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INTERRELATIONSHIPS OF KNOWLEDGE OF DISEASE, KNOWLEDGE OF TREATMENT, SOCIAL SUPPORT, PERCEIVED IMPACT OF DISEASE AND STATED COMPLIANCE IN A GROUP OF PATIENTS WITH COPD

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INTERRELATIONSHIPS OF KNOWLEDGE OF DISEASE, KNOWLEDGE OF TREATMENT, SOCIAL SUPPORT, PERCEIVED IMPACT OF DISEASE AND STATED COMPLIANCE IN A GROUP OF PATIENTS WITH COPD

By

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ABSTRACT

INTERRELATIONSHIPS OF KNOWLEDGE OF DISEASE, KNOWLEDGE OF TREATMENT, SOCIAL SUPPORT, PERCEIVED IMPACT OF DISEASE AND STATED COMPLIANCE IN A GROUP OF PATIENTS WITH COPD

By

Sharon K. King

Chronic obstructive pulmonary disease constitutes a major health problem in the United States. Compliance to a complex therapeutic regimen is of vital importance in slowing progress of the disease and maintaining maximum quality of life for the patient. In this correlational study levels of compliance, social support, knowledge of disease and of treatment and perceived impact of disease were measured in a group of 31 COPD patients. Data were collected four weeks following subject participation in patient education by use of a self-administered questionnaire.

Using Pearson Product Moment Correlation coefficients, statistically significant relationships between knowledge of disease and compliance ($r = .39$, $p < .02$) and between perceived impact of disease and social support ($r = -.44$, $p < .007$) were determined to exist in the study sample. Additionally, descriptive statistics resulted in the development of a profile of attitudes, beliefs and behaviors common to COPD patients participating in the study.

This thesis is dedicated to the COPD patients who willingly and openly shared of their thoughts and fears, with the sincere desire that their efforts may aid in the promotion of increased understanding of patients with chronic lung disease.

ACKNOWLEDGEMENTS

Without the efforts of many people this study could never have been brought to a successful completion.

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The interest, enthuasism, and cooperation of many health care providers in the community made contact with potential subjects possible and is acknowledged with pleasure. The pulmonary staff at Ingham Medical Center and at Lansing General Hospital have all contributed greatly to the very possibility that this research might exist.

Most special appreciation is reserved for my family for helping me to learn the meaning of and enjoy the benefits of the truest form of social support. To my parents, LeRoy and Marjorie Hammond, my mother-in-law, Merle King and my wonderful daughters, Nancy, Carol and Amy...thank you for your help and your caring. And for my husband, Darrell, who listened to me, cared about what I was doing and helped every step of the way...Thank You.

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CHAPTER I

THE PROBLEM

Introduction

Chronic obstructive pulmonary disease (COPD) constitutes a health problem which is growing in magnitude and significance at an alarming rate in the United States. COPD has been cited as showing the greatest rate of increase as a cause of death among major disease groups over the last decade, exceeding cancer, heart disease and stroke. In the state of Michigan 20,000 residents are hospitalized each year for the treatment of COPD (American Lung Association of Michigan, 1979).

The person who is afflicted with COPD faces a number of years of living an extremely restricted existance and often avoids both physical and emotional exertion to the extent of virtual self-seclusion (Goldenson et al, 1978). The constant physical and emotional limitations encountered by the person with COPD frequently result in psychological alterations and a pattern of depression. COPD cannot be cured and lung damage sustained as a part of the disease cannot be repaired.

Research has demonstrated that through conscientious adherence to a regimen including medication, regulated exercise and reduction of modifiable risk factors, the person afflicted

with COPD may slow the disease process and increase their exercise tolerance (Petty, 1973). Modifiable risk factors include smoking, exposure to environmental respiratory irritants, exposure to respiratory infection, personal coping patterns and life style. Risk factors which are significant and cannot be altered by the patient are sex, alpha-1 antitrypsin deficiency, family history and aging (American Lung Association, 1977; Hugh-Jones, 1978).

Except for periods of extreme difficulty in breathing or respiratory infection, the COPD patient is managed on an outpatient basis. Effective management of the patient with COPD is largely dependent upon the willingness and ability of that person to assume responsibility for carrying out the recommended treatment regimen (Cherniack, 1977).

The typical treatment regimen for the person with COPD is complex and frequently involves a large number of medications, exercise reconditioning and alteration of behaviors which may have been incorporated into the individuals life style over a number of years. Compliance with the recommended treatment regimen will slow the disease process but will not result in rapid or dramatic improvement in the patient's physical condition.

Compliance with medical regimens has been acknowledged as a significant problem in the management of a wide variety of medical conditions (Marston, 1970; Vincent, 1971; Sackett and Haynes, 1976). Based on a review of the literature, Zisook (1980)

has estimated that as many as 93 percent of patients do not comply with recommended treatment regimens. Several factors combine to make compliance a particular problem for patients with COPD. Gradual onset of symptoms diminishes the patient's recognition of the severity of the disease, and treatment frequently involves significant behavioral changes.

Knowledge has frequently been addressed as a means to increase rates of compliance to medical regimens (Bille, 1977; Teglacozzo, 1970; Hecht, 1974). It is essential that patients possess at least minimal knowledge of their basic treatment regimen in order to modify behavioral patterns to concur with recommended prescriptions. Health care professionals endeavor to increase patient knowledge by presenting information regarding both the disease and its recommended treatment.

In the study of compliance, knowledge of disease has been differentiated from knowledge of treatment by only a few researchers (Teglacozzo, 1970; Caplan, 1976). Teglacozzo (1970) concludes that the role of knowledge of disease remains unclear in relation to compliance. Caplan (1976) reports that hypertensive patients with the most accurate knowledge of their regimens had the lowest blood pressures in a longitudinal study conducted at the University of Michigan. A further finding of Caplan's study was that patients with complex regimen demands were less likely to have accurate knowledge concerning their regimen.

Social support theory and research, developed by behavioral scientists, has been adopted by the field of mental health as a

basis for patient assessment and intervention (Caplan, 1976). Recent research documents the value of viewing social support as a positive influence on both self-esteem and compliance with treatment regimens in patients with a variety of medical conditions (Caplan, 1976; Berkman and Syme, 1979; DeAraujo et al, 1972). Research linking social support with compliance is of recent origin and interacting variables are still ill-defined.

A person's perception of the probable severity of the consequences of contracting a disease is cited by Becker (1974) in development of a health belief model for predicting compliance. Persons with COPD already have a disease which places limitations upon their life. A measure of the number of changes in usual activities of daily living and occupational activities may be used to assess the health status of the already ill patient (Gilson et al, 1975; Bergner et al, 1976; Pollard et al, 1976). Donabedian and Rosenfeld (1965) have found evidence that patients with severe disabilities are more likely to comply with treatment regimens, while Davis (1968) found patients with severe illness had lower rates of compliance than patients with less serious illness. Although there is a lack of congruence in the literature concerning the identification of factors affecting compliance and the relationships of social support, knowledge and perceived impact of disease to compliance, the fact that compliance is vital to the success of medical treatment is undisputed.

Purpose

The purpose of this study is to identify interrelationships between social support, knowledge of disease, knowledge of treatment, perceived impact of disease and stated compliance in patients with COPD. Increased understanding of the relationships of these variables to compliance will assist health care professionals to make knowledgeable assessments of a patient's compliance potential and plan appropriate interventions to enhance compliance to treatment regimens. Increased compliance with recommended treatment regimens may result in improved health status and greater independence for the patient with COPD.

Statement of the Question

The goal of this study is to measure social support, knowledge of disease, knowledge of treatment, perceived impact of disease and stated compliance in a group of patients with COPD. The results of these measures will then be analyzed to answer the question: Are there relationships between social support, knowledge of disease, knowledge of treatment, perceived impact of disease and stated compliance in a group of patients with COPD?

Hypotheses

Hypothesis I: There is a significant relationship between social support and stated compliance with the treatment regimen in the patient with COPD.

Hypothesis II: There is a significant relationship between social support and knowledge of the treatment regimen in the patient with COPD.

Hypothesis III: There is a significant relationship between social support and knowledge of disease in the patient with COPD.

Hypothesis IV: There is a significant relationship between social support and perceived impact of the disease in the patient with COPD.

Hypothesis V: There is a significant relationship between knowledge of the treatment regimen and stated compliance in the patient with COPD.

Hypothesis VI: There is a significant relationship between perceived impact of the disease and stated compliance in the patient with COPD.

Hypothesis VII: There is a significant relationship between knowledge of disease and stated compliance with the treatment regimen in the patient with COPD.

Hypothesis VIII: There is a significant relationship between knowledge of disease and perceived impact of the disease in the patient with COPD.

Schematic Representation of Hypotheses

Schematic representation of hypothesized interrelationships is shown in Figure 1. In this model, factors hypothesized to be related to stated compliance are indicated to be social support,

knowledge of disease, knowledge of treatment, and perceived impact of disease. In addition, the model demonstrates hypothesized relationships of social support to knowledge of disease, knowledge of treatment and perceived impact of disease. A relationship between perceived impact of disease and knowledge of disease is indicated by the model in Figure 1.

Definition of Terms

The following definitions of terms utilized in the research question will be employed for the purpose of this study.

COPD Patient: A patient who is medically diagnosed and under medical treatment for COPD, emphysema or chronic bronchitis.

Social Support: The degree to which the COPD patient reports a pattern of consistent communications, assistance and mutual evaluation with other persons and the degree to which the COPD patient reports a belief that he/she is understood, cared for and esteemed in relation to his/her disease by those other persons (Caplan, 1976).

Stated Compliance: The extent to which the patient reports that he/she carries out the therapeutic recommendations of health care providers concerning prescribed medications, behaviorial modification (stress management, cigarette smoking, relaxation techniques), exercise, postural drainage, methods of preventing exacerbation, and follow-up care.

Patient Knowledge of Disease: The factual information that the patient is able to recall and report in response to questions concerning COPD, its etiology, symptoms, complicating factors

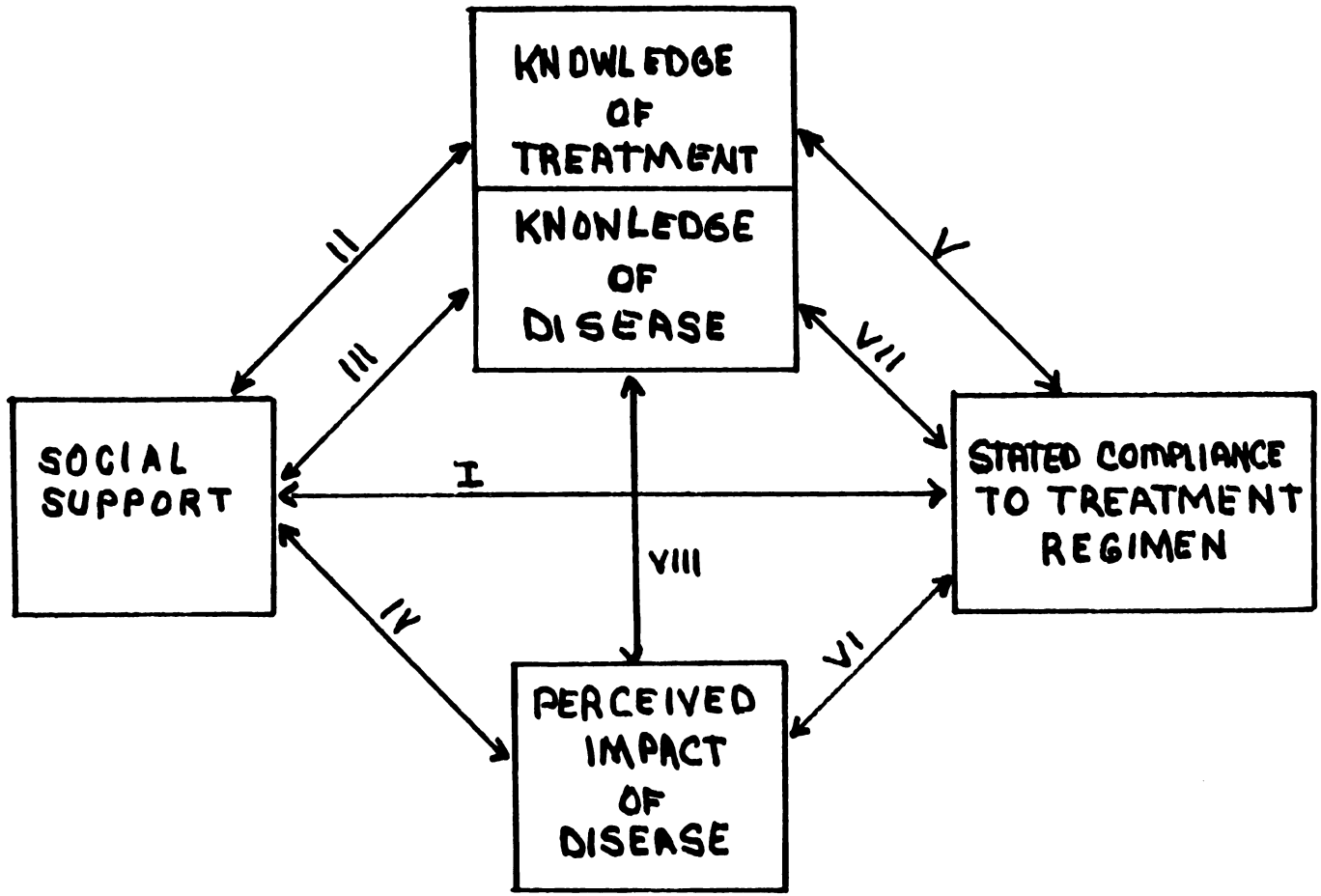

Figure 1: Schematic representation of hypotheses. The numerals on each arrow are used for reference in the text and refer to a specific hypothesis. Arrows between boxes indicate the hypothesized interrelationship.

and prognosis.

Patient Knowledge of Treatment Regimen: The factual information that the patient is able to recall and report in relation to questions concerning his/her prescribed medication (purpose, side-effects), breathing and coughing techniques, exercise, symptoms of infection, methods of preventing infection, and follow-up care.

Perceived Impact of Disease: The number of changes necessitated by symptoms of COPD which are reported by the patient in relation to social activities and functional ability to perform customary activities of daily living.

Limitations of the Study

Limitations of the study include the following:

(1) The small number of patients participating in the study due to local availability result in data which are not generalizable to larger populations.

(2) The study participants were a convenience sample and random selection of study participants was not employed in obtaining the study population. The variables which were not measured cannot be assumed to be normally distributed and the potential for bias exists.

(3) Standardization of patient education does not exist. The information received by the patient from health care providers may vary in respect to content and manner of delivery.

(4) Stated compliance is based on the participant's report of individual treatment regimens and compliance to that regimen

rather than what was specifically prescribed by the health care provider.

(5) This study does not address major variables such as perceived benefits, barriers or susceptibility which are of acknowledged importance but are beyond the scope of this study.

(6) Study participants were obtained from three different sites. Differences between those sites, and the possible resultant differences in patients obtained at those sites, may act as a confounding variable.

(7) The study participants were relatively homeogenous in relation to severity of disease. Because of the lack of variability of severity the potential for bias exists.

Assumptions of the Study

For the purpose of this study the investigator makes the following assumptions:

(1) That COPD is a chronic degenerative disease causing symptoms which require changes in living habits and social activities.

(2) That measures of knowledge, compliance, social support and perceived impact of disease developed by the investigator are sensitive enough to quantify variations in these variables.

(3) That participants in the study have been given information in regard to treatment regimens recommended to them by health care providers.

(4) That participants will answer questions related to compliance, social support and perceived impact of disease

honestly and that these concepts have meaning to study participants.

Overview of the Chapters

Presentation of this research study is organized into six chapters. Included in Chapter I are an introduction, purpose of the study, statement of the question, hypotheses, definition of terms, and a statement of the limitations and assumptions of the study.

In Chapter II, the concepts and theories revelent to this study are integrated into a conceptual framework upon which the hypotheses are based.

A review of the literature presented in Chapter III indicates pertinent background relevant to the research question and those variables which it addresses.

Discussion of methodology and procedures are presented in Chapter IV. A description of the population and setting of the study, data collection procedure, instruments, scoring procedures and human rights protection are included in this chapter.

The data collected relevant to the research question and general descriptive data are presented in Chapter V.

Research findings are summarized and interpreted in Chapter VI. Recommendations and conclusions resultant of the research study are presented in this chapter along with implications for professional practice.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

The individual with chronic obstructive pulmonary disease (COPD) possesses a number of symptoms, both physical and emotional, which are common to all persons afflicted with the disease. One body of precepts essential to the understanding of the person afflicted with COPD are the pathophysiology, clinical manifestations and treatment which are standard for the disease. In this chapter the concepts and theories relevant to this study are integrated into a conceptual framework upon which the hypotheses are based.

Pathophysiology of COPD

The word chronic denotes an ever-present and continuing disease entity. COPD is a progressive, irreversible and degenerative process which includes chronic bronchitis and emphysema after each disease has reached the point at which chronic alveolar distension causes air trapping to occur (MacDonnell and Segal, 1977).

The basic pathophysiology common to COPD is characterized by constant hyperinflation of the alveola caused by weakened bronchiolar walls and disrupted alveoli which results in

decreased efficiency of gas exchange at the alveolar level. Decreased ciliary and mucous blanket function, coupled with degenerative changes in alveola, lessen the area available for gas exchange between the alveolar air and pulmonary blood. Continuation of this degradation process results in "wasted" or dead-space ventilation (Shapiro et al, 1975).

Uneven distribution of ventilation and the resulting hypoventilated areas in relation to pulmonary blood flow cause arterial hypoxemia and an increased cardiac workload. Pulmonary arterial hypoxemia and the resulting vasoconstriction of the pulmonary arteries causes a backpressure which leads to right ventricular overload. This, in time, leads to enlargement of the right ventricle and eventually to cor pulmonale (MacLeod, 1977).

In the 1950's COPD was commonly recognized as a disease characterized by the anatomic destruction of the alveola. Studies conducted during this time confirmed this anatomic definition but caused confusion because of their observation that patients presenting clinical symptoms of COPD were sometimes found to exhibit different postmortem abnormalities. Histologic research conducted by Reid at the same time found evidence of hypertrophy of the bronchial mucous glands in patients with chronic bronchitis (Shapiro et al, 1975). During the ensuing two decades numerous studies were conducted in an attempt to classify chronic respiratory disease and correlate the patients' subjective complaints, physical symptoms and physiologic measures

with observed histologic abnormalities (Marks, 1973).

Throughout the continuing reevaluation of criteria to specify and classify COPD, two common tests have been routinely used to diagnose and measure progress of the disease. These are pulmonary function tests and the evaluation of arterial blood gases. Pulmonary function testing is used to evaluate the purely mechanical abilities of the patient with regard to ventilation. Forced vital capacity (FVC) is representative of the patients' maximum breathing ability and is determined with a spirometer which allows direct measurement of pulmonary gas volumes. The forced expiratory volume in one second (FEV_1) is the measure of the volume of air which the patient is able to forcefully expire in one second. Pulmonary function tests in the COPD patient reveal a decreased forced expiratory volume per second (FEV_1) and a reduced ratio of forced expiratory volume to forced vital capacity (FEV_1/FVC).

As diagnostic tools, forced vital capacity and forced expiratory volume per second are compared to norms which have been derived for persons of a similar age, sex, and body size. A schematic diagram of the forced expiratory spirogram is shown in Figure 2.

As the perfusion and distribution of ventilation within the lungs becomes altered from normal, arterial blood gases show a partial pressure of oxygen (P_aO_2) which is lower than normal. Further progress of the disease results in generalized hypoventilation, causing the decreased P_aO_2 to be accompanied by an

increased partial pressure of carbon dioxide (P_aCO_2), eventually resulting in respiratory acidosis and ventilatory failure. Failure of the lungs to clear the blood of carbon dioxide wastes is an immediate life threatening situation.

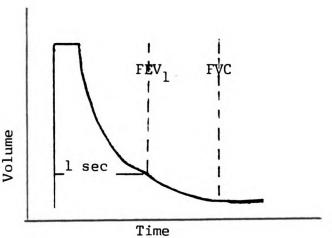

Figure 2: Schematic representation of a forced expiratory spirogram. The maximum inspiration is depicted by a rapid increase in volume. The total air expelled is the forced vital capacity. The volume expelled in the first second is the forced expiratory volume in one second (FEV_1). Adapted from Shapiro, Application of Blood Gases, 1977.

Clinical Manifestations of COPD

Symptoms of progressively severe dyspnea on exertion are often subtle and insidious, causing the patient to remain unaware of this disability until it becomes quite advanced. It is not uncommon for the COPD patient to exhibit a cough productive of a thick, tenacious sputum. Physical examination may show pursed lip breathing, distant breath sounds, hyperresonnance and wheezes or rhonchi (MacLeod, 1977). The COPD patient eventually experiences hospitalization as a result of severe dyspnea and/or respiratory infection. The disease may progress over a period of months or years before symptoms become debilitating enough to cause the patient to seek medical treatment.

The COPD patient is a chronically ill individual with overwhelming physical and emotional symptoms, always hypoxemic, and often a carbon dioxide retainer (Shapiro, 1975). The patient attempts to avoid physical activity that precipitates shortness of breath and this limitation of activity produces lazy muscles which require more oxygen to do less work. The COPD patient's exercise tolerance is diminished, sleep patterns are disturbed, and the patient becomes dependant primarily upon his cardiac reserve to maintain homeostasis. The patient lives in a hostile environment where he is threatened in his ability to perform ordinary activities or daily living. This may lead to a state of depression that becomes overwhelming (Shapiro, 1975).

Clinical Management of COPD

Treatment of the patient with COPD is highly individualized and is aimed at achievement of maximum self-reliance for each patient. As summarized by Cherinack and Lenzman (1977) "the major thrust of the management of patients suffering from chronic airflow obstruction is directed at overcoming, insofar as possible, the functional disturbances that are present. The measures are designed to reduce the work of breathing, to prevent acute exacerbations, to improve the performance of daily activities and to lessen the complications of chronic hypoxemia".

Although treatment for COPD is primarily pallitative, progress of the disease can be slowed and disabilities lessened with compliance to the treatment program. Statistics reported by Petty (1973) indicate that loss of pulmonary function can be slowed, and exercise tolerance increased in spite of decreasing pulmonary function when COPD patients participate in a comprehensive care plan involving patient education, pharmacologic therapy and physical reconditioning.

The COPD patient is commonly instructed in specific ways of avoiding respiratory infection, such as avoidance of crowds during flu season, the importance of dressing appropriately for the weather and avoidance of contact with persons known to have colds or flu. Bronchodilating medications are customarily prescribed to expand the airways and COPD patients are instructed in the purposes and dosages of these medications. Additionally, patients are cautioned concerning toxic side-effects which accompany over-

dosage with bronchodialtors. Patient education for the COPD patient includes teaching the importance of ceasing cigarette smoking and the avoidance of respiratory irritants such as smoky rooms, spray products and areas of high concentration of air pollutents. The importance of adequate hydration is stressed unless contraindicated by accompanying symptoms of congestive heart disease.

Breathing retraining is an important part of patient education for the COPD patient. Through the practice of diaphragmatic breathing techniques patients are able to maximize the efficiency and decrease the work of breathing. For patients who are productive of significant amounts of sputum, instruction in postural drainage and productive coughing offers a way of clearing the airways of secretions.

Symptoms which must be promptly reported to the physician by the patient are reviewed as a part of the patient education program for COPD patients. The importance of consistant graded exercise is stressed and efforts are made to aid the patient in planning activities to make the mose efficient use of available energy. Techniques of relaxation and stress reduction are frequently incorporated into patient education programs for persons with COPD.

The spectrum of the disease can be as long as twenty to thirty-five years and effective management can improve the patient's quality of life and lead to avoidance of the life of a "respiratory cripple" (MacLeod, 1977). Except for periods of

acute ventilatory distress or pulmonary infection, COPD patients are managed on an out-patient basis and the responsibility for compliance to the prescribed treatment lies with the patient and his family (Petty et al, 1973).

Compliance

Compliance with medical regimens on the part of the COPD patient is expected to be reflected in alterations in the behavior and life style of the patient for the remainder of that person's lifetime. The disease is not self-limiting and cure cannot be promised or provided. Diagnosis and prescription are normally made during the fifth decade of the patients life, by which time patterns of living have been well established and are changed only with consious and deliberate effort on the part of the patient.

