

A Study of the Concerns of People with
Chronic Obstructive Pulmonary Disease©

by

Elizabeth Borycki R. N., HBScN

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

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**A STUDY OF THE CONCERNS OF PEOPLE WITH
CHRONIC OBSTRUCTIVE PULMONARY DISEASE**

BY

ELIZABETH BORYCKI

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of
MASTER OF NURSING**

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ABSTRACT

Although many researchers have examined the stressors present in chronic obstructive pulmonary disease (COPD), few have studied the concerns of people living with this disease from the affected individual's perspective. The purpose of this study was to explore and describe the concerns of people living with COPD according to stage in disease trajectory and gender, and the relationships among concerns to stage in disease trajectory and gender. A qualitative, ethnographic research approach was used to identify the concerns of individuals living with COPD. Data were collected from four sources; two audio taped interviews with each participant, an adapted version of "The Perceived Support Network Inventory", patient chart notes and observations. Qualitative data analysis revealed two types of concerns: primary and secondary. Dyspnea was the primary concern. Dyspnea acted as either an antecedent or consequence to several other concerns. All remaining concerns were secondary in nature. Secondary concerns were classified into five categories: environmental, functional, biological, psychological, and social. Although, many of the concerns identified by the participants have been addressed in the literature, a few new concerns have emerged. These include the effect of wind, oxygen and oxygen equipment use, death and dying, communication, and a lack of understanding by others. Few concerns differed according to disease trajectory and gender. Findings from this study illustrate the need for further research addressing the concerns of individuals affected by COPD and the subsequent education of health professionals regarding the needs and care of their patients.

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CHAPTER ONE: INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a major health problem in North America (American Thoracic Society, 1995; Sexton & Munro, 1988).

COPD encompasses a wide spectrum of diseases, including individual or combinations of asthma, emphysema and chronic bronchitis (American Thoracic Society, 1995; Canadian Thoracic Society Workshop Group, 1992; Sexton, 1981; Shekleton, 1987). According to Tames (1991, p. v), more than 600, 000 Canadians were diagnosed with chronic bronchitis, emphysema and asthma as well as combinations thereof. COPD is the seventh leading cause of death in Canada. Statistics indicate that COPD results in the loss of 120 years of life for every 100,000 individuals (Wilkins & Mark, 1992, p. 113). Each year 8.5 billion patient visits are made to Canadian hospitals for treatment of COPD (Health and Welfare Canada, 1991, p. 32), resulting in direct and indirect health care costs of 5.2 billion dollars (Wigle, Mao, Wong & Lane, 1991, p. 6). Chronic obstructive pulmonary disease is a significant cause of death, disability, and economic cost to the health care system (American Thoracic Society, 1995; Doll, Peto, Wheatley, Gray & Sutherland, 1994).

Chronic Obstructive Pulmonary Disease and Disease Trajectory

Chronic obstructive pulmonary disease has a lengthy disease trajectory.

COPD develops over a period of several decades, progressing from mild through to severe stages in disease trajectory. In the early or mild stages of COPD, the individual may only experience a gradually decreasing exercise tolerance, dyspnea on exertion, and or a cough which may or may not be accompanied by sputum. Often individuals in the mild stage of COPD are able to lead an active life, unaware of the presence of a disease process (Doll et. al., 1994; Kniesl & Ames, 1987; Sexton, 1981; Tames, 1991). Inevitably, respiratory tract infections lead to a worsening of symptoms and lung function. The individual seeks medical attention and often a diagnosis of moderate or severe stage of COPD results. Eventually, a cyclical pattern of wellness, disease exacerbation, and further lung deterioration develops until dyspnea accompanies most activities. With further deterioration, dyspnea becomes a characteristic feature of all activities of daily living including rest. Deterioration in lung function and dyspnea lead to hypoxemia, heart failure and eventual death (American Thoracic Society, 1995; Kniesl & Ames, 1987; McCarthy, 1990; Sexton, 1981; Tames, 1991).

Lung deterioration in COPD is a gradual process interspersed with periods of rapid decline. Average declines in forced vital capacity of 50 ml occur each year in those affected (Dudley, Glaser, Jorgenson & Logan, 1980, p. 549), however, such declines are dependant on individual differences such as genetics and smoking behaviours (Emirgil, Sobol, Varble, Waldie & Weinheimer, 1971). Treatment can slow or stabilize lung function, but it is not a cure and deterioration of the lung is inevitable (American Thoracic Society, 1995; Shekleton, 1987; Webster & Kadah, 1991).

Influence of Chronic Obstructive Pulmonary Disease on Individual and Society

Because COPD involves progressive deterioration and debilitation, its effects can be felt at both individual and societal levels. At the individual level, a multitude of biological, psychological and social factors must be coped with (Dudley, 1981; Post & Collins, 1981-82; Sandu, 1986; Shekleton, 1987). On a societal level, the cumulative effects of COPD result in costs to the health care system in terms of utilization of services (Stoddart, Labelle, Barer, & Evans, 1986; Walters, 1991; Wigle et. al., 1991). Furthermore, economically, COPD imposes losses in productivity (Luce & Schweitzer, 1978; Stoddart et. al., 1986; Wigle et. al., 1991) that affect the development of Canadian society (Stoddart et.

al., 1986; Walters, 1991). As a consequence, COPD can be described as a disease whose impact is felt at all societal levels in varying forms.

The Growing Population of Individuals Affected by COPD

Several attempts have been made to discover the underlying causes of COPD. Many risk factors; for example, smoking, air pollution and heredity, have been implicated in the development of the disease (American Thoracic Society, 1995; Higgins, 1984; Holland, 1988; Joint Committee on Smoking and Health, 1995; Tames, 1991; Webster & Kadah, 1991), but smoking has remained its primary cause (American Thoracic Society, 1995; Hogg, 1990; Joint Committee on Smoking and Health, 1995; Petty, 1990). In the last three decades, the number of smokers has steadily decreased (Gelisky, MacDonald & Young, 1991; Insight Canada Research, 1992; Stephens, 1995). Consequently, society has developed the false perception that the number of individuals affected by COPD has also steadily decreased. In fact, the opposite is true (Canadian Thoracic Society Workshop Group, 1992). In 1993 with the decrease in tobacco taxes and the increase in cigarette smuggling, the prevalence of smoking increased (Stephens, 1995). The number of individuals 15 years of age and older who smoke has increased from 27 (Statistics Canada, 1991, p. 7) to 31 (Health Canada, 1994, p. 12) percent of the Canadian population.

Additionally, characteristics of the smoking population have changed with reported increases in the number of female (Eliany & Cartemanche, 1992; Greaves, 1990; Stephens, 1995) and heavy smokers (Eliany & Cartemanche, 1992). Since symptom development and disease diagnosis take place after a latency period that lasts 20 to 30 years (Doll et. al., 1994; Tames, 1991, p. 27), many of those individuals in the 15 to 54 year old age group will not be diagnosed until they reach their middle to late fifties (Kanner, 1987, p. 173; Stephens, 1995, p. 27). Individuals who smoked during the postwar years are only just beginning to be identified as COPD sufferers (Canadian Thoracic Society Workshop Group, 1992).

COPD and Gender

Changing smoking trends have altered the incidence and prevalence of COPD in specific populations (Health & Welfare Canada, 1982; Stephens, 1995). In the past, COPD has predominantly affected males (Health & Welfare Canada, 1982). As a result, most research on COPD has utilized male populations (Barstow, 1973; Emirgil et. al., 1971; McSweeney, Grant, Heaton, Heaton, Adams & Timms, 1982; Sexton & Munro, 1985). In recent years, with the increasing numbers of female smokers (Lamarche, 1990; Gelskey et. al., 1991;

Greaves, 1990; Stephens, 1995), the incidence of COPD has risen among women (Semenciw, Hill, Mao, & Wigle, 1989; Stephens, 1995).

Feminist science has verified that gender specific differences exist in several areas from patterns of thought (Fee, 1981) to societal expectations (Simmons, 1992). Because of the concentration of research on male populations, little investigation has been conducted examining the differences which may exist among females with COPD (Sexton & Munro, 1988). Some limited study and subsequent discovery of gender based variations in the experience of COPD has occurred (Barstow, 1974; Janson-Bjerklie, Carrieri, & Hudes, 1986; Sexton & Munro, 1988). Differences between males and females have been noted in such areas as life expectancy (Miyamoto, Aida, Nishimura, Aiba, Kira & Kawakami, 1995), the sensation of dyspnea (Janson-Bjerklie et. al., 1986), the experience of anxiety (Emery, Leatherman, Burkner & MacIntyre, 1991) and the perception of body image (Hahn, 1989; Kravetz, 1982). Further research is needed to more fully understand COPD from the female's perspective (Sexton & Munro, 1988), and to provide a more complete and accurate representation of the disease experiences of both genders (Sexton & Munro, 1988).

COPD, Coping and Concern

Because of the ongoing debilitating nature of the disease and the lack of a cure, physical deterioration and lifestyle change are hallmarks of COPD (Sexton & Munro, 1988; Shekelton, 1987; Webster & Kadah, 1991). Consequently, coping becomes a necessary component in both adjusting to the disease process (Ben-Sira, 1984; Bombardier, D'Amico & Jordan, 1990; Felton & Revenson, 1984, Felton, Revenson & Hinrichsen, 1984; Gift & Austin, 1992; Keller, 1988; Lipowski, 1970; Mattlin, Wethington & Kessler, 1990; Viney & Westbrook, 1984) and the maintenance of functional integrity (Shekelton, 1987). Coping functions to protect the individual from stressors. Coping changes, removes and moderates stressors as well as the emotional responses associated with stress (Pearlin & Schooler, 1978). Stressors are demands, environmental and or internal, that exceed or tax the individual's resources (Monat & Lazarus, 1985). Concern develops when the individual experiencing the stress appraises a stressor as an immediate or future threat to him or herself (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984).

Coping may be specific to gender (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984) and moderated by the environment (Lazarus & Folkman, 1984; Lennon, Dohrenwend, Zautra & Marbach, 1990 & McHaffie, 1992). Differing

gender (Barstow, 1974; Sexton & Munro, 1988) and environmental circumstances (Lazarus & Folkman, 1984; McHaffie, 1992) may alter the perception of immediate and future threats as well as the subsequent perception of stressors as concerns (Carrier & Janson-Bjerklie, 1986; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Sexton & Munro, 1988). For example, women perceive higher levels of dyspnea in COPD than men (Janson-Bjerklie et. al., 1986).

Consequently, the stressor dyspnea is a greater concern for women. Similarly, individual perception of the quality of their social network may influence their perception of concerns. For example, those who perceive their immediate social network as supportive may report severity of concerns to be diminished in comparison to individuals having no support network (Oritt, Paul & Behrman, 1985; Sexton & Munro, 1988). Such differing male and female appraisal of stressors or concerns as well as environmental circumstances may result in distinct gender and environment specific diversity in the use of coping within the biopsychosocial context (Folkman & Lazarus, 1980; Lazarus & Folkman 1984).

Biopsychosocial stressors concomitant with the disease foster concerns.

Biologically, the individual may appraise physiologic stressors such as increasing dyspnea, fatigue, cough, wheeze and mucosal secretions as concerns requiring coping responses (Barstow, 1974; Dudley, 1981; Pet, Speizer, Cochrane, Moore,

Fletcher & Tinker, 1983). Psychologically, concerns can emerge in the form of body image, depression, anxiety (Dudley, 1981; Gift & Austin, 1992; Prigatano, Wright & Levin, 1984), and losses of income and independence (Barstow, 1974). Socially, concerns range from limitations in socialization to an inability to participate in pleasurable recreational activities (Gift & Austin, 1992; Shekleton, 1987). Concerns involve a wide spectrum of appraised stressors within the biopsychosocial context and are not limited to those just mentioned.

Nursing Role in Coping with Chronic Illness

Nursing facilitates coping in individuals by utilizing the processes of assessment, planning, intervention and evaluation (Clarke, 1984; Panzarine, 1985; Roberts et. al., 1987). Through assessment the nurse is able to determine those areas requiring support, promotion, and maintenance of coping (Clarke, 1984; Roberts, Browne, Brown, Byrne & Love, 1987). Planning involves examining the concerns of individuals in order to determine those interventions that best facilitate coping and reduction of perceived stressors (Brailey, 1984; Clarke, 1984; Kniesl & Ames, 1987; Roberts et. al., 1987). Nursing interventions in COPD take two forms: health promotion and support. Health promotion involves the use of education to strengthen coping resources, and facilitate living with disease (Clarke, 1984). Here, the nurse facilitates the ability of individuals to

prevent exacerbations and slow disease progression by teaching the individual self-care. Nursing support assists disabled individuals who are unable to care for themselves or cope. Supportive nursing intervention ensures that disabled individuals have their needs met by family or health personnel. Evaluation, an important aspect of nursing care, enables the nurse to determine the effectiveness of his or her role in facilitating an individual's coping. The nurse who successfully fosters coping may eliminate or decrease an individual's concerns, may slow the disease process, and maintain an individual's independence and functioning (Janelli, Scherer & Schmieder, 1991; Keller, 1988; Leidy, 1989).

In order to ensure successful promotion and support of coping, the nurse must be able to identify and understand those concerns perceived by the individual as requiring coping responses. Both health care professionals and patients have appraised specific stressors that are germane to COPD (American Thoracic Society, 1995; Barstow, 1974; Chalmers, 1984; Post & Collins, 1981; Sexton & Munro, 1988). At present, the majority of the literature examines COPD associated stressors from a medically defined, clinician perspective rather than the individual's perspective of concern. For example hypoxemia is often described by health professionals in terms of the stress it causes on the body instead of the effects the individual has observed it to have on his or her lifestyle

(McSweeney et. al., 1982; Prigatano, Wright, & Levin, 1984). In patient studies, specific concerns are discussed or described peripherally (Barstow, 1974; Chalmers, 1984; Post & Collins, 1981-82; Sexton & Munro, 1988) and primarily from a male perspective (Barstow, 1974; Emirgil et. al., 1971; McSweeney et. al., 1982; Sexton & Munro, 1985; Small & Graydon, 1993). As well, the relationships among concerns, disease trajectory and gender are not well understood.

There is a lack of literature regarding concerns in all stages of the disease trajectory. The existing literature addresses concerns within the context of moderate and severe stage COPD (Barstow, 1974; Chalmers, 1984). No examination of concerns in the mild stage of COPD has occurred. This is primarily because it is difficult to identify individuals in the mild stage of disease process. Most individuals affected by COPD do not seek medical attention and are not diagnosed until they reach the moderate to severe stages of COPD, when concerns develop (McCarthy, 1990; Tames, 1991). Consequently, individuals affected by COPD do not report concerns until medical attention is sought.

With the growing numbers of individuals affected by COPD, nurses will need to take a greater role in facilitating client coping. Nurses need to identify the concerns of individual's in order to promote, teach and support appropriate and

effective coping that will reduce or eliminate an individual's concerns. Once concerns are identified and coping is addressed individuals may be able to slow the rate of disease process and debilitation by carrying out behaviours that prevent exacerbation of disease (Leidy, 1989).

Further investigation of concerns of individuals living with COPD according to stage in disease trajectory and gender, and the exploration of the relationships of concerns to stage in disease trajectory and gender are needed to uncover effective and appropriate interventions specific to the individual. For each individual, concerns or appraised stressors define the illness experience and the subsequent implementation and use of coping. Successful description of concerns and establishing the relationships between gender and disease trajectory is necessary to make effective educational and care interventions capable of fostering positive adjustment, and promoting physical integrity (Agle, Baum, Chester & Wendt, 1973; Gilmartin, 1986; Janelli et. al., 1991; Leidy, 1989; Leidy, 1990; Petrie, 1990). Ultimately this may lead to a successfully coping individual who is in a state of optimal wellness.

Purpose of the Study

The purpose of this study is to explore and describe the concerns of people with COPD according to stage in disease trajectory and gender, and the relationships of concerns to stage in disease trajectory and gender. The specific research questions to be investigated are:

Stage in Disease Trajectory

What are the concerns of individuals diagnosed with moderate COPD?

What are the concerns of individuals diagnosed with severe stage COPD?

Gender

What are the concerns of males diagnosed with COPD?

What are the concerns of females diagnosed with COPD?

Stage and Gender

What are the concerns of females diagnosed with moderate COPD?

What are the concerns of males diagnosed with moderate COPD?

What are the concerns of females diagnosed with severe COPD?

What are the concerns of males diagnosed with severe COPD?

Definition of Terms

For the purpose of this study, terms will be defined as follows:

Chronic Obstructive Pulmonary Disease (COPD)

COPD is a common respiratory disease characterized by airflow obstruction (Burrows, 1990; Canadian Thoracic Society Workshop Group, 1992; Shekleton, 1987). It is a progressive, irreversible chronic illness involving a symptomatic presentation of dyspnea, cough and gradually increasing levels of disability. The condition involves a medical diagnosis of individual or combinations of emphysema, chronic bronchitis and or asthma (with persistent obstruction of airways) (American Thoracic Society, 1995; Canadian Thoracic Society Workshop Group, 1992; McCarthy, 1990; Shekleton, 1987; Webster & Kadam, 1991).

Disease Trajectory

Disease Trajectory refers to the course and prognosis of a disease process from onset to end stage. Chronic obstructive pulmonary disease progresses through mild, moderate and severe stages of disease trajectory.

Mild Stage

Mild stage in disease trajectory refers to pulmonary function test FEV1 values of 60 to 70 percent of the predicted normal for age, sex and height (Anthonisen, personal communication, August 11, 1993)

Moderate Stage

Moderate stage in disease trajectory refers to pulmonary function test FEV1 values of 40 to 60 percent of the predicted normal for age, sex and height (Anthonisen, August 11, 1993).

Severe Stage

Severe stage in disease trajectory refers to pulmonary function test FEV1 values of 40 percent and less of the predicted normal for age, sex and height (Anthonisen, August 11, 1994).

Coping

Coping is a dynamic, adaptive and multidimensional process (Lazarus, 1987; Zeitlin, 1980) where behavioural and cognitive efforts are utilized to reduce, master, or tolerate stressors (Lazarus & Folkman, 1984).

Stress

Stress refers to "any event in which environmental demands, internal demands, or both tax or exceed the adaptive resources of an individual, social system, or tissue system" (Monat & Lazarus, 1985, p. 3).

Stressor

A stressor is an event or agent that causes stress (Monat & Lazarus, 1985).

Appraisal

Appraisal refers to the cognitive process of evaluating a situation for threat.

Threat is evaluated by assessing for available options and coping resources (Folkman & Lazarus, 1980).

Concern

A concern refers to a client appraised stress. Once a concern is identified by a client in the form of appraisal as a stress, coping is always initiated (Folkman & Lazarus, 1985).

Patient

A patient refers to an individual living in the community who is medically monitored for his or her chronic obstructive pulmonary disease.

