnea. Patients used the terms "difficulty breathing" and "shortness of breath". Since fatigue was named as a descriptor by 97% of the patients, it may be construed as synonymous with dyspnea among patients with lung cancer. Patients might have been unable to clearly separate the fatigue from breathing from dyspnea as a sensation.

The answers to questions related to physical activity and precipitants to the dyspnea revealed many concerns. Since physical activity was a common precipitant to the dyspnea experienced by these patients, the consistent pattern of slow onset, plateau and gradual reduction in dyspnea becomes significant. The need to rest more and the changes needed to deal with activities of daily living and activities in general demonstrate extensive alterations in lifestyle.

The Karnofsky and Grade of Breathlessness scores verify the decreases in activity levels experienced by the subjects.

Poor concentration, loss of memory and loss of appetite were related physical sensations described frequently in this sample. Though loss of appetite is common to cancer patients, it is not known if this was due to the symptom of dyspnea or to the disease process itself. Poor concentration and loss of memory were unexpected responses from the study subjects. Patients voiced concern about these phenomena, and it is possible that they are in some way connected to the loss of control issue frequently discussed by cancer patients (Marino, 1980). Lack of control in cancer patients has been discussed within the context of choices about the course of disease, type of treatment and impact on patient and family (Marino, 1980). Perhaps patients feel little control over their symptoms, further intensifying the symptoms and adding to patient distress. The chronicity of the disease, and the necessary lifestyle alterations may influence patients to view these problems as indicative of advanced disease unmanageable by health care providers.

Several emotional precipitants were described by the study subjects. These precipitants are difficult to evaluate from the information given by the sample since detailed questions were not asked about specific emotional responses described by subjects. It is clear, however, that most any emotional disturbance would cause some dyspnea.

The patients were concerned about the effect of their disability on others. The need to try to deal with the symptoms of their disease without involving others was obvious to the investigator. General debilitation made this self sufficient mode of behavior even more difficult for several subjects.

The lack of patient education exhibited from the sample was shocking. Not one patient reported nursing input into managing their dyspnea and only three reported help from a physician or respiratory therapist. Similar findings about the lack of patient education were reported by Dodd in a study assessing patient self-care behaviors for side effects of cancer chemotherapy (1982). The findings from both studies represent patient education as an area needing emphasis by all nurses. In the present study, it is not known how many of the COPD patients were approached about pulmonary rehabilitation and neglected to participate prior to the lung cancer diagnosis, but this would have been interesting to ask.

Relationship of Findings to Conceptual Framework

In conceptualizing the data, problems discussed by the patients in the sample can be related to the underlying framework used for the study. These subjects clearly fit the criteria for chronic illness described by Strauss and Glaser (1975) and MacVicar and Archbold (1976).

Most patients had other chronic illnesses, and in discussing what was happening to them, the themes of loss, change and response to being ill were common.

The data reinforced the concepts in Figures 1 and 2. Patients experienced acute episodes of illness from complications of disease and treatment. Occasionally, these exacerbations resulted in hospitalization. Adjustment to long term medical and nursing interventions was reinforced by the need for ongoing treatment usually aimed at disease palliation or efforts to change the course of the disease and the status of the dyspnea.

The phenomenon of social isolation was clearly described by the study subjects. Patients expressed little interest in socialization due to fatigue and decreased energy. This is of concern, since spouse and family members have expressed their need for social support during the illness of a loved one. The social stigma of cancer and the nature of its societal unacceptability must also be considered when discussing social isolation.

The chronic illness trajectories described by Strauss and Glaser (1975) are also seen in the study population. When asked to describe the course of their illness, patients were aware of a general downward course and occasional plateaus. The dyspnea pattern most commonly described is also a type of trajectory that could be superimposed upon the illness trajectory.

The study subjects had developed strategies to manage activities altered by their dyspnea. These strategies can be related to the physical and psychological "work" done by the chronically ill described by Strauss, Fagerhaugh, Siczek and Weiner (1975). Patients described both physical and psychological adaptations to their illness and also discussed the helping efforts of family and friends. It is not known how many people were mobilized to support the ill person. The "work" done by these people should also be considered in the development of strategies necessary to provide care for the patient.

From this discussion, it is appropriate to suggest that the chronic illness framework can aid in organizing the data presented by these subjects. Following this organization, priorities for interventions can be determined based on strategies for each physical and psychological problem identified in the framework. These strategies could then be utilized as interventions for other dyspnea patients in order of their efficacy.

Suggestions for Further Research

In reviewing the data from this study, several questions for future research can be posed. The eight week period during which dyspnea was measured in lung cancer patients could be changed to yield more significant information. Conceivably, patients could be studied for several months beginning with diagnosis. This type of control over Time 1 may provide more complete data about the lung cancer patient's dyspnea experience, and more information about the sensitivity of the instruments to detect change over time. Further research into the commonly identified areas of social isolation, fatigue loss of concentration and memory, and the effect of energy conservation on dyspnea is indicated from this study.

Sample. Some characteristics of the lung cancer patients in this study are noteworthy. The high incidence of oat cell cancer did not correlate with the national statistics for this particular disease. This raises several questions. Do oat cell cancer patients experience more dyspnea than lung cancer patients with other cell types? Because of the nature of oat cell cancer and the advanced disease status at presentation, are these patients more likely to experience a greater degree of dyspnea? Do these patients have a higher incidence of pre-existing pulmonary disease also causing dyspnea? Is there any relationship between cigarette smoking in oat cell cancer patients and dyspnea perception?

The high numbers of women in the study example clearly demonstrate the evidence for increased rates of lung cancer in females. Smoking became acceptable for women in the 1940's, and this can be correlated with the 20 to 30 year period seen between onset of smoking and onset of disease. This suggests that more research is needed to specifically study dyspnea in women with lung cancer.

Implications for Nursing

The information obtained from this study about the perception of dyspnea in a sample of lung cancer patients provides baseline information from a select group of subjects. The documented trends in the dyspneic event as well as statistical realtionships between a visual analogue and two activity scales were accomplished, and demonstrate that dyspnea experienced by the patients in this sample was a significant problem.

Instruments. The information obtained from the ATS Respiratory Disease Questionnaire was useful to obtain an overview of concerns and symptoms expressed by these patients. The Dyspnea Interview Schedule can be used to obtain specific information about the description of dyspnea. Though lengthy, both of these tools provided the investigator with valuable data.