Compliance is a vital factor in both controlling the progress of the disease process and in maintaining functional abilities which add to the quality of life for the individual with COPD. A number of factors combine to make compliance a particular problem for patients with COPD. Gradual onset of symptoms diminishes the patients recognition of the severity of the disease, and the treatment program to which the COPD patient is expected to comply is complex and frequently demands major changes in life style for both the individual with COPD and the patients family.

Many studies have been done in an effort to determine rates of compliance of various groups of patients to their prescribed

medical regimens. Reported compliance rates are often inconsistant and misleading with compliance rates of patients with acute, self-limiting illness compared to those of patients with a chronic illness (Marston, 1970). Operational definitions of compliance differ from one study to another and lack of objective measures of compliance provides an obstacle to the interpretation of research results. Nevertheless, it is generally acknowledged that the scope of noncompliant behavior is significant (Marston, 1970).

Based on a review of the literature, Zisook (1980) has estimated that as many as 93 percent of patients do not comply with recommended treatment regimens. It has been concluded by researchers that factors beyond pathophysiology and clinical manifestations of the disease are influential in determining the rate of compliance to medical regimens. One of those frequently studied factors which is independent of the disease is knowledge.

Knowledge

A large number of studies have shown that knowledge alone concerning disease and its treatment does not provide sufficient motivation on the part of the patient to produce compliant behavior (Bille, 1977; Davis, 1963; Vincent, 1971). Traditionally nurses have felt it to be important for the COPD patient to become aware of the basic anatomy and physiology of the lung in order to understand both his symptoms and the reasons for various aspects of his care. As necessitated by their treatment regimen, patients have additionally been instructed in the importance of

ceasing cigarette smoking, medications to relieve bronchospasm, avoidance of inhaled irritants, insurance of adequate hydration, avoidance of infection, breathing retraining, and exercise reconditioning.

The success of therapy is dependent upon the level of cooperation and compliance with the treatment regimen exhibited by the patient and the patients family (Cherniack and Lentzman, 1977). It is paramount in home treatment that the therapeutic regimen be followed as directed by the physician. It has been observed by Litman (1974) that once treatment is prescribed, it is assumed that the patient and family will follow through.

According to Moser (1980) education of the patient must be the central objective of all pulmonary rehabilitation programs. Cherniack and Lentzman (1977) also emphasize the vital nature of education of the COPD patient and state additionally that it is essential to continually reinforce all instructions given to patients. Although knowledge alone has not been found to be predictive of compliance it has been concluded by Caplan (1976) that knowledge is one factor which does have an indirect effect upon patient rates of compliance. Psychological factors have also been identified as being important in the outcome of treatment efforts for COPD patients (Agle et al, 1973).

Social Support

It has been acknowledged by behavioral scientists that adaptive processes are facilitated in the presence of a strong social or family support system. Caplan (1974) defines social

support systems as consisting of "enduring interpersonal ties to a group of people who can be relied upon to provide emotional sustenance, assistance and resources in times of need, who provide feedback, and who share standards and values". During the past three decades a substantial amount of research has been conducted which indicates that the availability and strength of social support provides a protective psychosocial influence against both physical and psychosocial stressors.

Cassell (1974) postulates that social support functions as a protective buffer and that an individual with an absent or disorganized social support system experiences an increased susceptibility to physical illness. Strong social support networks have been correlated with low mortality rates in a nine year longitudinal study of residents in Alameda County, California (Berkman and Syme, 1979). A number of studies have demonstrated that various indicators of social support are key predictors of patient compliance. Results of research done by Caplan (1976) at the University of Michigan strongly indicate that the answers to questions concerning the factors involved in patient compliance are more complex than current health education practices would suggest.

Perceived Impact of Disease

The perceived severity of illness and the number of alterations in daily life style have been found to be factors related to the degree of compliance in a number of research studies (Charney, 1967; Becker, 1972; Francis, 1969). The perceptions of

an individual with respect to the severity of his illness may differ from the clinical measures of the amount of physical dysfunction which is actually present. The behavior of the individual is a manifestation of the overall impact of illness, reflecting the effects of both clinical and subjective dimensions, as well as their interactive effects on daily activities. Measurement of an individuals behavior will therefore reflect the perceptions of the person in relation to the severity of his illness as well as the actual amount of clinical dysfunction which is present.

Relation to Nursing Theory

The goal of nursing in working with the patient who has COPD is to assist that person in achieving their maximum health potential. Four primary objectives are employed toward this end: (1) maintenance of the greatest possible function and integrity of the individual; (2) prevention of further limitation; (3) promotion of maximum quality of life; and (4) modification of behavior or environment to accomodate limitations and promote maximum function (Redman, 1971). Theorists in the field of nursing subscribe to the concept of holistic man, a being who affects and is affected by his environment (Rogers, 1970). Viewing the patient in this manner requires that the nurse develop a recognition of the importance of assessing both psychosocial and physiological factors as a part of planning and evaluating interventions for the COPD patient.

According to Rogers (1970) "positive health measures will be directed toward determining individual differences and assisting people to develop patterns of living coordinate with environmental changes rather than in conflict with them". It is imperative to recognize that the patient is an intergal participant in the intervention process and that the patient functions within the context of his environment.

The conceptual framework of nursing developed by Rogers closely parallels general system theory. Fundamental to the understanding of Roger's model are five basic assumptions about human beings. The model utilized for the development of this study is based upon these assumptions and Rogers framework of nursing.

The first assumption is that the human being is a unified whole possessing an individual integrity and manifesting characteristics that are more than and different from the sum of the parts (Rogers, 1970). For the purpose of this study both the COPD patient and the nurse are viewed as interacting individuals, capable of both releasing and receiving energy and information from one another.

Rogers' second assumption is that there exists a constant and continuous interchange of matter and energy between the individual and the environment. This assumption is characteristic of the definition of an open system developed by von Bertalanffy (von Bertalanffy, 1968).

The third assumption of Rogers framework holds that the life process of human beings evolves irreversibly and unidirectionally. This assumption is particularly relevant when considering the patient with a chronic, irreversible disease such as COPD.

Fourth of Rogers assumptions is that there exists a pattern and organization which identifies individuals and identifies their inovative wholeness. It is this assumption which necessitates the actions of the nurse in assessing characteristics which are unique to each individual with COPD.

The human capacity for abstraction and imagery, language and thought, sensation and emotion make up the fifth assumption of Rogers framework and additionally the opportunity for meaningful nursing interventions.

Using these five assumptions as a base, the life process of human beings becomes a phenomen of wholeness, of continuity, of dynamic and creative change (Rogers, 1970). The life process possesses its own unity and is inseparable from the environment. According to Rogers (1970), the science of nursing is directed toward describing the life process of humanity, and toward explaining and predicting the nature and direction of its development.

Increased understanding of the roles played by the patient's perceptions of the impact of their disease, the effects of their social support systems and their level of knowledge are important aspects of enhancing compliance potential. Assessment of the patient's strengths and limitations in areas known to effect

compliance will enable the nurse to plan appropriate intervention strategies with the patient. Aiding the patient in integrating a pattern of compliance into their own individual life style whould result in an improved health status and maximum quality of life for the patient.

Schematic Representation of the Conceptual Model

Both the factors common to all patients with COPD (pathophysiology, clinical manifestations and management) and the factors of knowledge, support and perceived impact of the disease which are unique to each individual are shown in Figure 3 to interact and exert an effect on the individuals degree of compliance. The degree of compliance exhibited by the COPD patient is additionally shown to exert an effect upon these factors.

The nurse is shown to possess knowledge of those factors common to all COPD patients (pathophysiology, clinical manifestations and management), which combined with the knowledge gained by assessment of those factors unique to each individual with COPD (level of knowledge, social support and perceived impact of disease), guide nursing interactions with the patient and assessment of the patients degree of compliance.

Both the nurse and the COPD patient are shown to effect and be effected by one another through their interactions.

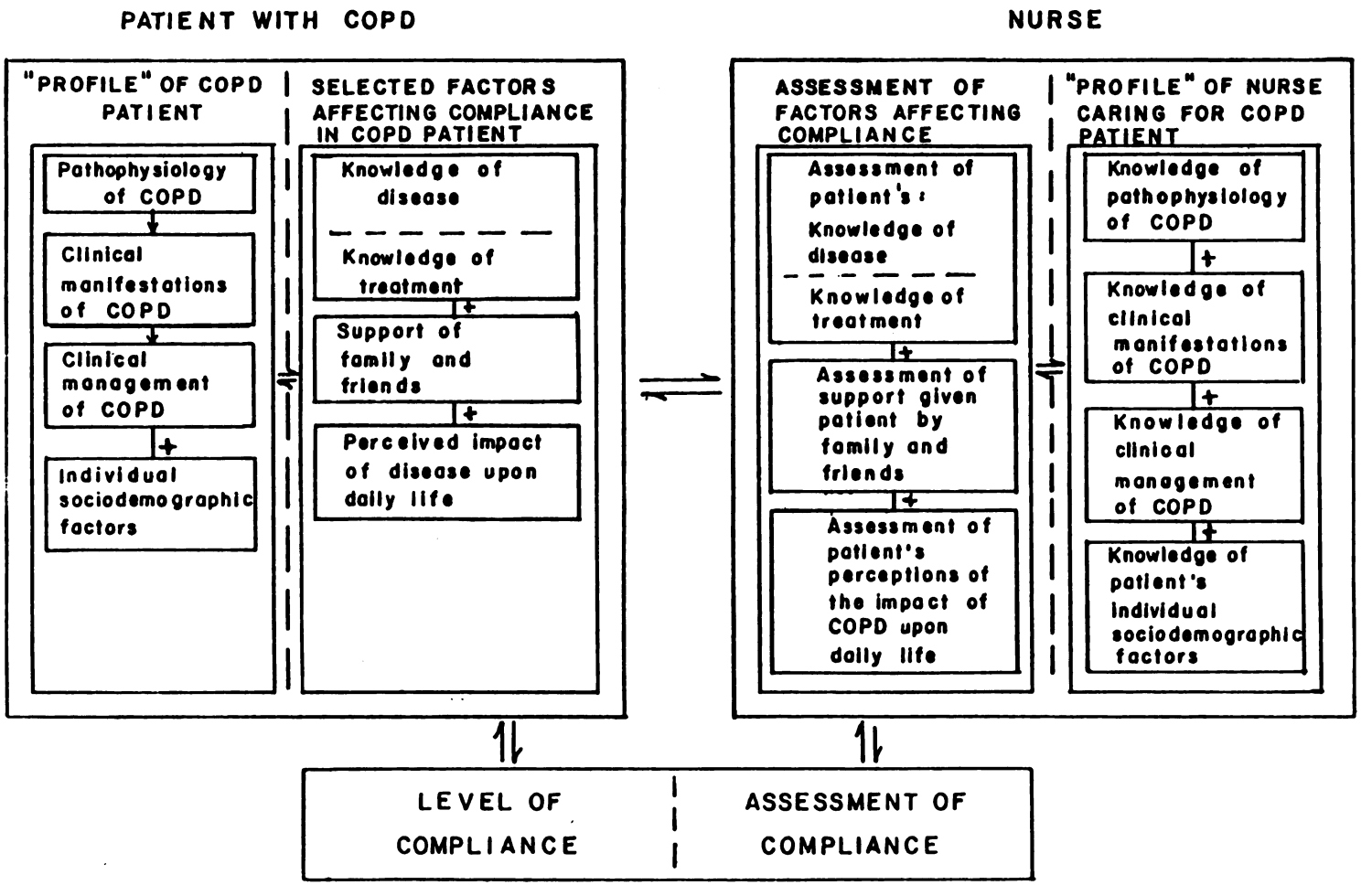

Figure 3: Schematic Representation of Conceptual Model.

CHAPTER III

REVIEW OF THE LITERATURE

Introduction

The research question posed in this study is concerned with the determination of relationships between compliance, knowledge of disease, knowledge of treatment, social support and perceived impact of disease in a group of patients with COPD. The focus of the review of the literature will be an in-depth review of compliance literature, specifically addressing the areas of knowledge, social support and perceived impact of disease. The discussion of compliance will be limited to recent research which is pertinent to compliance in patients who have chronic diseases as opposed to acute illness.

Compliance as a Health Care Problem

The definition of compliance most frequently ascribed to by researchers is "the extent to which the patient's behavior (in terms of taking medications, following diets, or executing other life-style changes) coincides with the medical prescription" (Marston, 1970; Sackett and Haynes, 1976; Becker, 1974). Sackett (1976), acknowledging that the word "compliance" carries with it the connotation of a dictatorial attitude on the part of health care providers, encourages continued use of the term to describe

patient behaviors in relation to health care prescriptions, feeling that the "precision and rigor" implied by the term are highly appropriate for this area of research.

Noncompliant patient behaviors have existed since the evolution of one person caring for the health care needs of his fellow man. Hippocrates is reported to have observed that "(the physician) should keep aware of the fact that patients often lie when they state that they have taken certain medicines" (Gordis, 1976). In more recent times noncompliance has been acknowledged as a health care problem and has been studied extensively during the past thirty years.

The issue of compliant behavior on the part of patients has intensified as the care of patients in hospitals has become increasingly focused upon acute care. Patients who previously may have been hospitalized and whose care would have been carefully supervised are now assuming responsibility for their own care in increasing numbers.

Noncompliant patient behaviors are a frustration to the health care provider who is attempting to evaluate the efficacy of the treatment regimen that they have recommended to the patient. Because of noncompliant behaviors many patients are receiving less than maximal benefit from the health care they have sought. Matthews (1975) additionally cites noncompliant behavior as functioning as a significant barrier hindering the implementation of many of the important advances made by medical science in the past several decades.

A multitude of studies have been done in efforts to ascertain predictors of noncompliant behaviors and to develop a theoretical model for explaining compliance. Several extensive reviews of compliance research studies have been published (Marston, 1970; Mitchell, 1974; Sackett and Haynes, 1976).

Several research studies indicate that levels of compliance are effected by the nature of the illness and the treatment. Stone (1979) cites evidence that compliance rates are lower in patients who have a chronic disease than for those with an acute illness, especially in instances where the acute illness is accompanied by overt symptoms. In a study of cardiac patients, Davis and Eichhorn (1963) observed that participants made those changes which required the least adjustment in their lives. Hulka et al (1976), in research involving diabetes and congestive heart disease patients, found medication taking errors of less than 15 percent when only one drug was prescribed. The error rate increased to 35 percent for patients who had five or more drugs prescribed as part of their treatment regimen.

Measures of Compliance

In the compliance studies which have been conducted in the past a number of different methods have been used to measure the degree of compliant behavior exhibited by patients. The most objective measures of patient compliance used in research studies have been blood tests and drug excretion tests. In an exhaustive review of the literature, Marston (1970) reports that even those

criterion as exacting as drug excretion testing or blood tests have presented difficulties in an accurate estimate of patient compliance. Although the techniques for determining patient compliance, drug excretion tests or blood tests, have been the same the operationalized definition of compliance has varied from one study to the next. Marston (1970) reports that some researchers have based their determination of compliant behavior upon one urine test, collected either at an out-patient clinic or at an unannounced home visit to the patient, while others have used a series of urine tests upon which to base their estimates of patient compliance with drug taking recommendations. Gordis (1976) additionally points out that even when a series of physiologic measures are used there is a wide variation in the percentage of negative tests which will be used to differentiate between behavior which is compliant or noncompliant, ranging from 50 percent to 100 percent positive urine tests as being indicative of compliance in various studies.

Another direct but somewhat less objective method of determining patient compliance has been the use of pill counts for patients who have had medication prescribed as part of their therapeutic regimen. Use of this method has required that researchers be dependent upon the patient to remember to return their supply of medication for the count to take place. As with blood tests or drug excretion tests there has been a wide variation in the percent of deviation from 100 percent of the medication being used which would be interpreted as compliant

behavior on the part of the patient. These variations in the manner in which compliance is operationalized have made comparisons between different studies perplexing if not impossible (Marston, 1970).

Other measures of patient compliance which are detailed in Marston's (1970) review of compliance literature include the number of follow-throughs of referrals, the numbers of patients who remain under medical supervision, the direct observation of patients, and self-report on the part of patients. With each of these methods there remains variation in the criterion used to define compliant behavior.

Self-report by the patient has been measured both through personal interviews and by the use of written questionnaires. Questionnaires used have employed both open-ended questions, closed-ended questions, or a combination of both types of questions. Some researchers are reported to have utilized a combination of two or more types of measures in an effort to ascertain levels of compliance in groups of patients (Marston, 1970; Gordis, 1976).

Gordis (1976) cites eight studies which were designed to utilize both pill counts and interviews to measure patient compliance to medication taking. In analyzing the results of those studies Gordis (1976) concludes that in all studies patients who were compliant tended to overestimate in interviews the degree of their compliance, while noncompliant behaviors were consistantly understated by patients. No study cited by

Gordis found compliant patients misrepresenting themselves as noncompliant, nor any evidence that patients who report themselves as noncompliant were lying. Thus, Gordis concludes, if the objective of the researcher is to identify noncompliers many can be identified by indirect methods such as questionnaire or interview while some will misrepresent themselves as compliers.

The fact that practical constraints must play a part in the measurement of patient behaviors is emphasized by both Marston (1970) and Gordis (1976). Many aspects of the therapeutic regimen for the COPD patient, such as exercise, avoidance of inhaled irritants, breathing techniques, and relaxation techniques are not compatible with direct physiologic measurement techniques.

The time and cost efficiency in measuring directly only one portion of the therapeutic regimen, such as medication taking behaviors, must also play a part in the decision as to the method of measurement to be used in a compliance study. Although there is a loss of precision resulting from combining compliance scores for more than one recommendation (such as smoking, medications, exercise and relaxation) there does emerge a more comprehensive picture of the patients degree of compliance to a multifacated regimen.

Polit and Hungler (1978) cite as important advantages of questionnaires in studies where direct methods of measure are not applicable the following considerations: (1) questionnaires are relatively inexpensive, (2) questionnaires offer the possibility

of complete anonymity to the respondent, and (3) the absence of an interviewer assures the study freedom from any interviewer bias.

Compliance in the broadest sense is concerned with the extent to which a patient follows the total treatment regimen recommended by health care providers. A number of methods have been devised by researchers for the purpose of measuring patient compliance. More direct methods, such as drug excretion tests, blood tests, or a count of follow-up visits have the limitation of reflecting only a portion of the patients compliance behavior. More subjective methods, such as interviews or questionnaires, are limited in their degree of accuracy but reflect the patients behavior in relation to the total treatment regimen.

Predictors of Compliant Behavior

A large number of research studies have been conducted in an effort to understand factors which might function as predictors of compliant behaviors in patients. Early studies concentrated on the gathering of sociodemographic data and an attempt to correlate those data with noncompliant behaviors. Later research became increasingly complex and attempted to gather information regarding social and psychological factors, variations in compliance behavior accompanying various types of illnesses, and factors surrounding the interactions of the patient and the health care provider.

Sociodemographic Factors

Research studies have been conducted in an attempt to correlate such factors as age, sex, level of education, race, religion and marital status to the level of compliant behavior exhibited by patients.

In a study of 24 myocardial infarction patients Bille (1977) found a statistically significant correlation ($r = .49$, $p < .03$) between age and compliance behavior, such that the older patients attained higher reported compliance with the medical regimen prescribed by their doctors. Bille asked the patient to estimate the extent to which he felt that he had followed each piece of advice in the month since he was discharged from the hospital. Except for age, further demographic variables were not reported by Bille.

A study of appointment keeping behaviors of 159 chronically ill Negro patients conducted by Tagiacozzo and Ima (1970) found that sex, age, occupation, income and welfare status did not relate to patients appointment keeping behaviors. Davis and Eichhorn (1963) conducted a longitudinal study of 369 males with cardiovascular impairment. Interviews and medical examinations were used as measures of the patients degree of acceptance of their medical regimen. No relationship was found between level of education and compliance in the study population. Younger (below 45 years of age) patients were found to continue a pattern of compliance over the four year study period with greater

frequency than did patients over the age of 45 years although the difference was not great enough to be statistically significant.

Nelson et al (1978) studied patient noncompliance in a group of 142 patients under treatment for hypertension. Compliance was measured by a combination of several criteria: self-report of medication taking behavior, appointment keeping, and blood pressure control. Analysis was done using a multivariate log linear technique to control confounding. Demographic variables measured in Nelson's study population included age, sex, race, education and current employment status. Of these demographic factors, age was found to be significantly related (d = 26 percent) with self-reported medication taking, with patients 50 years of age or older being significantly more likely to report compliance in drug taking than those patients younger than 50 years or age. Patients reporting less than a high school education experienced significantly higher (d = 21 percent) levels of blood pressure control than did high school graduates. With regard to appointment keeping, Nelson found a significant positive correlation with patients age 50 or above (d = 33 percent) and with patients who were currently employed (d = 18 percent). It was a part of the conclusion of Nelson's study that the health care provider should anticipate a higher risk of noncompliance among younger patients.

In a study of glaucoma patients and their use of prescribed eye drops, Vincent (1971) reports that married women exhibited a

lesser degree of compliance than did widows, and that women aged 45 to 64 were more compliant than men. Additionally, Vincent found that patients of the Catholic faith 59 percent were compliant with the prescribed use of eye drops while only 38 percent of those patients who were protestant reported compliance. In relation to the level of education of patients, 50 percent of those patients who had less than eighth grade education were compliant, 32 percent of those patients who had completed eighth through eleventh grades were compliant, and 42 percent of the patients who had completed twelfth grade or more reported that they had used the eye drops as prescribed. Fifty-seven percent of the caucasian patients who participated in Vincent's study reported compliance while 33 percent of the non-white subjects reported that they had followed the medical recommendations in the use of eye drops. Only race and religion were found to be statistically significant at the .05 level in Vincent's study of demographic factors and compliance.

Haynes and Sackett's (1974) review of 190 research studies dealing with demographic features of the patient and compliance found that 141 (73 percent) concluded that there was no relationship between compliance and demographic variables, while 49 studies (26 percent) reported some relationships. Haynes (1976) suggests that the effect of demographic factors might appear to be much greater upon access to health services than upon compliance.

Diers (1979) emphasizes the importance of a complete and precise description of the sample in relation-searching studies. Borg and Gall (1979) additionally cite the importance of an adequate description of the sample used in research studies and state that "one of the major pitfalls of correlational studies is inadequate description of sample characteristics".

Fagerhaugh (1963) interviewed 22 emphysema patients in an effort to learn the effect of their disease upon daily living patterns. Only sex of the patient was reported as a descriptor of the group of patients interviewed. In the evaluation of an in-hospital program for the rehabilitation of COPD patients, Kimbel (1971) used sex, average age and severity of disease as descriptors of two sample groups of 46 and 61 patients.

Brown et al (1981) compared measures of life satisfaction for a group of 32 patients with COPD and 51 patients with coronary artery disease. Demographic data was not reported for either group of patients. Black and Mitchell (1977) used written tests to evaluate a patient education program for 65 patients with COPD. The sample used by Black and Mitchell was described according to age, sex, level of education and occupation.

No published studies of levels of compliance were found for any group of patients with COPD. Although some researchers have described sample groups of COPD patients according to demographic characteristics (Burrows and Earle, 1969; Kass et al, 1975; Black and Mitchell, 1977; Perry, 1981), others have reported so

little demographic data that it is not possible to describe the study sample in relation to the general population of COPD patients (Brown et al, 1981; Agle and Baum, 1977; Fagerhaugh, 1963).

The review of compliance literature published by Sackett and Haynes (1974) emphasizes that demographic characteristics of patients are unreliable predictors of compliance behavior. Nevertheless, instructional texts in research design stress the importance of a complete description of sociodemographic characteristics of participants in research studies. Although demographic factors are of controversial value as predictors of compliance behavior their value as descriptors of sample characteristics is undisputed.

Knowledge

The role of knowledge in relation to patient levels of compliance behavior has been studied extensively and there has been a lack of concordance in the results reported by these studies. Sackett and Haynes (1976) report reviewing six studies which concluded a positive relation between patients knowledge and compliance and an additional eight studies showing no such relationship.