Significance For Nursing

The nursing profession has sought to prevent illness, facilitate optimal wellness and promote health in terms of outcomes for the individual (Burckhardt, 1987; Chalmers & Kristjanson, 1989; Brundage, Swearengen & Woody, 1993). An illness such as chronic obstructive pulmonary disease requires extensive use of coping skills by patients. Coping is an essential component in managing the permanent changes to lifestyle, dignity, self-esteem and resources concomitant with a chronic illness (Burckhardt, 1987; Leidy et. al., 1990). Consequently, this presents nursing with the challenge to effectively promote, support and maintain an individual's coping (Clarke, 1984; Leidy et. al., 1990; Panzarine, 1985; Roberts et. al., 1987). Identifying an individual's concerns, recognizing the presence of differences in concern across the disease trajectory and in terms of gender enables the nurse to facilitate the coping of each individual (Burckhardt, 1987).

Presently, nursing interventions and suggested coping strategies for individuals address medically defined, clinician identified stressors that are not specific to gender or stage in disease trajectory. Consequently, the effectiveness of current interventions is questionable. Nurses need to be able to describe, understand and address the concerns of individuals as well as the relationships among concerns. Furthermore, nurses need to identify if concerns are altered by

stage in disease trajectory and gender in order to provide interventions that are specific to the disease stage and gender of the individual. Such research will allow nurses to develop and implement interventions in response to the concerns and coping needs of individuals. As a result, nursing practice may enhance the coping of individuals and produce a healthier chronically ill population.

CHAPTER TWO: REVIEW OF THE LITERATURE

Chronic obstructive pulmonary disease has a biopsychosocial effect on the individual. Health care professionals have studied a myriad stressors in individuals affected by COPD. Similarly, individuals with chronic obstructive disease have identified concerns or appraised stressors that have had an effect on lifestyle and required the use of coping resources. The purpose of this chapter will be to review the literature addressing chronic obstructive pulmonary disease, coping, concern, and the role of nursing. The literature review encompasses relevant literature addressing COPD, stress and coping, concerns and the impact of this disease on individuals and family.

Chronic Obstructive Pulmonary Disease

COPD is a disease which has received much study in recent years because of its extensive effect on the individual as well as society. Chronic obstructive pulmonary disease (COPD) is a leading cause of death and disability (Sexton & Munro, 1981; Wigle et. al., 1991; Wilkins & Mark, 1991). Presently, over 600,000 individuals in Canada are reported to be COPD sufferers (Tames, 1991, p. v). COPD is the seventh leading cause of death (Wilkins & Mark, 1991, p. 13), contributing to 44 out of every 100, 000 deaths (Wong & Wilkins, 1991, p. 73) and, the loss of 147 years of life for every 100, 000 individuals in Canada

(Wilkins & Mark, 1991, p. 13). The following section will review those diseases which comprise COPD, the trajectory of COPD, its assessment, and etiology.

COPD has been identified as the most common form of respiratory disease involving ventilation (Shekleton, 1987). COPD is a progressive, marginally reversible form of airflow obstruction (Burrows, 1990; Canadian Thoracic Society Workshop Group, 1992) which encompasses a wide spectrum of respiratory disorders including chronic bronchitis, emphysema, and asthma or combinations thereof (American Thoracic Society, 1995; Sexton, 1981).

Chronic Bronchitis

Chronic bronchitis is symptomatically diagnosed when the individual develops a persistent productive cough (Canadian Thoracic Society Workshop Group, 1992; Webster & Kadah, 1991) lasting at the minimum three months of the year for two consecutive years (Tames, 1991, p. 15). Chronic bronchitis is characterized by the obstruction and inflammation of the bronchi, mucosal edema and mucus hypersecretion (Kneisl & Ames, 1987; Sexton, 1981; Webster & Kadah, 1991). The inflammation of the bronchi stimulates hypertrophy and hyperplasia of the mucus glands, causing inflammatory cell infiltration and bronchial edema. These conditions in addition to the hypersecretion of mucus, narrow and increase airflow resistance in bronchial airways (American Thoracic

Society, 1995; Kniesl & Ames, 1987). Furthermore, because of the inflammatory state of the bronchi, ciliary activity is destroyed or diminished, providing a medium for bacterial growth, future respiratory infections, and further inflammation and mucus secretion (American Thoracic Society, 1995; Traver, 1982).

Emphysema

Emphysema involves a destruction of elastic lung fibres (Sexton, 1981; Tames, 1991) and an enlargement and destruction of peripheral bronchioles and the alveoli distal to the terminal non-respiratory bronchioles (Webster & Kadah, 1991, p. 31). The lost lung elasticity reduces inspiratory and expiratory lung pressures and as a consequence impairs the lung's ability to exchange respiratory gases. Additionally, the destruction of supporting lung tissue causes expiratory collapse of airways, alveolar air trapping and eventual alveolar destruction. This in turn results in a reduction in the size of the lung capillary bed and further respiratory impairment (Sexton, 1981; Tames, 1991).

Asthma

Asthma is characterized by a clinically reversible form of airflow obstruction resulting from physiologically responsive airways (Kniesl & Ames, 1987; Webster & Kadah, 1991). Characteristic symptoms include dyspnea,

wheezing, cough and varying levels of airflow obstruction (Tames, 1991). Even though many of the symptoms in asthma are not unlike those of chronic bronchitis and emphysema, asthma alone is not considered to be COPD. This is because most asthmatics experience relief from symptoms with the use of bronchodilators and anti-inflammatory agents (Burrows, 1990; Tames, 1991).

Asthma is COPD when dyspnea, cough and wheezing are persistently experienced even with the use of the previously mentioned conventional therapies (Burrows, 1990; Kniesl & Ames, 1987; Tames, 1991). This form of asthma is known as asthmatic bronchitis. It is included among the diseases which comprise COPD because the ongoing unresponsiveness of symptoms to conventional therapies can result in an irreversible progression of disease (Burrows, 1990; Tames, 1991).

Disease Trajectory

COPD develops over a period of twenty to thirty years (Tames, 1991). Initially, the individual may not even be aware of its development because of its slow progression. In the early or mild stages of the disease, COPD manifests as a slowly increasing exercise intolerance and dyspnea on exertion. "COPD may also present as a persistent or recurrent 'chest cold'" (Tames, 1991, p. 27), accompanied by a chronic cough, dyspnea and possible sputum production. At

this point in the disease, the individual is still able to live an active, normal, productive life in the presence of impaired lung function (Kanner, 1987). In many cases diagnosis of mild COPD is difficult, if not impossible: symptoms are often not identifiable (Kanner, 1987).

Often diagnosis does not occur until the individual reaches his middle to late fifties (Kanner, 1987, p. 173), when moderate to severe stages in disease process are present (Tames, 1991) and limitations are significant (Kanner, 1987). As the age of the individual advances, disease related disability gradually becomes even more pronounced (Kanner, 1987). Symptoms often worsen following disease exacerbations or respiratory tract infections (Kniesl & Ames, 1987; Tames, 1991). Frequent cough, increasing dyspnea, further exercise intolerance and wheezing become more apparent with the progression of time (Kanner, 1987; Tames, 1991). This is primarily because COPD has a progressive and debilitating disease course, which is punctuated by frequent exacerbations and gradually increasing levels of disability (American Thoracic Society Workshop Group, 1995; Sexton & Munro, 1987).

When the individual reaches the moderate to severe stages of the disease, dyspnea and wheezing are characteristic of previously tolerated activities such walking (Tames, 1991). Eventually, the severity of the disease will increase to the

point where the individual is even dyspneic at rest (Tames, 1991). The resulting hypoxemia leads to cor pulmonale (Fishman, 1971; Openbrier, Hoffman & Wesmiller, 1988), and ventricular failure (Rao, Cohn, Eldridge & Hancock, 1968). Supplemental oxygen, and periodic ventilation may be necessary once this stage is reached. Eventually, death by respiratory failure in the presence of respiratory infection and cardiac failure occurs (Canadian Thoracic Society Workshop Group, 1992; Tames, 1991).

Treatment and rehabilitation slows the disease process, but does not prevent the eventual physical decline of the individual (American Thoracic Society, 1995; Kniesl & Ames, 1987; Shekelton, 1987). Treatment includes the use of bronchodilators, corticosteroids, expectorants, mucolytics and postural drainage to reduce airflow obstruction (Faling, 1986; Gross, 1990). Antibiotics are used to treat exacerbations (American Thoracic Society, 1995; Gross, 1990). Finally, breathing exercises and exercise training are used to rehabilitate clients by improving activity tolerance (Belman, 1986; Faling, 1986; Punzal, Ries, Kaplan & Prewitt, 1991).

Assessment of Chronic Obstructive Pulmonary Disease

Assessment of COPD can be achieved through several means including physical assessment, pulmonary function tests, chest x-rays, CT scans, and arterial blood gases (Bates, 1987; Johannsen, 1994; Kniesl & Ames, 1987; Sexton, 1981; Tames, 1991). Pulmonary function tests are the most frequently used means of diagnosing and managing airflow obstruction (American Thoracic Society, 1995; McCarthy, 1990). The pulmonary function test is a non-invasive method of acquiring objective data regarding the type and degree of lung dysfunction, progression of disease, and effectiveness of medication (Burrows, 1990; Kniesl & Ames, 1987; Sexton, 1981; Tames, 1991; Thurlbeck, 1990). FEV₁, forced expiratory volume during the first second, and FVC, forced vital capacity are utilized in the diagnosis and monitoring of COPD (Kniesl & Ames, 1987). The FEV₁ and the FEV₁/FVC ratio are compared to the predicted normal pulmonary function values based on age, sex and height to determine the presence of airflow obstruction (American Thoracic Society, 1995; Burrows, 1990). An FEV₁ of less than 75 percent and a reduced FEV₁/FVC ratio indicates pulmonary dysfunction (Burrows, 1990; p 16S; Kneisl & Ames, 1981). FEV₁ values of 70 to 60 percent of predicted norms indicate mild airflow obstruction, 60 to 40 percent indicate moderate airflow obstruction and less than 40 percent indicate severe airflow

obstruction (Anthonisen, personal communication, August 11, 1993). Decline of lung function in COPD is slow with episodic periods of rapid deterioration. Initially following diagnosis and treatment, lung function may improve or remain stable, but eventual deterioration is inevitable (Dudley et. al., 1980). For the most part, decline in lung function is dependent on the individual (Emirgil et. al., 1971), although most clients with chronic bronchitis and emphysema generally lose 50 ml of their forced vital capacity yearly (Dudley et. al., 1980, p. 549).

Etiology

Many factors contribute to the development of COPD. Several risk factors have been cited in the literature as contributing to disease development including gender, air pollution, heredity abnormalities, occupational exposures and cigarette smoking (Holland, 1988; Petty, 1990; Tames, 1991) (See Appendix A for list of Risk Factors for COPD). Although many factors are influential in the genesis of COPD, cigarette smoking has been identified as its primary cause (Petty, 1990; Thurlbeck, 1990). Smoke from cigarettes damages and destroys lung tissue by stimulating inflammatory processes within the respiratory system that lead to the eventual development of COPD (Canadian Thoracic Society Workshop Group, 1992; Gross, 1990; Kniesl & Ames, 1987; Tames, 1991). As a result, smoking

prevention and cessation have been identified as a means of eliminating (Petty, 1987) or decreasing the incidence of the disease (Campbell, 1987).

Smoking and Chronic Obstructive Pulmonary Disease

Even though many preventative programs have been presented to the public, smoking still remains a lifestyle choice for many individuals in our society. Although the numbers of individuals who presently smoke have decreased among the teenage and old adult populations, 72 percent of all Canadian smokers are between the ages of 20 to 54 years (Eliany & Cartemanche, 1992, p. ix). The characteristics of the smoking population have also changed, whereas before a predominantly male, lighter smoking population existed, now an increasing number of female and heavy smokers exist (Eliany & Cartemanche, 1992; Greaves, 1990). Trends indicate a growing number of heavy smokers among both sexes, with the heaviest female and males smokers being 25 to 44 years of age and 45 to 64 years of age respectively (Greaves, 1990, p. 8). Additionally, women in the 15 to 34 age group smoke as much as their male counterparts, even though men make up the greater proportion of smokers in older age categories (Cartemanche, 1992, p. ix).

Although the presented perspective on smoking behaviour may seem pessimistic, changes are occurring among the Canadian population. Statistics

indicate that the use of tobacco is gradually decreasing with the greatest declines occurring among the teenage population (Eliany & Cartemanche, 1992).

Furthermore, the percentage of Canadian smokers has decreased from 50 to 32 percent in the 24 year period between 1965 and 1989 (Eliany & Cartemanche, 1992, p. 2).

Future Trends in the Development of Chronic Obstructive Pulmonary Disease

Since recent statistics reflect a decrease in smoking behaviour, it may appear that the incidence of COPD will gradually decline. A significant decrease in the number of COPD sufferers will not take place, however, until the cohort of present and past smokers has been replaced by those who are presently teenagers. Many of those who are current and past smokers are still at risk for developing COPD because of the 20 to 30 year latency period between exposure and disease onset (Tames, 1991, p. 27). Future and present COPD sufferers will be diagnosed when they reach their middle to late fifties (Kanner, 1987, p. 173). Consequently, past and present smokers from the postwar years are now just beginning to enter the health care system as COPD patients (Canadian Thoracic Society Workshop Group, 1992).

Economic Costs of Chronic Obstructive Pulmonary Disease

The present and future health and economic costs from smoking habits are great (Stoddart et. al., 1986; Walter, 1991) . Although arguments have been made that taxes on tobacco products pay for direct health care costs arising from smoking induced illness within a Canadian context (Stoddart et. al., 1986), the complete account of the consequences of smoking reach beyond direct cost (Luce & Schweitzer, 1978; Walters, 1991). Economic costs of smoking on society include decreased human productivity, loss of earnings, and production losses (Luce & Schweitzer, 1978; Stoddart et. al., 1986; Wigle et. al., 1991). According to Wigle et. al.. (1991, p. 6) respiratory disease is the sixth most costly disease category, involving direct and indirect costs of over 5.1 billion dollars. Alone, direct, hospital expenditures total over 1 billion dollars, and indirect income losses, due to premature mortality involve a 1.3 billion dollar loss each year. In summary, the taxation of tobacco products does not protect society from the human and economic costs of COPD. Society still experiences losses in productivity, earnings, production, and health care dollars.

Stress, Appraisal, and Coping

As previously mentioned, COPD imposes an extensive economic burden on society, but the impact of COPD can also be felt at the individual level in terms of lifestyle adjustment and quality of life. When clients are compromised by the physiologic, psychologic or sociologic stressors of disease, health can be endangered (Lazarus & Folkman, 1984) or disease may be exacerbated (Antonovsky, 1972). Coping is multifaceted in its relationship to chronic illness (Lazarus & Folkman, 1984). Coping maintains the physical, psychological and social integrity of individuals, facilitating adaptation to disease (Adams & Lindeman, 1974; Burckhardt, 1987) and developing positive outcomes (Adams & Lindeman, 1974). In order to understand coping (Lazarus & Folkman, 1984), one must first examine those processes which initiate coping as well as coping itself (See Appendix B for Folkman and Lazarus's Diagrammatic Relationship of Stress, Appraisal and Coping).

Stress

Coping is initiated as a protective behaviour in response to stress. Coping mediates stress by changing or removing the conditions which cause the stress, or controlling the emotions associated with the stress (Pearlin & Schooler, 1978).

Stress, a natural element of daily life, is responsible for mobilizing coping (Kneisl

& Ames, 1987). Stress has many meanings. Various definitions of stress have been purposed, but little consensus exists as to its meaning (Monat & Lazarus, 1985). One conceptualization is "any event in which environmental demands, internal demands, or both tax or exceed the adaptive resources of an individual, social system or tissue system" (Monat & Lazarus, 1985, p. 3). Stress can be physiologic, sociologic or psychologic (Lazarus, 1966). Physiologic stress involves the disruption of body tissues. Psychologic stress requires appraisal of events as threatening, and sociologic stress arises from disturbances to social systems or units (Lazarus, 1966; Monat & Lazarus, 1985) such as families. Stress arises from stressors or "specific events that involve change, ongoing negative environmental conditions, and certain types of situations where no change occurs" (Monat & Lazarus, 1985, p. 3). Consequently, stress can be acute and thereby time limited, or chronic, spanning extended periods of time (Elliot & Eisdorfer, 1982). Chronic stress is linked to chronic illness (Ben-Sira, 1984; Bombardier, D'Amico & Jordan, 1990; Felton, Revenson & Hinrichsen, 1984; Leidy, 1989; Viney & Westbrook, 1984). Chronic stress, if uncontrolled carries the potential for exacerbations of disease (Antonovsky, 1972).

Appraisal

Identification and mastery of stressors is moderated by perception or appraisal. Appraisal is the cognitive process of evaluating a situation for threat and the available options and resources for coping. Like stress, appraisal takes three forms: harm-loss, threat, and challenge. Harm-loss appraisal refers to any loss resulting from a harm having occurred. Threat involves harms or losses, having not yet occurred, but perceived to be taking place in the future. Finally, challenge deals with those appraisals that motivate individual resources, allowing opportunity for mastery and accomplishment (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). Harm-loss and threat are negative concepts, associated with future or existing harms. On the other hand, challenge is a positive concept, indicating the ability to master and overcome stress (Folkman & Lazarus, 1985; Kobasa, 1985).

The degree of stress experienced is determined by an individual's appraisal of his or her environment. Appraisal of contextual or environmental influences can moderate one's perception of stress and subsequent perception of harm-loss, threat or challenge (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Folkman et. al., 1986). Two types of appraisal exist: primary and secondary appraisal. Primary appraisal involves recognizing coping resources within the

environment. Secondary appraisal entails determining the method in which to manage the stress (Folkman & Lazarus, 1980). Once appraisal has occurred coping is mobilized as an active response to an appraised stress.

Coping

The concept of coping has spawned a plethora of literature (Fleishman, 1984; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Lennon et. al., 1990; Panzarine, 1985; Perlman, 1975; Zeitlin, 1980). Coping can be conceptualized in several ways (Beutel, 1985; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Panzarine, 1985; Perlman, 1975). Initial attempts to define coping operationalized it in the form of a defensive or ego behaviour. Defensive behaviours were identified as those actions used by individuals to avoid or remove stresses (Murray & Zentner, 1975). These behaviours served to reduce stress and tension, (Folkman & Lazarus, 1980; Lazarus, 1987; Lazarus & Folkman, 1984; Perlman, 1975) thereby restoring a state of equilibrium in the individual (Folkman & Lazarus, 1980). Ego mechanisms are affective or cognitive behaviours (Perlman, 1975) aimed at the delay of gratification. As a result, ego mechanisms produce a state in which the individual feels a sense of mastery. Once mastery is achieved, the individual adapts to the physical and or social environment (Murray & Zentner, 1975). This particular conceptualization

of coping has been criticized because it is difficult to evaluate ego and defense mechanisms. Furthermore, the ego defense mechanism conceptualization does not address the problem-solving component of coping (Panzarine, 1985).