Although correlations were moderate, the Dyspnea Visual Analogue Scale (DVAS), the Grade of Breathlessness Scale (from the ATS Questionnaire) and the Karnofsky Performance Scale (KPS) can be used in the clinical area to assess the level of dyspnea across time and evaluate the corresponding activity level. The Grade of Breathlessness Scale and KPS both measure activity, with the Grade of Breathlessness Scale more specifically measuring dyspnea. Since these two scales are significantly correlated, clinical applicability is clear. From this information, the conclusion may be drawn that dyspnea is related to activity level in this sample. This relationship was also verified by subjects in information obtained from the ATS Questionnaire and the Dyspnea Interview Schedule.

Although the KPS scores significantly decreased during the eight week study period, the dyspnea as measured by the DVAS and Grade of Breathlessness Scale did not change significantly. It is not known if a decreased KPS score indicates less activity and therefore less dyspnea. In considering the KPS, two questions may be asked: (1) Are subjects less active in order to prevent increased dyspnea or are they physically unable to be more active and therefore less dyspneic? (2) Does the patient's perception of the Karnofsky score correlate with the investigator's perception?

These instruments can all be used in any clinical setting to aid nurses in determining the nature of this subjective concept which profoundly affects the quality of life of many patients. The use of these instruments could enable nursing to deal more effectively with the complex symptomatology expressed by patients.

The Setting, Patient Education and Screening. Certainly the ambulatory care setting is an ideal place to collect and record data about specific symptoms identified by patients. Methods of communicating this information to all care providers, in addition to intervention implementation and evaluation can also be done in the ambulatory-outpatient areas.

The issue of providing appropriate teaching for patients with advanced disease must also be considered. Given the poor performance of all care providers in this area, there could be concern about discrimination against those with shortened life expectancies. Appropriate teaching to alleviate symptomatology is generally considered central to nursing, and it is nursing's responsibility to explore the entire area of patient education to determine what is being taught to patients about their disease and treatment. It is also important to verify what the patient knows and what the patient is able to practice.

Nursing's role in screening and detection are very clear in this study. More than disease prevention, identifying those patients at risk for problems related to their disease is certainly a nursing function. The DVAS, KPS and Grade of Breathlessness Scale can all be used clinically to aid in detecting the level of dyspnea a patient may experience. The information obtained can then lead to appropriate nursing interventions based on sound evidence of the subjective symptom of dyspnea.

The lung cancer patient experiencing dyspnea represents a unique challenge to the cancer nurse. Dealing with patients with advanced disease and debilitating symptoms can be rewarding for the nurse in clinical practice if appropriate assessment tools and practical interventions are available.

Nurses can provide research questions and design interventions to aid in alleviating the lung cancer patient's dyspnea. These interventions can then be tested for efficacy. The information from this study should aid in these efforts and provide some improvement in patient care.

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Appendix A

Outcome Standard for Cancer Nursing Practice

Ventilation

A. Standard

The client and family recognize factors that may impair ventilatory function and can intervene with measures that may enhance optimum ventilatory capacity.

B. Rationale

1. Impaired ventilatory function, e.g., effusions, obstruction, or pulmonary fibrosis, may be caused by the cancer therapy or disease.
2. Psychological factors may potentiate respiratory distress.
3. Ventilatory problems can be distressing and limiting factors to optimum life-style of the cancer patient.
4. Through environmental, mechanical and activity modifications, respiratory function can be enhanced.

C. Outcome Criteria

The client and family--

1. state plans for daily activity that demonstrate maximum conservation of energy.
2. list measures to reduce or modify pulmonary irritants from the environment, such as smoke, dry air, powders and aerosols.
3. describe the effect of environmental extremes on ventilatory function and oxygen utilization.
4. state effective measures to maintain a patent airway.
5. identify reasons for altered ventilation, such as decreased hemoglobin, infection, anxiety, effusion, and obstructed airway.
6. identify an appropriate plan of action should altered ventilation occur.
7. develop a plan for managing an altered airway.

Appendix B

Oncology Nursing Society
Clinical Practice Committee

Guidelines for Nursing Care of Patients with Altered Ventilation

ONS Standard X: The client and family recognize factors that may impair ventilatory function and can intervene with measures that may enhance optimum ventilatory capacity.

Topic: Gas exchange, impaired, related to disease/treatments

Written by: Andrea Krzysko, RN, MS; Salley Erdel, RN, MS; Mary Greiner, RN, BSN; Anita Lawrance, RN, BSN.
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Population at Risk: Patients who have tumors of the lung, mediastinum, neck or central nervous system tumors involving the respiratory center; received radiation therapy to chest or neck region; received chemotherapeutic agents with known pulmonary toxicities; pleural effusions, pneumonia, pulmonary emboli, concurrent chronic obstructive pulmonary disease or congestive heart failure; surgery which involves the head, neck trachea, chest or a portion of the lung; history of tuberculosis, lung infections or smoking; increased risk from occupational/environmental hazards; reduced hemoglobin.

Patient Problem	Expected Outcome	Nursing Management
LEVEL I		
Potential impaired gas exchange	(1) Patient demonstrates knowledge of risk factors and prevention of impaired gas exchange as evidenced by:	Assessment 1. Assess history of risk factors (e.g. infections, environmental exposure,

Appendix B (continued)

Patient Problem	Expected Outcome	Nursing Management
	- Identifies occupational/ environmental hazards - Identifies early signs and symptoms of impaired gas exchange - Designs plan for behavioral changes - Identifies strategies for optimal pulmonary health	radiation therapy to lung area, chemotherapy with pulmonary toxicity, concurrent respiratory disease, previous thoracic surgery) 2. Assess history of symptoms of respiratory difficulty (e.g. dyspnea, tachypnea, sputum production, hemoptysis, shoulder or arm pain, change in activity level, headache)
	(2) Patient maintains adequate pulmonary health as evidenced by one of the following (from the Karnofsky scale): - Normal; no complaint, no evidence of disease (10) - Able to carry on normal activity; minor signs or symptoms of disease (9) - Normal activity with effort, some signs or symptoms of disease (8)	3. Inspect ventilatory abilities (e.g. respiratory movements, quality and number, use of accessory muscles, anterior-posterior diameter, patency or airway via nares, fingertip clubbing, nail bed, skin and mucous membrane color, wasting, paresthesias and paralysis of arm and hand)
		4. Palpate chest region for abnormalities (e.g. crepitation, fremitus, nonsymmetrical chest expansion, deviation of trachea)
		5. Percuss chest region for density (e.g. consolidation, displacement of organs, other densities)
		6. Auscultate lung and airway regions (e.g. absent or diminished breath sounds, voice sounds, adventitious sounds)