In an extensive review of compliance literature Marston (1970) cites two studies which have reported a positive association between compliance and knowledge and five studies which showed no relationship to exist. Marston concludes that knowledge alone concerning illness and its treatment has not

been shown to have an unqualified association with compliance behaviors.

Caplan et al (1976) in a longitudinal study of hypertensive patients at the University of Michigan (n = 200) noted that the patients who had the highest knowledge levels regarding their treatment regimens also had the lowest blood pressures. Additionally, Caplan reported that knowledge of the treatment regimen seemed to be more important than knowledge regarding the nature of hypertension in relation to blood pressure control and compliance to the therapeutic regimen.

Given et al (1978) studied the effect of patients knowledge of their medications on levels of compliance with medication taking in a group of 88 hypertensive patients. Results of Given's study showed patient's knowledge of their medications was positively related to their level of compliance in drug taking ($p < .05$) both at the beginning and end of the five month study period.

Tagiacozzo and Ima (1970) studied compliance in appointment keeping behaviors in 159 Negro patients with hypertension and/or diabetes. A test to ascertain knowledge levels of four common chronic diseases was given to each participant upon the first encounter. All patients were given the same test, regardless of diagnosis, and records were subsequently surveyed to determine the extent of compliance in clinic attendance behaviors. After four clinic visits a statistically significant ($x^2 = 13.08$, $df = 1$, $p < .001$) relationship between knowledge and appointment

keeping was observed, with those patients possessing low knowledge less likely to continue keeping clinic appointments than those patients with higher levels of knowledge. The correlation between knowledge and compliance was modified by a patients past experience with illness, level of anxiety, and perceptions as to the degree to which the illness they possessed interferred with their daily life.

In a study of 24 myocardial infarction patients Bille (1977) found no statistically significant correlation between the patients levels of knowledge and compliance. McKenney et al (1973) studied the effect of clinical pharmacy services on patients with essential hypertension. Results of the experimental services provided to 25 patients were a significant increase in the patients knowledge of hypertension ($p<.001$), accompanied by a significant increase in compliance levels and blood pressure control ($p<.001$).

Sackett et al (1975) conducted a randomized controlled trial to increase compliance with antihypertensive regimens in a group of 230 men. The experimental group which received intensive instruction showed an increase in knowledge of hypertension but showed no greater increases in compliance rates than the control group.

Tirrell and Hart (1980) studied health knowledge and exercise compliance following coronary bypass in semi-structured home interviews with 32 post surgical patients. Knowledge of the disease process was not measured in this study and although no

statistics are reported, the authors cite deficits in the patients knowledge of their regimens. The authors state that "relationships between knowledge of regimen and compliance with that regimen are not at a level that would allow for reliable clinical prediction. However, the findings did indicate that knowledge seemed to be acting as an enabling factor in compliance".

Vincent (1971) reported on research conducted with a group of 62 outpatients who had glaucoma and factors relating to their level of compliance in using eye drops as prescribed. Vincent found that being aware of the fact that glaucoma can cause blindness and that the eye drops can prevent this blindness did not discriminate between compliers and noncompliers.

Written tests were used by Black and Mitchell (1977) to determine knowledge levels of COPD patients (n = 30) in the evaluation of a patient education program. This study did not attempt to relate knowledge levels to the compliance rates of patients. No compliance studies involving knowledge of patients with COPD were located in the literature.

Haynes (1976) concludes in a review of compliance literature that "while it is obvious that a patient who does not know the therapeutic instructions cannot comply, it is becomming equally clear that the proportion of patients who fail to comply because they lack knowledge is small indeed". In a more recent overview of compliance literature Kirscht and Rosenstock (1979) include knowledge regarding recommendations and their purpose as one of those factors most associated with high levels of compliance.

Social Support

Social support has been widely acknowledged as a factor in the health and well-being of patients. Haynes and Sackett (1979) reviewed 22 research articles in shich support relevant variables were measured in relation to patient levels of compliance. One study was reported which gave evidence contrary to the hypothesis that social support is positively associated with compliance, six studies found no association and 15 reported positive relationships.

Norbeck (1981) cites a lack of conceptual agreement among researchers regarding both the definition of social support and the manner in which it functions in relation to health and illness. The multidimensional nature of social support is endorsed by all of the researchers who have utilized social support as a study variable.

Cobb (1976) defined social support as information that leads persons to believe that they are loved, esteemed and that they belong to a network of communication and mutual obligation. Caplan (1976, 1979) utilizes Cobb's definition but further deliniates support into that which is tangible and that which is intangible (emotional).

Tangible support is described by Caplan as behavior which provides a person with goods which have mass or energy (objective) or the persons perceptions and report of such behavior (subjective). Intangible or emotional support is behavior which is directed toward providing the person with cognitions (values,

attitudes, beliefs, perceptions) and towards inducing affective states that are hypothesized to promote well-being (objective) or a persons perceptions of such behaviors (subjective).

In one early longitudinal study, Davis and Eichhorn (1963) studied compliance rates of cardiac patients as they persisted over a four year time span. In this study group (n = 369) 52 percent reported being highly influenced by family and friends. Fifty percent of those patients who reported being highly influenced by friends and relatives continued compliant behavior over the four years as compared to 34 percent of those patients who reported that they were only slightly influenced by family and friends.

In another early study New et al (1968) conducted research on the support structure of a group of 48 heart and stroke patients following their hospital discharge. Self-evaluation by patients of their capabilities in eleven activities of daily living according to the scale developed by Katz were compared to evaluations by significant others of the patients level of function. In these interviews New found 45.7 percent agreement between the patients and significant others concerning the dependency status of the patient. Central to the premise of New's research was the belief that agreement between patient and significant other was indicative of support being available to the patient, in that the supportive person held beliefs in keeping with the patient in regard to their physical capabilities. Patients levels of compliance to therapeutic regimens were not

measured in New's research.

The effect of pharmacy services on a group of 50 patients with hypertension was studied by McKenney et al (1973). Patients were randomly selected for a control group (n = 25) or a study group (n = 25) where each subject was seen once monthly by a pharmacist for a period of five months. The pharmacist evaluated problems reported by patients, therapeutic responses to medicinal and diet prescriptions, and served as an additional support person for the patient. Patients in the control group received their customary care without seeing the pharmacist. Compliance was analyzed using a two-way contingency table and chi square analysis. Compliance rates in the study group were significantly greater (x^2 = 14.487, $p < .001$) than for subjects in the control group.

The effect of social support in preventing joint swelling precipitated by job loss in patients suffering from arthritis was the focus of research conducted by Cobb (1976). He found that four percent of the men who received such support had two or more swollen joints, in contrast to 41 percent of the men receiving little support. Compliance to the therapeutic regimen was not measured in Cobb's study.

Haynes et al (1976) reported on a group of 38 Canadian steelworkers who were hypertensive and were neither compliant with their medication regimens nor at goal blood pressure six months after starting treatment. Lay support in the form of encouragement and reinforcement were provided every two weeks to

subjects in the study group whose average compliance had risen by 21.3 percent over a six month period while average compliance in the control group fell by 1.5 percent.

Nelson et al (1978) studied a group of 142 patients under treatment for hypertension to determine levels of compliance. Interviews with patients included five items concerning the subjects rating of the frequency that family members reminded them to take prescribed medications and how much they assisted the patient in following the treatment plan. Multivariate analysis of data did not indicate a correlation between social support as measured by these five items and the subjects level of compliance.

Research on patient compliance with antihypertensive medication was conducted by Hershey et al (1980). Hershey used a questionnaire to measure components of the Health Belief Model and interviews to determine patients compliance with medication taking prescriptions. A random sample of 132 patients from existing hypertension programs revealed no significant relationship between compliance and support given the patient by their family. Support given by the family was measured by one item on the questionnaire which was administered.

Caplan et al (1976) reported on a pilot study with the goal of examining relationships between patient perceptions of the nature of the regimen, the health care environment, other environments of the patient, self-perceptions of competence, psychological well-being, and indicators of compliance.

Primary among Caplan's measures of the patients environment was concern with measures of social support. Social support of the spouse was measured by two items on the questionnaire, three questions addressed the number of friends and social visits reported by the patient, and four questions were included to determine the frequency of supportive behaviors directed toward the patient. Findings indicated that social support from the spouse was associated with low levels of depression ($\gamma = -.33$, $p<.05$). Social support from the spouse and physician tended to be highest for patients who were highly motivated toward compliance.

Experimental research designed to test the theory that emotional support should operate to increase compliance was reported on by Caplan et al (1979). A sample of 483 hypertensive patients were randomly assigned to a control group, a social support group and a partner group. In the social support group especially prepared nurses met with the patient, explained the regimen and how to follow it, provided encouragement by praising compliant behavior, provided the patient the opportunity to express anxiety or concern. In the partner group a partner selected by the patient met with the nurse who explained the patients regimen, benefits to the patient and family of the patients compliance, ways of helping the patient achieve compliance, and the need to provide encouragement and reassurance to the patient. A positive correlation was found between social support from the nurse in the social support experimental

group and self-reported compliance (r = .30, p<.05). Caplan et al (1979) reported that compliance appeared to determine support as well as be determined by it.

Knowledge of regimen, compliance, regimen difficulty, blood pressure, social support, somatic complaints, depression and motivation to comply were additionally measured by Caplan et al (1979). Motivation to comply was measured by an index composed of regimen difficulty, self-competence, belief that compliance is worthwhile, perceived seriousness of noncompliance, belief that hypertension is present and belief that the blood pressure is elevated. Strong correlations between compliance and social support were not reported but in the conclusion of the report of research Caplan stated that "compliance was highest when both social support and motivation were present".

Retrospective interview data obtained from 314 patients was used by Davidson (1981) to study social support and post burn adjustment. Using social support and network measures advanced by Cobb, Davidson found social support to be related to self-esteem (r = .40; p<.01), life satisfaction (r = .37; p<.01), and social and recreational activities (r = .14; p<.01). Compliance was not a variable which was measured in this study.

Brown et al (1981) conducted research aimed at explaining differences in life satisfaction of persons with different chronic diseases. Through stepwise multiple regression, an assessment was made of the effects of social activity, perceived health, health locus of control and degree of disability on the

life satisfaction of patients with coronary artery disease (n = 51) and patients with COPD (n = 32). Social activity emerged as the single best predictor of life satisfaction both for patients with coronary artery disease (r = .31; $p < .05$) and for patients with COPD (r = .57; $p < .05$). Compliance was not addressed in this research.

In a longitudinal study of 432 hypertensive patients Glanz et al (1981) used social support as one of four educational interventions aimed at producing change in compliance behavior. Compliance, as measured by patients self-report when interviewed, was reported by 36.9 percent of patients as having been positively effected by the social support intervention which involved a meeting with the patient, nurse and a social support person during which the social support person was instructed by the nurse in specific aspects of the patients regimen and their assistance was solicitated in aiding the patient in carrying out the regimen.

Interviews conducted by Barstow (1974) with a sample of emphysema patients resulted in the reported finding that the "single most important influence of adjustment was the presence of a supportive significant other in the home". Barstow did not report on measures used in gathering information from patients nor are study statistics reported. No measure of compliance behavior is reported in Barstow's study.

Avery et al (1972), as reported by Matthews and Hingson, examined the use of social support techniques with asthmatic

patients. Comparing asthmatic patients placed in discussion groups focusing on the ways the patients could prevent asthma attacks with controls drawn from the same emergency room population they found that subsequent visits to the emergency room by patients in the discussion groups during the next four months were but half the number made by controls.

DeAraujo et al (1974) studied the average daily steriod doses needed to stabalize severe asthmatic patients (n = 36) in relation to stress and social support. Psychological assets of patients were measured using the Berle Index. Patients with little stress and much support needed 5 mg/day and those with little stress and little support needed 6.7 mg/day. Patients with much stress and much support needed 5.6 mg/day and those with much stress and little support needed 19.6 mg/day. A strong negative correlation ($r = -.564$; $p < .001$) was observed between psychological assets and steroid dosage.

No studies relating social support and compliance in groups of patients with COPD were located in the literature. Several studies designed to relate social support and compliance in other chronic disease populations were noted to include only from one to seven questions as a measure for social support. Other studies did not detail their measures of social support. Weissman et al (1981) reviewed twelve scales developed since 1975 for the assessment of social support. Of these dozen recent assessment tools, eleven were designed specifically to diagnose or evaluate psychiatric populations while one was

developed to measure the impact of illness on significant others. Although assessment of social support has not been described or measured in a consistant manner, more studies have reported positive correlations between social support and compliance (Davis and Eichhorn, 1963; McKenney et al, 1973; Haynes, 1976; Caplan et al, 1976, 1979; Glanz et al, 1981) than studies reporting no correlation (Nelson et al, 1978; Hershey et al, 1980).

Perceived Impact of Disease

Perceived impact of disease is a measure of the number of changes in usual activities of daily living which the patient attributes to the disease and its symptoms. The perceptions of an individual with respect to the severity of their illness may differ from the clinical measures of the amount of physical dysfunction which is actually present. The behavior of the individual is viewed as a manifestation of the overall impact of illness, reflecting the effects of both clinican and subjective dimensions, as well as their interactive effects, on daily activities.

German (1981) in a review of measures of functional disability cites three specific areas which have been addressed in the existing measures of functional disability. First, measurement of the ability to perform activities of daily living such as Katz's Index of Activities of Daily Living (Katz and Akpom, 1979) which measures capabilities in batheing, dressing, toileting, transfer, continence, and feeding. Secondly is the

measurement of the degree of mobility of an individual such as the Mobility Scale (Densen and Jones, 1976) which assesses five levels of mobility from the ability to go outside without help to confinement to bed. The third area involves assessment of the mental state of individuals, such as the Mini-Mental State measure developed at Johns Hopkins by Folstein et al (1975) which rates orientation to time and place.

Bergner et al (1981) report on a Sickness Impact Profile which has been the subject of their research for a period of six years. The Sickness Impact Profile was designed to be a measure of perceived health status, which would be broadly applicable across types and severities of illnesses and across demographic and cultural subgroups. The final revision of the Sickness Impact Profile resulted in 136 questions designed to measure three seperate dimensions of the patients perceptions about their illness. (1) Dimension I: including physical categories such as ambulation, mobility, body care and movement. (2) Dimension II: including psychosocial categories such as social interaction, alertness behavior, emotional behavior and communication. (3) Dimension III: including independent categories such as sleep and rest, eating, work, home management and recreation.

In a field test of the final revision of the Sickness Impact Profile utilizing a stratified random sample of 696 individuals Bergner et al (1981) report two reliability measures. Test-retest reliability yielded an $r = .97$ and internal consistancy

analysis resulted in an r = .94. Validity measures included correlating self-assessment by patients with the results of the Sickness Impact Profile (γ = .56) and correlating results of the National Health Interview with the Sickness Impact Profile (γ = .52). According to the final report of the revision of the Sickness Impact Profile the instrument is currently being experimentally utilized as an outcome measure in clinical trials of therapy for a group of COPD patients.

LaRue et al (1979) conducted research to study the relationships of physicians ratings of health with self ratings in a sample of 69 aged individuals (mean age 84.25). Self-reports of health of the participants were significantly correlated with the ratings of the physicians which were based on physical examinations of the study participants ($\emptyset$ = .409, $x^2(1) = 10.69$, $p < .01$). The authors conclude that the results of the research suggest that self-reports can provide a valid means of health status assessment.

Barofsky et al (1979) studied compliance in relation to quality of life assessment of 103 soft tissue sarcoma patients. Quality of life was defined as consisting of (1) impact statements, including level of independence, measures of mobility and frequency of interpersonal conflict, and (2) statements of well-being, including subjective assessment of happiness, feelings of achievement and degree of identification with other persons or groups of persons. Using chi square statistics Barofsky found a significant relationship between compliance

(those patients remaining in treatment) and an increased number of changes in activities of daily living since onset of the disease ($p < .025$).

Milazzo reported on a study of compliance and perceived illness in a group of 18 COPD patients at the May 1981 meeting of the American Lung Association. Unpublished data from Milazzo's study revealed a compliance rate to medication taking ranging from 85 percent to 275 percent. Compliance was measured by the numbers of entries in diarys kept by patients of medication utilized in the period of one week, with percentages over 100 percent indicating use of medications in excess of prescribed dosages. Compliance to non-medication treatments including exercise, postural drainage and utilization of diaphragmatic breathing techniques averaged 63 percent in the group of COPD patients studied by Milazzo. Perceived illness was measured by use of a structured interview guide modified from Radius *et al* (1978). Although statistics were not reported, the patients perceptions of their illness was classified by the investigator as "very high".

Studies relating compliance to the perceived impact of disease were not located for groups of patients with chronic diseases. One study of compliance in a group of patients with a simple acute illness was found to have contained measures which include some aspects of perceived impact of disease.

Becker *et al* (1972) studied motivations as predictors of compliance behavior in a group of 125 mothers whose children had

been treated for otitis media and given prescriptions for a ten day course of oral penicillin. Included in measures of motivation were the mothers perception of the problems that the illness may have created for the mother and the child. Mothers who perceived high levels of interference caused by the childs illness were significantly more likely to administer medication as prescribed ($\gamma = .30$, $p<.05$) and to keep future clinic appointments for their child ($\gamma = .32$, $p<.05$).

Although perceived impact of disease as defined in this study has not been the subject of research regarding compliance related variables, several studies have been located which contain aspects of perceived impact of disease. Becker et al (1972) and Barofsky et al (1979) have published compliance study results which have included variables similar to perceived impact of disease and Milazzo's unpublished research included a measure of perceived illness.

Conclusion

Compliance is a widely recognized problem in the area of health care which has been the subject of extensive research. Substantial difficulty exsists in the interpretation of the findings of compliance research as the result of three primary factors:

1) The frequency of absent or inadequate descriptions of characteristics of the sample.
2) Lack of concordance in the operational definition of compliance.

3) Incomplete descriptions of measures of compliance and factors being studied in relation to compliance.

Few studies were located which addressed the perceptions of patients in relation to the impact of disease upon their usual activities of daily living. Studies of compliance and compliance related variables in groups of patients with COPD were not located in a search of the literature. One unpublished study of levels of compliance in COPD patients would indicate that compliance in this population is an issue meriting further inspection.

CHAPTER IV

METHODOLOGY

Overview

Levels of stated compliance to the therapeutic regimen in a group of patients with COPD were examined in this study. Knowledge of disease, knowledge of treatment, social support and perceived impact of the disease were hypothesized to be related to stated compliance and were measured as major study variables. Information concerning the patients sociodemographic status and clinical status of COPD were collected in order that the sample might be described and the presence of possible modifying variables might be ascertained.

A discussion of the methodology and procedures utilized in this research study is presented in this chapter. The sample, collection sites, questionnaires, human rights protection procedures, and procedures for statistical analysis are discussed in detail.

Sample

The study participants were a convenience sample of 31 COPD patients who voluntarily agreed to complete study questionnaires and met the following criteria:

(1) were medically diagnosed as having emphysema, chronic bronchitis, or COPD;

(2) were able to read and write in the English language;

(3) were age 50 to 70 years;

(4) had a telephone in their place of residence;

(5) were not documented as being alcoholic or psychotic; and

(6) were not documented as having cancer or any other terminal disease.

Because the sample was voluntary and was not the result of random selection the results of this study can be generalized only to COPD patients possessing characteristics which are like those of the sample. Results should not be considered to be representative of all patients with COPD.

Data Collection Sites

Three sites were utilized in obtaining subjects for this study. The procedure utilized in procuring participants was identical at all of the sites. All sites were located in a mid-western urban area with a population of approximately 200,000 (U. S. Statistical Abstracts, 1980).

Site I:

Ten study participants were obtained from patients hospitalized on a medical respiratory unit within a 250 bed acute care hospital. Approval and written permission was obtained from the hospital research committee and the executive committee of the board of the hospital (Appendix A) to allow patients to be contacted by hospital employed staff nurses in behalf of the researcher for the purpose of explaining the research study.

Site II:

Seven participants were obtained from an out-patient pulmonary rehabilitation program conducted by two physicians and one nurse in a second clinical setting. This clinic operated out of a 246 bed osteopathic hospital. The focus of this pulmonary rehabilitation program was exercise reconditioning for COPD patients and patient education was managed on a one-to-one basis with the individual patient and the pulmonary nurse. Approval and permission to obtain patients from this site were granted by both of the participating physicians and the hospital Director of Nursing.

Site III:

Fourteen out-patients volunteered to participate in the study from a group of 27 patients taking part in an eight week pulmonary rehabilitation and education program conducted by an interdisciplinary team at the same hospital from which in-patients were contacted. The rehabilitation and education program consisted of a series of eight one hour group meetings during which information was presented and questions were answered by members of the pulmonary rehabilitation team. The pulmonary team consisted of a physician, a physicians assistant, a respiratory therapist, a social worker, a pharmacist, and a dietition. Approval and permission to obtain subjects from this site were obtained from the director of the pulmonary rehabilitation team.

Data Collection Procedure

The nurse (or physicians assistant in the case of Site III) ascertained the patients appropriateness for inclusion in the study by using a written checklist (Appendix B) furnished by the investigator. The procedure for contacting patients and obtaining consents is depicted in the Procedure Flowchart in Figure 4.

It was explained to the patient that in an effort to help nurses learn more effective methods of helping patients with COPD a study was being conducted by Sharon King, RN, a graduate student at Michigan State University in the College of Nursing. It was further explained that becoming involved in the study would entail answering questions about COPD and about their treatment on a written questionnaire which would take about 30 minutes of their time. Patients were assured that their names and all of the information on the questionnaire would be kept confidential. The patients were informed that some questions would be asked on the questionnaire regarding their age, income, length of illness, etc.

The patients were informed that becoming a participant in the study would not change the medical treatment that they were receiving and that they might withdraw from the study at any time. A letter explaining the study and reiterating the above information was left with the patient along with a consent form to be signed and returned to the nurse (or physicians assistant) for patients choosing to participate in the study (Appendix C).

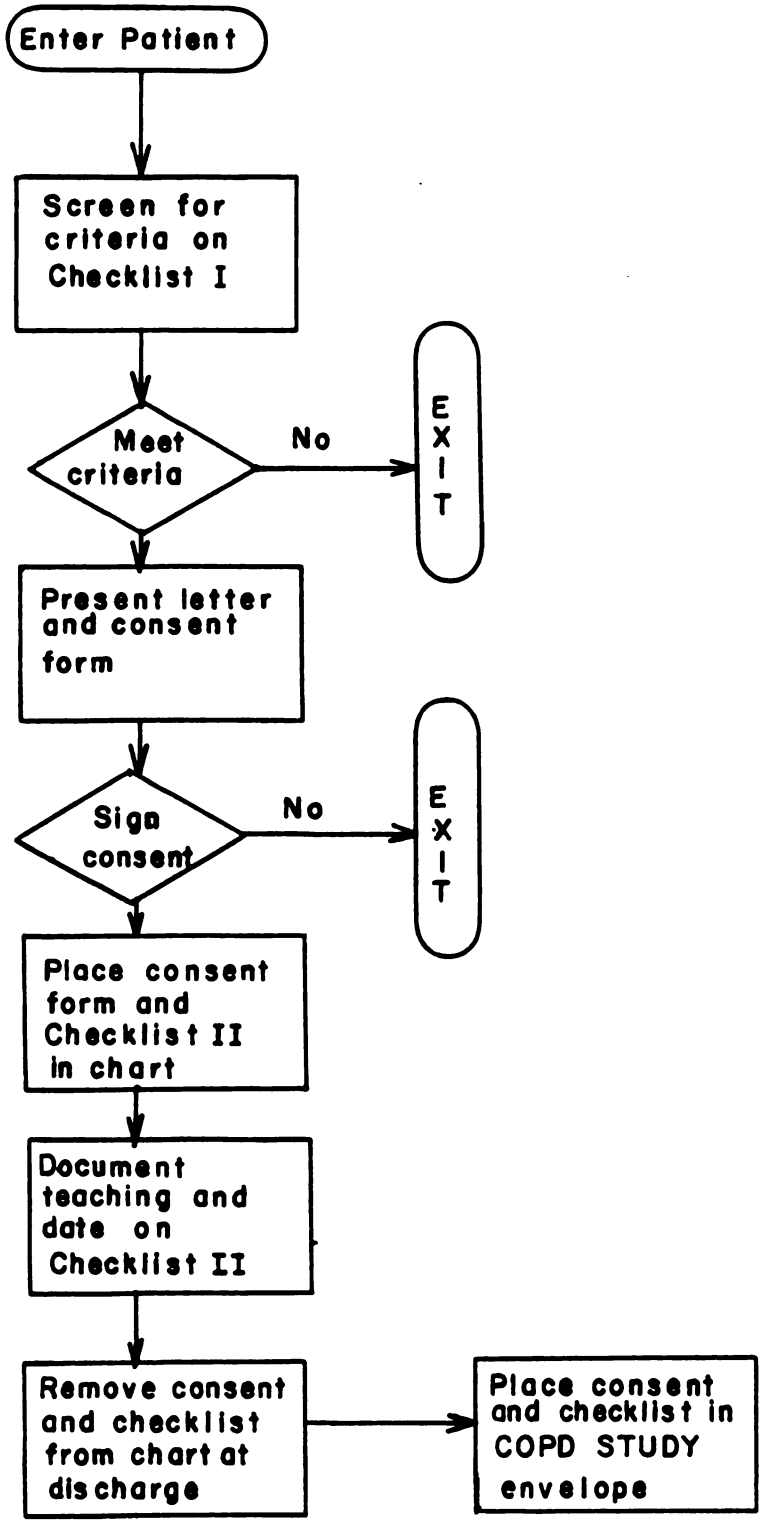

Figure 4: Flowchart Depicting Collection of Consent Forms.