Coping can also be conceptualized as a personality trait or a set of cognitions and behaviours (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). In terms of personality traits, coping addresses those overt and covert behaviours, and cognitive decisions that result in the reduction or elimination of stress (Fleishman, 1984; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Individuals are perceived to use the same cognitions and behaviours or personality traits to cope across different situations. This particular conceptualization has been identified as a limited indicator of coping (Fleishman, 1980; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Presently, little documented evidence verifies the consistent use of specific behaviours and cognitions across situations (Fleishman, 1984; Folkman & Lazarus, 1985). Furthermore, according to Folkman & Lazarus, (1980) a description of coping in terms of personality traits, is unidimensional. Instead, researchers have suggested the inclusion of situational context in the study of coping to account for its multidimensional character (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Folkman & Lazarus, 1985; Lipowski, 1970; Panzarine, 1985; Pearlin & Schooler, 1978).

This suggestion has resulted in the emergence of a situation oriented approach to the conceptualization of coping (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Lennon et. al., 1990). Here, different situations are identified as key determinants in the use of coping strategy. Each situation demands specific coping strategies (Folkman & Lazarus, 1985; Lennon et. al., 1990; Mattlin, Wethington & Kessler, 1990; Pearlin & Schooler, 1978) which "are grouped into functional categories; for example, strategies for maintaining or restoring interpersonal relationships, seeking information, feeling better, maintaining self-esteem, and making good decisions" (Folkman & Lazarus, 1980, p. 222). Unfortunately, the situation oriented perspective is limited, describing coping only in unusual and or specific situations. The ability to generalize such coping descriptions to other situations is limited (Folkman & Lazarus, 1980).

Pearlin and Schooler (1978) attempted to improve the generalizability of this approach by examining coping within the context of stressors experienced in daily living. Individuals were asked to report on the coping strategies used in the role areas of marriage, parenting, household economics and occupation. The results indicated that individual coping behaviours were effective in dealing with the stresses of the interpersonal role areas of marriage and parenting. In contrast, coping behaviours were least effective in dealing with the impersonal problems

present in the occupational context. The researchers also delineated the use of specific coping strategies in response to situations experienced daily. In situations where economic and employment stressors could not be controlled, individuals coped by reassessing personal goals and placing a greater value on those life processes independent of employment. In marriage and parenthood, such value modification was identified as ineffective in mediating stress, therefore avoidance and withdrawal coping strategies served as a means of dealing with these stressors.

Unfortunately, limitations exist in the Pearlin and Schooler (1978) study . Pearlin and Schooler (1978) fail to identify coping responses that are effective in reducing stress. Additionally, the results of their study are questionable. According to Folkman & Lazarus (1980), there is a poor relationship between what individuals report and what they actually do. Consequently, the results of this study are difficult to generalize. Therefore, further investigation is required to ensure that the situation oriented approach of conceptualizing coping is a true representation of the concept.

The final means for conceptualizing coping was developed from cognitive-phenomenological theory. Here, coping is operationalized within cognitive and behavioural terms (Lazarus & Folkman, 1984). Coping consists of those

behaviours and cognitive processes involved in mastering, reducing or enduring "external and internal demands and conflicts among them" (Folkman & Lazarus, 1980, p. 223). Individuals are perceived to have a reciprocal relationship with the environment. Coping seeks to mediate stressful emotions or manage relationships between individuals and the environment. This conceptualization of coping accounts for the use of coping strategies or those thoughts and actions aimed at dealing with appraised stressors (Folkman & Lazarus, 1980; Folkman et. al., 1986; Lazarus & Folkman, 1984) .

Problem and Emotion-focused Strategies

Coping strategies diminish or eliminate stress (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Zeitlin, 1980). Coping strategies take two forms: emotion-focused and problem-focused. Problem-focused coping strategies involve the use of problem-solving strategies to manage or alter stress (Folkman & Lazarus, 1980; Folkman & Lazarus, 1985; Folkman et. al., 1986; Lazarus & Folkman, 1984) such as information or advice seeking (Fleishman, 1984). Emotion-focused strategies are the cognitive and behavioural methods generated by the individual to reduce and manage discomfort emotionally (Folkman & Lazarus, 1980; Folkman et. al., 1986; Lazarus & Folkman, 1984); for example,

selective ignoring, passive acceptance, resignation, and reassurance of self (Fleishman, 1984).

Coping with Chronic Illness

Living with a chronic illness demands the use of coping resources that exceed those needed to deal with daily stresses, short term, or acute illness (Burckhardt, 1987; Lennon et. al., 1990; Mattlin et. al., 1990). Individuals who are chronically ill must make lifestyles changes, deal with developmental disruptions, learn to preserve dignity and self-esteem, and live in the presence of diminishing resources (Burckhardt, 1987). Stressors associated with chronic illness constantly challenge and threaten the ill individual. Consequently, chronic illness stressors may lead to self-destructive behaviour, anxiety, depression, anger and deteriorations in physical health (Burckhardt, 1987; Lennon et. al., 1990; Lipowski, 1970).

Coping is a resource used to alleviate the stress a chronically ill individual faces. Often individuals who become chronically ill learn that existing coping strategies are no longer effective as they adjust to physical, psychological, and social changes. As a result, new coping strategies are developed (Burckhardt, 1987; Leidy, 1989). According to Lipowski (1970) coping behaviour in illness is the product of the patient characteristics, situational context, and stage of illness.

Several researchers have attempted to identify the relationship between the use of coping strategy, adjustment to chronic illness and function of the individual (Ben-Sira, 1984; Bombardier et. al., 1990; Felton & Revenson, 1984; Felton, Revenson & Hinrichsen, 1984; Keller, 1988; Lennon et. al., 1990; Lipowski, 1970; Mattlin et. al., 1990; Viney & Westbrook, 1984).

Keller (1988) is one such researcher. In 1988, using a small sample of individuals (n=43), Keller (1988) identified that the chronically ill use emotion-focused and problem-focused coping strategies to moderate disease related, economic and social stresses. Using the Jalowiec Coping Scale and the Multidimensional Health Locus of Control Scale, Keller (1988) noted that those who controlled their illnesses primarily used problem oriented coping strategies whereas those whose illnesses were unmanageable mainly used emotion-based strategies. High scores of personal dysfunction were indicative of the use of emotion-based strategies; for example, withdrawal or ignoring problems. Although Keller's (1988) study was effective in examining coping in chronic illness, several limitations were present. The study utilized a non randomly selected, middle-aged, gender biased sample of males and females. Additionally, Keller's (1988) research sample encompassed a variety of chronic diseases thereby limiting the ability to generalize study results to populations with COPD.

Viney and Westbrook (1984) also studied coping in a sample of individuals with varying chronic diseases. Using a convenience sample of ninety-two participants, the researchers examined several coping strategies. In the first part of their study, optimism and fatalism coping strategies were studied in hospital and seven months later in the patient's home. Viney and Westbrook (1984) reported optimism was used more frequently than fatalism by study participants. Additionally, the researchers noted that patients utilized significantly more optimism than fatalism strategies in hospital rather than in the home. Viney and Westbrook (1984) postulated that chronic illness and situational preferences altered the use of specific coping strategies.

In the second part of their study, the researchers noted that problem focused strategies were associated with patient feelings of control, and emotion-focused strategies such as holding back or avoidance were associated with depression and poor adjustment. Acceptance or the belief one could change ones condition, was indicative of social adjustment. The reader is cautioned in interpreting the results of the research primarily because the associations which arise from correlational research do not establish causal relationships. Furthermore, the diversity of diagnoses among the participants of the study, prevent the generalizability of the results to a population of individuals affected by COPD.

Felton and Revenson (1984) and Felton et. al., (1984) are included among the researchers who concluded that emotion-focused strategies are characteristic of poor adjustment in chronic illness (Keller, 1988; Viney & Westbrook, 1984). In addressing problem-focused coping, both studies expounded the positive effects of such strategies on the chronically ill. Felton et. al. (1984) were specific in examining stress and coping as it relates to psychological adjustment in chronically ill adults, specifically those affected with hypertension, diabetes mellitus, cancer and rheumatoid arthritis. The researchers noted that diagnosis is minimally related to use of coping strategy and accepting illness is a crucial component in minimizing perceived threat. The researchers caution readers in interpreting these results primarily because the coping instrument used in the research provides information regarding reactions to illness rather than specific illness stresses.

Two types of coping strategies were identified in this study: cognitive and emotion-focused. Cognitive strategies were related to positive affect where as emotion focused strategies, especially those involving avoidance, blame and ventilation of feelings were associated with negative affect and low self-esteem. Unfortunately, due to the cross-sectional nature of the data, it is unclear as to

whether the emotion-focused strategies produced negative feelings or were behavioural responses to stress. (Felton et. al., 1984).

Felton and Revenson (1984) studied one specific strategy from both the problem-focused and emotion-focused domains. Using a sample (n=151) of middle-aged and older adults affected with rheumatoid arthritis, cancer, hypertension and diabetes, Felton and Revenson (1984) examined the consequences of using two different coping strategies, namely information seeking and wish fulfilling fantasy in relation to the controllability of an illness and psychological adjustment. Results indicated that information-seeking, a problem-focused strategy, was associated with psychological adjustment to illness whereas wish-fulfilling fantasy, an emotion-focused strategy, was indicative of negative adjustment. Information-seeking was identified as a positive coping strategy, because it fostered self care and enabled individuals to derive meaning from illness. On the other hand, wish-fulfilling fantasy was identified as a negative coping strategy because it was associated with self pity and an inability to escape the stresses associated with illness. Controllability of illness was identified as a factor in accepting and adjusting to illness. Caution in interpreting the results of the study is recommended since the researchers have not yet identified all the possible social and health consequences of coping. Furthermore,

the research itself is correlational and therefore causal relationships should not be drawn.

Adding to the research involving chronic illness and coping, Bombardier et. al. (1990) examined the relationship of appraisal and coping to adaptation in chronic illness. Using a sample of one hundred patients admitted to a medical/psychiatric unit with a diversity of chronic conditions, the researchers measured depression, functional capacity, symptom severity and coping . Coping was measured using the Ways of Coping Checklist (Folkman & Lazarus, 1980). According to the researchers, appraisal and coping are strongly related to psychosocial and emotional adjustment. Because of the chronicity of the variety of illnesses studied, greater acceptance and social adjustment was present among the study participants. In the sample, the belief that one could influence, change or accept one's condition was directly related to the use of problem-focused strategies. Emotion-focused coping involving wishful thinking, self-blame, and avoidance, indicated that poor adjustment to illness was present. Furthermore, a positive relationship emerged between emotion-focused coping and symptoms of depression. Individual emotion-focused strategies were identified in the study as leading to poor adjustment. The authors hesitated in concluding any direct relationship between coping strategy and adjustment. Correlational research

design prevents one from establishing causal relationships (Zautra & Manne, 1992).

The use of "holding back" as a coping strategy indicated the presence of depression and poor psychosocial adjustment. Avoidance as a strategy was associated with the experience of severe symptoms of illness and greater psychosocial impairment. In contrast to the other studies, even though problem-focused strategies were identified, little relationship was noted between problem-focused strategies and enhanced function. The results suggest that employing problem-focused strategies may not be as important as not using some emotion-focused strategies in adapting to illness. However, one must note that only negative emotion focused strategies were studied, therefore no attempt was made to identify any positive effects of any positive emotion focused strategies such as optimism. Furthermore, the researchers did not examine the emotion focused strategies in the research in terms of any possible positive effects they may have. Consequently, generalizing the results of this study are limited.

With the exception of the Keller (1988), and Viney and Westbrook (1984), studies, the remaining research uses some form of the "Ways of Coping Checklist", a sixty-six item self-administered measurement instrument. The checklist was developed by Lazarus and his colleagues from coping literature and

theory. A panel of experts, subject testing and statistical analysis were all used to test the instrument for internal consistency (Lazarus & Folkman, 1980), thereby producing a means of measuring emotion and problem-focused strategies (Lazarus, 1987). In using the checklist, the individual first identifies a stressful situation and then completes the checklist indicating those actions and thoughts utilized in a described stressful situation. The study participants then state the frequency with which each thought or action is employed (Lazarus, 1987). Answers are then classified into emotion or problem-focused categories.

The researchers in the above mentioned studies do not use the "Ways of Coping Checklist" as Folkman and Lazarus (1980) originally intended: in its original form, on a healthy population, and in relation to a stressful event identified by the participant. In every case the authors of the studies indicated that the checklist was altered from its original form. Additionally, all the participants who used the checklist were chronically ill and did not answer the checklist questions in relation to a stressful situation. Instead, they completed the checklist indicating those thoughts and actions that are presently being used to cope with chronic illness. This use of the instrument compromised the validity of the checklist, and therefore made the results of the studies questionable. On the other hand, the consistent use of the checklist among each of the study populations

served as a viable means comparing the use of problem and emotion-focused strategies in several chronically ill populations (Bombardier et. al., 1990; Felton & Revenson, 1984; Felton et. al., 1984; Zautra & Manne, 1992).

In summary, even though some would still argue that little relationship exists between problem-focused coping and enhanced functioning (Bombardier et. al., 1990), the majority of studies indicate problem-focused coping strategies are associated with positive adjustment to illness and improved physiologic and psychologic function (Felton & Revenson, 1984; Felton et. al., 1984; Keller, 1988; Vitaliano, DeWolfe, Maiuro, Russo & Katon, 1990). For the most part, the use of emotion-focused strategies in chronic illness is indicative of poor adjustment (Bombardier et. al., 1990; Felton & Revenson, 1984; Felton et. al., 1984; Keller, 1988; Viney & Westbrook, 1984; Vitaliano et. al., 1990), and depression (Bombardier et. al., 1990; Viney & Westbrook, 1984; Vitaliano et. al., 1990).

On the other hand, one must be cautious in making such sweeping statements regarding the effectiveness of problem-focused coping and the ineffectiveness of emotion-focused coping. In essence many of the reviewed studies are flawed. There is a consistent misuse of the "Ways of Coping Checklist" in gathering data, thereby making many of the results questionable.

Furthermore, in many cases the studies suggest causal relationships among the variables. In the use of correlational research, such as is the case in many of the studies, causal relationships cannot be inferred (Zautra & Manne, 1992).

Additionally, with the use of such variable and small sample sizes generalizability to larger populations or populations with COPD is difficult if not impossible. The focus of the studies on only negative forms of emotion-focused strategies such as withdrawal, limits the opportunity of the researchers to examine positive emotion-focused strategies such as optimism. Also, the researchers focus on the negative outcomes of the negative strategies instead of the possible positive outcomes of such negative strategies. Therefore, the reader must take caution in interpreting the research and determining its value.

Coping with COPD.

COPD is a chronic illness (Kniesl & Ames, 1987). Several researchers have undertaken the opportunity to study coping in COPD both qualitatively and quantitatively and have published their results (Barstow, 1974; Chalmers, 1984; Fagerhaugh, 1986; Carrier & Janson-Bjerklie, 1986; Jannelli, Scherer & Schmieder, 1991; Small & Graydon, 1993). The following will be a review of some of that research.

Initial research involving coping and chronic obstructive pulmonary disease sought to describe coping. Client coping with COPD was originally conceptualized in terms of pacing and the simplification of activities of daily living (Barstow, 1974). Those activities of daily living (ADL's) that were determined to be affected by COPD included: bathing, dressing, eating, grooming, and sleeping. Barstow indicated that those clients affected by COPD altered, modified or acquired assistance in the performance of activities (See Appendix C for Alterations in Activities of Daily Living in COPD Patients) because of the influence of fatigue, dyspnea, weakness and coughing on the performance of self-care. Barstow (1974) also noted that factors such as economic stability, access to health care services, transportation, treatment regimes, and the support of significant others were influential in facilitating modification in the performance of ADL's.

Chalmers (1984) expanded upon Barstow's (1974) initial work in a qualitative study examining the concerns and coping strategies of (n=30) clients in the mild, moderate and severe stages of COPD. Through the use of interviews, Chalmers was able to identify several participant concerns related to employment, family and physical functioning. Analysis of interviews revealed three coping strategies: cognitive, behavioural and expressive. Cognitive

strategies to manage COPD required thought; for example, clients thought of consciously pacing activities. Behavioural strategies involved actions such as avoiding those with respiratory infections, and expressive strategies revolved around venting emotions as in the form of crying.

Fagerhaugh (1986) examined patient coping with the problems of physical mobility and sociability. Limited oxygen reserves were cited as the primary cause of changing lifestyle habits. Energy, time and money were the resources that were primarily drawn upon. Using a sample size of 22 patients ($n=22$), Fagerhaugh interviewed end stage emphysema patients regarding their coping strategies. Strategies involved lifestyle changes to prevent the state of dyspnea. The participants in her study used the following strategies to cope with dyspnea: planned activities, moved to a location where there was ample public transportation, asked for assistance and avoided emotionally charged situations. Misjudging the use of a coping strategy was a source of distress and panic because of the physiologic implications; for example, of suffocation, loss of consciousness and severe fatigue (Fagerhaugh, 1986).

Jannelli et. al. (1991) identified the use of coping strategies as part of a study involving a pulmonary health teaching program. The researchers believed that individuals would seek out information regarding their physical condition or use

denial as a coping process, depending on the situation. Using a small (n=30), predominantly female sample, the researchers were able to identify affective and problem-oriented coping methods used by individuals affected with COPD using the Jalowiec Coping Scale. Using a pre and post-test design, Jannelli et. al. identified those coping strategies used before and after the administration of an educational program. The use of coping strategies did not significantly change from before to after the educational program intervention. The results did indicate that study participants primarily used affective rather than problem-oriented means to cope. Identified affective coping strategies included blaming others, and letting someone else solve the problem. Little change in coping strategy use arose from participation in the educational program. The little change that did occur took the form of an increased use of problem-solving strategies by participants. However, the study was not without limitation. The researchers identified a bias based on gender within the sample population. Since the preponderance of the study population was female, the coping study results reflect the coping strategies of females. Jannelli et. al. (1991) also noted that the Jalowiec Coping Scale had not been extensively used in older populations. Therefore, measured coping strategies could be a function of age rather than reaction to a disease process.

Carrieri and Janson-Bjerklie (1986) chose to study coping from a different perspective. Coping strategies were identified as a means of preventing and or controlling dyspnea. A decrease in dyspnea was observed as facilitating the performance of physical activity and activities of daily living . Carrieri and Janson-Bjerklie (1986) sought to describe client strategies initiated to cope with the dyspnea, and promote activity. Two types of coping strategies emerged: immediate and long-term. Immediate strategies involved attempts to reduce acute dyspnea and long-term strategies involved preventing future occurrences of dyspnea. Additionally, within each immediate and long-term strategy, problem and emotion-focused coping strategies were identified. For example, an immediate strategy to manage dyspnea involved the use of controlled breathing, a problem-focused strategy (See Appendix D for Problem and Emotion Focused Classification of Coping Strategies in COPD).

More recently McBride (1993) has examined coping in terms of controlling disease process. In a qualitative study of 32 individuals the participants in her study identified acceptance and determination as methods of coping or controlling COPD. For participants, acceptance involved living within the constraints of this disease. Determination referred to the ability of participants to maintain a fighting spirit. Here, participants maintained a positive attitude and performed as many

activities as possible. Although many participants accepted their disease and remained determined, some participants became impatient, preferring to begin activities as soon as possible rather than to experience delays in planning. The researcher identified the above mentioned coping strategies were situation specific. She recommended examining the triggers for specific coping strategies (McBride, 1993).