Appendix B (continued)

Patient Problem	Expected Outcome	Nursing Management
		<u>Patient Teaching</u> 1. Signs and symptoms to report to health care team (e.g. increased sputum production, unusual shortness of breath, chest pain or tightness, change in sputum color, inability to maintain normal activity, blood sputum, persistent cough) 2. Relationship between environmental/occupational hazards and current physical status. 3. Function of the lungs (e.g. anatomy and physiology, purpose, specific alteration in their lung tissue) 4. Measures to maintain adequate ventilatory abilities (e.g. keep work area well ventilated, use of masks in areas of high pollution, pneumovax vaccine, avoidance of contact with people with upper respiratory infection, contraindication of smoking) 5. Availability of local resources (e.g. stop cmoking clinics, Lung Association, American Cancer Society, etc.)

Appendix B (continued)

Patient Problem	Expected Outcome	Nursing Management
LEVEL II		
Impaired gas exchange	(1) Patient demonstrates knowledge related to altered ventilation as evidenced by: - Verbalizes signs and symptoms of impaired gas exchange - Identifies factors that influence impairment/maintenance of gas exchange - Identifies potential sequelae/complications - Identifies relationship between psychological status and ventilatory abilities	Assessment (as in Level I) 1. Assess psychological and social status (e.g. coping style, support systems, patient outlook of present health and therapy and prognosis, social activities, reactions of significant others, financial situation, physical environment in which he/she lives) 2. Monitor results of diagnostic testing (e.g. arterial blood gases, complete blood count, electrolytes, cytology results, culture results, bacteriology results, biopsy results, pulmonary function studies, chest x-rays, scans) 3, Assess pain (e.g. intensity, duration, precipitation factors, relief measures, location)
	(2) Patient identifies/demonstrates measures to promote gas exchange as evidenced by: - Performs necessary treatments/procedures - Demonstrates proper knowledge/administration of medication and oxygen - Identifies signs and symptoms to report to health care team - States ways to conserve ventilatory abilities	Nursing Actions 1. Maintain an environmentally beneficial atmosphere (e.g. bed placement according to oxygen use, humdification, adequate ventilation) 2. Maintain optimum patient activity (e.g. encourage regular exercise/rest as tolerated)

Patient Problem	Expected Outcome	Nursing Management
	(3) Patient achieves/maintains adequate pulmonary health as evidenced by one of the following (from the Karnofsky scale): - Cares for self, unable to carry on normal activity or do active work (7) - Requires occasional assistance, but is able to care for more of own needs (6) - Requires considerable assistance and frequent medical care (5)	3. Maintain nutritional and hydration status (e.g. oxygen use with meals if necessary, two to three liters clear fluid per day unless contraindicated) 4. Administer medications and oxygen to enhance respiratory status (e.g. Brethine, Aminophylline, Aarane, Codeine, Romilar, Terpin Hydrate, Nasal Decongestants) 5. Assist in breathing and posturing techniques as appropriate (e.g. pursed lip breathing, forced abdominal breathing, percussion and vibration, postural drainage, effective coughing techniques) 6. Promote comfort (e.g. premedicate before physical activities, use of medications, of stimulators and of splinting techniques, posturing for comfort) 7. Decrease of stimuli in environment (e.g. anti-anxiety medications, relaxation techniques) 8. Referrals to other professionals (e.g. physical therapy, occupational therapy, social service, nutritional support)

Appendix B (continued)

Patient Problem	Expected Outcome	Nursing Management
		<u>Patient Teaching</u> (as in Level I) 1. Medications (e.g., name, purpose, dose, side effects, administration) 2. Oxygen (e.g. amount, safety techniques, dose related toxicities) 3. Measures to maintain optimal ventilatory abilities (e.g. oxygen sparing techniques as appropriate, necessity of rest periods, need for humidification) 4. Trach care if necessary 5. Signs and symptoms to report to health care team (e.g. increased fever, shortness of breath, increased sputum production, increased shortness of breath, chest pain or tightness, change in mental status) 6. Relaxation techniques (e.g. controlled breathing, diversion, use of imagery or similar methods, use of touch, massage) 7. Management of dyspneic episode 8. Relationship between ventilatory abilities and disease progression and prognosis based on MD revelations

Patient Problem	Expected Outcome	Nursing Management
LEVEL III		
Severe impaired gas exchange	(1) Patient/caregiver demonstrate knowledge related to severely altered ventilation, as evidenced by: - Identifies signs and symptoms to report to health care team - Identifies signs and symptoms of complications, sequelae - Identifies purpose and ramnifications of medical interventions (2) Patient/caregiver demonstrate measures to manage severly impaired ventilation, as evidenced by: - Performs necessary treatments/ procedures - Demonstrates proper knowledge/ administration of medication and oxygen - Verbalizes/demonstrates adequate nutrition and fluid intake - Identifies and demonstrates emergency treatments for management of acute ventilatory distress - Plans daily activities with attention to ways to conserve ventilatory abilities	<u>Assessment</u> (as in Levels I & II) 1. Inspect chest drainage system, if present (e.g. patency of tubes; drainage fluctuation, amount, color, consistency, character, odor; absence of air leak) 2. Note conditions associated with acute respiratory change (e.g. pulmonary emboli, mediastinal shift, chest pain, tension pneumothorax, increase of pulse, decrease blood pressure, shock, change in level of consciousness, pulmonary edema) <u>Nursing Actions</u> (as in Level II) 1. Monitor chest drainage system (e.g. keep tubes free of kinks and dependent loops, keep drainage system lower than patient, keep connections air tight, check insertion site, check every four hours for drainage amount and notify MD if volume greater than 200cc/hr or if dramatic change in fluid volume over short period of time, keep hemostats and occlusive dressing near patient)

Appendix B (continued)

Patient Problem	Expected Outcome	Nursing Management
	(3) Patient achieves/maintains pulmonary health as evidenced by one of the following (from the Karnofsky scale): - Disabled; requires special care and assistance (4) - Severely disabled; hospitalization is indicated, although death not imminent (3) - Very sick, hospitalization necessary; active supportive treatment necessary (2) - Moribund; fatal process progressing rapidly (1)	2. Assist with breathing efforts (e.g. pulmonary hygiene, use of assistive devices, suctioning as appropriate)
		3. Assist with hydration (e.g. accurate I & O or weights, IV's as necessary, available fluid at bedside)
		4. Facilitate patient/family adjustment to deteriorating condition
		Patient Teaching (as in Levels I & II)
		1. Signs and symptoms to report to health care team (e.g. change of sensorium, acute ventilatory distress)
		2. Pulmonary hygiene methods (e.g. suctioning, oral care, use of assistive devices)
		3. Rationale for treatment, procedures and assistive devices
		4. Probable events prior to death

Appendix C

1902 Hamilton Avenue
San Jose, California 95125
17 May 1982

Dear Dr.