At the time of patient teaching for consenting patients the health care provider working with the patient documented on a written checklist (Appendix D) the time spent in teaching, whether or not a family member or friend was in attendance during teaching, and if so, the relationship of the family member to the patient. Included on the checklist was a list of items customarily included in patient teaching. The health care provider checked those items from the list which were actually discussed with the patient in order to verify that there was uniformity in the material covered during patient teaching.

The date of teaching (and hospital discharge in the case of patients from Site I) was recorded and four weeks post teaching or discharge the investigator telephoned the patient, introduced herself, and reminded the patient of the study. Information about the study, confidentiality and the right to withdraw was repeated to the patient and the patient was asked to reaffirm willingness to participate in the study.

Patients who indicated continued willingness to participate in the study were mailed a questionnaire one week following the telephone conversation. Included with the questionnaire were a letter of instruction (Appendix E) for filling out the questionnaire and a stamped, addressed envelope for return of the questionnaire to the investigator. Patients who did not return questionnaires were telephoned seven to ten days following mailing of the questionnaire. At this time they were asked if the questionnaire had been received, if they had difficulty in

understanding the questionnaire directions and if they still desired to fill out the questionnaire. Patients who no longer desired to participate in the study were reassured of confidentiality and thanked for their time and consideration.

Consents were obtained from a total of 16 patients at Site I. Of those 16 patients, 10 patients completed and returned questionnaires, four patients expired before receiving questionnaires, and two patients decided not to participate in the study. Those patients who decided not to participate cited current family disruptions (death in the immediate family, hospitalized spouse) as being instrumental in their decision not to participate in the study.

Seven patients consented to take part in the study from Site II and questionnaires were returned by all of those patients. At Site III 15 patients volunteered to participate in the study. Telephone calls were made and questionnaires were mailed to all of those patients. One patient expired before returning the questionnaire and questionnaires were returned by the remaining 14 patients.

Operationalization of Study Variables

Knowledge of Disease

Knowledge of disease was measured by ten questions concerning COPD, the disease process, etiology of the disease, symptoms common to the disease, complicating factors and prognosis of the disease (Appendix E). The format of the questions regarding the patients knowledge of disease was multiple choice with three

possible answer foils for each question. Each question had one correct answer and a score was derived for each patient on the basis of the total number of correct answers given to questions related to the course, symptoms and prognosis of COPD.

Knowledge of Treatment

Knowledge of treatment was measured by ten questions concerning medications (purpose and side-effects), symptoms of infection, methods of preventing infection, breathing and coughing techniques, exercise and follow-up care (Appendix E). The format of the questions regarding the patients knowledge of treatment was multiple choice with three possible answer foils for each question. Each question had one correct answer and a score was derived for the patient on the basis of the total number of correct answers given to questions related to the treatment of COPD.

Compliance

Compliance was measured by the use of 25 questions (Appendix E) which measured the patients stated frequency of compliance with the use of medications (items 6, 25), avoidance of inhaled irritants (items 1, 8, 15, 24), smoking cigarettes (item 2), reporting symptoms (items 3, 4, 13, 16), exercise (items 11, 19, 22), relaxation and stress reduction (items 12, 23, 7), breathing techniques (items 5, 9), avoidance of infection (items 14, 20, 21), postural drainage (item 17), diet (item 16), and follow-up care (item 10).

The format of the questions was a statement of action followed by a five point likert-type scale on which the patient was able to indicate whether they carried out that action all of the time, more than one-half of the time, one-half of the time, less than one-half of the time or never. Responses were weighted such that those persons responding with a greater number of affirmative responses received a higher score.

The degree of compliance was ascertained by assigning a numerical score to each of the possible responses such that a high score was indicative of a high degree of compliance. For example:

"I practice relaxed breathing (diaphragmatic breathing) when short of breath"

Always	More than one-half the time	One-half the time	Less than one-half the time	Never
4	3	2	1	0

Scoring was reversed for questions which were negatively worded.

For example:

"I forget to schedule check-ups with my doctor"

Always	More than one-half the time	One-half the time	Less than one-half the time	Never
0	1	2	3	0

Subjects received one score which was indicative of their degree of compliance to the total treatment regimen.

Social Support

A total of 25 items were used to measure social support (Appendix E). Tangible support behaviors perceived by the patient were measured in relation to tangible social support from family (items 6, 11, 19), tangible social support from friends (items 2, 21, 23, 24) and tangible social support from family and/or friends (items 4, 14, 15, 16, 17, 20).

Emotional supportive behaviors perceived by the patient were measured in relation to emotional social support from family (items 1, 9, 13), emotional social support from friends (items 12, 18, 22) and emotional social support from family and/or friends (items 3, 5, 7, 8, 10, 25).

The degree of social support was ascertained by assigning a numerical score to each possible response such that a high score was indicative of high social support.

For example:

"I feel that my family and friends make an effort to understand my lung disease and how it effects what I am able to do"

Strongly Agree	Agree	Disagree	Strongly Disagree
4	3	2	1

Scoring was reversed for statements which indicated perceptions of a lack of social support.

For example:

"I do not know enough people with whom I feel free to talk about the problems I have due to my lung disease"

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

Perceived Impact of Disease

Perceived impact of disease was measured using 25 questions (Appendix E) modified from the Sickness Impact Profile (SIP) developed and reported by Bergner et al (1981). Dimension I, which is concerned with ambulation, mobility, body care and movement, was measured with four items (items 12, 15, 18, 22). Dimension II, concerned with social interaction, alertness behavior, emotional behavior and communication was measured with 13 items (items 2, 3, 4, 5, 6, 9, 10, 11, 16, 17, 19, 23, 25). Dimension III, concerned with sleep and rest, eating, work, home management and recreation was measured with eight items (items 1, 7, 8, 13, 14, 20, 21, 24).

The format of the questions was a statement of action followed by a four point likert-type scale on which the patient was able to respond whether the statement pertained to their current daily activities by marking strongly agree, agree, disagree or strongly disagree.

The degree of perceived impact of disease was ascertained by assigning a numerical score to each possible response such that a high score was indicative of a high perceived impact of disease. For example:

"I am cutting down on the length of visits with friends"

Strongly Agree	Agree	Disagree	Strongly Disagree
4	3	2	1

Scoring was reversed for questions which indicated a lesser perception of impact of disease.

For example:

"I am doing the regular daily work around the house that I usually do"

Strongly Agree	Agree	Disagree	Strongly Disagree
1	2	3	4

Modifying Variables and Sociodemographic Data

Questions were included (Appendix E) to gather information in relation to personal and environmental factors such as age, sex, race, income, occupation and education (items 1, 2, 3, 7, 8, 9, 10, 11). Marital status and family composition were ascertained (items 4, 5, 12). Seven additional questions measured factors relating to the subjects illness status (items 13, 14, 15, 16, 17, 18, 19).

Development of Instrument

Questions utilized to measure the subjects knowledge of disease, knowledge of treatment and stated compliance were based on a review of patient education materials (Chronic Lung Disease, flip-chart teaching manual, 1974; Brecher, 1975) utilized at the collection sites and discussions with two nurses and one physician involved in patient education at the collection sites. No material which was not customarily presented to patients at all sites was included as either a knowledge or compliance question on the questionnaire.

Social support was measured by questions which were developed using Caplan's (1979) definition of social support

as a guide. Questions were included to measure both tangible and intangible (emotional) social support as perceived by the subject as being provided by both family and friends.

Perceived impact of disease questions were modified from the Sickness Impact Profile (SIP) developed and reported by Bergner (1981). Questions were included to measure the mobility categories, psychosocial categories and independent categories which are part of the original Sickness Impact Profile. Questions to measure compliance, social support and perceived impact of disease were worded in roughly equal numbers of positively and negatively phrased statements in order to avoid response set bias.

Pretest of Instrument

Two patients with COPD who did not participate in the study critiqued the instrument for readability and for suitability of the questions. Two graduate nursing students, one physician, one physicians assistant and members of the nursing faculty critiqued the instrument for both validity of the questions and the structural format of the instrument.

Reliability and Validity

The quality and adequacy of a measurement instrument are evaluated by the reliability of that instrument (Polit and Hungler, 1978) Reliability is concerned with the degree of internal consistancy within the instrument and is expressed in terms of a correlation coefficient with a normal range of -1.00 to 1.00 (Anastasi, 1976). Interiten consistancy may be found from the single administration of a single test by using the

Kuder-Richardson formula 20 for test questions which are scored as either correct or incorrect, or coefficient alpha for questions which are multiple scored. A reliability coefficient of .70 or above is considered satisfactory for group level comparisons as are involved in correlational research (Polit and Hungler, 1978).

Validity refers to the degree to which an instrument measures that trait or concept which it is intended to measure. It is not possible to develop objective criteria against which to compare measures of abstract traits such as social support or perceived impact of disease. Therefore it becomes necessary to depend on subjective criteria upon which to base evaluation of the validity of an instrument. The ultimate decision concerning the validity of an instrument rests with the investigators estimation of the degree to which that instrument will measure the concept of interest. Efforts toward a high degree of validity of the instrument used in this study were made by consulting with patients with COPD, faculty and physicians, and by an extensive review of the literature.

Hypotheses

Hypothesis I: There is a significant relationship between social support and stated compliance with the treatment regimen in the patient with COPD.

Hypothesis II: There is a significant relationship between social support and knowledge of the treatment regimen in the patient with COPD.

Hypothesis III: There is a significant relationship between social support and knowledge of disease in the patient with COPD.

Hypothesis IV: There is a significant relationship between social support and perceived impact of the disease in the patient with COPD.

Hypothesis V: There is a significant relationship between knowledge of the treatment regimen and stated compliance with the treatment regimen in the patient with COPD.

Hypothesis VI: There is a significant relationship between perceived impact of the disease and stated compliance with the treatment regimen in the patient with COPD.

Hypothesis VII: There is a significant relationship between knowledge of disease and stated compliance with the treatment regimen in the patient with COPD.

Hypothesis VIII: There is a significant relationship between knowledge of disease and perceived impact of disease in the patient with COPD.

Statistical Analysis of Data

Sociodemographic data and information regarding illness factors were analysed using descriptive statistics. The range, mean and percentages, along with tables summarizing frequencies, of sociodemographic components and factors relating to illness

are presented in Chapter V.

Because all hypotheses in this study consisted of statements of hypothesized relationships between study variables a correlation matrix was constructed to correlate each of the study variables with all other variables. The Pearson Product Moment Coefficient was used in the development of the correlation matrix and the level of significance was set at .05. The following interpretion of the Pearson Product Moment Coefficient computed between study variables was utilized for deciding acceptance of hypotheses: (Borg and Gall, 1979)

0.00-0.20	no relationship
0.20-0.35	slight relationship
0.35-0.65	moderate relationship
0.65-0.85	marked relationship
0.85-1.00	high relationship

Protection of Human Rights

Specific procedures were followed to assure that the rights of study participants were not violated. Approval of the human rights protection procedures was granted by the Michigan State University College of Nursing Human Subjects Review Committee on November 6, 1980.

An explanation of the research study and goals, the approximate time involved in participation, the nature of the questions to be encountered, and assurances of anonymity were provided each participant as part of the letter of explanation and consent form (Appendix C). Number coded questionnaires were seperated from patient identifying data upon receipt by the investigator and all data were transcribed in aggregate form for computor analysis.

Summary

A discussion of methodology utilized in this study was presented in Chapter IV. A detailed discussion of the sample, collection sites, questionnaires, human rights procedures, and procedures for statistical analysis was presented.

In Chapter V the sample will be described in relation to sociodemographic and clinical characteristics. The reliabilities obtained for measurement instruments will be presented. Values obtained for study variables and relationships between variables will be presented in relation to study hypotheses. Additional findings will be reported in areas concerned with sociodemographic characteristics of subjects, clinical characteristics of subjects, and conditions of patient education.

CHAPTER V

DATA ANALYSIS

Introduction

In this chapter the sample will be described in relation to socio-demographic and clinical characteristics. A discussion of the reliability measures established for each of the scales used in measurement of study variables will be presented. The data obtained in this study will be presented and analyzed in relation to the hypotheses of the study. Additional study findings will be presented in the areas of socio-demographic findings, clinical findings and conditions of patient education.

Sample Characteristics

Socio-demographic

The sample consisted of 31 persons who were medically diagnosed and under medical treatment for chronic bronchitis, emphysema or COPD. Twenty of the subjects (64.5 percent) were male and eleven (35.5 percent) were female. All of the subjects participating in the study were Caucasian.

Subjects ranged in age from 50 to 70 years, with a mean age of 61.7 years. Distribution of subjects according to age is summarized in Table 1.

Table 1

Age Distribution of Subjects (n = 31)

Age Range	Number of Subjects	Percent
50-55	9	29.0
56-60	2	6.4
61-65	9	29.0
66-70	11	35.6
Total	31	100.0

Marital status of subjects was determined and analyzed. Twenty-two (71 percent) of the subjects were married, two (6.5 percent) were divorced and seven (22.5 percent) were widowed.

Subjects reported having from zero to eight living children, including adopted and stepchildren. The mean number of living children was 2.96. The number of living children reported by study participants is summarized in Table 2.

Table 2

Number of Living Children (n = 31)

Number of Children	Number of Subjects	Percent
0-1	8	26.0
2-3	12	38.5
4-5	7	22.5
6-8	4	13.0
Total	31	100.0

Nine respondents (29 percent) reported that they lived alone, 16 (51.6 percent) lived with their spouse, and six

(19.4 percent) lived with their spouse and children.

Three of the subjects (9.7 percent) did not respond to the question regarding total household annual income. The mean range of reported income was $11,000-$14,999. Distribution of income levels for study participants is presented in Table 3.

Table 3

Income Levels of Subjects (n = 28)

Income	Number of Subjects	Percent
Less than $5,000	2	6.5
$5,000-$6,999	0	0.0
$7,000-$8,999	4	12.9
$9,000-$10,999	5	16.1
$11,000-$12,999	5	16.1
$13,000-$14,999	4	12.9
$15,000-$16,999	1	3.2
$17,000-$19,999	1	3.2
$20,000-$24,999	2	6.5
$25,000 or more	4	12.9
Total	28	100.0

Only four of the respondents in this study were employed at the time they filled out the study questionnaire. All others listed their major activity as retired (13 subjects), disabled (8 subjects) or housewife (5 subjects).

Educational levels of subjects ranged from "none to some grammar school" (6.5 percent) to "postgraduate college or professional education" (6.5 percent). One subject did not respond to the question regarding level of education. Distribution of subjects according to educational level is summarized in Table 4.

Table 4

Educational Levels of Subjects (n = 30)

Level of Education	Number of Subjects	Percent
None to some grammar school	2	6.5
Junior High School	3	9.7
Some High School	2	6.5
Graduated High School	5	16.1
Technical, business or Trade	7	22.6
Some College	5	16.1
Graduated College	4	12.9
Postgraduate or Professional	2	6.5
Total	30	100.0

Clinical

In relation to clinical status, subjects were asked to report the length of time that they had COPD, the number of hospitalizations they had experienced during the past year due to their lung disease, the presence of other chronic disease and the extent to which activity caused them to experience shortness of breath. Pulmonary function tests (FEV_1/FVC) were obtained for all subjects on whom test results were available.

Of the 31 respondents, 12 (38.7 percent) reported the presence of other chronic disease in addition to COPD. Diseases in addition to COPD which were reported included arthritis (four subjects), ulcer (one subject), heart disease (three subjects), diverticulosis (one subject), liver disorder (one subject), sinusitis (one subject) and hiatus hernia (one subject).

The duration of diagnosed chronic lung disease ranged from one year to more than 15 years. The average duration of COPD

was between six and 12 years. The distribution of subjects according to duration of chronic lung disease is summarized in Table 5.

Table 5

Duration of COPD in Years (n = 31)

Number of Years	Number of Subjects	Percent
1-2	2	6
3-5	9	29
6-8	5	16
9-11	4	13
12-14	3	10
15 or more	8	26
Total	31	100

The number of hospitalizations due to COPD during the past 12 months ranged from no hospitalizations to six hospitalizations. The mean number of hospitalizations due to COPD was 1.7. The distribution of subjects according to number of hospitalizations due to COPD in the past 12 months is presented in Table 6.

Table 6

Number of Hospitalizations in Past 12 Months (n = 31)

Times Hospitalized	Number of Subjects	Percent
0	10	32
1	5	16
2	7	23
3	5	16
4	3	10
5	0	0
6	1	3
	31	100

All of the subjects reported that they did experience some difficulty in breathing. Subjects were asked to respond to specific examples of activities which caused them to have difficulty in breathing. Examples were created using the behaviorial criteria for classes of respiratory impairment published by the American Lung Association (1977). The classes of respiratory impairment and behaviorial criteria presented for response by study participants are:

Class 1 (no impairment): dyspnea occuring only when doing very strenuous activity.

Class 2 (20-30 percent impairment): dyspnea occuring when climbing hills or stairs but not during normal daily activities.

Class 3 (40-50 percent impairment): dyspnea occuring sometimes during normal daily activities but not while at rest.

Class 4 (60-90 percent impairment): dyspnea occuring sometimes at rest and frequently during normal daily activities.

Distribution of responses expressed by class of respiratory impairment are presented in Table 7.

Table 7

Class of Respiratory Impairment by Activities Causing Dyspnea (n = 31)

Class of Impairment	Number of Subjects	Percent
Class 1	1	3
Class 2	1	3
Class 3	8	26
Class 4	21	68
Total	31	100

Pulmonary function test (FEV_1/FVC) results were recorded for all subjects when such tests were available. There were no test results for two subjects. Pulmonary function tests were classified in accordance with the classes of respiratory impairment utilized by the American Lung Association (1977) as follows:

Class 1 (no impairment): Not less than 85 percent of predicted.

Class 2 (20-30 percent impairment): 70 to 85 percent of predicted.

Class 3 (40-50 percent impairment): 55 to 70 percent of predicted.

Class 4 (60-90 percent impairment): Less than 55 percent of predicted.

Distribution of pulmonary function test results for subjects expressed by class of respiratory impairment are summarized in Table 8.

Table 8

Class of Respiratory Impairment by Pulmonary Function Test (n = 29)

Class of Impairment	Number of Subjects	Percent
Class 1	0	0
Class 2	1	3
Class 3	5	17
Class 4	23	80
Total	29	100

Profile of COPD Patient

Responses to individual questions on the questionnaire were analyzed in order to establish a profile of the COPD patients participating in this study. The factor of social isolation has previously been addressed in descriptions of the impact of COPD symptoms upon the life of a patient. Several questions within the questionnaire addressed the area of isolation.

Responses of study participants substantiate inclusion of isolation as a common reaction of COPD patients to their disease. In response to the statement "I stay away from home only for brief periods of time" 81 percent (n = 25) of study participants agreed that the statement was descriptive of their situation. Sixty-five percent (n = 20) of the subjects responded affirmatively to the statement "I am cutting down on the length of visits with friends".

Over half (55 percent, n = 17) of study participants agreed that "I stay at home most of the time" and 42 percent (n = 13) agreed with the statement "I stay alone most of the time". The isolation of the COPD patients in this study exists to some extent even within the confines of the family according to 29 percent (n = 9) of the study participants who agreed with the statement "I isolate myself as much as I can from the rest of the family".

Isolation for the COPD patients participating in this study appeared to transcend the physical aspect and for many of the patients included emotional isolation as well. Nearly one-half

(45 percent) of the COPD patients participating in this study responded in agreement with the statement "I do not know enough people with whom I feel free to talk about the problems I have due to COPD". The feeling that "friends don't understand the problems I have in my life as a result of COPD" was reported by 39 percent (n = 12) of the study participants. Thirty-five percent (n = 11) of the subjects responded that they did not have friends who visited them in their home when they were unable to get outside due to their lung disease.

Thirty-two percent (n = 10) of the subjects responded in agreement with the statement "I sometimes feel that my relatives or friends are not understanding when I am upset or irritable due to my lung disease". Responses of study participants to the statement "I try not to let my family or friends know when a situation or activity is causing me stress" indicated the possibility that feelings of isolation on the part of the COPD patient may, to some extent, be self-imposed with 80 percent (n = 25) agreeing that they acted in this fashion one-half of the time or more.

Fagerhaugh (1963) reported on the depth of concern of COPD patients regarding the conservation of their limited supply of physical energy. Responses of study participants yield similar observations with 94 percent (n = 29) of the subjects reporting that they "rest often when doing work around the house" and 45 percent (n = 14) responding in agreement to the statement "I don't walk if I can avoid it". In response to the statement

"I plan my activities so that I can make the best use of the energy I have" 94 percent (n = 29) of the subjects reported that their activities coincided with the statement one-half of the time or more.

Questions concerning sleep patterns revealed evidence of disturbance of normal sleep patterns in many of the COPD patients participating in the study. Seventy-seven percent (n = 24) of the participants responded in agreement to the statement "I sleep less at night (for example, I wake up early, can't fall asleep, awaken frequently)" and 48 percent (n = 15) of the subjects reported sleeping or napping during the day.

Several questions addressed the ability of subjects to manage normal daily tasks and recreational activities. Sixty-eight percent (n = 21) of the respondents reported that they were both doing less of the regular daily work around the house than usual due to their lung disease and that they were not doing their usual physical recreation or activities. Fourteen of the subjects (45 percent) responded in agreement with the statement "I could use more help in managing my usual responsibilities."

While many respondents acknowledged a decrease in carrying out usual daily tasks and recreation, responses to two further questions indicated that the majority of subjects exhibited considerable resolve to maintain as much independence and self-reliance as possible. Only 19 percent (n = 6) of study participants reported that they had given up taking care of personal or household business affairs (for example, paying

bills, banking, working on budget) and 74 percent (n = 23) reported "I push myself to keep active even when an activity causes me shortness of breath" one-half of the time or more.

Responses to several questions indicated the possibility that changes in mood and/or mental function may accompany the symptoms of COPD. Sixty-eight percent (n = 21) of the COPD patients participating in this study responded in agreement with the statement "I act nervous or restless" and 45 percent (n = 14) of the subjects agreed with the statement "I act irritable and impatient with myself (for example, talk badly about myself, swear at myself, blame myself for things that happen)".

Thirty-nine percent (n = 12) of study participants agreed with the statement "I often act irritable toward family members". In response to the statement "I forget a lot (for example, things that happened recently, where I put things, appointments)" 52 percent (n = 16) of the subjects indicated that the statement was consistant with their situation. Twenty-nine percent (n = 9) of study participants reported difficulty in "reasoning and solving problems (for example, making plans, making decisions, learning new things)" and "difficulty doing activities involving concentration and thinking".

Reliability of Questionnaire

Knowledge of Disease

The procedure utilized for determining reliability of the questions used to measure knowledge of disease was the

"Kuder-Richardson formula 20". The Kuder-Richardson formula is applicable to tests whose items may be scored as right or wrong (Anastasi, 1976).