The severity of disease in COPD is not indicative of the level of successful coping; instead, research has identified that coping is dependent on a number of factors. McSweeney et. al. (1982) identified depression, anxiety and fatigue as factors influencing quality of life and coping in a large convenience sample (n=203). The researchers noted that some individuals are better able to cope with their disease than others. According to McSweeney et. al. (1982), the severity of the disease is probably not the most influential factor in determining coping; the researchers instead suggested that factors such as age, neuropsychological functioning or socioeconomic factors may be important in facilitating coping. For example, neuropsychological impairments arising from hypoxemia, may inhibit successful coping because the individual may become impaired in terms of understanding treatments, cooperation, and flexibility in choosing alternative means of coping with his or her disease. Limitations of the study include the use

of a predominantly male sample. Male roles (Sexton & Munro, 1985; Sexton & Munro; 1985) and methods of coping (Janelli et. al., 1991) have been identified as different from those of females thereby influencing results .

Lee, Graydon and Ross (1991) concurred with McSweeney et. al. (1982) reporting that physical status alone did not indicate a successful ability to cope. Coping in the Lee, Graydon and Ross (1991) study (n=30) was defined in terms of functional ability. The researchers examined the relationship of psychological well-being, physical status and social support on the level of functioning or coping in oxygen dependent COPD clients. The presence of psychological well-being, physical status and social support was found to be correlated with coping. According to the researchers, study participants experienced a greater number of physical symptoms if they had lower FEV1 scores or were identified as being in a state of poor psychological well-being. On the other hand, higher FEV1 scores were associated with psychological well-being and fewer physical symptoms. Physical symptoms such as fatigue, congestion and especially dyspnea had the greatest impact on the individual, diminishing physical function. Furthermore, subjective reports by clients instead of objective measures such as pulmonary function tests were better predictors of functional ability or coping. Finally, those participants having social supports had higher functional abilities or levels of

copied than those who did not. As a result, the researchers postulated that those individuals having high social support, psychological well-being and better pulmonary function tests were better able to cope. Caution is encouraged in interpreting the results of this study because correlational research cannot establish causal relationships.

Summary of Coping in Chronic Obstructive Pulmonary Disease

In reviewing the literature, regarding coping and chronic obstructive pulmonary disease, one quickly becomes aware of the relevance and essential nature of coping. Yet coping as a process does not exist alone, but is a response to an event appraised as being stressful by an individual. Clinicians and affected individuals, alike, have identified stressors associated with the illness experience in an attempt to facilitate client coping. Presently, a predominant portion of COPD research has examined specific, clinician identified stressors. Such research is limited in its usefulness because stress involves the element of appraisal (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Stress emerges only when an individual appraises a stress to be present (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Since the perception of stress from a clinician perspective may differ from that of a client, stressors recognized by clinicians may not be identical to those stressors or concerns identified by clients. Because

individuals cope only when they identify a stress, a client will not cope with a stressor which he or she does not believe is an appraised stressor or concern. Stressors appraised by clinicians may not be recognized as concerns and as a result coping processes will not be initiated. Therefore identifying patient concerns is essential in initiating coping processes and subsequent adjustment to illness (See Appendix E for Stress, Appraisal, Concern, and Coping Framework).

Unfortunately, patient appraised stressors or concerns are only addressed peripherally in the course of studies examining other aspects of COPD (Barstow, 1974; Chalmers, 1984; Fagerhaugh, 1986; Gift & Jacox, 1992). As a result, little is known regarding client concerns. Instead, the available literature concentrates on a range of medically defined stressors (Anthonisen, Manfreda, Warren, Hershfield, Harding & Nelson, 1987; Fishman, 1971; Krop, Block & Cohen, 1973; Rhodes, 1987). Since stress can endanger health (Lazarus & Folkman, 1984; Lennon et. al., 1990) or exacerbate disease (Antonovsky, 1972), studying client concerns can facilitate coping (Fleishman, 1984; Sexton, 1981). A literature review of concern and stresses in COPD was undertaken to avail the researcher of the existing knowledge, and the context and quality of the previous research (Brink & Wood, 1989; Polit & Hungler, 1991).

Concerns in COPD

A brief history of the biopsychosocial origins of stress will be presented and a detailed review of the biological, psychological and sociological concerns present in COPD will be reviewed (See Appendix F for Complete List of Concerns and Stresses). Henceforth, stressors identified by clinicians will be referred to as stressors and client appraised stressors will be addressed as concerns.

The earliest investigations of stress concentrated on its biologic origins, functions and effects on the individual (Mason, 1980; Monat & Lazarus, 1985; Selye, 1956). The biologic or physiologic aspects of stress remained prominent in the literature until 1966 when Lazarus integrated much of the psychological stress literature in Psychological Stress and Coping (Monat & Lazarus, 1985) and introduced sociologic stress (Lazarus, 1966). Lazarus (1966) recognized the multidimensional origins of stress assigning value to biologic, psychologic and sociologic forms of stress. Since such discussion of stress has occurred, researchers and clinicians have recognized the importance of identifying and examining the effects of physiologic, psychologic and social stresses influencing the individual (Folkman & Lazarus, 1980; Lazarus, 1966, Monat & Lazarus, 1985; Selye, 1956). As a result this investigator chose to examine the stressors

and appraised stressors or concerns in COPD clients within a physiologic, psychologic and sociologic context.

Biologic Stressors and Concerns

According to Monat & Lazarus (1985) physiologic stress involves a disruption of tissue systems. Indicators of physiologic stress exist in the form of symptoms of disease (Lazarus, 1966; Leidy, 1990; Monat & Lazarus, 1985). Both clinicians and clients alike have identified symptoms of COPD to be influential stressors in the lives of affected individuals (American Thoracic Society, 1995; Hanson, 1982; Small & Graydon, 1992). Physiologic stressors for the COPD client are numerous; for example cough, dyspnea and wheezing. The symptoms of cough, dyspnea, and wheezing are primary physiologic stressors because they indicate the presence of disease or a disruption to tissue systems (Bates, 1987; Lazarus, 1966; Leidy, 1990; Monat & Lazarus, 1985). Each is considered by health professionals as a stress for the individual, but from the client perspective only two of these stressors have been identified as client concerns. Wheezing, an indicator of airway obstruction (Fuhs & Stein, 1976; Leidy, 1990) has been addressed in the literature as a stressor: in the form of a narrowing of the airway passages, the presence of mucosal edema, and mucosal secretion retention (Fuhs & Stein, 1976; Pet, Speizer, Cochrane, Moore, Fletcher

& Tinker, 1983; Webster & Kadah, 1991). Cough, unlike wheezing, has been observed to be a concern by clients. Clinicians have identified cough as a stressor indicating disruption of body tissue in COPD (American Thoracic Society, 1995; Kinney, 1967; Kniesl & Ames, 1987; Webster & Kadah, 1991). In 1975, Traver identified cough is a common complaint or concern among COPD clients (Traver, 1975). Cough can be a source of discomfort and anxiety because it causes sleeplessness (Callahan, 1984) and is often associated with respiratory infection (Kinney, 1967).

Dyspnea, a source of client anxiety, has also been established by clients as a concern (Barstow, 1973; Chalmers, 1984; Carrieri & Bjerklie, 1986; Mahler, 1992; Parsons, 1990; Traver, 1975; Williams & Bury, 1989). Dyspnea results from an increase in the work of breathing through obstructed airway passages; airway passages may become obstructed by bronchospasm, mucus retention, mucosal edema, inflammation, or a reduction in bronchiolar elasticity (American Thoracic Society, 1995; Pet et. al., 1983).

A plethora of research has been generated in an attempt to describe and decrease the psychophysiologic sensation of dyspnea in response to the frequent complaints of those suffering from breathlessness (Barstow, 1973; Callahan, 1982; DeVito, 1990; Gift, Plaut & Jacox, 1986). Barstow (1973) was among the

first to describe dyspnea from a client perspective as an unpleasant sensation, a source of limitation, and the impetus for lifestyle change. According to Barstow (1974), dyspnea impacts on all aspects of an individual's life from the performance of activities and loss of occupational roles to socialization with peers. Barstow (1974) noted many of her study participants aimed their activities at preventing or limiting the dyspneic experience.

Chalmers (1984) in her study of coping in COPD concurred with Barstow's observations (1974), reporting that dyspnea prevented the fulfilment of role obligations and hindered socialization within her study sample population (n=30). Furthermore, Chalmers indicated that the dyspnea imposed limitations resulted in feelings of frustration, powerlessness, and fear of future deteriorations in health.

In 1986, Carrieri and Janson-Bjerklie sought to examine dyspnea specifically in an attempt to determine the coping strategies used by clients when experiencing breathlessness (n=68). Breathlessness coping strategies were classified into problem and emotion focused categories. Again, many subjects were observed to utilize coping strategies aimed at preventing or limiting dyspnea. Subject attempts at limiting or coping with breathlessness included altering activities of daily living, isolating oneself from emotional stimulation, the use of relaxation techniques and breathing exercises.

Janson-Bjerklie et. al. (1986) using semi-structured interviews provided an extensive description of dyspnea. A convenience sample of 68 subjects was selected, 50 of whom were affected by COPD. The researchers selected three breathlessness related variables to examine: personal factors, precipitating activities, and situational variables. Personal factors such as emotions, states of personal health and behaviours or actions were linked to the dyspneic state. Dyspnea was also associated with precipitating activities; for example, walking, stooping, bathing, or dressing. Situational variables causative of a dyspneic response included environmental conditions; for example, pollution or weather and situations involving pressure or tension. In general, the researchers found subjects described breathlessness in terms of suffocation, tightness and congestion. The investigators also reported differences among disease groups and gender. The researchers identified that females reported higher levels of dyspnea and had higher levels of fear, loneliness, irritability and hyperventilation. Furthermore, sensations accompanying dyspnea were noted to be different among the sexes. Here, the researchers noted males described the accompanying sensations of numbness and tingling in association with dyspnea where as females noted the sensation of a loud heart-beat and dizziness with greater frequency (Janson-Bjerklie, et. al., 1986). As one can see, the direct impact of

dyspnea on the affected individuals' lifestyle and activities of daily living has been well documented, but dyspnea can also alter an individuals' life indirectly.

The physiologic implications of dyspnea are extensive. As a clinician appraised stressor dyspnea has been associated with fatigue, sleep disruptions (Barstow, 1974; Callahan, 1982; McSweeney et. al., 1982; Prigatano et. al., 1984; Trask & Cree, 1962; Williams & Bury, 1989), decreases in appetite (Gift et. al., 1986), and respiratory infections (Friedman, 1968). Cough and dyspnea during sleep lead to restlessness and fatigue (Trask & Cree, 1962; Williams & Bury, 1989). Fatigue, as a symptom of dyspnea has been identified by both clinicians and clients as a source of stress (Callahan, 1982; Chalmers, 1984; Dudley, 1981; Dudley et. al, 1973; Fagerhaugh, 1986; Sexton, 1983; Sexton & Munro, 1988; Small & Graydon, 1992; Williams & Bury, 1989). Kinsman, Fernandez, Schacket, Dirks and Covino (1983) in the developing of the Bronchitis Emphysema checklist, found fatigue to be a significant symptom . Furthermore, sleep disturbances along with fatigue were reported as a frequently occurring symptom by study participants. Small and Graydon (1992), added to the research on fatigue in COPD reporting clients who had greater levels of fatigue experienced high levels of negative mood. Small and Graydon (1992) noted that the relationship of fatigue to mood is influential to the quality of life in this

population. Further research is needed to assess the role of fatigue in the lives of individuals affected by COPD, but initial clinician reports suggest an influential nature of fatigue in the lives of affected individuals (Barstow, 1974; Callahan, 1982; McSweeney et. al., 1982; Prigatano et. al., 1984; Small & Graydon, 1992; Trask & Cree, 1962).

Decreased appetite, another sequelae of dyspnea, (Gift et. al., 1986) has been demonstrated to increase with the level of air-flow obstruction in COPD (Wilson, Rogers, & Openbrier, 1986). According to Rhodes (1987, p. 70), 40 to 60 percent of COPD patients experience significant weight loss during the course of the disease. Since adequate nutrition is an important factor in facilitating lung tissue repair, promoting the maintenance of adequate lung metabolism and structure, (American Thoracic Society, 1995; Wilson et. al., 1986) and maintaining respiratory muscle strength (American Thoracic Society, 1995; Rhodes, 1987; Webster & Kadah, 1991), health professionals have identified the lack of dietary intake by some individuals as a significant stressor (Rhodes, 1987; Webster & Kadah, 1991; Wilson et. al., 1986). Although the precise mechanisms involved in malnutrition in COPD are still unknown, dyspnea has been implicated (Wilson et. al., 1986). Many COPD patients are dyspneic during the ingestion of food and as a result choose to limit or avoid dietary intake (Rhodes, 1987; Sexton & Munro,

1981; Wilson, et. al., 1986). Furthermore, patients have reported the intake of specific foods as a source of symptom exacerbation thereby citing this as a reason for avoiding such food consumption; for example, dairy products have been identified by some patients as increasing sputum production (Rhodes, 1987). The stressors imposed by avoiding some food groups or decreasing dietary intake on the whole can result in a deterioration in patient health.

Respiratory infection, as indicated by dyspnea, is also a significant stressor responsible for physical deterioration of the COPD patient (American Thoracic Society, 1995; Anthonisen, Manfreda, Warren, Hershfield, Harding & Nelson, 1987; Friedman, 1968; Rhodes 1987;). Typically, respiratory infections are responsible for aggravating airway obstructions as well as precipitating respiratory failure (Rhodes, 1987). As a consequence, respiratory infection is associated with increasing symptom levels and disease mortality (Anthonisen et. al., 1987; Rhodes, 1987). According to Anthonisen and associates (1987), individuals left untreated for respiratory infection have poorer respiratory outcomes following exacerbation. Furthermore, patients receiving no treatment have slower recoveries in peak flow rates following infection. As a consequence, respiratory infection is considered to have a significant role as a stressor as identified by clinicians.

Numerous researchers have noted the significant impact of hypoxia as a physiologic stressor in COPD (Fishman, 1971; Krop, Block & Cohen, 1973; McSweeney et. al., 1982). Hypoxia has an extensive effect on the individual, producing cortical and myocardial dysfunction (American Thoracic Society, 1995; Fishman, 1971; Krop et. al, 1973; Krop, Block, Cohen, Croucher & Shuster, 1977; McSweeney et. al., 1982). In a study conducted by McSweeney et. al. (1982) 77 percent of participants exhibited cortical functioning disturbances in complex perceptual-motor integration of tasks and abstraction. These results were in keeping with earlier studies which indicated that the use of oxygen improved memory in hypoxemic individuals (Krop et. al., 1973; Krop et.al., 1977). Such cognitive disturbances contributed to patient irascibility, anxiety, inflexibility, confusion, depression and non-compliance (McSweeney et. al., 1982). This led the researchers to suggest that concomitant findings of poor social functioning, resulted from hypoxemia related cognitive impairment (McSweeney et. al., 1982).

Prigatano et. al. (1984) contributed to this growing body of research in studying a sample of 985 mildly hypoxemic COPD patients. Using a sub-sample of 100 individuals, the investigators identified significant disturbances in "tension-anxiety, depression-dejection, anger-hostility, fatigue, and vigor" (Prigatano et.

al., 1984) following an examination of the scores obtained from the administration of the Profile of Moods State instrument. The reports of family members confirmed these results. Relatives concurred with the researchers, reporting psychiatric and emotional disturbances in the functioning of the affected relative. In both studies effects of hypoxemia on the psychosocial health of the individual resulted in significantly lower reported levels of patient quality of life (McSweeney et. al., 1982; Prigatano et. al., 1984).

Hypoxemia, a physiologic stress for the body, in COPD not only causes cognitive dysfunction, but is also responsible for myocardial hypertrophy (cor pulmonale) and congestive heart failure (Fishman, 1971; Klinger & Hill, 1991; Roa et. al., 1968). In COPD, alterations in airway integrity and the presence of secretions diminish alveolar ventilation, and cause mismatches in ventilation and perfusion ratios. Disruptions to alveolar ventilation and ventilation perfusion ratios in turn become the source of alveolar hypoxia and hypercapnia. The hypoxia and hypercapnia cause the proliferation of pulmonary vasoconstriction and the subsequent induction of pulmonary arterial hypertension. Pulmonary arterial hypertension increases the work load of the heart and thereby becomes the basis for developing of right sided myocardial hypertrophy (Openbrier et. al., 1988; Sexton & Munro, 1981; Smeltzer & Bare, 1992). Hypercapnia adds to

myocardial hypertrophy, as the heart dilates and hypertrophies in an attempt to improve the levels of oxygen it is receiving. Should oxygen delivery to the heart further worsen, the left myocardium will also dilate and hypertrophy. With the continued hypoxemia, respiratory distress, pulmonary congestion and edema will ensue. The resulting low oxygen levels in the myocardium will lead to ventricular failure (Fishman, 1971; Rao et.al., 1968) and pulmonary vessel leakage (Fishman, 1971). In summary, the disruptions to the ventilation perfusion ratios and alveolar ventilation trigger hypoxia and hypercapnia and the heart hypertrophies, physically stressing the individual.

Cardiopulmonary dysfunction and hypoxemia have an additive effect, emerging in the form activity intolerance. This in turn prevents and limits participation in socialization, performance of activities of daily living and mobility (Barstow, 1974; Carrieri & Janson-Bjerklie, 1986; Chalmers, 1984; Fagerhaugh, 1986; Small & Graydon, 1993). In many cases the ability to maintain self-expected levels of activity (Chalmers, 1984) involves the use of problem and emotion focused strategies (Barstow, 1974; Carrier & Janson-Bjerklie, 1986; Small & Graydon, 1993). According to Fagerhaugh (1986), the physical limitations associated with emphysema are a significant problem for patients. In analysing her research material, Fagerhaugh (1986) noted that her

study population spent extensive periods of time planning for activities such as shopping for necessities, managing the home and performing activities of daily living. Subjects in her study were painfully aware that miscalculations in terms of time and energy in performing activities could result in episodes of severe physical distress and, as a result, considered their physical limitations a source of frustration and concern.

Alterations to the physical integrity of the individual also impairs sexual function (Agle & Baum, 1977; Hahn, 1989; Kniesl & Ames, 1987). Activity intolerance stemming from dyspnea, cardiac abnormalities and fatigue is the primary cause of such dysfunction (Dudley et. al., 1980; Hahn, 1989; Hanson, 1982; Sandu, 1986). According to Dudley et. al., (1980), fear of dyspnea, fatigue and failure during intercourse prevents many individuals from engaging in sexual activity. As a consequence, self-esteem, depression (Agle & Baum, 1977) and marital discord may occur (Sandu, 1986). Hanson (1982, p. 438) in a survey of adults receiving outpatient care for COPD, reported that more than 50 percent of her study subjects perceived lung disease to have a negative effect on sexual expression. Hahn (1989) concurred, reporting seven (n=12) respondents in her support group cited dyspnea as a source of impaired sexual activity. The reports of spouses of affected individuals also support these results. Sexton and Munro

(1981) report spousal dissatisfaction with current levels of sexual activity. Additionally, the investigators noted 54 percent of their study population no longer engaged in sexual activity. This is in keeping with Agle and Baum's (1977) report of affected individuals being impotent for several years.