As a graduate student at the University of California, San Francisco, I am in the process of collecting data for my thesis: The Lung Cancer Patient's Perception of Dyspnea. This study is being done in conjunction with Virginia Carrieri, R.N., D.N.S., who is doing a similar study on patients with other pulmonary pathology.

To gain access to subjects I am requesting your cooperation and asking that you assist me in gaining patients for the study. In order to protect patient-physician confidentiality, either you or a designated member of your office staff should make the initial contact with the patient.

The criteria for sample selection are as follows:

1. Have a histologically confirmed diagnosis of lung cancer
2. Be experiencing dyspnea
3. Be mentally competent
4. Be able to read and write the English language
5. Be 18 years old or older
6. Have given informed consent

The patients will be requested to answer a series of questions which will take about one hour. These questions can be asked in the hospital, physician's office, or at a mutually convenient place, including the patient's home. I will remain with the patient to answer questions and assist where necessary. Eight weeks following the initial interview, I will again contact the patient and repeat part of the questions from the first interview. The estimated time for the second interview is twenty minutes.

This study has been submitted to the Committee on Human Research at the University of California, and pending approval, will be submitted to appropriate committees at local hospitals where patients may be located for either interview.

There will be no risk for taking part in the study, other than the extra time spent by the patient. Participating will not interfere with office or hospital routine.

While there will probably be no direct benefit to the patient participating in the study, it is hoped than an improved understanding of shortness of breath will be of help in planning nursing care for patients experiencing the symptom.

Appendix C (continued)

All information will be confidential, and the patient's identity will not be revealed to anyone else, or in any publications.

Answers will be used only in the analysis of data. Participation is completely voluntary, and patients may refuse to be in the study or withdraw at any time without affecting care in any way.

I appreciate your consideration in this matter and look forward to your cooperation. Should you have any questions or need further information regarding the study, please do not hesitate to contact me.

Sincerely,

Mary L. Brown, R.N., B.S.N.
(408) 371-3183

Appendix D

UNIVERSITY OF CALIFORNIA SAN FRANCISCO
SCHOOL OF NURSING
DEPARTMENT OF PHYSIOLOGICAL NURSING

Mary Brown, R.N., B.S.N., from the School of Nursing, University of California, San Francisco, is conducting a study to learn more about shortness of breath and how people live with it, a problem I may or may not have as a result of my lung cancer. I have been invited to participate in this study.

If I agree to be in the study, I will do the following special things:

1) I will be interviewed for about one hour at a time convenient to me. I will be asked questions related to shortness of breath, such as what makes it better or worse, how has it changed my life, and what it feels like.

2) I will be interviewed for about twenty minutes eight weeks after the first interview also at a time convenient to me and will again be asked questions related to shortness of breath, and what changes I have noticed since the first interview.

3) I will be aware that information regarding my medical history and treatment will be obtained from my medical records.

If any questions are uncomfortable for me to answer, I don't have to answer them. The interview could momentarily increase my shortness of breath and at any time I can stop the interview and continue on another day if I would like to do so.

My name will be given a code number to identify the information that I give. The list of matching names and code numbers will be locked separately so that my confidentiality will be protected as much as possible under the law. There will be no direct benefit from me participating in this study. However, nurses hope to learn more about shortness of breath which may help patients like me in the future.

I have talked with Ms. Brown about this study and have had my questions answered. If at any time I have other questions, I may call Ms. Brown at (408) 371-3183. I have a copy of the consent form and the Experimental Subject's Bill of Rights. I have the right to refuse to participate or to withdraw without any jeopardy to my medical or nursing care.

______________________	______________________
Date	Subject's Signature
938316-01*	______________________
CHR Approval Number	Witness's Signature

Appendix E

Explanation of Consent Form

My name is Mary Brown, R.N., B.S.N., and I am a graduate student at the School of Nursing, University of California, San Francisco. I am conducting a study with patients who are experiencing shortness of breath, a problem you may or may not have as a result of your lung cancer. Your doctor has given me permission to ask you to participate, but the decision to participate is entirely yours. The following explanation is about the project.

This study is being done to determine how you perceive your shortness of breath. This information is important so that adjustments can be made in planning for patients experiencing shortness of breath.

If you agree to participate in this study I will ask you to complete questionnaires that will take about one hour. I will remain with you to answer questions and assist where necessary. This interview could momentarily increase your shortness of breath and at any time you can stop the interview and continue on another day if you would like to do so.

About two months from now I will meet with you in the physician's office (or in the hospital or at home) to ask you to complete part of the questions from the initial interview. This second interview will take about 20 minutes. Again, I will remain with you to answer your questions. Should you experience any shortness of breath during this interview, you may stop and continue at another time if you choose to do so.

Your responses will be confidential and your anonymity will be

Appendix E (continued)

protected. Your name will not appear on the questionnaires.

No one on the hospital staff including your doctors, will know your specific answers. When I report the results of the study to them, I will summarize all the responses I obtain from all the patients who participate so that no one individual can be identified.

As I mentioned earlier, you are free to decide to participate or not. Whether you participate or not will not affect the care you receive from your physician or hospital staff.

You may refuse to answer any questions you do not wish to answer, and you are free to stop at any time without explanation. Any questions you have will be answered.

Your participation will not interfere with your doctor's appointment or hospital routine today or when I meet with you again. If your doctor is ready to see you before you finish the questionnaires, you may complete the questionnaires after your appointment or hospital routine or you may withdraw from this study.