Items 1, 7 and 9 were eliminated from the knowledge of disease scale because all subjects answered these questions correctly and they therefore were not discriminating of a lack of knowledge. Items 3 and 10 were deleted from the knowledge of disease scale because they correlated negatively with the total test scores, indicating that those items were confusing to the subjects or were not well constructed. The reliability coefficient for items 2, 4, 5, 6 and 8, obtained by using the Kuder-Richardson formula 20, was .62.

Knowledge of Treatment

Kuder-Richardson formula 20 was used for computing the reliability of questions measuring knowledge of treatment. Items 5 and 8 were eliminated from the knowledge of treatment scale because all subjects answered these items correctly. Items 2 and 10 correlated negatively with the total scale and were eliminated from the scale. The reliability coefficient obtained for items 1, 3, 4, 6, 7 and 9 was .62.

Compliance

The 25 item scale for determining compliance to the treatment regimen was reduced to sixteen items upon which reliability was computed by use of coefficient alpha. Items 1, 9, 14, 15, 18, 19, 21, 22 and 25 correlated negatively with the total scale and were deleted. Reliability determined for the 16 item

compliance scale using coefficient alpha was .76.

Social Support

Coefficient alpha was used to determine reliability for the 25 item social support scale. No items were deleted from the scale. A coefficient alpha of .90 was obtained for the total social support scale.

Coefficient alpha was also computed for social support subscales measuring tangible social support ($r = .87$) and emotional social support ($r = .79$). Subscales were found to have a marked to high correlation with one another and with the total scale as shown in Table 9. The high correlation between subscales indicates that the instrument was measuring a single variable, therefore social support was viewed as a single score for the purpose of statistical analysis.

Table 9

Correlation Between Social Support Scales

	Emotional Social Support	Tangible Social Support
Tangible Social Support	.71*	
Total Social Support	.90*	.94*

*$p < .001$

Perceived Impact of Disease

Coefficient alpha was used to compute reliability of the 23 item scale measuring perceived impact of disease. Items 2 and 16 correlated negatively with the total scale and were deleted from the original 25 item scale. A coefficient alpha of .90 was computed for the total scale measuring perceived impact of disease.

Reliability was also determined for the subscales of perceived impact of disease using coefficient alpha. Dimension I, measuring ambulation, mobility, body care and movement, had a reliability of .76. Dimension II, concerned with social interaction, alertness behavior, emotional behavior and communication, had a reliability of .81. A coefficient alpha of .80 was obtained for items measuring Dimension III, concerned with sleep and rest, eating, home management and recreation.

Subscales were found to have a marked to high correlation with one another and with the total score for perceived impact of disease as shown in Table 10. The high correlation between subscales indicates that the instrument was measuring a single variable, therefore perceived impact of disease was viewed as a single score for the purpose of statistical analysis.

The reliabilities computed for all measurement scales are summarized in Table 11.

Table 10

Correlation Between Perceived Impact of Disease Scales

	Dimension I	Dimension II	Dimension III
Dimension II	.67*		
Dimension III	.75*	.63*	
Total Scale	.88*	.89*	.89*

*$p < .001$

Table 11

Summary of Reliabilities of Scales

Scale	Reliability
Knowledge of Disease	.62
Knowledge of Treatment	.62
Compliance	.76
Social Support	.90
Tangible Social Support	.87
Emotional Social Support	.79
Perceived Impact of Disease	.90
Dimension I	.76
Dimension II	.81
Dimension III	.80

Quantification of Study Variables

Each study variable was addressed using descriptive statistics to determine the frequency distribution, range and mean. Raw frequencies for all items are presented in Appendix F.

Knowledge of Disease

Study participants obtained a range of from two to five correct answers on the five questions measuring knowledge of disease. The mean number of correct answers was 4.4 (88 percent). Distribution of knowledge of disease scores is summarized in Table 12.

Table 12

Distribution of Knowledge of Disease Scores

Number of Correct Responses	Number of Subjects	Percent
5	22	70
4	3	10
3	3	10
2	3	10
Total	31	100

Knowledge of Treatment

Study participants obtained a range of from no correct answers to six correct answers on the six questions measuring knowledge of treatment. The mean number of correct answers was 4.3 (71.5 percent). Distribution of knowledge of treatment scores is summarized in Table 13.

Table 13

Distribution of Knowledge of Treatment Scores

Number of Correct	Number of Subjects	Percent
6	6	19.4
5	9	29.0
4	8	25.8
3	6	19.4
2	1	3.2
1	0	0.0
0	1	3.2
Total	31	100.0

Compliance

With a possible score of 64 on the 16 items measuring compliance, subjects responses ranged from 26 (41 percent) to 64. The mean score for compliance was 43.6 (68 percent). Distribution of compliance scores by percent of total possible is summarized in Table 14.

Table 14

Percent of Compliance

Percent Compliance	Number of Subjects	Percent
Below 50	4	12.9
51-60	4	12.9
61-70	10	32.2
71-80	7	22.6
81-90	5	16.2
Above 90	1	3.2
Total	31	100.0

Social Support

With a possible score of 100 on the 25 items measuring social support, subjects responses ranged from 49 to 99. The mean score for social support was 74. Distribution of social support scores is summarized in Table 15.

Table 15

Distribution of Social Support Scores

Social Support Score	Number of Subjects	Percent
Below 50	1	3.2
51-60	0	0.0
61-70	9	29.0
71-80	16	51.7
81-90	2	6.4
91-100	3	9.7
Total	31	100.0

Perceived Impact of Disease

With a possible score of 92 on the 23 items measuring perceived impact of disease, subjects responses ranged from 32 to 90. The mean score for perceived impact of disease was 58. Distribution of scores for perceived impact of disease is summarized on Table 16.

Table 16

Distribution of Perceived Impact of Disease Scores

Perceived Impact Score	Number of Subjects	Percent
Below 40	1	3.2
41-50	5	16.0
51-60	15	48.0
61-70	8	25.8
71-80	1	3.2
81-90	1	3.2
Above 90	0	0.0
Total	31	100.0

Correlations Between Study Variables

The goal of this study was to measure the variables of knowledge of disease, knowledge of treatment, stated compliance, social support and perceived impact of disease in a group of patients with COPD and to analyze those measures to identify relationships between variables. Using Pearson Product Moment Coefficient a correlation was computed between variables addressed by study hypotheses. Hypotheses were accepted or not accepted based on the correlation coefficient and level of significance computed between variables.

Each study hypothesis will be presented, followed by the correlation coefficient and level of significance computed for that hypothesis and a statement of acceptance or non-acceptance.

Hypothesis I: There is a significant relationship between social support and stated compliance with the treatment regimen in the patient with COPD.

A correlation coefficient of .18 (p = .17) was computed between social support and stated compliance. Both the correlation coefficient and level of significance were below acceptable limits and Hypothesis I was not accepted.

Hypothesis II: There is a significant relationship between social support and knowledge of the treatment regimen in the patient with COPD.

A correlation coefficient of -.13 (p = .17) was computed between social support and knowledge of the treatment regimen. Both the correlation coefficient and level of significance were below acceptable limits and Hypothesis II was not accepted.

Hypothesis III: There is a significant relationship between social support and knowledge of disease in the patient with COPD.

A correlation coefficient of .03 (p = .44) was computed between social support and knowledge of disease. Both the correlation coefficient and level of significance were below acceptable limits and Hypothesis III was not accepted.

Hypothesis IV: There is a significant relationship between social support and perceived impact of disease in the patient with COPD.

A correlation coefficient of -.44 (p = .006) was calculated between social support and perceived impact of disease. Because the level of significance surpassed acceptable limits and the correlation coefficient indicated a moderate relationship Hypothesis IV was accepted.

Hypothesis V: There is a significant relationship between knowledge of the treatment regimen and stated compliance in the patient with COPD.

A correlation coefficient of .06 (p = .38) was computed between knowledge of the treatment regimen and stated compliance. Both the correlation coefficient and level of significance were below acceptable limits and Hypothesis V was not accepted.

Hypothesis VI: There is a significant relationship between perceived impact of disease and stated compliance with the treatment regimen in the patient with COPD.

A correlation coefficient of -.16 (p = .19) was computed between perceived impact of disease and stated compliance. Both the correlation coefficient and level of significance were below acceptable limits and Hypothesis VI was not accepted.

Hypothesis VII: There is a significant relationship between knowledge of disease and stated compliance with the treatment regimen in the patient with COPD.

A correlation coefficient of .39 (p = .02) was computed between knowledge of disease and stated compliance. Because the level of significance surpassed acceptable limits and the correlation coefficient indicated a moderate relationship Hypothesis VII was accepted.

Hypothesis VIII: There is a significant relationship between knowledge of disease and perceived impact of disease in the patient with COPD.

A correlation coefficient of .10 (p = .29) was computed between knowledge of disease and perceived impact of disease. Both the correlation coefficient and level of significance were below acceptable limits and Hypothesis VIII was not accepted.

Summary of Correlations

Correlation coefficients computed between variables are summarized in Table 17.

Table 17

Correlations Between Study Variables

	Knowledge of Disease	Knowledge of Treatment	Stated Compliance	Social Support
Knowledge of Treatment	-.06			
Stated Compliance	.39**	.06		
Social Support	.03	-.13	.18	
Perceived Impact of Disease	.10	.09	-.16	-.44*

* $p<.007$
** $p<.02$

Additional Findings

Significant additional findings were categorized into three primary areas: (1) findings concerning socio-demographic characteristics of study participants, (2) findings concerning

conditions of patient education, and (3) findings concerning clinical status and characteristics of subjects.

Findings concerning sociodemographic characteristics

Age of subjects was found to be negatively correlated with perceived impact of disease with a correlation coefficient of -.44 (p = .007). This correlation indicated that with increasing age subjects reported a lesser number of changes in usual living patterns which they attributed to the presence of COPD.

A positive correlation between sex and stated compliance was computed (r = .37, p = .02), giving evidence that within the study sample female subjects reported higher levels of compliance to the treatment regimen.

A slight negative correlation was observed between level of education and perceived impact of the disease (r = -.31, p = .04), with those subjects possessing higher educational levels reporting fewer changes in usual daily activities which they attributed to COPD.

Findings Concerning Conditions of Patient Education

Information obtained from the "Checklist for Teaching" (Appendix D) was analyzed to determine the effect of the presence of differences in teaching conditions encountered by subjects. It was ascertained that health care providers consistantly reported presenting information to subjects in all categories addressed on the checklist.

There was considerable variability in the time spent in teaching as recorded by health care providers, ranging from five

minutes to over four hours. The amount of time spent in teaching did not correlate significantly with subjects knowledge of disease, knowledge of treatment or any other variable.

The presence of a friend or family member during patient teaching was recorded by the health care provider. No subject was accompanied by a friend during teaching. The presence of a family member during teaching was found to correlate with the presence of higher levels of perceived emotional social support (r = .33, p = .04). Additionally, the presence of a family member during teaching was found to correlate negatively with perceived impact of disease (r = -.53, p = .001), indicating that those subjects accompanied by family during teaching reported significantly fewer changes in usual daily activities which they attributed to COPD.

No statistically significant differences between sites and study variables were observed.

Findings Concerning Clinical Status

Several factors relating to the clinical status of study participants were found to be significantly related to study variables.

Duration of disease correlated negatively with subjects knowledge of treatment (r = -.31, p = .04), indicating that the longer a subject had COPD, the lower the subjects level of knowledge regarding the treatment regimen.

The number of hospitalizations resulting from COPD during the previous year was found to correlate with the subjects

perceived impact of disease (r = .47, p = <.004), indicating that those subjects experiencing more hospitalizations reported greater numbers of changes in usual daily activities which they attributed to COPD.

The subjects report of class of respiratory impairment as indicated by instances causing dyspnea was found to correlate significantly with perceived impact of disease (r = .48, p = .03) indicating that subjects reporting more severe respiratory impairment also reported greater numbers of changes in usual daily activities which they attributed to COPD.

Responses of study participants in relation to activities causing dyspnea (class of respiratory impairment) were also found to correlate significantly with level of stated compliance (r = .29, p = .05). Subjects reporting more severe levels of respiratory impairment also reported higher levels of compliance to the therapeutic regimen. Pulmonary function test results did not correlate significantly with variables measured in this study.

Summary

A description of the study sample in relation to socio-demographic and clinical status was presented in Chapter V. Reliabilities of scales designed to measure study variables were reported and correlations between variables were presented. Additional findings relating to sociodemographic characteristics of subjects, conditions of patient education and clinical characteristics of subjects were reported.

A discussion of study findings and the implications of findings for nursing practice, nursing education and further research will be presented in Chapter VI.

CHAPTER VI

SUMMARY AND IMPLICATIONS

Overview

In Chapter VI study findings will be discussed and summarized. The implications of findings for nursing practice and nursing education will be discussed and recommendations for further research will be presented.

Descriptors of Study Sample

Distribution of subjects by age was fairly even across the 50 to 70 year age range (Table 1), with some concentration of subjects in the oldest age grouping (age 66-70). The mean age of study participants was 61.7 years, similar to COPD patients studied by Black and Mitchell (1977) who had a mean age of 64 years, Kimbel et al (1971) whose sample had a mean age of 61 years, and Perry (1980) who reported on a group of COPD patients with a mean age of 60.5 years. Several studies have been reported where subject ages were younger than in this study sample. Kass et al (1973) studied one group of COPD patients with a mean age of 54 years and another group of patients whose mean age was 53.5 years. Agle et al (1973) reported studying a group of COPD patients whose mean age was 50.5 years.

Although a lower age limit of 50 years was specified in this study, no potential subjects were encountered who were not considered for inclusion in the study because of being younger than 50 years of age. Some potential subjects were not included, however, because they were more than 70 years of age.

All subjects in this study were Caucasian. Several other studies which included race as a descriptor of COPD populations reported a predominance of Caucasian patients. Kass et al (1973) studied 140 COPD patients of whom 139 were Caucasian and one was Negro, and Burrows and Earle (1969) reported that 89.5 percent of the 200 COPD patients they studied were Caucasian.

Female COPD patients comprised a greater proportion (n = 11, 35.5 percent) of the sample in this study than reported by most other researchers who have studied COPD populations. In the 200 COPD patients studied by Burrows and Earle (1969) only 11 percent were female, and Kass et al (1973) studied a group of 140 COPD patients of whom 13.5 percent were female. Female patients comprised 15 percent of the sample studied by Perry (1981) and 16.7 percent of the COPD patients reported on by Kimbel et al (1971). Only one other study of COPD patients included a similar proportion of female subjects. In the experimental COPD patient education program reported on by Black and Mitchell (1977) 32 percent of the study participants were female.

Marital status of COPD patients participating in research studies was reported on by only one other investigator. In the study by Kass et al (1973) of the correlation between clinical

background and pulmonary function tests 71 percent of the subjects were married and 20 percent were divorced or widowed. An additional nine percent of the subjects reported on by Kass et al (1973) had never married. Married subjects comprised an identical 71 percent (n = 22) of the sample in this study, while 22.5 percent (n = 7) were widowed and 6.5 percent (n = 2) were divorced.

Because of rapidly fluccuateing economic conditions comparisons of income levels between study populations obtained in different years is difficult to interpret. Only Kass et al (1973) reported on the income status of a group of COPD patients. Of the 140 patients studied by Kass et al (1973), only nine percent reported an annual income in excess of $10,000. Because the mean age in the group studied by Kass et al (1973) was 54 years it would seem reasonable to assume that a greater number of those subjects remained in the work force than was reported by subjects in this study. A majority of the participants in this study (n = 23, 75 percent) reported incomes below $15,000 for 1981. Poverty level at this period of time was established as $4,310 for persons living alone, $5,690 for couples and $7,070 for three persons (Federal Register, March 5, 1981). Nine respondents (29 percent) in this study reported that they lived alone, 16 (51.6 percent) lived with their spouse, and six (19.4 percent) lived with their spouse and a child.

Only four of the respondents in this study were employed at the time they filled out the study questionnaire. All others listed their major activity as retired (13 subjects), disabled

(8 subjects) or housewife (5 subjects). Had the question been worded so as to include both past and current occupational activities a more accurate description of the socio-economic status might have been obtained. With the information that was obtained it is not possible to accurately describe the socio-economic status of the study sample. The predominance of subjects who were not employed might, however, explain the high proportion of relatively low incomes and also add to understanding of the frequency that feelings of isolation were reported by subjects.

Educational levels of COPD patients were reported upon in only one other study. Black and Mitchell (1977) reported that 29 percent of the COPD patients they studied had less than a ninth grade education, 38.5 percent reported having completed grades nine through twelve, and 32 percent had completed from one to four years of college. When classified into similar categories 16 percent (n = 5) of the subjects in this study reported completing less than ninth grade, 22.5 percent (n = 7) completed grades nine through twelve, and 58.5 percent (n = 18) reported having completed from one to four years of college or more. Levels of education varied widely, from grammar school education (6.5 percent, n = 2) to post graduate or professional education (6.5 percent, n = 2), and would appear to be fairly representative of levels of education in the general population of the community in which the sample was obtained.

In summary, subjects in this study of COPD patients were similar in age to patients in three other studies but averaged

from seven to ten years older than patients in an additional three studies. The predominance of Caucasian subjects in this study did not differentiate it markedly from other studies in which the race of subjects was reported. This study sample contained more female subjects than reported in most other studies of COPD populations. The marital status of subjects in this study was nearly identical to that reported previously by Kass et al (1973). The income level of COPD patients participating in this study was higher than in one other study reporting income of a group of COPD patients and participants in this study reported somewhat higher levels of education than was found in the one other study which reported educational background of subjects. Most of the subjects (87 percent, n = 27) in this study were not currently employed.

Only a small number of other studies were located which described the sociodemographic characteristics of groups of COPD patients. Except for a somewhat higher proportion of female subjects, this sample of COPD patients appeared to be fairly representative of those other groups which have been described.

Clinical Characteristics

The study sample was quite homogenous in relation to severity of disease. According to the results of pulmonary function tests, nearly three-quarters (n = 23) of the sample suffered from Class IV respiratory impairment, an additional five subjects were classified as suffering from Class III respiratory impairment, and the pulmonary function test of one subject indicated Class II

respiratory impairment. This distribution of level of severity is similar to that encountered by Perry (1981) who reported on a sample comprised of 70 percent Class IV respiratory impairment, 15 percent Class III, and 10 percent Class II respiratory impairment.

Awareness by subjects of greater severity of disease as indicated by responses to experiences resulting in dyspnea was accompanied by both increased perceptions of impact of disease and increased levels of compliance. The severity of disease as indicated by pulmonary function test results was not, however, correlated with either perceived impact of disease or compliance. This seeming incongruity in study findings would suggest that the beliefs of patients regarding the severity of their disease have a greater effect on perceptions of impact of disease and compliance than do actual clinical measures of severity.

Restriction in the range of severity of disease for patients contacted at both in-patient and ambulatory sites may suggest the possibility that patients are not routinely being diagnosed and/or treated in the early stages of COPD.

The restriction in range of severity of disease in this study sample was accompanied by a broad range of duration of disease, ranging from one year to more than 15 years. Duration of disease was not reported by other researchers studying COPD populations. The range in duration of disease would indicate that, in spite of the fact that the majority of the subjects were severely ill, they and their families had encountered

vastly divergent periods of time in which they could adjust to the disease and its accompanying limitations. The time period for adjustment of living style to disease may account for some of the variation in perceived impact of disease scores encountered in this study.

The number of hospitalizations encountered during the past year as a result of COPD was measured in this group of COPD patients. The number of hospitalizations of subjects was not reported on by other researchers studying groups of COPD patients. The correlation of increased numbers of hospitalizations with an increase in perceived impact of disease may indicate an awareness on the part of COPD patients of an increased effect of the disease on their usual daily activities, or increased debilitation of the patient causing a greater effect of the disease on daily activities.

Information regarding other chronic diseases experienced by subjects was obtained from the questionnaire. Twelve subjects (39 percent) reported the presence of other chronic diseases ranging from arthritis and heart disease to sinusitis. When analyzed in relation to study variables, those subjects did not differ from the study sample as a whole.

Conditions of Patient Education

The subjects obtained from different sites had experienced considerable variation in the conditions of patient teaching. Two factors comprise the most obvious differences: (1) the amount of time in which subjects were exposed to the patient

teaching experience, and (2) the degree of structure incorporated into the patient teaching experience by health care providers.

The amount of time spent in teaching ranged from five minutes to over four hours. The average amount of time spent in teaching at Site I was 45 minutes, the average time at Site II was one hour, and at Site III the average amount of time spent in teaching was over four hours. No significant correlations were observed between the amount of time spent in teaching and other study variables, indicating that teaching time alone is not a major factor in patient levels of knowledge, compliance, social support or perceived impact of disease.

The second major difference between conditions of patient education was the degree of structure incorporated into the patient teaching situation. It was verified by use of the "Checklist for Patient Teaching" (Appendix D) that there was uniformity in the content of the material which was presented to patients in the process of patient education.

At Site I the situation of patient teaching was unstructured, with the individual staff nurse conducting a teaching session with the individual patient, usually at a point in time close to the patients discharge from the hospital. An unstructured format for the presentation of information to patients was also followed at Site II, where patient teaching was also conducted on a one-to-one basis by the pulmonary nurse with individual patients.

At Site III patient teaching was highly structured, with material presented to an organized group of patients by a speaker.

Higher levels of knowledge of disease were observed in patients from Site III which, although not statistically significant, do indicate the need for further research concerning conditions of patient education in relation to the degree of structure which is utilized. Observed differences in conditions of patient education relating to the presence of a family member at patient teaching are discussed in the section of this chapter relating to social support.

Measures of Variables

Knowledge of Disease and Knowledge of Treatment

Knowledge of disease was defined in this study as the factual information that the patient is able to recall and report in response to questions concerning COPD, its etiology, symptoms, complicating factors and prognosis. Knowledge of treatment was defined as the factual information that the patient was able to recall and report in relation to questions concerning prescribed medications (purpose, side-effects), breathing and coughing techniques, exercise, symptoms of infection, methods of preventing infection and follow-up care.

In the sample of COPD patients which were questioned in this study, knowledge of disease test scores were both consistantly higher than, and considerably less variable than, knowledge of treatment test scores. Participants in this study consistantly possessed more accurate knowledge concerning the disease process of COPD than the recommended treatment for the disease.

The relatively high levels of knowledge of disease with little variance may have two possible explanations. The questions used to measure knowledge of disease may not have been adequate to differentiate knowledge levels concerning the disease process, etiology and prognosis. Another possible explanation may be that the subjects in this study had indeed been well informed concerning the disease process, etiology and prognosis, and the baseline levels of knowledge of disease were well established.

When viewed in conjunction with knowledge of treatment scores it would appear evident that subjects were consistantly more aware of the disease process, etiology and prognosis than they were of the appropriate methods of treatment. One possible conclusion is that this group of COPD patients had more consistantly been presented with information concerning the disease than with more personalized information regarding how they, as patients, could most effectively control symptoms of the disease. Aspects of treatment which were the subject of questionnaire items measuring knowledge of treatment were consistantly checked off by health care providers on the "Teaching Checklist" (Appendix D) indicating that the information had been presented to the patient. No measure was obtained, however, on the manner in which the information was presented.

When additionally considering the negative correlation between duration of disease and knowledge of treatment, a possible conclusion is that when knowing that a patient has

suffered from COPD for a number of years health care providers may assume that the patient possesses adequate knowledge of treatment and neglect reinforcement of that material. Information regarding the disease process would appear to be less likely to be "forgotten" by the subject who has been constantly enduring those symptoms upon which the questions focused. Subjects may, however, have forgotten information regarding regarding treatment which was presented over a period of years, or with increased duration of disease the patients spouse or other family members may have assumed responsibility for aspects of the treatment regimen, leaving the patient essentially unaware of factual information regarding treatment.

Interestingly, level of education of the subjects did not correlate significantly with levels of knowledge. In view of the broad range of educational backgrounds reported by subjects (Table 4) this lack of correlation takes on added practical significance, leading this investigator to conclude that deficiencies in educational background of patients should not automatically be viewed as barriers to effective patient learning.

Compliance

Compliance, in this study, was defined as the extent to which the patient reports carrying out the therapeutic recommendations of health care providers concerning prescribed medications, behavioral modification (stress management, cigarette smoking, relaxation techniques), exercise, postural drainage, methods of preventing infection, and follow-up care.