In examining the physiologic implications of COPD, one quickly becomes aware of the multitude of clinician identified stressors. Many stressors associated with COPD physiologically impair the physical integrity of the body and thereby have received the attention of clinicians. From a psychological perspective more research has emerged identifying psychological concerns of clients in response to physiologic stressors. Physiologic stressors have multifaceted systemic impacts on the lives of individuals. Physiologic stressors, in many cases, become concerns when they begin to affect the lifestyle of the individual and are expressed within the psychological context.

Psychological Concerns and Stressors

As mentioned earlier, stressors involving physiologic change often emerge in psychological form. For example, individuals affected by COPD often become frustrated with bodily change (Dudley, 1981) and concerned with appearance (Agle & Baum, 1977; Agle, Baum, Chester & Wendt, 1973). Individuals become self-conscious and concerned about their barrel chests, swollen ankles, and

clubbed extremities (Dudley, 1981; Kravetz, 1982). Alterations in breathing patterns, excess sputum production, coughing and wheezing add to impair self-esteem (Dudley, 1981; Hargreaves, 1968). The use of inhalers and oxygen may be appraised as unattractive appearance. The use of medications such as steroids may enhance physical changes already present, further damaging the individuals self-esteem (Dudley, 1981).

In many cases, attempts are made by patients to hide those symptoms or features that are perceived as unattractive in order to avoid the risk of rejection and embarrassment (Barstow, 1974; Kravetz, 1982). According to Barstow (1974), the subjects in her study utilized several techniques to disguise or limit exposure of others to the symptoms of illness. Techniques for hiding the illness included such measures to dispose of sputum in decorated cups, concealing medications, and pretending to rest when dyspneic (Barstow, 1974). Carrier and Bjerklie (1986) reported that similar patient body image concerns led to more extreme measures. The researchers noted that some of their study participants chose to cope with the expression of physiologic symptoms by avoiding social contact. Isolation was identified as a means of coping with social impact of symptoms (Carrier and Bjerklie, 1986; Dudley et. al., 1980).

The effect of body image changes on self esteem have also been noted to have an impact on relationships (Hahn, 1989; Hanson, 1982; Kravetz, 1982). Hahn (1989) reported individuals who participated in a support group she facilitated (n=12) often expressed concerns over disturbances in gender identity. Male participants expressed feelings of inadequacy because of their inability to perform culturally ascribed male roles (Hahn, 1989; Kravetz, 1982). Female participants were similar to their male counterparts. Again, the inability to perform societally ascribed sex roles was influential in the perception of self and self-esteem. Females differed from males in that they perceived themselves as less physically attractive as a result of their disease (Hahn, 1989; Kravetz, 1982).

Because of the poor prognosis associated with COPD, the individual is often affected by feelings of powerlessness, helplessness and frustration (Chalmers, 1984; Dudley et. al., 1973; Dudley et.al., 1980; Dudley, 1981; Post & Collins, 1981-82; Sandu, 1986; Shekleton, 1987). According to Chalmers (1984), powerlessness and frustration arise from concerns relating to the inability to perform activities and to fulfill role expectations. Chalmers in her research cited several cases where disease symptoms such as dyspnea interfered with the performance of roles or participation in activities that were valued by clients.

According to Post and Collins (1981-82) such frustration can be a predecessor to respiratory dyspnea (Post & Collins, 1981-82) and anger.

Emotions such as anger, fear and anxiety can be provoked by social situations or by the symptoms of disease (Fagerhaugh, 1986; Lisella, 1993; Sandu, 1986). Increased skeletal muscle activity, expenditures of energy and dyspnea are all caused by emotions (Bass & Gardner, 1985; Dudley, Martin & Holmes, 1964; Dudley et. al, 1973; Lisella, 1993). Emotions, as a result, can incapacitate and disable an individual (Dudley et. al., 1980). Fear of emotions (Shekleton, 1987) because of their ability to foster symptoms results (Agle et. al., 1973). In some cases such fear results in patient suppression of emotion in order to prevent exacerbations of disease symptoms (Dudley et. al., 1980). In the advanced stages of disease, this suppression of activity to prevent disease symptoms leads patients to use coping strategies such as self isolation, denial, repression and the avoidance of conflict (Dudley et. al., 1980; Post & Collins, 1981-82). This diminishes the participation of recreational activities and family encounters (Carrieri & Janson-Bjerklie, 1986) and fosters frustration and interpersonal problems for the individual (Dudley et. al., 1980).

One particular emotion which has received much attention is anxiety.

Anxiety can arise from many areas. Fagerhaugh in her 1986 study described anxiety in relation to mobility. According to Fagerhaugh (1986), many of her study participants experienced anxiety because of social and activity situation concerns. Some of her study participants indicated anxiety was felt when they misgauged mobility situations. In these cases, individuals had underestimated their ability to perform activities and as a result experienced anxiety and physical distress. On other occasions study participants stated they felt anxiety in social situations which often led to dyspnea. Fagerhaugh (1986) observed that the study participants spent much of their time planning activities and compensating for their diminished physical mobility in order to prevent anxiety and its sequelae, dyspnea. When uncontrolled events occurred such as forgetting an item at home, anxiety also emerged. This anxiety is due in part to irritation with the self over the forgotten item in addition to a dread of the physical distress over having to return for it.

Anxiety has been noted to be both a cause and outcome of dyspnea (Agle & Baum, 1977; Agle et. al., 1973; Barstow, 1973; Dudley et. al., 1980; Dudley et. al., 1973; Fagerhaugh, 1986; Gift et. al., 1986; Janson-Bjerklie et. al., 1986). As a result, anxiety and dyspnea have been described as a cyclic phenomenon (Dudley,

1981; Dudley et. al., 1980; Dudley et. al., 1973; Gorman & Uy, 1987; Sandu, 1986). Many individuals affected by COPD, have attempted to control anxiety and subsequently dyspnea. Functional strategies to cope with anxiety and subsequent dyspnea include relaxation techniques and breathing exercises (Gift, Moore & Soeken, 1992; Renfroe, 1988). Dysfunctional strategies include the use of withdrawal and self isolation (Agle & Baum, 1977; Carrier & Janson-Bjerklie, 1986; Post & Collins, 1981-82). According to Agle and Baum (1977), this prevents patients from participating in activities. The anxiety some patients experience is of such a disabling level that activity, whether it be physical or recreational, are limited or curtailed (Agle et. al., 1973; Prigatano et. al., 1984). This can be a problem of significant importance among females because women with COPD experience higher levels of anxiety than males (Emery et. al., 1991). Consequently such experience of anxiety by individuals predisposes them to loneliness, frustration and depression (Post & Collins, 1981-82).

Depression has long been a stressor in COPD. Several researchers have reported high prevalence of depression among this population (Gift, Wood & Cahill, 1989; Light et. al., 1985; McSweeney et. al., 1982; Prigatano et. al., 1984). McSweeney et. al. (1982) report depression is a major psychologic disturbance in

COPD citing the reports of patients and relatives as well significant scores on the Mean Minnesota Multiphasic Personality Inventory as indicators. Other researchers concurred with the findings of McSweeney et. al. (1982) (Light et. al., 1985; Prigatano et. al., 1984).

Prigatano et. al., (1984) in support, reported that COPD patients (n=981) had significantly higher scores on the depression-dejection subscale of the Profile of Mood State tool and Mean Minnesota Multiphasic Personality Inventory in a 1984 study. Prigatano et. al. (1984) suggested that depression may be a function of biological state. This is in keeping with Dudley et. al.'s ,1973 findings that depression increased during periods of high arterial carbon dioxide. Furthermore, Prigatano et. al. (1984) postulated that decreased functional ability and hypoxemia of the brain impairs psychosocial function thus altering lifestyle and causing depression (Prigatano et. al., 1984). Psychosocial functioning of the individual undergoes significant change throughout the course of COPD (Barstow, 1974; Chalmers, 1984; Dudley, 1981; Light et. al., 1985). Psychosocial alterations in lifestyle include limitations on activities of daily living, decreased social interaction, physical disability, alterations in employment, early retirement (Dudley et. al., 1980) and or bodily change (Kravetz, 1982). Such changes eventually lead the individual to realize that he or she can no longer maintain the

pace of peers and depression results (Light et. al., 1985; McSweeney et. al., 1982). Psychological change in COPD is extensive, and often rooted in physiologic symptoms. Physiologic change serves to alter appearance, functioning and thought processes, but the implication of such change does not become apparent until the psychological impact is examined in terms of quality of life, perception of self, and ability to enjoy activities in the presence of COPD.

Social Concerns and Stressors

The effect of COPD on the lives of individuals is not limited to the psychologic and physiologic domains (Barstow, 1974; Chalmers, 1984). Social concerns also exist in COPD. One such concern is that of having the "ability to maintain a desired role" in family and society (Chalmers, 1984, p. 34). Even though the extent of self perceived levels of involvement in specific roles differs, the ability to maintain the responsibilities inherent in a role is considered a relevant issue by those affected (Chalmers, 1984). In society, each individual has roles to which they ascribe.

A role affected by COPD is the occupational role (Barstow, 1974; Chalmers, 1984; Simon & Williams, 1989). Maintaining this role is difficult among people living with COPD. As the disease progresses, the ability to maintain active physical activity gradually diminishes over time. Physically disabling fatigue

associated with the disease often forces individuals to retire or curb work activities at a time when career and family responsibilities peak (Barstow, 1974; Chalmers, 1984; Dudley et. al., 1980). According to Barstow's finding (1974), this is a particularly disabling event for the individual, requiring much adjustment. Chalmers (1984) reported similar results. Chalmers (1984) noted that maintaining employment was a significant concern to men in her study; several of her study participants indicated they experienced anguish when this role was lost (Chalmers, 1984). Light et. al. (1985) have even suggested that such role change may cause depression.

The loss of the occupational role is also of significant concern from a financial perspective. In many cases, affected individuals experience further stress when financial difficulties ensue. Early retirement or part-time work affects income levels thus influencing the lifestyle of the individual (Barstow, 1974; Davis, 1981; Dudley et. al., 1980; Fagerhaugh, 1986). Limited income has been observed to influence lifestyle in two ways. In Fagerhaugh's 1986 study, the researcher identified that money facilitated the activities and the independence of individuals. Money, if available, was used on transportation, recreation and activities of daily living. In being able to finance these activities, individuals were able to have a higher quality of life and conserve energy that would otherwise be

spent on meeting daily needs (Fagerhaugh, 1986). Barstow (1974) in an earlier study, reached similar conclusions. Barstow (1974) found that a lack of money contributed to the problems experienced by individuals. Lack of money was observed to hinder the ability of individuals to maintain entertainment opportunities, obtain basic necessities and retire at an earlier date.

Eventually the disabling nature of COPD impinges on recreational activity (Barstow, 1974; Chalmers, 1984; Williams & Bury, 1989). In many cases, activities requiring great expenditure of physical energy can no longer be performed (Barstow, 1974; Light et. al., 1985; Sandu, 1986). In other cases the environment prevents the individual from establishing and or maintaining social contact (Chalmers, 1984). Environmental conditions are perceived as a source of symptom exacerbation. Limitations on socialization may arise from weather; temperature, humidity, and environmental pollutants which all have potential to act as exacerbants of illness (Davis, 1981; Shekleton, 1987). Isolation in the home becomes a means of preventing acute episodes of illness (Carrieri & Janson-Bjerklie, 1986). According to Chalmers (1984), several of her study participants indicated they limited their recreational and social activities when they occurred in smoky environments. Participants also described conflicting feelings; subjects felt they had to curtail enjoyable events in order decrease exposure to smoke

(Chalmers, 1984). Regardless, with the progress of disease, social contact with friends and family eventually decreases and causes the loss of social roles (Barstow, 1974; Light et. al., 1985; McSweeney et. al., 1982; Sandu, 1986).

Physically disabling aspects of COPD further affect family relationships and roles (Barstow, 1974; Chalmers, 1984; Cossette & Levesque, 1993); for example, the affected individual may be unable to parent a child because he or she is physically unable to do so. This is best exemplified in the study by Chalmers (1984), where a subject indicated a sense of loss over being unable to fulfill the parenting role of teaching a child to drive. Additionally, dependence on family and others gradually increases as the disease progresses (Barstow, 1974; Cossette & Levesque, 1993). A spouse or children gradually take on those roles the affected individual is no longer able to perform.

COPD and Family Development

The sequelae of chronic illness ripple throughout the family (Hedlund, 1981; Rolland, 1987). Since COPD affects those individuals in their middle fifties and older (Kanner, 1987, p. 173), those families who are in the middle years, retirement and old age stage of development may be influenced by COPD. Families in the middle years stage of development experience great change. With the advent of the last child leaving the home, roles and relationships are redefined

within the family. The couple has the opportunity to nurture contacts with children as well as parents while devoting time to strengthening their own marriage. At this stage, members within the family will have reached career peaks and may experience career dissatisfaction. Recreational activities are cultivated and retirement is planned (Friedman, 1986). The physical changes of aging become a concern, as they multiply in number and effect. Physical changes lead to health concerns, affecting physical functioning and performance of activities of daily living (Ebersole & Hess, 1985).

The developmental stage of retirement and old age begins with the retirement of one spouse and ends with the deaths of both spouses (Duvall, 1977). "Maintaining satisfying living arrangements is a most important task of aging families" (Friedman, 1986, p. 71). Many of the elderly attempt to maintain their homes until they are forced to move because of financial or health reasons. Financially the elderly couple must adjust to a reduced income (Friedman, 1986). Health may deteriorate with onset of yet more physical changes (Ebersole & Hess, 1985). Time is spent maintaining the marital relationship. Family becomes the primary source of support and interaction (Friedman, 1986). The deaths of friends and acquaintances are experienced (Ebersole & Hess, 1985) and eventually the death of a spouse occurs (Friedman, 1986).

Chronic illness can be disruptive to the healthy development of the family (Leahey & Wright, 1987). Milestones in family development may be disturbed or delayed. In the middle years developmental stage, and retirement and old age stage of development, the family may grow and develop differently. COPD isolates the individual and the caregiver physically, psychologically and socially (Shekleton, 1987). Because of the disease, the family affected by COPD may be unable to nurture contacts with children (Shekleton, 1987) and recreational activities may not be fully explored. Ill individuals in the family may be unable to reach their employment peak because the disease may have necessitated early retirement (Barstow, 1974; Chalmers, 1984). Tension and anxiety may result (Prigatano et. al., 1984). Financial problems may arise from the loss of a source of income (Sexton & Munro, 1985). According to Barstow's U. S. study (1974), financial difficulties that exist as a result of retirement may be exacerbated by the medical expenses, resulting in earlier moves from the family home (Friedman, 1986). Spousal caregivers may have to postpone retirement goals, in choosing to continue working or having to obtain employment as a means of supporting the family (Sexton & Munro, 1985). Child caregivers may have to learn to deal with the care of their parents as well as their own children (Smoyak, 1987). Frustration, guilt and grief may be result, leading to low life satisfaction

and high levels of stress (Sexton, 1981; Leahey & Wright, 1987), as well as predisposing caregivers to increased frequency of illness (Cossette & Levesque, 1993; Sexton, 1984; Sexton & Munro, 1985; Smoyak, 1987), and possible abuse against the affected individual (Ebersole & Hess, 1987). The development of the family drastically changes in the presence of chronic obstructive pulmonary disease.

COPD, the Family and Concerns

In the last decade, a growing body of knowledge has accumulated delineating a link between social networks and the well-being of individuals (American Thoracic Society, 1995; Folkman & Lazarus, 1985; Lubben, 1988; Oritt & Paul, 1985). The presence of social support networks in the form of family and friends have been shown to diminish or eliminate concerns as well as facilitate coping (Cossette & Levesque, 1993; Folkman & Lazarus, 1985; McHaffie, 1992; Oritt & Paul, 1985). Family and friends can provide a number of forms of social support: emotional support, material aid, advice and information, physical assistance and social participation which serve to alter the environment of the individual and moderate or eliminate stressors (Oritt & Paul, 1985; Procidano & Heller, 1983). Several studies have documented the social support both family and friends who provide to individuals affected by COPD (Cossette &

Levesque, 1993; Sexton & Munro, 1988; Sexton & Munro, 1985). In many cases such support has facilitated the well-being of the individual even in the presence of otherwise daunting concerns (Ross, 1991; Sexton & Munro, 1988). This is primarily because the presence of supports alters the environment of the individual and his or her subsequent perception of concern (Oritt & Paul, 1985; Procidano & Heller, 1983). For example, the individual who easily becomes short of breath and has difficulty going out on long trips to buy groceries may be less likely to perceive this as a concern if he or she has a child who can buy the groceries for him or her.

Several measurement instruments have been developed in the last ten years to measure social networks and or the quality of social support (Lubbin, 1988; Oritt & Stephen, 1985; Procidano & Heller, 1983). The "Perceived Support Network Inventory" is a self-report measure of perceived social support from family and friends. Tested on a large sample of individuals ($n=146$), the measure has yielded a test-retest reliability of 0.72 for the total score and 0.88 for the scores of its subscales. The internal consistency of the instrument is 0.77 and estimates of construct validity from 0.27 to 0.57 (See Appendix N for The Perceived Support Network Inventory). According to Oritt et. al. (1985), the instrument can be used in the clinical setting to determine the dimensions of the

individual's perceptions of social support, and to clarify support roles provided by family and friends (Oritt et.al., 1985). It is also a useful instrument to use as a guide to explore perception of social support in an interview because of its brevity, comprehensiveness and clarity. It also examines social support from the individual's perspective rather than attempting to measure the size of the network (See Appendix L for Interview Guide).

Summary

In this chapter the researcher reviewed the current research regarding coping, concerns and chronic obstructive pulmonary disease. Coping was addressed as an expansive process instrumental in facilitating the ability of individuals to manage the stresses associated with daily living, chronic illness and chronic obstructive pulmonary disease. Stress was identified as the process which initiates coping, and appraisal was noted to be the factor which differentiated between a stressor and concern. A concern was identified as being different from stressor because it involved the individual's appraisal of stress. Additionally, a myriad disease-specific stressors within a biopsychosocial context were examined. Furthermore, the effect of COPD on the family and the effect of a social network on the individual were discussed. Distinct gaps in the current literature addressing coping and most stressors was noted; namely that stressors were defined from a

clinician identified medical perspective rather than the client perspective of concern and little of the literature described the relationships of concerns to each other, disease trajectory and gender. Concern is an important concept in enhancing the coping of clients. With the growing number of individuals affected by COPD, nurses need to take a greater role in facilitating client coping. Part of the process of addressing coping involves understanding the concerns of clients as they perceive them. If a client does not perceive a stressor as a concern, he or she will not be motivated to care for themselves in a manner which will diminish the impact of that stressor and improve health. Nursing must identify client concerns in order to promote, teach, and support coping that will reduce or eliminate concerns. Researchers need to examine concerns in COPD, in relation to each other, disease trajectory, and gender. Once concerns are identified and addressed, nurses can attempt to facilitate reductions in stress and promote coping through the use of nursing interventions specific to client concerns. Therefore nurses will be able to teach, maintain and support those coping strategies that will maintain health, and possibly slow the rate of disease and debilitation.