There are no known risks to you for participating in this study, and the information you provide may be of great importance in improving the kind of care provided to patients like yourself.

If you are willing to participate, I would like you to read the consent form. It summarizes the information I have just given you and your rights as a participant in this study. After you have read and signed it, I will begin the questionnaires.

Appendix F

University of California, San Francisco

Experimental Subject's
BILL OF RIGHTS

The rights below are the rights of every person who is asked to be in a research study. As an experimental subject I have the following rights:

1) To be told what the study is trying to find out,

2) To be told what will happen to me and whether any of the procedures, drugs, or devices is different from what would be used in standard practice,

3) To be told about the frequent and/or important risks, side effects or discomforts of the things that will happen to me for research purposes,

4) To be told if I can expect any benefit from participating and, if so, what the benefit might be,

5) To be told the other choices I have and how they may be better or worse than being in the study,

6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study,

7) To be told what sort of medical treatment is available if any complications arise,

8) To refuse to participate at all or to change my mind about participation after the study is started. This decision will not affect my right to receive the care I would receive if I were not in the study.

9) To receive a copy of the signed and dated consent form,

10) To be free of pressure when considering whether I wish to agree to be in the study.

#

If I have other questions I should ask the researcher or the research assistant. In addition, I may contact the Committee on Human Research, which is concerned with protection of volunteers in research projects. I may reach the committee office by calling: (415) 666-1814 from 8:00 AM to 5:00 PM, Monday to Friday, or by writing to the Committee on Human Research, University of California, San Francisco, CA 94143.

Call 666-1814 for information on translations.

Appendix G

RESPIRATORY DISEASE QUESTIONNAIRE FOR USE WITH ADULTS IN EPIDEMIOLOGICAL RESEARCH PUBLISHED BY THE AMERICAN THORACIC SOCIETY

RESPIRATORY QUESTIONNAIRE

IDENTIFICATION NUMBER:____

NAME:____

ADDRESS:____

____
(zip code)

TELEPHONE NUMBER:____

INTERVIEWER:____

DATE:____

RESPIRATORY QUESTIONNAIRE INTERVIEW SITE:

1. _____hospital
2. _____home
3. _____clinic

1. Age in years:_______________

2.	Sex:	1. Male______
		2. Female______
3.	What is your marital status?	1. Single, never married______
		2. Married______
		3. Widowed______
		4. Separated/Divorced______

Appendix G (continued)

4. Ethnic-Cultural Background:
   1. Anglo-American______
   2. Black______
   3. Native American______
   4. Asian______
   5. Mexican American______
   6. Puerto-Rican______
   7. Middle Eastern______
   8. Other______

5. Years in school________________________

6. What has been your usual occupation or job -- the one you have worked at the longest?

   a. Job occupation:____
   b. Number of years employed in this occupation:______________
   c. Position-Job title:______________________________________
   d. Business, field, or industry:_____________________________

7. Are you presently:

   1. ______employed (30 hours per week or more)
   2. ______employed part-time (less than 30 hours per week)
   3. ______temporarily unemployed
   4. ______retired

8. Living situation: (check one)

   1. ______alone
   2. ______with spouse or partner
   3. ______with family members and spouse
   4. ______with family members only
   5. ______other

Appendix G (continued)

9. Residence: (check one)

1. ______private home 2. ______apartment

3. ______hotel 4. ______nursing home

10. Religion

1. ______Protestant

2. ______Catholic

3. ______Jewish

4. ______Moslem

5. ______Buddist

6. ______None

11. Current Average Annual Income:

1. ______less than $8,000

2. ______less than $15,000

3. ______less than $22,000

4. ______less than $29,000

5. ______$30,000 or greater

12. Income Source:

1. ______job by self or spouse

2. ______disability

3. ______social security/retirement/investments

4. ______welfare

5. ______family support

Appendix G (continued)

COUGH

13A. Do you usually have a cough? (Count a cough with first smoke or on first going out-of-doors. Exclude clearing of throat.) 1. Yes_____ 2. No_____

B. Do you usually cough as much as 4 to 6 times a day, 4 or more days out of the week? 1. Yes_____ 2. No_____

C. Do you usually cough at all on getting up, or first thing in the morning? 1. Yes_____ 2. No_____

D. Do you usually cough at all during the rest of the day or at night? 1. Yes_____ 2. No_____

E. Do you usually cough like this on mose days for 3 consecutive months or more during the year? 1. Yes_____ 2. No_____

F. For how many years have you had this cough? ______________________
(number of years)

PHLEGM

14A. Do you usually bring up phlegm from your chest? (Count phlegm with the first smoke or on first going out-of doors. Exclude phlegm from the nose. Count swallowed phlegm.) 1. Yes_____ 2. No_____

B. Do you usually bring up phlegm like this as much as twice a day, 4 or more days out of the week? 1. Yes_____ 2. No_____

C. Do you usually bring up phlegm at all on getting up, or first thing in the morning? 1. Yes_____ 2. No_____

D. Do you usually bring up phlegm at all during the rest of the day or at night? 1. Yes_____ 2. No_____

E. Do you bring up phlegm like this on most days for 3 consecutive months or more during the year? 1. Yes_____ 2. No_____

F. For how many years have you had trouble with phlegm? ______________________
(number of years)

Appendix G (continued)

EPISODES OF COUGH AND PHLEGM

15A. Have you had periods or episodes of (increased*) cough and phlegm lasting for 3 weeks or more each year? 1. Yes_____ 2. No_____
*(For persons who usually have cough and/or phlegm.)