Compliance scores ranging from 41 to 100 percent (Table 14) indicate a considerable range in reported patient compliance behaviors. Gordis (1976) states that "some noncompliant patients will misrepresent themselves as compliant but compliant patients are unlikely to misrepresent themselves as noncompliant". Thus, the reported scores for level of compliance may indicate an overestimate of compliance behaviors on the part of subjects in this sample.

The mean compliance score of 68 percent is relatively close to the mean score of compliance to non-medication treatment (63 percent) found by Milazzo (1981) in a group of 18 COPD patients. Milazzo (1981) computed separate compliance scores for medication taking behaviors and for non-medication taking behaviors for a group of COPD patients. In Milazzo's (1981) study of compliance in COPD patients instances of taking medications in excess of recommended dosages was reported as a positive compliance score, frequently resulting in percentages of compliance which exceeded 100 percent.

This study interpreted medication taking behaviors as part of the total treatment regimen and interpreted dosages in excess of recommendations as noncompliant behavior. The study conducted by Milazzo (1981) was the only compliance study specifically concerned with COPD patients which was located.

Findings in this study did not support the association between age and compliance which was reported by Bille (1977) or Nelson (1978). A moderate positive correlation which was

observed between female subjects and higher levels of compliance to the therapeutic regimen is similar to Vincent's (1971) finding that women aged 45 to 64 were more compliant than men. The infrequency with which sex has been associated with compliant behaviors in the literature would cause the investigator to view this finding with extreme caution. The possibility that the answers of female subjects in this age range reflect a greater awareness of and need for social desirability must be considered.

Responses of subjects in relation to activities causing dyspnea (class of respiratory impairment) were additionally found to correlate with compliance while class of respiratory impairment as determined by clinical measure (pulmonary function test) was not found to be associated with compliance. It would appear, on the basis of these findings, that those subjects who believed that they were more severely impaired responded to that belief with increased incidences of compliance.

Individual questions on the questionnaire were further analyzed in order to determine a profile of compliance behavior in relation to levels of knowledge for subjects participating in this study.

The first and most crucial restriction which is customarily presented to COPD patients is concerned with cessation of smoking. Nine of the study participants (29 percent) indicated that they did continue to smoke cigarettes and twenty subjects (64 percent) indicated continued exposure to cigarette smoke when responding to the statement "I stay in rooms where people are smoking".

Thirty of the thirty-one participants (97 percent) were aware that smoking cigarettes is an important cause of COPD and 26 subjects (84 percent) correctly recognized that a person who is most likely to develop a chronic lung disease has a history of heavy smoking. Additionally, 27 of the subjects (87 percent) correctly reported that chronic lung diseases such as COPD are made worse by continued exposure to respiratory irritants such as tobacco smoke.

Although 27 of the subjects (87 percent) were able to correctly identify the procedure for diaphragmatic breathing and all of the subjects were aware that diaphragmatic breathing was the appropriate response when short of breath, only 17 subjects (55 percent) reported that they always practiced this breathing technique when short of breath. It is possible that anxiety plays a substantial part in the disparity between patient awareness and practice of diaphragmatic breathing when short of breath. Seventy-one percent (n = 22) of the study participants indicated that they did become very anxious when short of breath.

Research on the medication taking behaviors of COPD patients conducted by Milazzo (1981) indicated a strong tendency of patients to over-medicate (ie. take dosages in excess of recommendations) when using bronchodilators to counteract shortness of breath. Thirty-two percent (n = 10) of the participants in this study did indicate that they did sometimes take extra doses of bronchodilators when they had trouble breathing. Seventy-seven percent (n = 24) of the subjects were able to correctly identify

the purpose of taking bronchodilators and the same number of subjects were able to correctly identify the toxic side-effects resulting from an overdosage of bronchodilators.

Analysis of compliance responses in relation to responses to knowledge questions indicates that patients more frequently are aware of the appropriate therapeutic responses than they report carrying through in practice that knowledge which they possess.

Social Support

Social support was defined in this study as the degree to which the COPD patient reported a pattern of consistant communications, assistance and mutual evaluation with other persons and the degree to which the COPD patient reported a belief that he/she was understood, cared for and esteemed in relation to his/her disease by those other persons.

The scale to measure social support was constructed in such a manner that subscales indicating emotional support and tangible support could be isolated. As reported in Chapter V, reliabilities proved to be high for both subscales and the total scale measuring social support. When Pearson Product Moment Coefficients were computed between each of the subscales and the total scale (Table 9, Chapter V) the value of those correlations was both high and statistically significant, leading the investigator to conclude that the instrument was measuring a single concept. The value of social support scores obtained in this study ranged from 49 to 99 out of a possible maximum of 100, with a mean of 74.

For the purposes of description, the responses or subjects will be presented in relation to their perceptions of tangible support and emotional support. In regard to the beliefs of subjects concerning tangible support 87 percent (n = 27) felt that they had friends who would look after their home if they had to be hospitalized and 84 percent (n = 26) felt that friends would drive them to the doctor if they had problems with transportation. Although most subjects (87 percent, n = 27) felt that their friends would help them, only 64.5 percent (n = 20) reported that they felt that their friends would come to visit them in their homes if they were unable to get outside due to their lung disease.

The belief that family members would relieve them of usual household responsibilities if they were ill was reported by 84 percent (n = 26) of the subjects and 74 percent (n = 23) felt that their families adjusted activities so that the subject could physically manage to be included. Twenty-seven subjects (87 percent) reported that they were able to manage well with the amount of assistance they received from others and 80 percent (n = 25) felt that they could depend on others for help. Nevertheless, 45 percent (n = 14) of the subjects reported that they could use more help managing their usual responsibilities. The majority of the subjects consistantly reported the belief that tangible support was available to them.

In relation to emotional support, 90 percent (n = 28) of the subjects reported the belief that their family cared about them

and what happened to them as a result of their lung disease, 80 percent (n = 25) felt that their families showed concern over their problems related to lung disease, and 71 percent (n = 22) felt that their families tried to encourage them when they felt sad or blue due to their lung disease. Subjects for the most part reported that family members did offer emotional support

Questions regarding emotional support from friends yielded similar responses. Most subjects (87 percent, n = 27) did feel that friends cared about them, and 80 percent (n = 25) reported receiving encouragement from friends when feeling sad or blue as a result of their lung disease.

The area in which subjects most consistantly reported lower levels of emotional support concerned feelings that their problems were understood by others. Fourteen of the 31 participants in the study (45 percent) felt that they did not know enough people with whom they felt free to talk about the problems they encountered due to their lung disease, while 32 percent (n = 10) reported that friends and relatives were not understanding when their lung disease caused them to be upset or irritable. Twelve subjects (39 percent) reported that their friends did not understand the problems that resulted from COPD.

When analyzing the perceptions of social support reported by study participants it would appear that most subjects reported their environment as being quite supportive of them in both tangible and emotional areas of support. The greatest numbers of responses indicating lower levels of support were concerned

with emotional support, most specifically with the area of feeling that problems caused by COPD are understood by others.

Their are two primary implications of this observation. First, nurses and other health care providers need to increase their understanding of the problems and perceptions common to the COPD patient. It then becomes imperative that these understandings be shared with the families and friends of persons with COPD. Communication of the problems and feelings common to persons with chronic lung disease through mass media might additionally serve to enhance the public understanding of individuals with COPD. This finding additionally indicates the need for and value of support groups for patients with chronic lung disease.

A significant correlation was observed between the presence of a family member during patient teaching and high patient perceptions of emotional support. It is possible that the family members who attended patient education gained an increased understanding of the patients problems and limitations, resulting in the advancement of increased supportive behavior toward the patient. An alternative explanation may be that family members who originally were most supportive chose to attend patient teaching as a part of that supportive behavior. Attendance at patient teaching on the part of family members was voluntary and was not requested of the family member.

Perceived Impact of Disease

Perceived impact of disease was defined in this study as the number of changes necessitated by symptoms of COPD which were reported by the patients in relation to social activities and functional ability to perform customary activities of daily living. Questions used to measure perceived impact of disease were modified from the Sickness Impact Profile (SIP) developed and reported by Bergner et al (1976, 1981).

The Sickness Impact Profile (SIP) is divided into three separate dimensions and the scale to measure perceived impact of disease was constructed such that these three dimensions could be isolated as separate subscales. Dimension I was concerned with ambulation, mobility, body care and movement. Dimension II was designed to measure social interaction, alertness behavior, emotional behavior and communication. Dimension III was concerned with sleep and rest, home management and recreation.

As was reported in Chapter V the reliability coefficients that were computed for each of the subscales and for the total scale were high. When Pearson Product Moment Coefficients were computed between individual subscales and the total scale (Table 10, Chapter V) the value of these correlations was both high and statistically significant, leading the investigator to conclude that the instrument was measuring a single concept. The value of perceived impact of disease scores ranged from 32 to 90 out of a possible maximum score of 92, with a mean score of 58.

For the purposes of description the responses of subjects will be presented in relation to the three separate dimensions of the total scale. Dimension I, concerned with ambulation, mobility, body care and movement, resulted in diverse responses by study participants. Over one-half (n = 17) of the subjects reported that they stayed at home most of the time, 45 percent (n = 14) reported that they did not walk if they could avoid it, and 80 percent (n = 25) reported that when they did leave home they stayed away only for brief periods of time. Only 48 percent (n = 15) of the subjects reported that they were going out as much as usual to visit people.

Dimension II of the perceived impact of disease scale measured social interaction, alertness behavior, emotional behavior and communication. Nearly all (97 percent) of the subjects reported that they felt they were considerate of family members, 77 percent (n = 24) felt that they were not demanding of their family, but 39 percent (n = 12) reported that they were often irritable in their actions toward family members.

Nervousness and restlessness was reported by 68 percent (n = 21) of the study participants and 45 percent (n = 14) felt that they were irritable and impatient with themselves. Forgetfulness was reported by 52 percent (n = 16) of the respondents, but most (71 percent) reported no difficulty in reasoning, solving problems, or activities involving concentration.

In the area of social interaction subjects reported a marked impact upon their usual activities. Social visiting by

phone rather than in person was reported by 52 percent (n = 16) of the subjects, while 29 percent (n = 9) stated that they isolated themselves as much as possible from the rest of their family and 42 percent (n = 13) reported that they stayed alone most of the time. In marked contrast to reports of irritability and isolation, 74 percent (n = 23) of the subjects reported that they talked about the future in a positive way.

Dimension III of the perceived impact of disease scale was concerned with sleep and rest, home management and recreation. The need to rest often while doing work around the house was reported by 93.5 percent (n = 29) of the subjects, and 77 percent (n = 24) stated that they were able to sleep less at night because of their lung disease. Forty-eight percent (n = 15) of the subjects reported sleeping or napping during the day.

Only 48 percent (n = 15) reported that they were doing their usual physical recreation and activities and 45 percent (n = 14) reported doing their usual daily work around the house. In spite of the difficulties reported by subjects in managing physical tasks and recreation only 19 percent (n = 6) reported that they had given up taking care of personal or household business affairs such as paying bills, banking and budgeting.

The areas in which a high impact of disease was most frequently reported were concerned with social interaction, d disruption of normal sleep patterns, nervousness, and difficulty in managing physical household tasks and recreation.

A negative correlation was observed between age of subjects and perceived impact of disease, such that older patients reported fewer changes in usual daily activities which they attributed to COPD. Because no such correlation was noted between duration of disease and perceived impact of disease one possible conclusion might be that older patients were attributing changes in their usual activities to the aging process rather than to the symptoms of COPD.

Also noted was a negative correlation between level of education and perceived impact of disease. It is difficult to speculate about the rationale of this correlation. A possible explanation may be that those subjects with higher levels of education had previously established living patterns requiring the expenditure of less physical energy and therefore experienced less change. An alternative explanation might involve differences in coping styles and a possible association between coping styles and level of education. In order to understand the meaning of this correlation further research would be required.

The presence of a family member at patient teaching was associated with significantly lower levels of perceived impact of disease. It might appear that in the process of attending patient education, family members gained an increased understanding of the limitations and expectations of the COPD patient. This increased understanding may then have been reflected in helping behaviors which affected the patients perceived impact of

disease. Because the attendance of a family member at patient teaching was neither requested nor required, the observed correlation may also be a reflection of the character of the family member who volunteerily participated in the patient teaching.

The observation in answers to items on the questionnaire which indicated that 45 percent of the sampled COPD patients did not walk when they could avoid it has definite nursing implications when working with a population of patients to whom exercise is an important therapeutic measure. Nurses should not neglect assessing the amount of exercise that the patient integrates into their normal daily routine and should additionally emphasize the value of regular exercise in the process of patient teaching. As a result of study findings nurses should also be aware of the need to assess sleep patterns of the COPD patient and to assist the patient in accomodating to changes in these patterns

Additional correlations between class of respiratory impairment and perceived impact of disease and between the number of hospitalizations experienced by the patient due to COPD and perceived impact of disease are discussed in the section of this chapter relating to clinical findings.

Statement of the Research Question

The research question stated in this study was: Are there relationships between knowledge of disease, knowledge of treatment, social support, perceived impact of disease and stated

compliance in a group of patients with COPD?

Research Hypotheses

Each research hypothesis is stated separately and followed by the findings of this study in relation to the hypothesis. A brief discussion of study findings in relation to expected relationships is presented for each hypothesis.

Hypothesis I: There is a significant relationship between social support and stated compliance with the treatment regimen in the patient with COPD.

A statistically significant relationship between social support and stated compliance was not observed in this study. On initial observation it might appear that this lack of an observed association is contrary to previously published findings. Substantial differences exist, however, in both design and measurement between this study and several others reporting relationships between social support and compliance.

Several reports indicating a positive association between social support and compliance (McKenney et al, 1973; Haynes et al, 1976) were experimental in design and introduced a new source of social support to subjects in experimental groups. No measure was obtained in these studies of either the original perceptions of support of subjects or their perceptions of support following completion of their exposure to the experimental groups. Therefore, the positive association reported from these studies might be viewed as existing between the support service offered as part of the experimental program and compliance, and not necessarily

between the broader concept of social support and compliance. In these experimental studies social support was assumed as a byproduct of the support group but was not measured.

Both Nelson et al (1978) and Hershey et al (1980) report finding no significant relationship between support and compliance in studies with a design similar to this correlational research. Both of these studies sampled over 100 hypertensive patients and measured patient perceptions of social support. The measures employed, however, consisted of only one item in the study conducted by Hershey et al (1980) and five items in the research reported by Nelson et al (1978). The concept of social support is multifaceted and measurement is complex. It would appear that the measurement of the degree of social support of a patient is unlikely to be accomplished with a high degree of accuracy when utilizing five items or less.

Precision in the measurement of social support must be established before reports of association or lack of association between social support and compliance will begin to gain practical significance.

Hypothesis II: There is a significant relationship between social support and knowledge of the treatment regimen in the patient with COPD.

The hypothesized relationship between social support and knowledge of the treatment regimen was not supported by study findings. Other research attempting to establish a relationship between social support and knowledge of the treatment regimen

was not located in a search of the literature. It can only be concluded that in this study sample a relationship between social support and knowledge of the treatment regimen did not exist.

Hypothesis III: There is a significant relationship between social support and knowledge of disease in the patient with COPD.

The hypothesized relationship between social support and knowledge of disease was not supported by study findings. A search of the literature did not locate other studies seeking a relationship between social support and knowledge of disease. It can only be concluded that in this study sample a relationship between social support and knowledge of disease did not exist.

Hypothesis IV: There is a significant relationship between social support and perceived impact of disease in the patient with COPD.

On the basis of study findings Hypothesis IV was accepted and it was concluded that a negative relationship between social support and perceived impact of disease did indeed exist in the sample of COPD patients which was studied. The reliabilities of both of the measurement scales was high, as was the level of significance of the correlation, resulting in confidence that the correlation was unlikely to have been the result of chance. Hypotheses in correlational research, however, seek to identify relationships and make no attempt to infer causality in those relationships which are observed.

Although studies were not located in the literature which attempted to establish a relationship between social support and perceived impact of disease the definition of social support used in this study (Caplan, 1976, 1979) is based upon the premise that social support is "behavior which is directed toward providing a person with perceptions...inducing affective states which are hypothesized to promote well-being". If it is assumed that decreased perceptions of impact of disease are indicative of patient perceptions of "well-being" then study findings would be interpreted as being supportive of published conceptual definitions.

Indirect evidence of support of the findings of this study in the literature were reported by Barstow (1974) who stated that "the single most important influence on adjustment (of emphysema patients) was the presence of a supportive significant other", and Davidson (1981) who reported social support as being significantly related to life satisfaction and self-esteem.

Hypothesis V: There is a significant relationship between knowledge of the treatment regimen and stated compliance in the patient with COPD.

A statistically significant relationship between knowledge of treatment and stated compliance was not observed in this study. This lack of association differs from the findings of Caplan et al (1976) who reported that in a group of 200 hypertensive patients those with higher levels of knowledge of their treatment had lower blood pressures which Caplan interpreted as

indicative of compliant behaviors. Given et al (1978) also found a positive association between the knowledge of medication in hypertensive patients and their levels of compliance in drug taking. Other studies, however, have reported no significant relationship between knowledge of treatment and compliance (Bille, 1977; Tirrell and Hart, 1980). In extensive reviews of compliance literature Marston (1970) and Sackett and Haynes (1976) cite a lack of concordance in the results of studies seeking relationships between knowledge and compliance.

Hypothesis VI: There is a significant relationship between perceived impact of disease and stated compliance in the patient with COPD.

A statistically significant relationship between perceived impact of disease and stated compliance was not observed in this study. A search of the literature did not locate other studies seeking a relationship between perceived impact of disease and stated compliance in any group of patients. It can only be concluded that in this study sample a relationship between perceived impact of disease and stated compliance did not exist.

Hypothesis VII: There is a significant relationship between knowledge of disease and stated compliance with the treatment regimen in the patient with COPD.

A statistically significant positive relationship between knowledge of disease and stated compliance was observed in this study. This finding is in agreement with study results reported

by Tagliacozzo and Ima (1970) which indicated increased levels of compliance in appointment keeping observed in subjects who had higher levels of knowledge of common chronic diseases. Another study (Bille, 1977) was conducted which did not find statistically significant relationships between knowledge of disease and compliance. The lack of agreement in study findings regarding a relationship between knowledge of disease and compliance has been cited by Marston (1970) and Sackett and Haynes (1976) in reviews of literature concerning compliance studies.

Hypothesis VIII: There is a significant relationship between knowledge of disease and perceived impact of disease in the patient with COPD.

A statistically significant relationship between knowledge of disease and perceived impact of disease was not observed in this study. A search of the literature did not locate other research which had sought an association between knowledge of disease and perceived impact of disease. It can only be concluded that in this study sample a significant relationship between knowledge of disease and perceived impact of disease did not exist.

Summary of Hypotheses

Both Hypothesis IV, which hypothesized a relationship between social support and perceived impact of disease, and Hypothesis VII, which hypothesized an association between knowledge of disease and stated compliance, were found to be statistically significant. Other hypothesized relationships

between study variables were not found to be statistically significant and it was concluded that those relationships did not exist in the study sample.

Limitations of this study which may have effected the possibility of obtaining statistically significant relationships include (1) the small size of the sample in this study, (2) the limited reliabilities of the scales measuring knowledge and compliance, and (3) the threat of bias because of social desirability which existed in the scales measuring compliance, social support and perceived impact of disease.

Implications for Nursing Practice

The results of this study have identified a number of significant relationships. The strength of these relationships must be viewed as low to moderate, however, and the findings should be applied with caution. When study findings are considered in relation to Roger's (1970) concepts concerning nursing a number of practical implications for the practice of nursing emerge.

According to Rogers (1970) the "professional practice of nursing seeks to promote symphonic interaction between man and environment" and "positive health measures will be directed toward determining individual differences and assisting people to develop patterns of living coordinate with environmental changes rather than in conflict with them".

The goal of determining individual differences is most clearly linked to the assessment phase of the process of nursing.

Study findings which have relevance in the assessment of COPD patients include the following:

1. Awareness by nurses that with increasing numbers of hospitalizations, COPD patients may experience an awareness that the disease is exerting a greater impact on their usual daily activities. Rogers (1970) states that "activities of daily living must encompass opportunities for rhythmic consistancy". Evaluating either expected changes in usual activities in the hospitalized patient or actual changes in the patient post-hospitalization will enable the nurse to gauge the extent to which the individuals pre-established patterns have been (or may be) disrupted. The extent of disruption for both the patient and the patients family should be assessed in keeping with Rogers (1970) philosophy regarding the man-environment interaction.

2. The negative association found between duration of illness and knowledge of treatment should clearly emphasize the need for nurses to make continuing reassessments of patient levels of knowledge throughout the entire course of the disease. It would appear unwise, based on study findings, to assume that the patient who has experienced the disease process for a number of years has been thoroughly instructed in and possesses adequate knowledge of elements of treatment. Because accurate knowledge of treatment may hold valuable substance which can enhance the unity of the patients existance, it is vital that the nurse assess the patients level of knowledge at frequent intervals to act as a guide in subsequent interventions.

3. The broad range of compliance scores obtained in this study would indicate the need for awareness by nurses that the COPD patients level of cooperation with recommendations directed toward the maintainance of their optimum function is likely to be less than complete. Assessment by the nurse of the patients levels of compliance and knowledge is essential as a basis for nursing interventions in the form of patient education. Additionally, the nurses assessment of patient compliance should be sufficiently detailed so as to locate both the specific areas of noncompliant behavior and barriers to compliance. Also the patients perceptions regarding the degree to which compliant behavior is or is not practiced and individual reasons for behaviors are vital areas for nursing assessment.

4. Social support is an intergal part of the environment in which the COPD patient functions. It has been demonstrated by this study that social support, as defined by Caplan (1979), may be measured with a high degree of reliability. Rogers (1970) refers to "human relationships as instruments of therapy" and states that "positive health measures will be directed toward determining individual divverences (between persons)". Toward the end of determining individual differences, the assessment of social support as perceived by the patient becomes essential and provides a base upon which the nurse may increase understanding of the patient and the patients reactions to the disease process. As the nurse seeks to assess social support as it exists within the environment of the patient it is vital that the nurse remain

cognizant of the fact that during the process of nurse-patient interactions the nurse has become a part of the patients environment, thereby affecting patient perceptions of social support.

5. The use of an instrument to measure the patients perceptions of impact of the disease process upon living patterns in this study establishes another area in which nurse assessment may add to the understanding of the COPD patient and his degree of harmony with his environment. A basic tenet of Rogers (1970) framework is that "activities of daily living must encompass opportunities for rhythmic consistanct". Symptoms of the disease process of COPD cause varying degrees of disruption of previously established patterns of daily living. It is only through assessment of this disruption that the nurse is able to plan interventions to assist patients to "develop patterns of living coordinate with environmental changes rather than in conflict with them" (Rogers, 1970).

6. The negative correlation between social support and perceived impact of disease observed in this study accentuates the validity of Rogers' postulate of man-environment interaction and emphasizes the merit of including both factors in patient assessment to increase understanding on the part of the nurse.

7. The restriction of range of severity encountered in subjects who participated in this study would point to the importance of nurses in all areas of prefessional practice to remain alert to the importance of assessment of risk factors

and physical findings in an effort to locate patients in the early stages of COPD.

Planning and intervention have traditionally been based upon assessment of the pathological conditions and their overt manifestations exhibited by the patient. Findings of this study would point toward the importance of basing interventions on additional aspects of both the patient and the patients environment as conceptualized by Rogers (1970). Figure 4 summarizes areas vital to patient-environment assessment as conceptualized by Rogers and substantiated by study findings.

Implications of study findings for nursing practice in the planning and intervention phases of the nursing process include:

1. Consideration by nurses of the apparent value of including family members in patient education programs. Subjects in this study who were accompanied during teaching by a family member reported lower perceptions of disruption of their usual activities by COPD and increased perceptions of emotional support.

2. The observed correlation between knowledge of disease and stated compliance in this study emphasizes the value of inclusion of information concerning the disease process, etiology and prognosis in patient education programs for COPD patients.