CHAPTER FOUR: CONCEPTUAL FRAMEWORK

Symbolic Interactionism

Symbolic interactionist theory attempts to explain the behaviours of groups and individuals. Through an examination of naturally occurring, everyday events in common settings, symbolic interactionists attempt to determine the meanings that humans attribute to events. In studying human actions and their relationships to beliefs, a symbolic interactionist can examine and determine the context within which actions take place, the underlying causes for undertaking actions and the subsequent consequences of actions (Blumer, 1969; Chenitz & Swanson, 1986; Burr, Leigh, Day & Constantine, 1979). In essence, symbolic interactionists believe that humans respond to the world around them, coping with events through the use of actions (Blumer, 1969). Each individual has a unique concept of the self and through interaction and communication with others learns more about him or herself (Chenitz & Swanson, 1986).

This interaction of the self with others creates the experiences and meanings within which an individual lives. Therefore objects, individuals and events have no meaning in of themselves, but develop meaning for the individual through his or her experiences (Blumer, 1969; Rose, 1962). Interactions between the self and objects, persons and events form meanings for a individual and a means of

defining and attributing value (Blumer, 1969; Burr et. al., 1969; Chenitz & Swanson, 1986; Rose, 1962).

Through socialization humans interact with each other and as a result groups develop, and behaviours become aligned within groups (Blumer, 1969; Chenitz & Swanson, 1986). Socialization is the means within which a common language and communication or interaction is created by humans (Chenitz & Swanson, 1986; Rose, 1962). As a result, meanings and values attributed to objects, individuals and events are shared and learned by the self (Chenitz & Swanson, 1986; Rose, 1962). Sharing meanings and values develops group consensus. The individual utilizes this knowledge and engages in behaviours which have meaning and value to the group in order to socialize (Blumer, 1962; Chenitz & Swanson, 1986). Consequently, consensus regarding shared and learned attributed meanings and values form the basis for the collective behaviours of families, institutions, organizations and society as well as the definition of self (Blumer, 1969; Chenitz & Swanson, 1986). Since the self and groups, are constantly experiencing new objects, individuals and events, change is inevitable. The experience of events becomes a way within which the individual redefines him or herself and influences the values, definitions and subsequent behaviour of groups (Blumer, 1962; Blumer, 1969; Chenitz & Swanson, 1986).

In order to understand how a person defines the self, symbolic interactionists examine individuals on three levels: the behavioural, interactional and symbolic. Within this framework, study of the individual occurs through an examination of behaviour in specific situations (Blumer, 1962; Chenitz & Swanson, 1986); for example, a symbolic interactionist investigator observes all possible verbal and nonverbal behaviours in a situation to determine symbolic meanings. Interaction is perceived by the researcher as a means through which symbolic meanings are expressed. Through the analysis of self definitions and shared meanings in interactions on macroscopic and microscopic levels, symbolic interactionists are able to identify the patterns and consequences of interaction and the values and meanings attributed to objects, individuals and events (Chenitz & Swanson, 1986)

Symbolic Interaction in Research

In research, human interactions must be examined in order to understand behaviour. As a result, setting and social forces must be analyzed to account for their influence on specific situations (Chenitz & Swanson, 1986). Furthermore, the full range of behaviour must be examined in terms events occurring in a situation to ensure an accurate, representation of meanings for the self as well as the group (Chenitz & Swanson, 1986). This is done when the researcher describes social behaviour in a natural setting. The setting serves as the context

within which social rules, ideologies and events emerge to illustrate meanings and ultimately affect behaviours (Blumer, 1969). In order for the researcher to understand the individual, he or she must function both as a participant and an observer. The researcher takes on the participant role to develop an understanding of the world from the perspective of the individual. In the role of the observer, the investigator becomes an interpreter, translating the meanings participants have attributed to objects, persons and events into a language that facilitates understanding among the members of his or her discipline (Blumer, 1969). The researcher therefore occupies a pivotal role between the world of the study participant and that of his colleagues acting as a conduit for valuable information regarding meanings and events.

Symbolic Interaction and Concerns in COPD

Chronic obstructive pulmonary disease, a debilitating illness, has a multifaceted effect on the individual. It is progressive by nature, involving physical deterioration and limitation. Consequently, affected individuals undergo constant changes in health status and therefore must cope with a variety of immediate and perceived future stressors or concerns. Concerns arise when present limitations or perceived future limitations imposed by COPD prevent or

hinder an affected person's participation in those aspects of life that are perceived as meaningful and valued.

According to symbolic interactionist theory, people define objects, individuals and events in terms of interaction. Individual interactions form the basis for learning individual, group and societal meanings (Blumer, 1969; Chenitz & Swanson, 1986). Consequently, the perception of a stressor as a concern occurs when illness is perceived as imposing current or future limitations on objects, individuals and events that are considered meaningful and valuable to the ill person. Groups such as health professionals, family, friends and society influence concerns by augmenting or displacing the ill person's learned values and meanings. Through interaction with groups and society, the individual learns to decrease or increase the meaning of concerns from interaction with others. Therefore an individual's concerns are the product of meanings and values learned by the self and influenced by society and groups. Concerns, as a consequence, for the COPD patient arise from his or her own meanings and values and are tempered by the values of family, friends, health professionals and ultimately society.

CHAPTER THREE: METHODOLOGY

In this chapter, the methodology is outlined. An ethnographic approach was used to explore the concerns of individuals with COPD across disease trajectory and in terms of gender. The sample was selected from a population of community residing adults living with COPD. Participants were recruited from a respiratory clinic. Data were collected in the clinic and the participant's home. A semi-structured interview was used to collect data. An adapted version of the "Perceived Support Network Inventory" was used to determine the individual's social supports. Data were gathered directly from participants and their charts. Ethical considerations underpinning the research were upheld throughout the study.

Research Design

Ethnography, a qualitative research approach, was used to explore the concerns of people living with COPD. "Ethnography is a way of collecting, describing and analyzing the ways in which human beings categorize the meaning of their world" (AAModt, 1991, p. 41). Ethnography is a research process in which the investigator engages, observes and records the lives of other individuals (Marcus & Fischer, 1986; Spradley, 1979). Ethnography develops concepts. It facilitates understanding of human behaviours from an emic perspective

(AAmodt, 1991; Field & Morse, 1985). Through intimate contact with the individual (Stein, 1991), ethnography enables the researcher to describe (Fetterman, 1989; Kleinman, 1992; Marcus & Fischer, 1986; Spradley, 1979), understand (Field & Morse, 1985; Spradley, 1979), classify and interpret the beliefs and practices of cultures or groups (AAmodt, 1991; Field & Morse, 1985; Spradley, 1979) by focusing in on human behaviour (AAmodt, 1991; Fetterman, 1989; Field & Morse, 1985). The ethnographer's focus is upon patterns of behaviour, physiologic responses, and emotions that represent human experiences (AAmodt, 1991).

An ethnographic design was selected for this study the following reasons. Few studies currently exist that qualitatively describe the concerns of people with COPD. Furthermore, research exploring the relationship of concerns to disease trajectory and gender is lacking. Describing the concerns of people living with COPD, is an essential component of developing knowledge and understanding, and a means of beginning the process of addressing key concerns for the individual. A qualitative, ethnographic approach facilitates this knowledge development and understanding by accessing the rich descriptions of the meanings, beliefs and values individuals with COPD attribute to objects, persons or events perceived as concerns (AAmodt, 1991; Fetterman, 1989; Field & Morse,

1985; Morse, 1991; Sandelowski, 1986). The result is health professionals understand the health behaviours of individuals from the participant perspective rather than that of the health professional (Field & Morse, 1985). Additionally, it enhances, expands and challenges the existing body of knowledge regarding the concerns of people living with COPD (Brink & Wood, 1989; Roberts & Burke, 1989). This result is researchers are able to evaluate and understand the effectiveness of current interventions aimed at addressing the concerns of affected individuals.

Sample

Many factors need to be considered in order to produce valid, reliable data for analysis. In qualitative research the investigator attempts to understand phenomena. Therefore, the characteristics of qualitative samples differ from those that are quantitative. In quantitative research investigators need to obtain samples representative of the population and of sufficient size to ensure the generalizability of results (Brink & Wood, 1989; Field & Morse, 1985; Polit & Hungler, 1991; Williams, 1989). In qualitative research, the investigator attempts to select a sample of participants, having an extensive knowledge of the phenomena he or she wishes to study (Field & Morse, 1985; Morse, 1990; Polit & Hungler, 1991; Williams, 1989). In this study a purposeful sample was used.

Purposeful sampling is a form of non-probability, convenience sampling where the participants who are best able to increase understanding and develop knowledge are recruited. In this research, a group of individuals living with COPD were recruited. Purposeful sampling facilitated an examination of participant concerns and an exploration of the relationships between concern, disease trajectory, and gender. Such a sample is typical of ethnographic research.

Since the researcher intended to study the concerns of individuals living with COPD, the sample was drawn from a population of community-residing adults affected by the disease. Recruitment was carried out in a respiratory outpatient clinic of a large tertiary hospital. Sexton (1983) recommends the use of community and hospital based organizations in locating participants. Those individuals affected by respiratory disease are often difficult to identify in the general population. Inclusion criteria for the sample also consisted of the following:

1. medically diagnosed and treated for chronic obstructive pulmonary disease in the form of emphysema, chronic bronchitis and/or combinations of asthma, chronic bronchitis and emphysema (Even though asthma occurs alone and has been identified as a member of the diseases known as chronic obstructive pulmonary disease, it was not included in the sample population.

The perception and physiologic effects of asthma differ from those of chronic bronchitis, asthmatic bronchitis and emphysema. Differences in the symptom experience associated with asthma are sufficient to warrant several researchers to separate and study the symptom experience of asthma from those of other respiratory diseases (Gift, 1991; Janson-Bjerklie et. al., 1986; Janson-Bjerklie, Stulbarg, Ruma & Carrieri, 1987; Kinsman et. al., 1983).

2. ability to read, write, speak, and understand English.
3. live within the city of Winnipeg.
4. give written, informed consent.
5. eighteen years of age and older.
6. not in a stage of disease exacerbation (During periods of exacerbation the individual, may be hospitalized, or experiencing respiratory distress. This may make research access to the study participant difficult and change the ability of the participant to meet the sample criteria [Sexton, 1983].)
7. having completed the interview without developing an uncomfortable level of shortness of breath. (The quality of stressors experienced during respiratory distress differ from those experienced during periods of optimal functioning (DeVito, 1990; Janson-Bjerklie et. al., 1986; Sexton, 1983)

Twenty participants formed the sample; ten participants were female and ten were male. As well, ten participants suffered from moderate airflow obstruction and ten of severe obstruction. Obtaining multiple perspectives of a given reality facilitates interpretation and creates a more complete understanding of the phenomenon under study (Fetterman, 1989; Williams, 1989).

A sample size of 20 participants was considered to be sufficient to ensure the study questions were answered. Small samples sizes in qualitative research are usually sufficient to derive knowledge from the data without a repetition of material (Polit & Hungler, 1991; Roberts & Burke, 1989).

In many qualitative studies, the sample size is not pre-determined prior to data collection, but the sample size is expanded until no new information is elicited (Field & Morse, 1985; Morse, 1990). The rationale for this is: the researcher may encounter participants who may be lacking in knowledge (Field & Morse, 1985; Morse, 1990), have a decreased ability to describe a phenomena (Fetterman, 1989; Field & Morse, 1985; Morse, 1990; Polit & Hungler, 1991; Roberts & Burke, 1989) or are unwilling to divulge information (Field & Morse, 1985; Morse, 1990; Polit & Hungler, 1991; Roberts & Burke, 1989). In this study, the sample size was pre-set (as described above), because of the need to put

some limits on the data collection process. Twenty participant interviews provided sufficiently rich data for analysis.

Equal numbers of male and female participants were selected for each stage in the disease trajectory in order to explore the relationship between concern and gender. Past research has primarily focused on male COPD patients (Barstow, 1974; McSweeney et. al., 1982; Sexton & Munro, 1985). With the growing number of female smokers (Gelisky et. al, 1991; Greaves, 1990; Lamarche, 1990) and the subsequent rise in the incidence of COPD among women (Semenciw et. al, 1989), more research representative of women with this disease needs to be conducted. Feminist research has identified differences between males and females in terms of biological function (Birge, 1993; Ganz, 1993; Houston, 1993; Miller & Kaiser, 1993; Roughan, Kaiser & Morley, 1993; Sherman, 1993), social roles (Goldstein & Perkins, 1993; Rose, 1990), and psychological characteristics (Goldstein & Perkins, 1993; Roughan, 1993; Simmons, 1992). Some gender differences in terms of concern have been identified in the COPD research. In studies where concerns have been peripherally addressed, concerns have been noted to differ between the genders (Barstow, 1974; Kline-Leidy, 1990; Sexton & Munro, 1988); for example, dyspnea is perceived to be more severe by women than men (Janson-Bjerklie et. al. 1986). Furthermore, the experience of stressors

varies in intensity on the basis of gender. Studies report women experience specific COPD concerns with greater intensity than their male counterparts; for example, dyspnea and anxiety (Emery et. al., 1991; Janson-Bjerklie et. al., 1986).

Disease trajectory has been identified as an influential factor in the perception of concerns. Currently, very little research has examined concern across disease trajectory. Additionally, no research has described the concerns of individuals with mild obstruction. Many individuals with mild COPD experience minimal physiologic impairment. Therefore, they are not aware of disease process, disease related stressors and/or concerns (Tames, 1991). Consequently, finding a sample population of individuals affected by mild COPD is difficult, if not impossible. When disease begins to influence lifestyle and concerns develop, medical attention is typically sought and the individual is diagnosed with either moderate or severe stage COPD (Tames, 1991).

In summary, existing research has addressed concern only peripherally in relation to the actual focus of the studies (Barstow, 1974; Carrieri & Janson-Bjerklie, 1986; Chalmers, 1984; Fagerhaugh, 1986; Parsons, 1990). There is a need for further exploration of disease trajectory as it affects concerns. Therefore, the researcher interviewed ten individuals from the moderate and severe stages, five males and five females in each stage of disease process.

Access

Permission to access a sample was obtained from the respiratory outpatient clinic of a large tertiary hospital (See Appendix G for Access Letter). Once access was approved, a copy of the criteria for inclusion was provided to the Assistant Head Nurse of the clinic. Potential participants who met the study criteria were approached by the Assistant Head Nurse in the clinic and asked if they would consider meeting with the researcher (See Appendix H for Assistant Head Nurse Approach for Participation). An intermediary introducing the research extends the trust of the population to the researcher (Fetterman, 1989).

The researcher was present in the respiratory outpatient clinic when individuals were approached to participate in the study. If the patient indicated they were interested, the researcher a) described the study, b) obtained the patient's verbal consent, c) asked permission to examine the patient's chart, d) selected a date, time and location for an appointment (See Appendix I for Verbal Explanation of Study) and e) provided a copy of the study consent to the participant (See Appendix J for Consent Form). Two interviews were later conducted. Each was conducted at an appointed date, time and location. Of the twenty two individuals who were approached by the Assistant Head Nurse, twenty chose to participate in the study.

Half way through the study, recruitment slowed. The Assistant Head Nurse reported that the cold prevented many participants from attending the clinic, and those who did attend the clinic sought attention only for disease exacerbations. Therefore, they did not meet the study criteria. Additionally, there were fewer moderately obstructed individuals attending the clinic as patient's wished to avoid the cold. Consequently, the method of recruitment was altered.

The following method was used to complete the recruitment for the study. The Assistant Head Nurse of the respiratory outpatient clinic telephoned individuals who fit the study criteria, briefly explained the study, and asked each individual if they would consider talking to the investigator. The Assistant Head Nurse then secured permission to provide the investigator with the telephone number of each interested individual. Once the investigator received this list, she explained the study in detail and asked if they would consider participating. If the prospective participant agreed, the researcher and the individual identified a mutually convenient time and place to review the study, obtain consent and conduct the first interview. This change in protocol was approved by the Ethics Committee Chair. (See Appendix R for Alterations in Method of Recruitment).

In total twenty of the twenty two individuals who were approached by the Assistant Head Nurse to agreed to participate. Eleven participants were recruited

in the manner that was originally purposed: the Assistant Head Nurse in the clinic approached individuals who fit the study criteria and asked if they would consider meeting with the researcher. Nine were recruited using the second method: the Assistant Head Nurse telephoned individuals who fit the study criteria and asked each individual if he or she would consider talking to the investigator. In each case, prior to beginning the initial interview, the study was reviewed, and a written consent was obtained from the participant (See Appendix J for Consent Form). The two interviews were conducted using an interview guide developed for this study (See Appendix L for Interview Guide). Within the interview guide the individual's social support network was assessed using an adapted version of the "Perceived Support Network Inventory" (See Appendix M for the Perceived Support Network Inventory and Appendix L Social Networks section of the Interview Guide for adapted version). Demographic data was collected using a short questionnaire (See Appendix K for Demographic Data Form).

Setting

Data were initially collected in the clinic and later in a location and at a time mutually agreed upon by both the study participant and the researcher. All of the participants chose to be interviewed in their own home in order to minimize the expenditure of energy. Many COPD patients have poor activity tolerance,

cannot readily obtain transportation to other sites and/or require a degree of privacy when participating in research studies (Sexton, 1983).

Data Collection

Data were collected from four sources: patient charts, two participant interviews, a demographic data form and observations. In addition, field notes were maintained detailing the nature of the home visits. This was used to facilitate interpretation of observed non-verbal behaviours (Sexton, 1983; Spradley, 1979; Swanson, 1986) and to define the context of both interviews (Schatzman & Strauss, 1973).

Patient charts were accessed in the respiratory outpatient clinic in order to confirm a medical diagnosis of: emphysema, chronic bronchitis and/or asthmatic bronchitis. Pulmonary function values from the charts were used to objectively measure the severity of illness and to determine stage in disease trajectory (Burrows, 1990; Kniesl & Ames, 1987; Sexton, 1983; Tames, 1991; Thurlbeck, 1990). FEV₁, forced expiratory volume during the first second, and FVC, forced vital capacity, are the primary means of diagnosis and monitoring of COPD (Burrows, 1990; Kniesl & Ames, 1987). Established norms of FEV₁ and FEV₁/FVC ratios for age, sex and height were compared to the patient's value to determine the severity of airflow obstruction.