IF YES TO 15A:

B. For how long have you had at least 1 such episode per year? _____________ (number of years)

WHEEZING

16A. Does your chest ever sound wheezy or whistling:

1. When you have a cold? 1. Yes_____ 2. No_____
2. Occasionally apart from colds? 1. Yes_____ 2. No_____
3. Most days or nights? 1. Yes_____ 2. No_____

B. For how many years has this been present? _____________ (number of years)

17A. Have you ever had an attack of wheezing that has made you feel short of breath? 1. Yes_____ 2. No_____

IF YES TO 17A:

B. How old were you when you had your first such attack? _____________Age in years

C. Have you had 2 or more such episodes? 1. Yes_____ 2. No_____

D. Have you ever required medicine or treatment of the(se) attack(s)? 1. Yes_____ 2. No_____

BREATHLESSNESS

18. If disabled from walking by any condition other than heart or lung disease, please describe and proceed to Question
Nature of condition(s):____

Appendix G (continued)

19. Are you troubled by shortness of breath hurrying on the level or walking up a slight hill? 1. Yes_____ 2. No_____

IF YES TO 19A:

B. Do you have to walk slower than people of your age on the level because of breathlessness? 1. Yes_____ 2. No_____

C. Do you ever have to stop for breath when walking at your own pace on the level? 1. Yes_____ 2. No_____

D. Do you ever have to stop for breath after walking about 100 yards (or after a few minutes) on the level? 1. Yes_____ 2. No_____

E. Are you too breathless to leave the house or breathless on dressing or undressing? 1. Yes_____ 2. No_____

20. Grade of Breathlessness______________________________

CHEST COLDS AND CHEST ILLNESSES

21. If you get a cold, does it usually go to your chest? (Usually means more than half the time.) 1. Yes_____ 2. No_____ 3. Don't get colds______

22A. During the past 3 years have you had any chest illnesses that have kept you off work, indoors at home, or in bed? 1. Yes_____ 2. No_____

IF YES TO 22A:

B. Did you produce phlegm with any of these chest illnesses? 1. Yes_____ 2. No_____

C. In the last 3 years, how many such illnesses with (increased) phlegm, did you have which lasted a week or more? ____________________ (number of illnesses)

Appendix G (continued)

PAST ILLNESSES

23. Did you have any lung trouble before the age of 16? 1. Yes_____ 2. No_____

24A. Have you ever had attacks of bronchitis? 1. Yes_____ 2. No_____

IF YES TO 24A:

B. Was it confirmed by a doctor? 1. Yes_____ 2. No_____

C. At what age was your first attack? __________Age in years

25A. Have you ever had pneumonia (include bronchopneumonia)? 1. Yes_____ 2. No_____

IF YES TO 25A:

B. Was it confirmed by a doctor? 1. Yes_____ 2. No_____

C. At what age did you first have it? __________Age in years

26A. Have you ever had hay fever? 1. Yes_____ 2. No_____

IF YES TO 27A:

B. Was it confirmed by a doctor? 1. Yes_____ 2. No_____

C. At what age did it start? __________Age in years

27A. Have you ever had chronic bronchitis? 1. Yes_____ 2. No_____

IF YES TO 27A:

B. Do you still have it? 1. Yes_____ 2. No_____

C. Was it confirmed by a doctor? 1. Yes_____ 2. No_____

D. At what age did it start? __________Age in years

Appendix G (continued)

28A. Have you ever had emphysema? 1. Yes_____ 2. No_____

IF YES TO 28A:

B. Do you still have it? 1. Yes_____ 2. No_____

C. Was it confirmed by a doctor? 1. Yes_____ 2. No_____

D. At what age did it start? _________Age in years

29A. Have you ever had asthma? 1. Yes_____ 2. No_____

IF YES TO 29A:

B. Do you still have it? 1. Yes_____ 2. No_____

C. Was it confirmed by a doctor? 1. Yes_____ 2. No_____

D. At what age did it start? _________Age in years

E. If you no longer have it, at what age did it stop? _________Age stopped

30. Are you allergic to:

1. _____animals
2. _____pollens
3. _____smoke
4. _____wool
5. _____certain foods
6. _____dust

31. Do you have pets?

1. _____dog
2. _____cat
3. _____fish
4. _____birds
5. _____horses
6. _____chieckens

32. Have you ever had:

A. Any other chest illness? 1. No_____

If yes, please specify____

B. Any chest operations? 1. No_____

If yes, please specify____

C. Any chest injuries? 1. No_____

If yes, please specify____

Appendix G (continued)

33A.	Has a doctor ever told you that you had heart trouble?	1. Yes_____	2. No_____
	IF YES TO 33A:		
B.	Have you ever had treatment for heat trouble in the past 10 years?	1. Yes_____	2. No_____
34A.	Has a doctor ever told you that you had high blood pressure?	1. Yes_____	2. No_____
	IF YES TO 34A:		
B.	Have you had any treatment for high blood pressure (hypertension) in the past 10 years?	1. Yes_____	2. No_____
35A.	Do you usually use bronchodilators?	1. Yes_____	2. No_____
B.	Do you take allergy shots?	1. Yes_____	2. No_____
C.	Do you usually use diuretics?	1. Yes_____	2. No_____
D.	Do you usually use digoxin?	1. Yes_____	2. No_____
E.	Do you usually use blood pressure medications?	1. Yes_____	2. No_____
F.	Do you usually use antiangina medicine?	1. Yes_____	2. No_____
G.	Do you usually use antiarrhythmics?	1. Yes_____	2. No_____
36.	Do you use oxygen at home?	_____1. No _____2. Continuously _____3. Intermittently	
37.	Do you usually take steroids?	_____1. No _____2. Orally _____3. Inhaled _____4. Both oral and inhaled	

Appendix G (continued)

OCCUPATIONAL HISTORY

38. Have you ever worked full time (30 hours per week or more) for 6 months or more? 1. Yes_____ 2. No_____

39A. Have you ever worked for a year or more in any dusty job? 1. Yes_____ 2. No_____

B. Specific job/industry______________________________

C. Total years worked____________

D. Was dust exposure: 1. Mild_____ 2. Moderate_____ 3. Severe_____ 4. None_____

40A. Have you ever been exposed to gas or chemical funes in your work? 1. Yes_____ 2. No_____

B. Specific job/industry______________________________

C. Total years worked____________

D. Was exposure: 1. Mild_____ 2. Moderate_____ 3. Severe_____ 4. None_____

TOBACCO SMOKING

41A. Have you ever smoked cigarettes? (No means less than 20 packs of cigarettes of 12 oz. of tobacco in a lifetime or less than 1 cigarette a day for 1 year.) 1. Yes_____ 2. No_____

IF YES TO 41A:

B. Do you now smoke cigarettes (as of one month ago)? 1. Yes_____ 2. No_____

C. How old were you when you first started regular cigarette smoking? __________Age in years

D. If you have stopped smoking cigarettes completely, how old were you when you stopped? __________Age in years

Appendix G (continued)

E. How many cigarettes do you smoke per day now?	________Cigarettes per day
F. On the average of the entire time you smoked, how many cigarettes did you smoke per day?	________Cigarettes per day
G. Do or did you inhale the cigarette smoke?	1. Does not apply_____ 2. Not at all _____ 3. Slightly _____ 4. Moderately _____ 5. Deeply _____