3. The nurse should consider plans for the care of the COPD patient with an awareness of the negative correlation between social support and perceived impact of disease which was observed in this study. According to Rogers (1970) "the nurse is an environmental component for the individual receiving

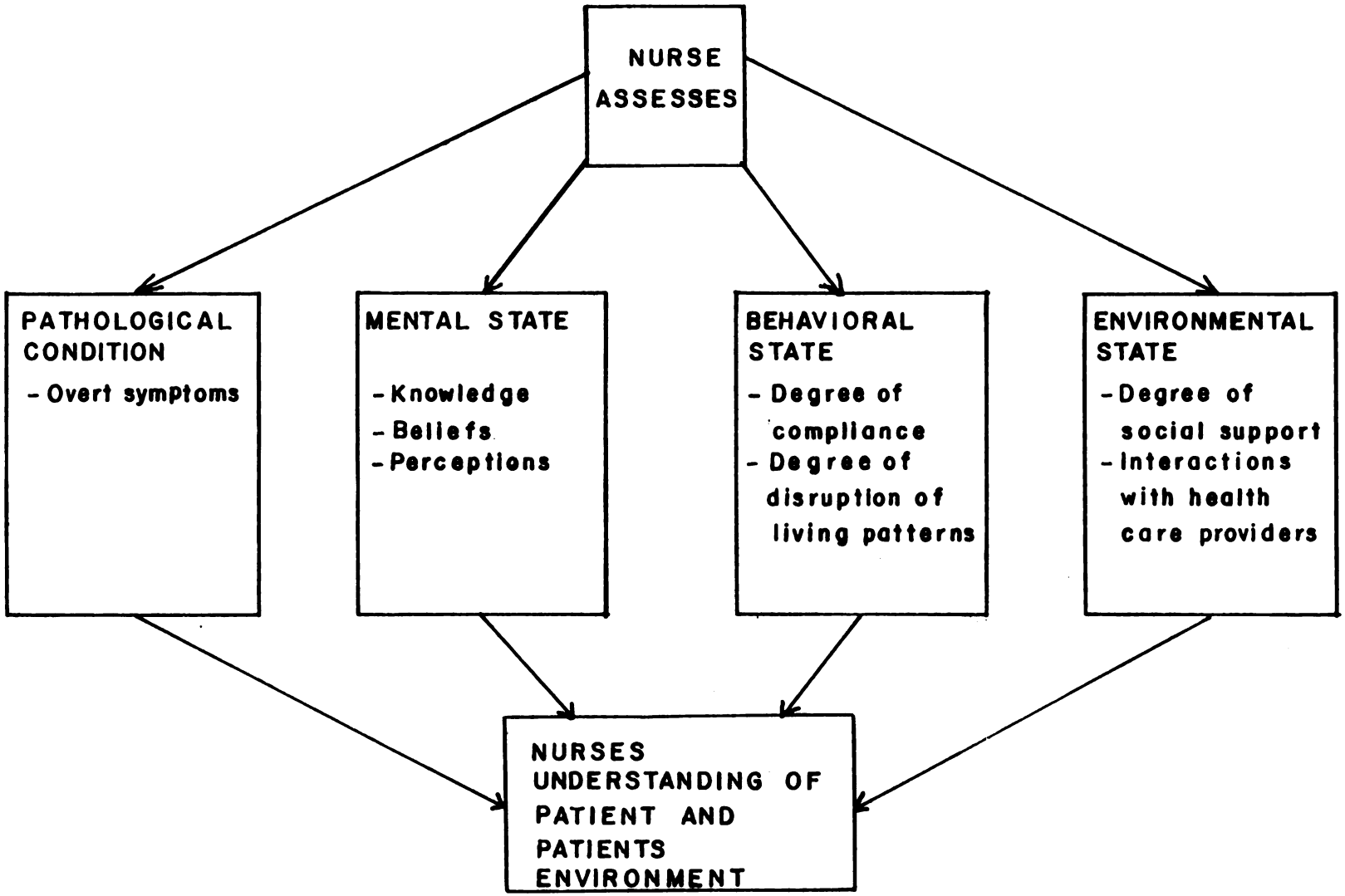

Figure 5: Nurse Assessment of Patient and Patient's Environment

services and is always a factor in the intervention process". The nurse, therefore, should remain aware that as an individual interacting with the patient he/she may effect the patients perceptions of support and impact of disease.

Implications for Nursing Education

Implications for nursing education may be drawn from study findings as they relate to the conceptual framework upon which this research was based. Fundamental concepts of the framework of this study will be presented, followed by pertinent study findings and the implications which they infer.

1. Commonalities exist in all patients with COPD which are the result of the pathology and it's manifestations.

Study findings have produced a profile of the beliefs and behaviors of a representative group of patients with COPD. Among the implications of this finding in the area of undergraduate education is the importance that information regarding those common factors which COPD patients possess as a result of their disease symptoms be included in the curriculum to enhance nurses understanding of COPD patients. The understanding first of the commonalities of a group of patients will provide the student with a base for later understanding the effect of differences encountered in individual patients.

There is additionally an implication for the development of in-service programs for nurses working with COPD patients to increase their understanding of the patients with whom they interact and disemination of these study findings in professional

literature to accomplish the same purpose. In the area of graduate education it is important that further research be encouraged in an effort to expand the present level of understanding and add to the knowledge base of nursing.

2. Individual differences exist in each patient which must be assessed in conjunction with commonalities when planning care for the COPD patient.

Those individual differences which were studied in this research were differences in levels of knowledge of both disease and treatment, differences in levels of compliance behavior, differences in levels of social support, and differences in perceptions of the impact of the disease. Study findings verify both that these differences do exist and that they may be assessed and measured.

The fact that these differences do exist and may be assessed should be an intergal part of the curriculum in the education of nurses at all levels. Assessment skills in these areas should be taught in both schools of nursing and in workshops and in-service programs for practicing nurses. The tools for the assessment of these differences in patients should be shared both with practicing professionals for direct use with patients and also with other researchers so that understanding of these differences may be advanced and added to the body of nursing knowledge.

An additional implication is for the development of standards for the care of COPD patients which take into consideration both factors common to these patients and the need to understand and

assess differences between individuals. There is also a need for nurses to participate in programs for public education and screening for early lung disease in order to increase the public awareness and understanding of chronic lung disease.

3. Compliance behavior in the COPD patient is influenced by a number of factors and the interactions of those factors in the patients life.

Study findings, as well as a study of pertinent literature, support the view that compliance behavior is influenced by numerous factors. The findings in this study of the negative relationship between social support and perceived impact of disease, the positive relationship between the patients perception of the severity of disease and the perception of the impact of disease, and the positive relationship between perceptions of severity and increased levels of compliance point to the interactive nature of factors influencing compliance.

There is a clear and strong implication for the continuation of research efforts to quantify and understand the interrelationships between those factors which influence compliance. Additionally, awareness of those factors known to influence levels of compliance should be included in nursing curriculums at all levels of education.

4. Behaviors in accord with the therapeutic regimen will enhance the well-being of the COPD patient and nurses may act to enhance compliance potential by utilizing knowledge of both the commonalities and individualities of each COPD patient.

While no finding in this study offers direct support for this assumption which was an intergal part of the framework upon which the study was based there are, nevertheless, implications for continued research. There is a need for the development of intervention studies to test the effect of nurses actions on compliance in the COPD patient. Additionally, correlational studies to determine the relationship of high levels of compliance to the feelings of both physical and mental well-being of the COPD patient would add valuable information upon which nurses could base knowledgable interventions.

Implications for Further Research

A number of implications for further research may be derived from this study. Suggestions for the improvement of the design of this study include the following:

1. Because a number of potential subjects were rejected because of age, the investigator would suggest moving the upper age limit of the study sample to 75 years. COPD is a disease which prevails in older populations and deleting subjects over age 70 may make the sample less representative of the population which is intended to be measured. No potential subjects were below age 50, therefore the lower age limit would appear to be appropriate.

2. An increase in sample size in order to both increase the generalizability of findings and enhance the possibilities of obtaining statistically significant correlations.

3. Stricter control of the environment in which the patient completes the questionnaire. Filling the questionnaire out at home in the presence of spouse or other family members may result in responses affected by social desirability bias.

4. Treatment of knowledge as a single variable, with knowledge of disease and knowledge of treatment utilized as subscales within that variable.

5. Incorporation of a short form depression scale would appear to add meaningful data with which information from the social support scale and the perceived impact of disease scale might be more comprehensibly related.

6. Statistical analysis seeking non-linear relationships. Relationships which may have been addative or curvilinear in nature are unlikely to be discovered through correlational statistical techniques.

7. Incorporation of clinical measures of severity of disease in relation to patient perceptions of impact of disease as a major study variable. Incongruence between the relationship of actual clinical measures and patient assessments of severity of disease to perceived impact of disease and to compliance would indicate a need for further research into the degree of reality in patient perceptions of their disease and the effect of those perceptions on levels of compliance.

8. Refinement of the scales used to measure knowledge of disease, knowledge of treatment and compliance.

Additional recommendations for further study include:

1. Utilization of refined scales as pre-tests and post-tests for pulmonary education groups to discover possible changes in levels of knowledge, compliance, social support, and perceived impact of disease.

2. Utilization of refined scales as outcome measures for evaluation purposes in pulmonary rehabilitation groups.

Summary

In Chapter VI a summary and interpretion of study findings was presented. Findings were related to the conceptual framework of this study and to nursing theory. Recommendations for nursing practice, education and research were presented.

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APPENDIX A

HOSPITAL APPROVAL OF STUDY PROTOCOL

INGHAM
MEDICAL
CENTER

401 WEST GREENLAWN, LANSING, MICHIGAN 48909 (517) 374-2121

April 15, 1981

Ms. Sharon King
1817 Ann Street
East Lansing, MI 48823

Dear Ms. King:

Please be advised that the Research Committee has recommended approval of your protocol entitled, "Interrelationship of Knowledge, Social Support, Perceived Impact of Disease and Stated Compliance in a Group of Patients with C.O.P.D." to the Executive Committee of Ingham Medical Center. This action took place and the protocol was approved by the Executive Committee.

Sincerely,

Ron Cline
Recording Secretary

ls

APPENDIX B

CHECKLIST: CRITERIA FOR STUDY PARTICIPANTS

CHECKLIST I

CRITERIA FOR STUDY PARTICIPANTS

(1) Medically diagnosed as having emphysema, chronic bronchitis, or COPD

(2) Able to read and write in the English language

(3) Age 50 to 70 years

(4) Possess telephone in place of residence

(5) Not documented as being alcoholic or psychotic

(6) Not documented as having cancer or any other terminal disease

APPENDIX C

LETTER OF EXPLANATION

AND

CONSENT FORM

MICHIGAN STATE UNIVERSITY

COLLEGE OF NURSING

This letter is to introduce you to a study which is being conducted by Sharon King, RN, a graduate student in the Michigan State University College of Nursing.

The experience of living with chronic lung disease affects people's lives in many ways. This research study is being conducted to help health care providers better understand the changes caused by chronic lung disease and things which may help people better tolerate those changes. It is the hope of the researcher that the information gathered through this study may provide a greater understanding of how health care providers may best help people with chronic lung disease.

Participation in this study will require approximately thirty minutes of your time. You will be asked to complete a questionnaire about chronic lung disease, the changes in your life that have been caused by chronic lung disease, your present health practices, and your view of the support that you have received from other people. In addition, you will be asked some questions about yourself. Should you agree to participate in this study a portion of your medical record will be reviewed in order to understand the severity of your lung disease.

Your participation in this study will in no way interfer with or change the care you are now receiving. There is no physical risk and no expense to you. You are free to ask questions now and throughout the study. You may withdraw from the study at any time without jeopardizing your future care. Your identity will be kept confidential and no information that could identify you will be used in any reports of the study. Responses you make on your questionnaire will not be revealed to any other person. A summary of the results of this study will be made available to you upon completion of the study at your request.

Should you feel that you might be interested in participating in this study please sign the attached participant's statement and return it to your nurse. About three weeks after you are discharged from the hospital I will telephone you to answer any questions you may have about the study and ask if you would like to receive a questionnaire to fill out. The questionnaire will be mailed to you along with a stamped, self-addressed envelope for it's return. Please save this letter and feel free to call me at 351-7918 if you have any questions about the study.

Sharon K. King, RN

Sharon K. King, RN
Graduate Student, MSU College of Nursing

Participant's Statement

I, the undersigned, am interested in learning more about the study of chronic lung diseases being conducted by Sharon King, RN.

I am willing to be contacted by telephone about three weeks after my discharge from the hospital and to receive a questionnaire by mail as part of the study.

I understand that this study may not benefit me personally but could help persons with chronic lung diseases in the future.

I understand that I am free to ask questions at any time during the study.

I understand that this study will not affect the care that I am now receiving.

I understand that my anonymity will be maintained and that all of my responses will be kept confidential.

I understand that my participation in this study is voluntary and that I may withdraw at any time.

I understand that my medical record will be reviewed as part of this study.

_____

Signature of Participant (Date)

APPENDIX D

CHECKLIST: TEACHING DOCUMENTATION

CHECKLIST FOR PATIENTS CONSENTING TO TAKE PART IN COPD STUDY

Name_____
Address_____
_____
Telephone_____
Patient discharge date_____
Length this hospitalization_____ (days)

Pulmonary Function Test in current chart?
_____Yes ——→ If Yes: Date PFT performed_____
_____No Reported FEV_1 (actual)_____
Reported FEV_1 (% predicted)_____

Discharge teaching information:
Initials of RN doing teaching_____
Date (s) of teaching_____
Length of time spent in teaching_____
Did family attend patient teaching?
_____Yes ——→ If Yes, who:_____
_____No (relationship to patient)
Did a friend attend patient teaching?
_____Yes
_____No

Material covered during patient teaching:
Please check those items covered with the patient during discharge teaching

Medications:
Name(s): _____
Dosages: _____
Purpose(s): _____
Side-effects: _____

Symptoms to report to doctor:
Increase in shortness of breath _____
Increase in sputum production _____
Change in color of sputum _____
Change in thickness of sputum _____
Temperature over 101 degrees _____
Mental confusion _____

Ways of avoiding infection _____
Importance of avoiding inhaled irritants _____
Importance of not smoking _____
Postural drainage _____
Diaphragmatic breathing _____

APPENDIX E

STUDY QUESTIONNAIRE

Dear

Thank you for agreeing to fill out this questionnaire about your experiences with chronic lung disease.

The questionnaire is divided into five sections. The first two sections are about chronic lung disease and how it is treated. Following that are questions about your current health practices and about the kind of help you receive from other people. The last section is general information about yourself.

The questionnaire you fill out will be kept completely confidential and anonymous. No other person will see the questionnaire and your name will not be used in any reports of the study results.

If you would like to receive a summary of the results of the study, please fill out and mail the enclosed stamped post card.

When you are ready to fill out the questionnaire please try to find a time when you can be alone and uninterrupted. It should take about one-half hour to complete the questionnaire.

Try to answer every question. If you aren't sure of the correct answer mark the response with your best guess. Each response you mark is very important whether it is correct or not.

If you have questions or feel confused by the questionnaire please feel free to call me at 351-7918. If you have special comments about any of the questions please write a note at the end of the questionnaire.

Thank you for your assistance.

Sincerely,

Sharon King

Sharon King, RN

THE FOLLOWING QUESTIONS ARE ABOUT CHRONIC LUNG DISEASES SUCH AS CHRONIC BRONCHITIS, EMPHYSEMA AND CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD). PLEASE CHECK THE ONE CORRECT OR BEST ANSWER FOR EACH QUESTION. IF YOU ARE UNSURE ABOUT THE CORRECT OR BEST ANSWER, ANSWER WITH YOUR BEST GUESS. PLEASE CHECK ONLY ONE ANSWER FOR EACH QUESTION.

1. Chronic bronchitis, emphysema and COPD are diseases that:
   _____a) can be cured in a short time with medicine.
   _____b) cannot be cured but can be helped by medicine.
   _____c) can be cured by surgery.

2. A common symptom of chronic lung disease is:
   _____a) chest pain.
   _____b) blood in the sputum.
   _____c) shortness of breath.

3. One important cause of chronic lung diseases such as chronic bronchitis, emphysema and COPD is:
   _____a) smoking cigarettes.
   _____b) lack of vigorous exercise.
   _____c) an accident which injures the lungs.

4. It is not unusual for people with chronic lung disease to:
   _____a) have frequent headaches which become worse with exercise.
   _____b) gain a lot of weight as they decrease their exercise.
   _____c) have a hacking cough which has been present for many years.

5. Chronic lung diseases such as chronic bronchitis, emphysema and COPD cause people who have them to:
   _____a) have difficulty moving air in and out of their lungs.
   _____b) become allergic to many things which did not used to bother them.
   _____c) undergo a change in the size and shape of their lungs.

6. Chronic lung diseases such as chronic bronchitis, emphysema and COPD are made worse by:
   _____a) straining the lungs with vigorous exercise such as jogging or swimming.
   _____b) continued exposure to irritants such as tobacco smoke and air pollution.
   _____c) living in an area where the weather is often damp or cold.

7. Mucus in the lungs becomes a problem for people who have a chronic lung disease because:
   _____a) it becomes trapped in the lungs and reduces the airflow.
   _____b) it increases their chances of developing blood clots and strokes.
   _____c) it eats away at the delicate tissue of the lungs.

8. The person who is most likely to develop a chronic lung disease such as chronic bronchitis, emphysema or COPD has:
   _____a) a history of many other diseases which run in their family.
   _____b) a history of heavy smoking for a period of ten to twenty years.
   _____c) a history of overweight and lack of exercise for a period of ten to twenty years.

9. One important function of the lungs is to:
   _____a) get oxygen to the blood so that it can be carried to the cells.
   _____b) filter the air breathed in so that impurities don't get to the blood.
   _____c) provide a cushion within the chest to give protection to the heart.

10. One reason that people don't quickly realize that they have a chronic lung disease such as chronic bronchitis, emphysema or COPD is:
   _____a) it is not possible for doctors to diagnose chronic lung diseases until a person gets a lung infection.
   _____b) chronic lung diseases occur most frequently in people from 40 to 60 years of age and it is normal for a person to be more short of breath as they get older.
   _____c) changes in breathing capacity happen so slowly that they are not noticed.

THE FOLLOWING QUESTIONS ARE ABOUT THE WAYS IN WHICH PEOPLE WITH CHRONIC LUNG DISEASES SUCH AS CHRONIC BRONCHITIS, EMPHYSEMA AND CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) ARE TREATED AND ADVISED TO TAKE CARE OF THEMSELVES. PLEASE CHECK THE ONE CORRECT OR BEST ANSWER FOR EACH QUESTION. IF YOU ARE UNSURE ABOUT THE CORRECT OR BEST ANSWER, ANSWER WITH YOUR BEST GUESS. PLEASE CHECK ONLY ONE ANSWER FOR EACH QUESTION.

1. If a person with a chronic lung disease catches a cold they should contact their doctor:
   _____a) as soon as they feel a cold starting.
   _____b) if they have a fever.
   _____c) if someone else at home catches cold too.

2. When a person has a chronic lung disease it is important for them to:
   _____a) keep active so that their muscles do not become weak.
   _____b) avoid activity so that it is easier to breathe.
   _____c) continue exercise when it is hard to breathe so that their lungs will have to expand.

3. To avoid catching cold a person who has a chronic lung disease should:
   _____a) stay indoors during cold weather.
   _____b) keep their home heat set at 75 or above.
   _____c) dress appropriately for the weather when going outdoors.

4. Broncho-dilators (such as Theolair, Bricanyl) are used in the treatment of chronic lung disease in order to:
   _____a) expand the airways.
   _____b) loosen secretions in the lungs.
   _____c) prevent infection.

5. The most important thing for a person with a chronic lung disease to do when short of breath is:
   _____a) lie down on a firm bed or a recliner chair.
   _____b) relax and breathe out (exhale) slowly.
   _____c) breathe faster to increase oxygen supply to the lungs.

6. Side effects of broncho-dilators (such as Theolair, Bricanyl) which should be reported to the doctor include:
   _____a) upset stomach, jitteriness and rapid heartbeat.
   _____b) headache, excessive sweating and fatigue (tiredness).
   _____c) skin rash, swollen glands and sore throat.

7. Inhaling (breathing in) through the nose rather than the mouth results in:
   _____a) less chance of getting an infection.
   _____b) increasing the percentage of oxygen which gets to the lungs.
   _____c) warming and moisturizing the air before it gets to the lungs.

8. When a person has a chronic lung disease coughing:
   _____a) helps move phlegm (sputum) out of the lungs.
   _____b) causes the spread of infection within the lungs.
   _____c) dries up the normal moisture in the lungs.

9. The most effective breathing pattern for a person who has a chronic lung disease is:
   _____a) inhale (breathe in) and exhale (breathe out) through the mouth, taking quick shallow breaths.
   _____b) inhale (breathe in) through the nose, exhale (breathe out) through puckered lips, breathing slowly.
   _____c) inhale (breathe in) and exhale (breathe out) through the nose, taking breaths as deeply as possible.

10. A person with chronic lung disease should be aware that if they develop an infection they may experience the following symptoms:
   _____a) chest pain, extreme fatigue (tiredness), headache with blurred vision and dizziness.
   _____b) nausea, vomiting, diarrhea, aching muscles and a feeling of extreme weakness.
   _____c) fever, change in color or thickness of phlegm (sputum), increased shortness of breath and coughing.

THE FOLLOWING QUESTIONS ARE ABOUT YOU AND THE WAY YOU TAKE CARE OF YOURSELF IN RELATION TO YOUR CHRONIC LUNG DISEASE. PLEASE CHECK THE BOX WHICH MOST CLOSELY DESCRIBES HOW OFTEN YOU DO EACH OF THE FOLLOWING ACTIVITIES. REMEMBER, YOUR ANSWERS ARE CONFIDENTIAL AND THERE ARE NO RIGHT OR WRONG ANSWERS.

	ALWAYS	MORE THAN ONE-HALF THE TIME	ONE-HALF THE TIME	LESS THAN ONE-HALF THE TIME	NEVER
1. I take care to avoid very dry air.....					
2. I smoke cigarettes.....					
3. I contact my doctor if my phlegm (sputum) is a different color or is thicker than usual.....					
4. I wait a few days before calling my doctor if I think I am having side effects from my medicine.....					
5. I practice relaxed breathing (diaphragmatic breathing) when short of breath.....					
6. I take extra doses of a broncho-dilator (such as Theolair, Bricanyl) when I have trouble breathing.....					
7. I plan activities which reduce stress for me (such as walking or gardening).....					
8. I avoid contact with spray products such as hair spray or spray deoderant.....					
9. I become very anxious when I am short of breath.....					
10. I forget to schedule checkups with my doctor.....					
11. I plan my activities so that I can make the best use of the energy I have.....					
12. I try not to let my family or friends know when a situation or activity is causing me stress.....					
13. I contact my doctor when I have more shortness of breath than usual.....					
14. I spend time with family and friends even when they have a cold or the flu....					
15. I avoid extremes of heat and cold.....					

	ALWAYS	MORE THAN ONE-HALF THE TIME	ONE-HALF THE TIME	LESS THAN ONE-HALF THE TIME	NEVER
16. I wait a few days before contacting my doctor if I develop a fever.....					
17. I do tilting exercises (postural drainage).....					
18. I do not do any special planning for my diet.....					
19. I keep as active as my physical condition allows.....					
20. I don't always dress appropriately for the weather when I go outdoors.....					
21. During the flu season I avoid crowded places.....					
22. I push myself to keep active even when an activity causes me to become short of breath.....					
23. I make no special time to do things which are relaxing for me.....					
24. I stay in rooms where people are smoking.....					
25. I do not take the medicine prescribed for me by my doctor.....					

THE FOLLOWING QUESTIONS ARE ABOUT THE KIND OF SUPPORT AND ASSISTANCE THAT YOU RECEIVE FROM FRIENDS AND FAMILY IN RELATION TO YOUR CHRONIC LUNG DISEASE. READ THE STATEMENT CAREFULLY AND DECIDE HOW YOU FEEL ABOUT IT. YOU WILL AGREE WITH SOME STATEMENTS AND DISAGREE WITH OTHERS. TO HELP YOU EXPRESS YOUR OPINION, FOUR POSSIBLE ANSWERS HAVE BEEN PLACED BESIDE EACH STATEMENT. CHOOSE THE ANSWER MOST LIKE YOUR OWN OPINION AND CHECK THAT BOX.