The two interviews acted as the second source of data. Each structured interview was used to gather data regarding individual concerns (See Appendix L for Interview Guide). According to Polit and Hungler (1991), the interview is a useful qualitative research methodology because of the quality and depth of data it generates (Polit & Hungler, 1991). Interviewing in ethnography serves as a means to explain, contextualize and understand the participant within the parameters of group beliefs and experiences (Fetterman, 1989). Semi-structured interviews were used because the structure of the topic, namely concerns, is known (Morse, 1990). At present, even though there is limited research addressing the concerns of individuals with COPD (Bastow, 1974; Carrieri & Janson-Bjerklie; Chalmers, 1984, Fagerhaugh, 1986), sufficient knowledge exists regarding the stressors experienced by this population to warrant the use of semi-structured interviews (Kniesl & Ames, 1987; Sexton & Munro, 1981; Tames, 1991) (See Appendix F for Complete List of Concerns and Stressors summarized from the literature).

A semi-structured interview guide was developed from the existing literature addressing the concerns and stressors experienced by individuals with COPD (See Appendix F for Complete List of Concerns and Stressors). The guide addressed the biological, psychological and sociological concerns and stressors

that an individual may be experiencing. Biological stressors and concerns addressed in the interview guide include shortness of breath, cough, sputum, wheezing, fatigue, sleep loss, weight loss, disease exacerbation, activity intolerance and hypoxemia. In terms of psychological concerns and stressors, the interview guide addressed body image, sexuality, frustration, powerlessness, emotions, depression and anxiety. Finally, sociological stressors and concerns including roles, financial problems, limitations on social activity and recreation were included in the guide (See Appendix L for Interview Guide).

Questions adapted from the "Perceived Support Network Inventory" were also included in the guide (Oritt et. al., 1985) (See Appendix M for the Perceived Support Network Inventory). These questions were incorporated into the guide in order to explore the quality of the individual's social environment. These data were helpful in providing information for interpreting the number and severity of concerns the individual experiences.

Both interviews were audio taped, a versatile means of recording the active nature of interviews (Morse, 1991; Spradley, 1979). Participants were interviewed twice in their home. Each interview lasted approximately one hour. Two interviews were utilized in order to improve the researcher's ability to

develop rapport, build a trusting relationship, and probe in greater depth into the lives of individuals (Fetterman, 1989).

The first interview was used to establish rapport and begin probing for COPD related concerns (Fetterman, 1989; Spradley, 1979). Following analysis of the first interview, the second interview facilitated further exploration and provided the participant with an opportunity to remember or recall additional details about their COPD related concerns (Spradley, 1979).

The opening question addressed concern from a broad perspective (Spradley, 1979). Participants were encouraged to discuss key concerns, their meanings, values and influence on their lives. Broad descriptive questions encourage the participant to speak freely, facilitate participant-researcher rapport (Fetterman, 1989; Spradley, 1979), introduce the topic of interest (Swanson, 1986) and focus the participant's thoughts (Fetterman, 1989). Allowing the participant to discuss concern in his or her own manner, helped to elicit information at a pace and from a perspective the individual was comfortable with (Field & Morse, 1985). Areas identified in the literature as potential stressors as well as concerns for people with COPD were probed to elicit further data (See Appendix F for Complete List of Concerns and Stressors). With the progression of the study, the focus of the research was narrowed to specific areas and in turn

produced an overview of the participant experiences (Fetterman, 1989).

According to Swanson (1986), probes encourage participants to describe experiences of specific interest to the researcher. Probing in an organized manner facilitates researcher understanding of the interviews of individuals (Field & Morse, 1985).

Two types of probes were used: detail and explanation. Detail probes were used to gather data regarding the concerns and stressors identified by the individuals (Strauss & Schatzman, 1973; Swanson, 1986). Explanation probes were used to determine the underlying reasons for the existence of specific individual concerns (Schatzman & Strauss, 1973). Asking questions, listening, and probing develops knowledge in ethnographic interviews (Fetterman, 1989). When the researcher's perceptions were not consistent with the participant, the researcher asked for clarification (Field & Morse, 1985; Spradley, 1979). The interviews gave participants the opportunity to divulge the individual's perspectives and experiences (AAmodt, 1991; Fetterman, 1989; Field & Morse, 1985; Spradley, 1979).

During the course of this study, it became apparent that the use of two interviews facilitated a greater exploration of concerns; two interviews with each participant improved the quality and depth of participant descriptions. In many

cases participants stated the time period between the two interviews allowed them to reflect upon the interview questions. As a result, many participants added to their original descriptions as well as identified several other concerns not mentioned during the initial interview. The researcher also found the second interview to be important when discussing sensitive topics such as sexuality. The participants were less anxious during the second interview. They had developed an increased level of comfort in speaking with the researcher. This prevented anxiety and dyspnea.

The demographic data form was used to collect data at the end of the interview. Demographic data were used to describe the sample (Polit & Hungler, 1991). Previous research has demonstrated the relevance of physical, psychological and social variables in influencing concern. This proved to be helpful in interpreting the data (Barstow, 1974; Chalmers, 1984; Fagerhaugh, 1986; Sexton & Munro, 1981; Sexton & Munro, 1988; Shekleton, 1987; Sjoberg, 1983).

Finally, field notes were made at the end of each interview to augment the data gathered during the interviews. Field notes consisted of observed events and actions that transpired during the course of the interview (Schatzman & Strauss, 1973; Swanson, 1986). Events defined the context of the interview and

provided the researcher with an understanding and insight into interview data (Schatzman & Strauss, 1973). Actions defined the non-verbal behaviours of the respondent. Actions included facial expressions, gestures, movement, pitch and tone of voice. Alterations and inconsistencies between the actions and responses formed the basis for clarification and interpretation of statements made by participants (Swanson, 1986).

Data Analysis

Audio tapes were transcribed verbatim to WordPerfect (Field & Morse, 1985; Morse, 1991; Spradley, 1979). Each audio tape represented one interview. Each interview was assigned a four digit number. The first number in each of the four digit numbers represented the interview from which the unit of analysis was drawn. The last two digits in each of the assigned numbers identified each of the participants. Notes from the audio tapes were then transferred to Ethnograph, a qualitative analysis computer program (Seidel, Kjolseth & Seymour, 1988). Data collection and analysis were concurrent (Fetterman, 1989). The ethnographic method of data analysis were used (Fetterman, 1989; Sewell, 1967). The unit of analysis consisted of words, phrases, sentences or paragraphs (Fetterman, 1989; Hammersley, 1992). Each unit consisted of the smallest unit of information that could be understood and stand alone (Fetterman, 1989; Hammersley, 1992;

Lincoln & Guba, 1989). The data from the first interview was examined for patterns. Patterns were classified and coded into categories of concerns (Aamodt, 1991; Fetterman, 1989). As the interview was examined for patterns, classified and coded, each category of concerns that emerged from the data was compared to previously coded categories of concerns for similarities as well as differences thereby developing patterns (Fetterman, 1989; Sewell, 1967). As a result, the dimensions and properties of each category of concern emerged. Subsequent interviews were coded into categories of concerns derived from the initial interview. New patterns, classifications and categories of concerns emerged in subsequent interviews. A comparison of concerns for similarities and differences took place among participant interviews (Fetterman, 1989; Glaser & Strauss, 1967; Spradley, 1979; Yin, 1989). The data were examined to identify gender differences and differences in concerns according to stage in disease trajectory (Fetterman 1989). Categories were integrated to produce a complete description of each concern, its properties and dimensions and differences among the differing groups in disease trajectory and gender (Fetterman, 1989; Glaser & Strauss, 1967).

In using the two semi-structured interviews, the demographic data form, patient charts and the field notes of participants, the researcher was able to ensure the quality of the data which was collected. Essentially, the researcher used triangulation or the process of testing one source of information against another (Fetterman, 1989, p. 89). This ensures the data are complete and the uncertainty associated with interpretation is decreased (Knafl & Breitmayer, 1991; Webb, 1981). Data from the each of the above mentioned sources were triangulated to ensure accurate interpretation during analysis.

Rigor in qualitative research is unlike that of quantitative research. Qualitative research maintains rigor through the use of four strategies: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1989). Qualitative research achieves credibility when the researcher engages in activities that will increase the probability of producing credible findings (Lincoln & Guba, 1989). The researcher used peer debriefing in order to ensure the credibility of the findings. Peer debriefing is a method by which the researcher is exposed to questions from another researcher experienced in the area of inquiry and methodology. The researcher probes the investigator's work attempting to identify biases while questioning meanings and interpretations (Lincoln & Guba, 1989). The thesis committee chair and internal member, investigators

experienced in the field of qualitative research, questioned and probed the data analysis and findings.

Transferability in qualitative research addresses the ability of the researcher to provide a data base that enables other individuals; for example, health professionals to apply the findings of the research to other situations (Lincoln & Guba, 1989). The researcher obtained a complete description of each of the concerns identified in the interviews. The first interview was used to explore the concerns documented in the existing literature. An analysis of the first interview, alerted the researcher to the concerns requiring further exploration and description (Glaser & Strauss, 1967). This resulted in the production of a rich descriptive data base and transferable findings (Glaser & Strauss, 1967; Lincoln & Guba, 1989).

According to Lincoln and Guba (1989), dependability is achieved in qualitative research through the use of audits. An auditor examines the analysis and interpretations of the research. The thesis committee chair audited the investigator's analysis and interpretations of the data in the following manner: All major categories as well as sub-categories were operationally defined by the researcher. The thesis chair examined codes and data bits for fit and congruence with the researcher's coding scheme. Coding discrepancies were examined and

re-evaluated. The researcher re-coded some of the data when discrepancies arose (Lincoln & Guba, 1989).

Confirmability is attained when the researcher ensures that a clear trail is left from the beginning to the end of the study. A clear trail enables other researchers to follow the events and subsequent logic of the study. Through the use of comparisons, the transcribed data was effectively examined for patterns, units of analysis were categorized, and attributes as well as relationships were identified. This enabled the thesis committee members to follow the logical progression of the study. Therefore when excerpts from the data were presented, the thesis committee members were able to understand the conclusions that were drawn as a result of the analysis (Glaser & Strauss, 1967). In ensuring credibility, transferability, dependability and confirmability of the research, rigor was maintained (Lincoln & Guba, 1989).

Descriptive statistics were calculated for the following demographic characteristics: age, employment status, occupation, household income, marital status, education, cause of the chronic obstructive disease, pulmonary function, respiratory diagnosis, years of respiratory diagnosis, smoking history, and number of pack years. Descriptive statistics were used to summarize and describe the characteristics of the sample (Polit & Hungler, 1991; Roberts & Burke, 1989).

Both gender and disease trajectory were examined in relation to the gathered data to determine the existence of patterns.

Ethical Issues

Three important ethical issues were present in this study: informed consent, maintenance of confidentiality, and risk for fatigue and shortness of breath during the interview. In order to eliminate and minimize these risks, the participants were asked to participate in the study, they were informed by the investigator of the nature of the research, the demands that would be placed upon them, and the possible costs and the benefits. The participants were also informed that they could withdraw from the study at any point and that any medical or nursing care attention they were receiving or would receive in the future would not be affected by their withdrawal. Additionally, contact numbers for the researcher and a faculty advisor were provided should the participants have had any questions or concerns they wished to discuss. No participants intimated a need for such contact.

Once informed consent was obtained, the researcher made every effort to maintain participant confidentiality. Participant's names were used neither in relation to any aspect of the research nor released to any individuals other than the researcher. All data and transcribed materials were kept in a locked cabinet in the

researcher's office. When the interview data was transcribed, the source's name and any data identifying the source of the information was not transcribed. Each of the transcripts was coded for identification, and the corresponding coded names, addresses, and phone numbers were kept in a separate locked cabinet in the researcher's office. Only the researcher had access to the codes and corresponding names, addresses and phone numbers. Only the researcher and her committee chair had access to the tape recordings.

Since this population was at risk for developing shortness of breath during activities, the researcher took measures to prevent the development of dyspnea during the interview process (Kniesl & Ames, 1987). Prior to beginning the study, the participants were informed in both written and verbal forms that if they perceived shortness of breath or fatigue during the interview, they were to tell the researcher to stop the interview for a rest or to continue the interview at another date and time. Only one individual stopped an interview and chose to begin it again at another time. The individual was overcome by emotion when she began discussing a concern which meant a great deal to her.

Fatigue was also an issue. Many participants asked that their interviews be scheduled in the late morning or afternoon. Consequently, the researcher scheduled each of the interviews in the late morning or afternoon as requested;

this allowed the participants to complete activities of daily living in the morning and allow for rest prior to the interview. Rushing activities may have caused undue anxiety, fatigue and shortness of breath (Fagerhaugh, 1986).

During the interview, the researcher, monitored the participant for signs of respiratory discomfort such as laboured breathing, and cyanosis (Kniesl & Ames, 1987). A few participants experienced some mild, transient dyspnea during conversation. The researcher paced the interview questions to prevent shortness of breath. A few participants also paced their responses to questions in order to control their symptoms. Pacing is a method of preventing shortness of breath (Sexton, 1981). As well, participants took frequent breaks during their interviews where they stopped talking, took their respiratory medication, engaged in pursed-lipped breathing and/or rested between responses. For investigators interviewing individuals affected by COPD, it is important to ensure that the participant is aware of their right to stop the interview at any time or to respond to questions without any given time limits. Additionally, the researcher should assess the level of dyspnea throughout the interview in order to prevent respiratory distress (Sexton, 1983). Finally, the researcher must adapt his/her interviewing techniques to meet the participant's need to pace, stop or rest during the interview (Carriere & Janson-Bjerklie, 1986). In this study, pacing, stopping, and resting were

employed as coping strategies by participants. These measures were taken because dyspnea is a physiologic stressor in COPD (Kniesl & Ames, 1987). Additionally, dyspnea may invalidate the data or prevent the collection of complete descriptions (Sexton, 1983).

Emotions and anxiety also influenced the interview process. Participants experienced both anxiety and emotions during their interviews. Many participants appeared anxious prior to beginning their first interview. Additionally, some of the participants experienced emotions while describing their concerns.

In studying individuals affected by COPD, the researcher must be aware of the role both anxiety and emotions play in evoking dyspnea that may lead to respiratory distress. Emotions and anxiety can be caused by interactions and conversations among individuals (Lisella, 1993; Sandu, 1986). Additionally, some topics which are sensitive to the individual may cause anxiety and emotions. Therefore, the researcher must make the effort to create an environment that will decrease anxiety and promote a calm expression of thoughts and feelings. The researcher undertook several strategies to do this. Prior to beginning an interview, the researcher discussed topics which were unrelated to the research; for example, the weather. Following this, a brief overview of the interview questions was undertaken. The participant was also made aware of his or her right to not answer

questions and have the tape recorder turned off, or stopped. Finally, if anxiety or emotions were not prevented, the researcher stopped the interview. If the investigator felt that the participant was distressed and/or needed time to deal with his or her emotions, the interview was stopped and the participant was given time to calm down. This happened on two occasions.

Summary

In this chapter, the methodology was outlined. Essentially, a sample of 20 community-residing individuals was used to study the concerns of people living with COPD across gender and disease trajectory. Recruitment took place in a respiratory clinic. Data were collected in the clinic and participants homes using demographic data form, field notes and two semi-structured interviews. An adapted version of the "Perceived Support Network Inventory" was used to determine the social supports of individuals. Finally, ethical considerations underpinning the research were discussed.

CHAPTER FIVE: THE FINDINGS

In this chapter, the characteristics, concerns, coping strategies and experiences of the participants are presented. Initially, the chapter begins with a brief discussion of the sample characteristics. Following this, participant descriptions of dyspnea, the primary concern, are presented. Later, the secondary concerns of participants are categorized and described according to their attributes, gender and disease trajectory based differences as well as coping strategies. Finally, the social supports of participants are presented to contextualize the experience of a concern.

As mentioned earlier, the participants identified dyspnea as the primary concern. All other concerns were secondary because of their antecedent or consequent relationship to dyspnea. In this chapter, each secondary concern is also described in terms of its relationship to the primary concern, dyspnea.

Sample Characteristics

The sample consisted of ten males and ten females, five individuals from each gender in the moderate and severe stages of disease trajectory.

Table 1

Description of Sample According to Gender and Disease Trajectory

Description of the Sample	Moderately Obstructed	Severely Obstructed
Female	5	5
Male	5	5
	10	10

Demographic Characteristics

The sample ranged in age from 59 to 82 years. The mean age of the sample was 70 years (median=72 , mode=72). Seventy percent of the sample had some form of high school education. The remaining 30 percent had either a community college (12 percent) or university education (18 percent). Fifty-five percent of the sample was married. The remaining 45 percent was either single, widowed or divorced. Seventy percent of the sample identified at least one form of support. Of those who identified at least one support, 55 percent indicated their spouse was their primary source of support.

Occupation, Employment and Income

All of the participants were retired at the time of the interview. The occupations held by the participants were varied; many held unskilled (30 percent), semi-skilled (40 percent) or professional positions (30 percent). In terms of income, all of the sample cited pension benefits as their primary source of income. Eighty six percent (n=17) of the participants had an income of at least \$10, 000 dollars a year. Eighty percent (n=16) of the participants who reported income data, stated that their income met all of their needs. Only 20 percent (n=3) stated their needs were sometimes not met.

History of Disease

Participants stated the length of time since diagnosis ranged from four months to 49 years (mean=15, median=12, mode=15). All of the participants reported a history of smoking. One participant continued to smoke. All others had quit smoking in the past. The length of smoking history varied from five to 66 years (mean=31, median=30, mode=30). Three quarters (n=15) of the sample did not use oxygen on an ongoing basis. Those who used oxygen (25 percent; n=5) required an average of 2 litres of oxygen per minute via nasal cannula.

In summary, the individuals who participated in this study were for the most part older, married, highschool educated, retired and pensioned. Although all the

participants had smoked an average of 31 years in the past, all but one had quit smoking. With the exception of five individuals, the majority of the sample was not oxygen dependent.

The Concerns of People Living with COPD

Dyspnea: The Primary Concern

All of the study participants identified dyspnea as their primary concern because of its ability to cause discomfort and unease. For the participants, dyspnea had its origins in physical activities, emotions, and the environment. Many of the participants noted that dyspnea affected biological, functional, psychological, sociological and spiritual aspects of life. The role of dyspnea in the participants' lives led to the development of concerns. Consequently, all of the participants identified dyspnea as both an antecedent and a consequence to the development of other concerns. Therefore, participants considered all other concerns to be secondary in nature. In this section, dyspnea's nature and characteristics are presented. Additionally, the coping strategies of participants are discussed. Dyspnea's role as an antecedent and a consequence to other secondary concerns is addressed in greater detail later in this chapter.