42. Pack years____________________

43A. Have you ever smoked a pipe regularly? (Yes means more than 12 oz. of tobacco in a lifetime.)	1. Yes_____ 2. No_____

IF YES TO 43A:

FOR PERSONS WHO HAVE EVER SMOKED A PIPE:

B. 1. How old were you when you started to smoke a pipe regularly?	________Age started
2. If you have stopped smoking a pipe completely, how old were you when you stopped?	________Age stopped
C. On the average over the entire time you smoked a pipe, how much pipe tobacco did you smoke per week?	_____oz. per week (a standard pouch of tobacco contains 1½ oz.)
D. How much pipe tobacco are you smoking now?	_____oz. per week
E. Do you or did you inhale the pipe smoke?	1. Never smoked_____ 2. Not at all _____ 3. Slightly _____ 4. Moderately _____ 5. Deeply _____

44A. Have you ever smoked cigars regularly? (Yes means more than 1 cigar a week for a year.) 1. Yes_____ 2. No_____

IF YES TO 44A:

FOR PERSONS WHO HAVE EVER SMOKED CIGARS:

B. 1. How old were you when you started smoking cigars regularly? ________Age started

2. If you have stopped smoking cigars completely, how old were you when you stopped? ________Age stopped

C. On the average, over the entire time you smoked cigars, how many cigars did you smoke perweek? ________Cigars per week

D. How many cigars are you smoking per week now? ________Cigars per week

E. Do or did you inhale the cigar smoke?

1. Never smoked_____
2. Not at all _____
3. Slightly _____
4. Moderately _____
5. Deeply _____

FAMILY HISTORY

45. Were either of your natural parents ever told by a doctor that they had a chronic lung condition such as:

	FATHER			MOTHER		
	1. yes	2. no	3. don't know	1. yes	2. no	3. don't know
A. Chronic bronchitis?	_____	_____	_____	_____	_____	_____
B. Emphysema?	_____	_____	_____	_____	_____	_____
C. Asthma?	_____	_____	_____	_____	_____	_____
D. Lung cancer?	_____	_____	_____	_____	_____	_____
E. Other chest conditions?	_____	_____	_____	_____	_____	_____

Appendix G (continued)

FOLLOWING INFORMATION TO BE COMPLETED BY INTERVIEWER

46. Primary disease category:

_____1. cardiac
_____2. pulmonary
_____3. neuro
_____4. renal
_____5. GI

47. Primary diagnosis________________________________

48. Pulmonary diagnosis______________________________

49. Cardiac ciagnosis________________________________

50. Pulmonary category

_____1. obstructive
_____2. restrictive
_____3. vascular
_____4. combination

51. Severity of pulmonary disease:

_____1. acute
_____2. chronic
_____3. acute-chronic
_____4. not applicable

Adapted from:

American Thoracic Society. Recommended Respiratory Disease Questionnaires for Use with Adults and Children in Epidemiological Research, American Review of Respiratory Diseases, 1978, 118(6), 7-53.

Appendix G (continued)

Additional questions to be added to the respiratory questionnaire:

Insurance Source: (check all that apply)

_____1. Medicare

_____2. Medi-Cal

_____3. Private Insurance

_____4. Coverage by spouse's insurance

_____5. No medical insurance

Current Treatment

Chemotherapy: Yes_____ No_____

If yes, drugs being used: 1.

2.

3.

4.

Radiation Therapy: Yes_____ No_____

Dates:

Rads:

Area irradiated:

Prophylactic cranial irradiation Yes_____ No_____

Dates:

Rads:

Tissue Diagnosis:

Stage of Disease at Diagnosis:

Other Medical Diagnoses:

Appendix H

Dyspnea Interview Schedule

Interviewer:____________________________

1. Perception of Shortness of Breath

Structured Questions

1. Have you ever had a problem with shortness of breath? (If yes, go on with question #2)

   1a. Interviewer note: If answer is "no" ask "What is it that you find most distressful about your illness? Please probe. Identify one symptom to focus remaining interview.

2. When were you first aware of having shortness of breath?

3. What did you do about it?

4. Did you talk to someone about it?

5. How long did you have shortness of breath before you sought medical advice?

6. What were you told was the cause of your shortness of breath?

Appendix H (continued)

7. Tell me about the last time you were short of breath. (If no answer, elicit responses with one of the following situations: exercise, psychological factors, anger, fear, depression, daily hassels, infection).

8. For any situation described, determine the following: Aggravating factors: What brought on the shortness of breath?

9. Description: Can you describe in your own words how it felt?

10. Prodromal indicators: (onset) Do you have any feelings that tell you that you are <u>about to become</u> short of breath?

Appendix H (continued)

11. Subjective physiologic correlates: (associated manifestations) What sensations do you notice? Do you feel things when you are short of breath? What happens to your body?

12. Psychosocial correlates: (setting, location) When you are actually short of breath what do you feel? What social situations are you in? Where were you? What were you doing?

13. Duration and course: When you're short of breath, how long does it last? Is there a typical pattern?

14. Behavioral correlates: (associated manifestations) If you couldn't tell anybody you were short of breath, how would they know? Do you do things that would let people know you are more short of breath?

Appendix H (continued)

15. Adaptive mechanism: What helps it go away? (actions and positions, needs, other) What are the little things you do that might not even tell people about that help your shortness of breath? What kinds of things help you live with or cope with your shortness of breath? Probe

16. Is this situation you've just described typical of most of the times when you've felt short of breath? Can you tell me about other times and how they differed?

17. Does your shortness of breath ever go away? When? (constant or sporadic)

18. How much of a problem is shortness of breath for you?

Appendix H (continued)

19. Does thinking about your shortness of breath bother you?

20. Do you prefer to talk with others about your shortness of breath? Who?

21. Have you ever had experiences with others that have had shortness of breath such as family members or friends?

22. Have you ever had any classes or learned about your shortness of breath? What kind of classes? Who has taught you about your illness?

Appendix H (continued)

23. Have you ever been taught or learned things you can do to make you more comfortable when you are having problems with your breathing?