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1. My family cares about me and what happens to me as a result of my lung disease.....				
2. I have a friend or friends who would look after my home if I was sick and had to be in the hospital.....				

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
3. I do not know enough people with whom I feel free to talk about the problems I have due to my lung disease.....				
4. I have someone I can count on who will help me out if I am sick (for example, drive me to the doctor, do my shopping).....				
5. I sometimes feel that my relatives or friends pay no attention to me when I talk about the problems I have due to my lung disease.....				
6. My family will take over my household responsibilities when or if I am sick and cannot manage myself.....				
7. I sometimes feel that my friends or relatives are not understanding when I am upset or irratible due to my lung disease.....				
8. If I feel like I need to talk to someone about my lung disease I know I can always find someone who cares and will listen to me.....				
9. I sometimes feel that my family doesn't show enough concern about the problems that I have due to my lung disease.....				
10. My family and/or friends are understanding of the limitations I experience as a result of my lung disease, (for example, they understand if I don't have enough energy to do things they would like to do).....				
11. My family expects me to carry out my usual activities when I feel sick.....				
12. My friends don't understand the problems that I have in my life due to my lung disease.....				
13. My family does all they can to encourage me when I feel sad or blue due to my lung disease.....				
14. I could use more help with managing my usual responsibilities.....				
15. My family or friends can be counted on to help me get the medical care I need (for example, drive me to doctor appointments, buy my medicine).....				
16. I can not depend on others to help me so I have to keep doing the things I usually do.....				

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
17. I am able to manage well with the amount of assistance that I receive from others.....				
18. My friends don't give me any encouragement when I feel sad or blue due to my lung disease.....				
19. My family adjusts their activities so that I can do things with them that are not too hard for me due to my lung disease.....				
20. Someone calls me on the telephone several times a week just to find out how I feel.....				
21. It would be fairly hard for me to get a ride from a friend if I was unable to use other transportation to get to my doctor.....				
22. I feel that I have friends who care about me and what happens to me as a result of my lung disease.....				
23. When I am not able to get outside due to my lung disease my friends visit me in my home.....				
24. It would be fairly hard for me to get help from a friend if I was unable to do something myself because of my lung disease.....				
25. I feel that my family and friends make an effort to understand my lung disease and how it effects what I am able to do.....				

THE FOLLOWING QUESTIONS ARE ABOUT YOU AND <u>YOUR DAILY ACTIVITIES</u> AS THEY RELATE TO YOUR CHRONIC LUNG DISEASE. READ EACH STATEMENT CAREFULLY AND DECIDE IF YOU AGREE OR DISAGREE THAT THE STATEMENT DESCRIBES THE WAY YOU ARE DOING THINGS NOW BECAUSE OF YOUR HEALTH. TO HELP YOU EXPRESS YOUR OPINION, FOUR POSSIBLE ANSWERS HAVE BEEN PLACED BESIDE EACH STATEMENT. CHOOSE THE ANSWER <u>MOST LIKE YOUR OWN OPINION</u> AND CHECK THAT BOX.

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1. I rest often when doing work around the house.....				
2. I am considerate of family members.....				

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
3. I often act irritable toward family members (for example, snap at them, criticize them).....				
4. I have no difficulty reasoning and solving problems (for example, making plans, making decisions, learning new things).....				
5. I do not make many demands of family members (for example, insist that they do things for me, tell them how to do things).....				
6. I act nervous or restless.....				
7. I sleep less at night (for example, I wake up early, can't fall asleep, awaken frequently).....				
8. I am doing my usual physical recreation or activities.....				
9. I isolate myself as much as I can from the rest of the family.....				
10. I do social visiting by phone rather than in person.....				
11. I have no difficulty doing activities involving concentration and thinking.....				
12. I don't walk if I can avoid it.....				
13. I am cutting down the length of visits with friends.....				
14. I am doing the regular daily work around the house that I usually do (for example, yard work, repairs, cooking, cleaning).....				
15. I stay away from home only for brief periods of time.....				
16. I act irritable and impatient with myself (for example, talk badly about myself, swear at myself, blame myself for things that happen).....				
17. I talk with people about my health.....				
18. I stay at home most of the time.....				
19. I forget a lot (for example, things that happened recently, where I put things, appointments).....				
20. I sleep or nap during the day.....				

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
21. I have given up taking care of personal or household business affairs (for example, paying bills, banking, working on budget).....				
22. I go out as much as usual to visit people.....				
23. I talk about the future is a positive way.....				
24. I am doing less of the regular daily work around the house than I usually do.....				
25. I stay alone most of the time.....				

THE FOLLOWING QUESTIONS DESCRIBE GENERAL THINGS ABOUT YOU. PLEASE ANSWER ALL OF THE QUESTIONS TO THE BEST OF YOUR ABILITY.

1. When were you born? _____
(month) (day) (year)

2. What is your sex?
_____Male
_____Female

3. What is your racial or ethnic background? (Check one)
_____White
_____Black
_____Mexican-American
_____American Indian
_____Oriental
_____Other (please specify)_____

4. What is your marital status? (Check one)
_____Married
_____Single, never married
_____Separated
_____Divorced
_____Widowed

5. How many living children do you have, including adopted and stepchildren?_____

6. Taking all sources of money into consideration, what was your family's total income before taxes and other deductions for the past 12 months? (Check one)

_____Less than $5,000	_____$13,000-$14,999
_____$5,000-$6,999	_____$15,000-$16,999
_____$7,000-$8,999	_____$17,000-$19,999
_____$9,000-$10,999	_____$20,000-$24,999
_____$11,000-$12,999	_____$25,000 or over

7. Are you working now at a regular job outside the home for money?

_____Yes, I am working

_____No → _____Unemployed, _____Retired, _____Disabled, _____Housewife, _____Other (write in) _____ → GO TO QUESTION 11

8. What is your main occupation? (What type of work do you do?) (write in)_____

9. What kind of business or industry is that in? (What do they make?)_____

10. Is it your own business? (write in)_____

11. What is the highest grade that you completed in school? (Check one)

_____None or some grammar school (less than 7 grades completed)
_____Junior high school (9 grades completed)
_____Some high school (10 or 11 grades completed)
_____Graduated high school
_____Technical, business or trade school
_____Some college (less than 4 years completed)
_____Graduated college
_____Postgraduate college or professional

12. Who lives in your household, besides yourself? (Check as many as apply)

_____No one else
_____Husband/wife
_____Children, write in number living at home_____
_____Other relatives (write in relationships; for example, niece, mother-in-law)_____
_____Non-related persons (write in; for example, 2 friends, 1 boarder)_____

13. Do you have a chronic lung disease such as emphysema, chronic bronchitis or C.O.P.D.?

_____Yes

_____No → GO TO QUESTION 15

14. How long have you had a chronic lung disease? (Check one)

_____Less than one year
_____One to two years
_____Three to five years
_____Six to eight years
_____Nine to eleven years
_____Twelve to fourteen years
_____Fifteen years or more

15. How many times have you been in the hospital due to a chronic lung disease problem during the past 12 months? (write in)_____

16. Do you have any other chronic health problem?
_____Yes _____No → GO TO QUESTION 18

17. What other chronic health problem do you have? (check all that apply)
_____High blood pressure
_____Arthritis
_____Diabetes
_____Cancer
_____Ulcer
_____Heart disease
_____Other, write in_____

18. Do you ever have difficulty breathing?
_____Yes _____No → GO TO END OF QUESTIONS

19. When do you have difficulty in breathing? (Check one)
_____Only when doing very strenuous activity
_____Only when climbing hills or stairs but not during normal daily activities
_____Sometimes during normal daily activities but not while at rest
_____Sometimes at rest and frequently during normal daily activities

END OF QUESTIONS

Thank you very much for the time and effort that you have contributed to this study. Assistance such as you have given is extremely important and will aid in the understanding of how to best help people with chronic lung diseases. Please fill out and mail the enclosed post card if you would like to receive a summary of the results of this study when it is completed.

APPENDIX F

RAW FREQUENCIES

THE FOLLOWING QUESTIONS ARE ABOUT CHRONIC LUNG DISEASES SUCH AS CHRONIC BRONCHITIS, EMPHYSEMA AND CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD). PLEASE CHECK THE ONE CORRECT OR BEST ANSWER FOR EACH QUESTION. IF YOU ARE UNSURE ABOUT THE CORRECT OR BEST ANSWER, ANSWER WITH YOUR BEST GUESS. PLEASE CHECK ONLY ONE ANSWER FOR EACH QUESTION.

* 1. Chronic bronchitis, emphysema and COPD are diseases that:
- 0 a) can be cured in a short time with medicine.
- 31 b) cannot be cured but can be helped by medicine.
- 0 c) can be cured by surgery.

2. A common symptom of chronic lung disease is:
- 2 a) chest pain.
- 0 b) blood in the sputum.
- 29 c) shortness of breath.

* 3. One important cause of chronic lung diseases such as chronic bronchitis, emphysema and COPD is:
- 30 a) smoking cigarettes.
- 1 b) lack of vigorous exercise.
- 0 c) an accident which injures the lungs.

4. It is not unusual for people with chronic lung disease to:
- 4 a) have frequent headaches which become worse with exercise.
- 1 b) gain a lot of weight as they decrease their exercise.
- 26 c) have a hacking cough which has been present for many years.

5. Chronic lung diseases such as chronic bronchitis, emphysema and COPD cause people who have them to:
- 28 a) have difficulty moving air in and out of their lungs.
- 3 b) become allergic to many things which did not used to bother them.
- 0 c) undergo a change in the size and shape of their lungs.

6. Chronic lung diseases such as chronic bronchitis, emphysema and COPD are made worse by:
- 1 a) straining the lungs with vigorous exercise such as jogging or swimming.
- 27 b) continued exposure to irritants such as tobacco smoke and air pollution.
- 3 c) living in an area where the weather is often damp or cold.

* 7. Mucus in the lungs becomes a problem for people who have a chronic lung disease because:
- 31 a) it becomes trapped in the lungs and reduces the airflow.
- 0 b) it increases their chances of developing blood clots and strokes.
- 0 c) it eats away at the delicate tissue of the lungs.

* Deleted from scale

8. The person who is most likely to develop a chronic lung disease such as chronic bronchitis, emphysema or COPD has:
   4 a) a history of many other diseases which run in their family.
   26 b) a history of heavy smoking for a period of ten to twenty years.
   1 c) a history of overweight and lack of exercise for a period of ten to twenty years.

* 9. One important function of the lungs is to:
   31 a) get oxygen to the blood so that it can be carried to the cells.
   0 b) filter the air breathed in so that impurities don't get to the blood.
   0 c) provide a cushion within the chest to give protection to the heart.

*10. One reason that people don't quickly realize that they have a chronic lung disease such as chronic bronchitis, emphysema or COPD is:
   3 a) it is not possible for doctors to diagnose chronic lung diseases until a person gets a lung infection.
   5 b) chronic lung diseases occur most frequently in people from 40 to 60 years of age and it is normal for a person to be more short of breath as they get older.
   23 c) changes in breathing capacity happen so slowly that they are not noticed.

THE FOLLOWING QUESTIONS ARE ABOUT THE WAYS IN WHICH PEOPLE WITH CHRONIC LUNG DISEASES SUCH AS CHRONIC BRONCHITIS, EMPHYSEMA AND CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) ARE TREATED AND ADVISED TO TAKE CARE OF THEMSELVES. PLEASE CHECK THE ONE CORRECT OR BEST ANSWER FOR EACH QUESTION. IF YOU ARE UNSURE ABOUT THE CORRECT OR BEST ANSWER, ANSWER WITH YOUR BEST GUESS. PLEASE CHECK ONLY ONE ANSWER FOR EACH QUESTION.

1. If a person with a chronic lung disease catches a cold they should contact their doctor:
   19 a) as soon as they feel a cold starting.
   12 b) if they have a fever.
   0 c) if someone else at home catches cold too.

* 2. When a person has a chronic lung disease it is important for them to:
   18 a) keep active so that their muscles do not become weak.
   1 b) avoid activity so that it is easier to breathe.
   12 c) continue exercise when it is hard to breathe so that their lungs will have to expand.

3. To avoid catching cold a person who has a chronic lung disease should:
   2 a) stay indoors during cold weather.
   0 b) keep their home heat set at 75 or above.
   29 c) dress appropriately for the weather when going outdoors.

* Deleted from scale

4. Broncho-dilators (such as Theolair, Bricanyl) are used in the treatment of chronic lung disease in order to:
   24 a) expand the airways.
   7 b) loosen secretions in the lungs.
   0 c) prevent infection.

* 5. The most important thing for a person with a chronic lung disease to do when short of breath is:
   0 a) lie down on a firm bed or a recliner chair.
   31 b) relax and breathe out (exhale) slowly.
   0 c) breathe faster to increase oxygen supply to the lungs.

6. Side effects of broncho-dilators (such as Theolair, Bricanyl) which should be reported to the doctor include:
   24 a) upset stomach, jitteriness and rapid heartbeat.
   5 b) headache, excessive sweating and fatigue (tiredness).
   1 c) skin rash, swollen glands and sore throat.

7. Inhaling (breathing in) through the nose rather than the mouth results in:
   6 a) less chance of getting an infection.
   8 b) increasing the percentage of oxygen which gets to the lungs.
   17 c) warming and moisturizing the air before it gets to the lungs.

* 8. When a person has a chronic lung disease coughing:
   31 a) helps move phlegm (sputum) out of the lungs.
   0 b) causes the spread of infection within the lungs.
   0 c) dries up the normal moisture in the lungs.

9. The most effective breathing pattern for a person who has a chronic lung disease is:
   4 a) inhale (breathe in) and exhale (breathe out) through the mouth, taking quick shallow breaths.
   27 b) inhale (breathe in) through the nose, exhale (breathe out) through puckered lips, breathing slowly.
   0 c) inhale (breathe in) and exhale (breathe out) through the nose, taking breaths as deeply as possible.

*10. A person with chronic lung disease should be aware that if they develop an infection they may experience the following symptoms:
   1 a) chest pain, extreme fatigue (tiredness), headache with blurred vision and dizziness.
   0 b) nausea, vomiting, diarrhea, aching muscles and a feeling of extreme weakness.
   30 c) fever, change in color or thickness of phlegm (sputum), increased shortness of breath and coughing.

* Deleted from scale

THE FOLLOWING QUESTIONS ARE ABOUT YOU AND THE WAY YOU TAKE CARE OF YOURSELF IN RELATION TO YOUR CHRONIC LUNG DISEASE. PLEASE CHECK THE BOX WHICH MOST CLOSELY DESCRIBES HOW OFTEN YOU DO EACH OF THE FOLLOWING ACTIVITIES. REMEMBER, YOUR ANSWERS ARE CONFIDENTIAL AND THERE ARE NO RIGHT OR WRONG ANSWERS.

		ALWAYS	MORE THAN ONE-HALF THE TIME	ONE-HALF THE TIME	LESS THAN ONE-HALF THE TIME	NEVER
* 1.	I take care to avoid very dry air	6	8	7	5	5
2.	I smoke cigarettes	0	4	2	3	22
3.	I contact my doctor if my phlegm (sputum) is a different color or is thicker than usual	14	6	4	4	3
4.	I wait a few days before calling my doctor if I think I am having side effects from my medicine	8	4	3	5	11
5.	I practice relaxed breathing (diaphragmatic breathing) when short of breath	17	8	2	3	1
6.	I take extra doses of a broncho-dilator (such as Theolair, Bricanyl) when I have trouble breathing	1	1	4	4	21
7.	I plan activities which reduce stress for me (such as walking or gardening)	11	9	3	3	5
8.	I avoid contact with spray products such as hair spray or spray deoderant	20	4	3	3	5
* 9.	I become very anxious when I am short of breath	11	6	5	5	4
10.	I forget to schedule checkups with my doctor	1	1	1	3	25
11.	I plan my activities so that I can make the best use of the energy I have	18	9	2	2	0
12.	I try not to let my family or friends know when a situation or activity is causing me stress	9	7	9	4	2
13.	I contact my doctor when I have more shortness of breath than usual	17	3	9	2	0
*14.	I spend time with family and friends even when they have a cold or the flu	0	3	7	5	16
*15.	I avoid extremes of heat and cold	14	7	5	4	1

* Deleted from scale

		ALWAYS	MORE THAN ONE-HALF THE TIME	ONE-HALF THE TIME	LESS THAN ONE-HALF THE TIME	NEVER
16.	I wait a few days before contacting my doctor if I develop a fever.....	1	6	6	3	15
17.	I do tilting exercises (postural drainage).....	3	4	2	9	13
* 18.	I do not do any special planning for my diet.....	4	6	4	5	12
* 19.	I keep as active as my physical condition allows.....	25	4	2	0	0
20.	I don't always dress appropriately for the weather when I go outdoors.....	5	3	4	9	10
* 21.	During the flu season I avoid crowded places.....	21	5	4	0	1
* 22.	I push myself to keep active even when an activity causes me to become short of breath.....	10	10	3	5	3
23.	I make no special time to do things which are relaxing for me.....	5	8	7	4	7
24.	I stay in rooms where people are smoking.....	4	3	3	10	11
* 25.	I do not take the medicine prescribed for me by my doctor.....	6	0	0	3	22

THE FOLLOWING QUESTIONS ARE ABOUT THE KIND OF SUPPORT AND ASSISTANCE THAT YOU RECEIVE FROM FRIENDS AND FAMILY IN RELATION TO YOUR CHRONIC LUNG DISEASE. READ THE STATEMENT CAREFULLY AND DECIDE HOW YOU FEEL ABOUT IT. YOU WILL AGREE WITH SOME STATEMENTS AND DISAGREE WITH OTHERS. TO HELP YOU EXPRESS YOUR OPINION, FOUR POSSIBLE ANSWERS HAVE BEEN PLACED BESIDE EACH STATEMENT. CHOOSE THE ANSWER MOST LIKE YOUR OWN OPINION AND CHECK THAT BOX.

		STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1.	My family cares about me and what happens to me as a result of my lung disease.....	18	10	3	0
2.	I have a friend or friends who would look after my home if I was sick and had to be in the hospital.....	12	15	1	3

* Deleted from scale

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
3. I do not know enough people with whom I feel free to talk about the problems I have due to my lung disease.....	3	11	13	4
4. I have someone I can count on who will help me out if I am sick (for example, drive me to the doctor, do my shopping).....	12	17	0	2
5. I sometimes feel that my relatives or friends pay no attention to me when I talk about the problems I have due to my lung disease.....	1	4	19	7
6. My family will take over my household responsibilities when or if I am sick and cannot manage myself.....	11	15	3	2
7. I sometimes feel that my friends or relatives are not understanding when I am upset or irratible due to my lung disease.....	3	7	17	4
8. If I feel like I need to talk to someone about my lung disease I know I can always find someone who cares and will listen to me.....	9	15	4	3
9. I sometimes feel that my family doesn't show enough concern about the problems that I have due to my lung disease.....	2	4	18	7
10. My family and/or friends are understanding of the limitations I experience as a result of my lung disease, (for example, they understand if I don't have enough energy to do things they would like to do).....	8	17	6	0
11. My family expects me to carry out my usual activities when I feel sick.....	1	2	21	7
12. My friends don't understand the problems that I have in my life due to my lung disease.....	2	10	15	4
13. My family does all they can to encourage me when I feel sad or blue due to my lung disease.....	8	15	5	3
14. I could use more help with managing my usual responsibilities.....	3	11	13	4
15. My family or friends can be counted on to help me get the medical care I need (for example, drive me to doctor appointments, buy my medicine).....	8	21	1	1
16. I can not depend on others to help me so I have to keep doing the things I usually do.....	3	3	16	9

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
17. I am able to manage well with the amount of assistance that I receive from others.....	7	20	4	0
18. My friends don't give me any encouragement when I feel sad or blue due to my lung disease.....	1	5	18	7
19. My family adjusts their activities so that I can do things with them that are not too hard for me due to my lung disease.....	9	14	6	2
20. Someone calls me on the telephone several times a week just to find out how I feel.....	7	15	7	2
21. It would be fairly hard for me to get a ride from a friend if I was unable to use other transportation to get to my doctor.....	3	2	19	7
22. I feel that I have friends who care about me and what happens to me as a result of my lung disease.....	8	19	2	2
23. When I am not able to get outside due to my lung disease my friends visit me in my home.....	5	15	9	2
24. It would be fairly hard for me to get help from a friend if I was unable to do something myself because of my lung disease.....	1	3	23	4
25. I feel that my family and friends make an effort to understand my lung disease and how it effects what I am able to do.....	9	18	3	1

THE FOLLOWING QUESTIONS ARE ABOUT YOU AND <u>YOUR DAILY ACTIVITIES</u> AS THEY RELATE TO YOUR CHRONIC LUNG DISEASE. READ EACH STATEMENT CAREFULLY AND DECIDE IF YOU AGREE OR DISAGREE THAT THE STATEMENT DESCRIBES THE WAY YOU ARE DOING THINGS NOW BECAUSE OF YOUR HEALTH. TO HELP YOU EXPRESS YOUR OPINION, FOUR POSSIBLE ANSWERS HAVE BEEN PLACED BESIDE EACH STATEMENT. CHOOSE THE ANSWER <u>MOST LIKE YOUR OWN OPINION</u> AND CHECK THAT BOX.

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1. I rest often when doing work around the house.....	7	22	2	0
* 2. I am considerate of family members.....	9	21	1	0

* Deleted from scale

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
3. I often act irritable toward family members (for example, snap at them, criticize them).....	5	7	16	3
4. I have no difficulty reasoning and solving problems (for example, making plans, making decisions, learning new things).....	6	16	6	3
5. I do not make many demands of family members (for example, insist that they do things for me, tell them how to do things).....	8	16	5	2
6. I act nervous or restless.....	3	18	10	0
7. I sleep less at night (for example, I wake up early, can't fall asleep, awaken frequently).....	9	15	5	2
8. I am doing my usual physical recreation or activities.....	0	15	13	3
9. I isolate myself as much as I can from the rest of the family.....	2	7	16	6
10. I do social visiting by phone rather than in person.....	3	13	13	1
11. I have no difficulty doing activities involving concentration and thinking.....	6	16	7	2
12. I don't walk if I can avoid it.....	3	11	13	4
13. I am cutting down the length of visits with friends.....	3	17	10	1
14. I am doing the regular daily work around the house that I usually do (for example, yard work, repairs, cooking, cleaning).....	3	11	13	4
15. I stay away from home only for brief periods of time.....	5	20	5	1
*16. I act irritable and impatient with myself (for example, talk badly about myself, swear at myself, blame myself for things that happen).....	3	11	13	4
17. I talk with people about my health.....	3	19	7	2
18. I stay at home most of the time.....	2	15	11	3
19. I forget a lot (for example, things that happened recently, where I put things, appointments).....	2	14	12	3
20. I sleep or nap during the day.....	2	13	12	4

* Deleted from scale

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
21. I have given up taking care of personal or household business affairs (for example, paying bills, banking, working on budget).....	4	2	15	10
22. I go out as much as usual to visit people.....	3	12	14	2
23. I talk about the future is a positive way.....	4	19	6	2
24. I am doing less of the regular daily work around the house than I usually do.....	5	16	9	1
25. I stay alone most of the time.....	4	9	14	4

THE FOLLOWING QUESTIONS DESCRIBE GENERAL THINGS ABOUT YOU. PLEASE ANSWER ALL OF THE QUESTIONS TO THE BEST OF YOUR ABILITY.

1. When were you born? _____
(month) (day) (year)

2. What is your sex?
_____Male
_____Female

3. What is your racial or ethnic background? (Check one)
_____White
_____Black
_____Mexican-American
_____American Indian
_____Oriental
_____Other (please specify)_____

4. What is your marital status? (Check one)
_____Married
_____Single, never married
_____Separated
_____Divorced
_____Widowed

5. How many living children do you have, including adopted and stepchildren?_____

6. Taking all sources of money into consideration, what was your family's total income before taxes and other deductions for the past 12 months? (Check one)

_____Less than $5,000	_____$13,000-$14,999
_____$5,000-$6,999	_____$15,000-$16,999
_____$7,000-$8,999	_____$17,000-$19,999
_____$9,000-$10,999	_____$20,000-$24,999
_____$11,000-$12,999	_____$25,000 or over