24. Who do you see as your chief source of strength and emotional support?

25. How does your family feel about your shortness of breath?

26. Is your family a source of comfort? Are they overprotective?

Appendix H (continued)

27. How does your shortness of breath affect your family? Other relationships with friends?

II. Activities of Daily Living

We'd like to know how being short of breath might effect your daily activities. I'm going to ask some questions about a typical day for you.

1. What about eating, for example? How do your present eating habits differ from what was normal for you before your illness?

    a. Do you need help from other people to eat? To fix your meals?

        Do people bring food to you?

        e.g. Are you able to cut your own food?

        Is pouring milk or coffee a problem for you?

    b. Are there any special eating utensils, such as enlarged fork handles or nonskid plates, that you use and find helpful?

(Dressing)

2. Do you have any problems dressing yourself now that you didn't have before your illness?

    a. Do you need help in putting on some of your clothes--fastening buttons, for example, or lacing your shoes?

Appendix H (continued)

b. Do you wear special clothing, or use special equipment, to make dressing easier?

c. Are there days you don't get dressed, but wear your bedclothes? About how many days a week would you say?

(Walking)

3. Do you walk and get about in the same way you did before your illness?

a. Do other people assist you in getting about?

How far do you think you can walk without getting short of breath?

e.g.

Do you need to be accompanied when you go on walks?

b. Do you use special equipment to help you walk?

Do you use a can or a crutch?

e.g.

Do you wear braces or special shoes?

Appendix H (continued)

(Travel)

4. How do your present travel and transportation patterns differ from what was normal for you before your illness?

    a. Do you drive a car to take a bus as often as you used to?

    b. How do you travel when you need to go somewhere?

    c. How do you get to the doctor for your medical appointments?

(Bathing)

5. How do your present bathing patterns differ from what was normal for you prior to your illness?

    a. About how often -- how many times a week -- do you bathe now?

Appendix H (continued)

b. How do you usually bathe? Of the ______ times a week you bathe, how many are tub baths?

showers?

sponge baths?

c. Are you assisted in bathing by other people?

Are water and equipment brought to you?

e.g. Do you need help getting in and out of the tub?

Do you need help in washing hard-to-reach areas, such as your back?

d. Are there special devices or equipment that you use and find helpful?

Perhaps a long-handled brush?

e.g. What about a shower or tub chair?

Do you have grabrails around the tub?

(Toileting)

6. Are you able to go to the bathroom in the same way as you did before your illness?

a. Do you need help from other people in getting to the bathroom?

e.g.

Does someone assist you in walking to the bathroom?

Does someone bring you a bedpan when you require it?

b. Do you use special equipment, such as grab bars or a raised toilet seat?

(Attentiveness and Memory)

8. Have you noticed any changes in your concentration or memory during the course of your illness?

a. How do you keep track of appointments?

b. Is it more difficult for you now to read or keep up with conversations?

c. How do you keep track of when it's time to take your medicine?

d. Do you find you are forgetful?

Appendix H (continued)

(Relationship with spouse)

9 - 11. Has your relationship with your spouse or living partner changed in any ways since your illness?

a. Are there things around the house that you used to do (e.g., yardwork, cooking) that you can no longer do? Who does these things now?

b. Do you spend as much time together -- with your spouse -- as you used to?

c. Do you still eat all your meals together?

d. Do you still sleep in the same room?

e. Has your illness had an effect on how well you and your spouse are able to share things with each other?

(Work Role)

12 - 14. a. How has the kind of work you do changed over the course of your illness?

Appendix H (continued)

b. Do you do your work in the same way now?

c. Do you still think about work-related things as much as you used to? Do they seem important to you now?

d. How often do you see the people you know at work? Did you used to see them more often than this? (For homemakers, you might ask about neighbors, shopping companions, etc.)

(Recreation and Socializing)

15 - 17. a. What kind of things do you do for recreation or just for fun?

b. Has this changed in any way since your illness?

c. How much contact do you have with people outside your family, and where does this occur?

d. Do you keep in touch with your friends like you used to?

Appendix H (continued)

e. Are there things you'd like to do in the way of recreation or entertainment that you just can't do anymore because of shortness of breath?

f. Are there friends you haven't seen for a while that you'd really like to see again?

g. What did you do (do you plan to do) on the most recent (upcoming) major holiday?

h. How do you spend spare time now compared to before your illness?

i. Do you find yourself reading more or less now than you used to?

Appendix I

Dyspnea Descriptive Scale

We are interested in knowing the degree of breathlessness that you live with.

1. Please mark an X on the scale at the point that shows the worst breathlessness that you have ever experienced.

0 10 20 30 40 50 60 70 80 90 100

No difficulty breathing | Moderate Difficulty Breathing | Unable to Breathe

2. Please mark an X on the scale that shows the degree of breathlessness that you usually experience day to day.

0 10 20 30 40 50 60 70 80 90 100

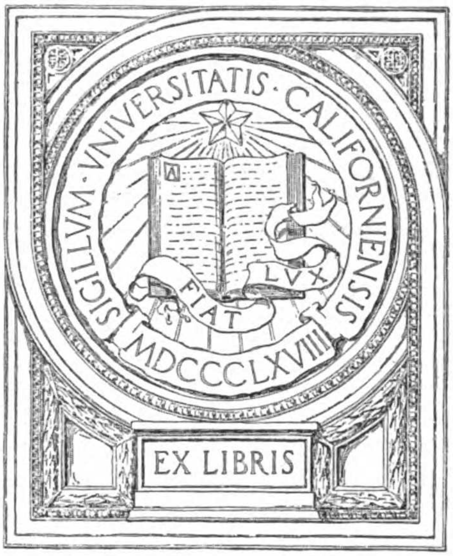
No difficulty breathing | Moderate Difficulty Breathing | Unable to Breathe

Appendix J

Evaluation of Performance Status

Karnofsky Performance Scale

Description	Scale, %	
Normal, no complaints	100	Normal Activity
Able to carry on normal activities; minor signs or symptoms of disease	90	Fully Ambulatory
Normal activity with effort	80	
Cares for self; unable to carry on normal activity or to do active work	70	Self-Care
Requires occasional assistance but able to care for most of his needs	60	Partially Ambulatory
Requires considerable assistance and frequent medical care	50	
Disabled; requires special care and assistance	40	Incapacitated
Severely disabled; hospitalization indicated though death not imminent	30	Non-Ambulatory
Very sick; hospitalization necessary active supportive treatment necessary	20	
Moribund	10	
Dead	0	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