Table 2

Concerns

<u>Primary Concern</u>		<u>Secondary Concerns</u>	
	<u>Classification</u>		
		<u>Antecedents</u>	<u>Consequences</u>
Dyspnea	Environmental	Cold	
		Humidity	
		Wind	
	Functional		Limitations in Physical Activity
	Biological		Limitations in Physical Ability
			Fatigue
			Sleeplessness
			Loss of Ability to Concentrate
			Food Consumption
			Oxygen and Equipment

	Psychological		Powerlessness
			Self-Blame
			Embarrassment
		Emotions	
			Death
		Anxiety	Anxiety
	Social	Communication	Social Role Change
			A Lack of Understanding among Others
			Limitations in Recreational Activities

Dyspnea: The Nature

All of the participants experienced varying degrees of discomfort and unease in response to dyspnea. Dyspnea was identified in terms of a symptom continuum anchored on one end by the sensation of discomfort and on the other end by the perception of threat to life. The participants described dyspnea as a "discomforting", "terrible", "erratic", "threatening", "traumatic" feeling of "chest tightening", "choking", "gasping", "suffocation", "drowning" or having your

breath "stopped." Consequently, the occurrence of dyspnea resulted in varying degrees of unease for participants.

Dyspnea: The Characteristics

The participants also described dyspnea in terms of situational context. The participants identified three forms of situational dyspnea: daily, infection related, and crisis. Each form of dyspnea involved varying levels of shortness of breath and limitations in the ability to perform activities.

Daily

Participants frequently referred to their daily experiences with dyspnea. As participants they commonly described their daily encounters with this symptom utilizing the phrases "good day" or "bad day. A "good day" was identified with lower levels of dyspnea and an increased ability to perform activities:

There are other days when I can walk to the bathroom and back. It [the shortness of breath] doesn't bother me that much. It [the shortness of breath] does bother me, but it's not that much. (1009)

If I have a good breathing day, I can do things. I can stand at the kitchen and do things. Okay, this morning we had left overs. We had sent out for Chinese food last night and there was a lot left over. My daughter and her husband were over and there were a lot of left overs. And we thought well instead of just taking those left overs and shoving them in the oven. I couldn't do that. I had to separate [the left overs] and make a special little dish out of it and everything. (2009)

I walked from the sun room to that [front hallway] to let you in the door. I would have been normally puffing like a steam engine [in walking] to open the door but I wasn't today. (1008)

Participant characterisations of "good days" differed only when disease trajectory was considered. On a "good day", individuals affected by moderate COPD stated they were not dyspneic nor did they have any difficulty in performing activities. In contrast, those affected by severe COPD experienced low levels of dyspnea and an increased ability to perform physical activities.

All participants identified "bad days" with increased dyspnea and decreased ability to perform physical activities. "Bad days" often occurred in conjunction with periods of disease exacerbation:

When you have a bad day your breathing is really, really bad. (1009)

I'm just puffing, chuffing, coughing and bringing up sputum. (1008)

But I have very, very bad days. Like it's [the bad days are] always there but I have very, very bad days. Like it's [the disease] is always [like] that, but I have days that I cannot do anything. There are days that I just have to hang on to the walls as I am walking to the bathroom. (1009)

Participant characterizations of "bad days" were influenced by stage in disease trajectory. Individuals affected by moderate disease process stated their dyspnea increased and their ability to perform physical activities decreased on bad

days. Those with severe disease process experienced extremes in dyspnea and limitations in physical activity on bad days.

Respiratory Infection Related

Among the participants, respiratory infection was identified with increased dyspnea and decreased ability to perform physical activities. This form of dyspnea was often accompanied by cough, excesses in green or yellow sputum production, and need for hospitalization:

It [shortness of breath] means getting dressed is a problem, sleeping is a problem, taking your medication is problem. Everything [is a problem]. You know if you are having trouble it's hard to cope. (1007)

I am drowning and you know. How can I describe it only drowning. Just gasping for breath and not getting enough. Not getting enough. Oh that is terrible and I thought it would clear but it gets worse until finally at midnight I decided it was too much for me. I decided to go to the hospital. I have to wake up people in the house to drive me and it was bad. (1020)

Terrible. I didn't know. I didn't know whether I was going to die in the hospital or at home. (2019)

Participants feared experiencing respiratory infection related extremes in dyspnea. Consequently, many identified this form of dyspnea as a concern. No gender or disease trajectory related differences were present.

Crisis

Some participants identified the presence of a third form of dyspnea: crisis dyspnea. Participants experienced crisis dyspnea in response to a stressful event; for example, a diagnosis of COPD, a death in the family, or the loss of a favoured activity:

I had a [child] that was very close to me and he died of [disease] just a couple of years ago and that sort of really set me spiralling down. It really affected me quite a bit and it made my breathing worse, and it stymied me in the way of my lifestyle. (1013)

I used to get a lot more short of breath at the beginning, when I first found out about it [the COPD], because I was afraid of it [COPD]. I was afraid that one day you are not going to be able to breathe and that would scare me, and of course would cause some hyperventilation. (1015)

Disease trajectory influenced the experience of this form of dyspnea.

Individuals affected by moderate COPD referred to their encounter with crisis dyspnea in the immediate past whereas those with severe COPD spoke of experiencing crisis dyspnea in the distant past. Gender did not influence the experience of crisis dyspnea.

In summary, the participants stated dyspnea was a discomforting, life-threatening, primary concern. Many of the participants described dyspnea in

terms of its daily, respiratory infection related, and crisis forms. All of the participants identified dyspnea as both the antecedent and consequence to varying environmental, biological, psychological, and sociological alterations in lifestyle or secondary concerns. Therefore, dyspnea acted as both a concern and a source of other concerns. Consequently, the lifestyle alterations imposed by dyspnea dictated the context for living with COPD.

Coping with Dyspnea

The environmental, functional, biological, psychological, and social influences of dyspnea on lifestyle resulted in the development of coping strategies. The participants identified coping strategies as behavioural and/or cognitive efforts aimed at preventing, reducing and/or accepting concerns. In the present study, the participants utilized three forms of coping strategy in response to dyspnea namely: prevention, reduction and acceptance. Preventative strategies encompassed those activities aimed at avoiding dyspnea. Reductionist strategies sought to decrease the level of experienced dyspnea. Acceptance strategies involved acknowledging the presence of dyspnea.

When dyspnea was caused by physical exertion, the participants coped with this symptom by preventing, reducing or accepting its expression. The participants prevented dyspnea by refusing to participate in physical or social

activities, and by delegating physically demanding tasks to others. In cases where dyspnea was unavoidable or necessary in order to complete a task; for example, in performing activities of daily living or in participating in a desired social activity, participants attempted to reduce their level of dyspnea by pacing activities, resting, utilizing purse-lipped breathing and/or pulmonary medications such as bronchodilators. Pacing or alternating between periods of activity and rest, enabled participants to reduce or slow their rate of breathing between periods of movement. Resting, like pacing, also assisted participants to lower their rate of breathing. Resting involved a cessation of activity followed by a slowing in the breathing rate. Purse lipped breathing was also used to reduce dyspnea; participants stated that purse-lipped or control of breathing was an essential component of coping with this symptom. Finally, medications such as bronchodilators were identified as a method of limiting dyspnea. Here, participants used bronchodialators during dyspneic episodes to lessen the severity of shortness of breath.

Participants also utilized prevention, reduction and acceptance in order to cope with the dyspnea caused by emotions. Many participants prevented or reduced dyspnea by withdrawing or restricting their level of participation in emotion producing situations. Participants also utilized acceptance as a strategy

to cope with the emotions associated with shortness of breath. Here, participants recognized and accepted the role of this symptom in effecting lifestyle changes and restricting activity.

Participants also attempted to prevent and/or reduce dyspnea during social situations. For the most part, participants identified communication with others as an antecedent to dyspnea; participants found that speaking caused shortness of breath. As a consequence, members of the sample avoided social situations in order to prevent dyspnea. In situations where speaking was unavoidable participants attempted to speak very little.

In summary, dyspnea's effect on the individual was extensive. Dyspnea existed on a continuum: from the sensation of discomfort to the perception of having life threatened. Dyspnea acted as both an antecedent and a consequence to the development of other concerns. As a result, dyspnea influenced many aspects of a participant's lifestyle. This lead to the creation of several other concerns. In response participants developed coping strategies to prevent, reduce and/or accept the role of dyspnea in altering their lifestyle.

Secondary Concerns

In this section, the secondary concerns of the participants are presented.

Each secondary concern has a relationship to dyspnea and coping that is environmental, functional, biological, psychological or social in nature.

Dyspnea's relationship to each of the secondary concerns is not exclusive.

Elements of each secondary concern can be found within other secondary concerns. For example, the functional secondary concern, limitations in physical activity, has psychological and social components. Consequently, one must be aware of the environmental, functional, biological, psychological or social elements of each concern.

Environmental Secondary Concerns

Some participants identified the weather as a concern. Participants stated the weather acted as an antecedent to dyspnea. Specifically, cold, humidity, and the wind were cited to have caused dyspnea. Each of these is discussed below.

Cold

Participants identified the cold as a concern. Men, women, and participants from both stages of disease trajectory stated the cold caused dyspnea, and dyspnea in turn, limited physical and social activity:

Oh yeah. Cold ... it just seems to catch. You can't seem to breathe quickly enough and so you get short of breath. (1005)

If you take a breath, the cold air shrinks up all your insides: your airways, your passages and your lungs. (2014)

Especially in the winter and you cannot catch your breath and you suddenly panic. You think you are going to freeze you know. Not from the cold, but you go dumb in the head. (1016)

Males and females described the impact of the cold differently. Women identified the cold with feelings of loneliness and isolation. The cold prevented them from participating in social activities:

Being alone too much when it's cold and you can't go out. Day after day or you wait for [a] phone call. For things to do or [to] expect somebody [to visit]. (1018)

I get fed up sometimes because if it's really cold out you can't even get in the car and go anywhere. (1017)

All I do is watch T. V. No. But, uhh, I don't know. I won't be able to get out this winter. Last winter I had trouble. I covered my mouth. (1017)

In contrast, men became angry when the cold limited their ability to participate in activities. They attempted to "fight" the restrictions on their activity. Consequently, men persisted in pursuing physical and social activities:

I won't go, but I've gone out many times where I've felt like staying home. But I've gone. I guess I suffer through it, but I also uhh felt good about doing it too. I just don't believe we should give in...I think we should fight it too. (2008)

Oh I get short of breath. Uhhh, that's why I have to wrap up my whole head up except my eyes, and that's very uncomfortable as it was, but it's terrible without it also. I have to protect my nose and my lungs from the cold [when I go outside]. (1020)

In the effort to limit shortness of breath and to maintain minimal levels of activity, participants coped by preventing their exposure to the cold. Preventative strategies consisted of avoiding or reducing exposure to the cold. This helped to limit the number and severity of dyspneic episodes. It also increased the potential to engage in social and physical activity. As well, it diminished feelings of loneliness, isolation and anger.

Participants prevented or avoided the cold by staying at home. When venturing outside was unavoidable, participants attempted to reduce their exposure to this element by wearing a scarf or mask or by parking their car near the entrance of the building they intended to visit. By covering the face or parking the car a short distance away, the participant was able to diminish his or her exposure to the cold and thereby reduced the severity of dyspnea.

In conclusion, the ability of cold to cause shortness of breath and subsequent limitations in activity was experienced by both sexes and stages in disease trajectory. However, men and women experienced the impact of cold differently. Women identified loneliness and isolation with the cold, while men attempted to

fight cold related restrictions. Both genders coped with the cold and its influence on dyspnea. Participants coped by avoiding or reducing their exposure to this element.

Wind

Like cold, wind was also a concern for the participants. Many participants identified their exposure to wind with dyspnea and/or the perception of "stopped" breathing:

- It just cuts off breathing. It's too hard to breath. Like you...you try to breathe but it is as if it wasn't there for some reason. I don't know why. It just takes twice, or three times the effort to breath with the wind. (2018)

The impact of wind on breathing resulted in a diminished ability to walk, feelings of panic and the perception that one's life was in danger:

You feel like you are going to die. (1015)

If you have ever had the breath knocked completely out of you, you would know what it is like. You start to gasp and the more you gasp, you can't get your lungs to work. It feels like someone is sitting on your chest and you just can't get your air in or out and the thing is you can't get it out to make room for any air to come in. That's when you start to get panicky. You almost stop breathing you know. (1015)

Participants used a number of strategies to cope with the wind. Coping strategies were aimed at preventing or reducing exposure to the wind in order to limit the level of dyspnea, panic, and/or reductions in physical activity.

Participants prevented dyspnea which was caused by the wind by avoiding outdoor excursions on windy days. When participants had to venture outdoors on windy days, coping strategies were aimed at reducing the wind's influence on dyspnea: either in protecting the face from the wind with a scarf or mask and/or in the use of dyspnea reduction strategies such as purse-lipped breathing, relaxing and/or pacing. Gender and stage in disease trajectory did not appear to influence participant experiences with the wind.

In summary, the exposure of individuals to the wind resulted in dyspnea, followed by feelings of panic as well as reduction in the ability to perform physical activity. As a result, affected individuals identified several methods of coping with the wind and its sequelae. Participants reduced the impact of wind by utilizing strategies aimed at preventing or reducing the severity of experienced dyspnea.

Humidity

Like cold and wind, humidity was also a concern for participants. Humidity became a concern for participants when it acted as an antecedent to dyspnea. Participants were affected by two forms of humidity: atmospheric humidity which was present in the earth's atmosphere and local humidity which existed in the form of steam following a shower. Participants disliked both forms of humidity.

Atmospheric and local humidity increased the occurrence of choking, wheezing, dyspnea, fatigue and limitations in physical activity:

Shortness of breath...more shortness of breath...it takes less...expenditure of energy to get short of breath. (1015)

Well the heaviness of the breathing will increase. I won't be as normal as I want to be. More often [with the humidity I have] heavy breathing. Heavy breathing: It's more harder for you to breathe. (1008)

It's exhausting. Even the summer humidity. I love the heat. Some people complain about the 28 to 30 [degree weather]. It can be 40 to me as long as it is dry in the shade with the breeze, but take that breeze away and that stale humid air. It's killing me. I can't breathe very well and I don't know. (2018)

It will be a heavy day like today when the air is heavy and you start to feel, well, that every breath is an effort. Everything you do is an effort. If you shave you get a little bit tired shaving. If you dress you get a little bit tired. (2015)

No differences were found between the experiences of men, women or individuals when experiencing humidity.

Participants coped with humidity by attempting to prevent, alter, or ignore their exposure to this element. Some participants prevented their exposure to humidity by staying in air-conditioned environments and avoiding trips outside the home during periods of high atmospheric humidity. Other participants altered their exposure to local humidity by promoting the circulation of air when in a highly humid environment. For example, when participants took a shower in the

bathroom, they left the bathroom door open while bathing. In cases where exposure to humidity was unavoidable, individuals accepted dyspnea as an outcome. Participants ignored or reduced their level of experienced dyspnea. Participants reduced dyspnea by utilizing strategies aimed at controlling anxiety and shortness of breath.

In summary, the participants identified two types of humidity: atmospheric and local. Both forms of humidity increased the difficulty experienced when breathing. Participants coped with humidity by preventing, altering or ignoring the associated dyspnea .

In conclusion, cold, wind and humidity are all environmental elements that have been identified as secondary concerns by participants in this study. Each of these elements contributed to the development of dyspnea. In response, participants coped with cold, wind and humidity by preventing and/or altering their exposure to these elements or by ignoring and reducing the difficulty they experienced when breathing.

Functional Secondary Concerns

The concerns of the participants were also functional in nature. Functional concerns refer to those perceived stressors that affect the ability of participants to

perform physical activities. The following section of this chapter will address the only identified functional concern: limitations in physical activity.

Limitations in Physical Activity

The limited ability to perform physical activity was a consequence of dyspnea as well as a participant concern. Concerns about physical limitation were experienced equally by male and female participants as well as severely and moderately obstructed individuals. Participants identified gradually increasing levels of shortness of breath and a decreased ability to perform physical activities with a worsening of disease process. When shortness of breath was severe, some physical activities were curtailed or given up completely and this loss of activity became a measure of physical limitation and a source of emotional strain. Participants assessed their ability to perform activities by monitoring the level of shortness of breath they experienced during an activity and/or the length of time taken as well as distance over which the activity was performed. Specific activities which were characterized in this manner included walking, running, dancing, lifting, participating in sports and exercising:

My lifestyle has completely changed right around. I was very active and I worked until I was 68 and my movements were very fast and now I can do nothing right now. Today, it is an effort to walk from one room to another.

That's how much it has changed...in the last year I would say it has gotten worse at a rapider rate. (1009)

You figure you want to take this chair from that side of the room to this side of the room and you pick it up and when you pick it up you're breathing normal and then all of a sudden you head across the room with the darn chair and you breath is as hard [as if you were] climbing the stairs. Then the anger, frustration sets in. (1001)

Participants who noted that several activities were lost or curtailed often experienced anger, frustration, depression and helplessness in response to this collective loss:

I know when the disease reaches a point where you just can't function anymore it can be very destructive to a person's mind, body, and soul because you just can't function. (1019)

Well it just makes me feel useless and depressed and I don't know. It just makes me feel awful. (1003)

Even if you've been active all your years. That's how you feel: depressed, bereft, [and] cheated. (1005)

In summary, the participants were emotionally strained by their limitations in physical activity caused by dyspnea. The emotional and physical losses that were associated with decreased functioning were a concern to them.

Participants found it difficult to cope with the physical limitations of COPD. Participants believed that increasing levels of dyspnea were responsible for a

decreasing ability to perform physical activities. In response participants utilized two coping strategies: they chose to either "fight" and/or "accept" their limitations. For some participants, fighting limitations in physical activity became an integral component in living with disease. Here, some individuals attempted to perform activities they had difficulty in completing. In such cases performing the activity, was viewed as an important component in limiting the progression of disease.

Acceptance was also seen as an integral component in coping with limitations in physical activity. Each individual learned to recognize and function within the context of their limitations. Some individuals challenged their physical capacity to do work and then performed physical activities until dyspnea prevented them from continuing further. When this point was reached, these individuals accepted their limitations and functioned within them. Other individuals attempted to reduce their level of shortness of breath during physical activity. For example, many participants utilized purse-lipped breathing while walking. Individuals paced their physical activities, rested and achieved their own accepted level of physical activity. Another group of participants defined their own activity limits; they did not perform or initiate activities beyond their own self-imposed boundaries. Instead, these individuals enlisted the assistance of family members,

avoided physical activity completely, or found some other activity to engage in lieu of physical activity. In general, the participants accepted dyspnea as a part of performing any physical activity.

In summary, many participants identified limitations in physical activity as a functional concern. Participants stated shortness of breath was often a barrier to engaging in physical activities. Several participants stated their level of dyspnea increased with time and many measured their deterioration by their diminishing ability to perform activities. Consequently, many participants experienced anger, frustration, depression and helplessness in response to this loss. Many found it difficult to cope. Participants coped by either "fighting" or accepting their limitations in physical activity.

Biological Secondary Concerns

Several participant concerns were also biological. Biological concerns refer to those perceived stressors that affect the physiologic processes and functions of the human body. The following section of this chapter will address the biological concerns of participants.

Fatigue

Participants identified fatigue as a concern. Several stated activities as simple as breathing or sitting, and as complex as eating, grooming or performing

housework were responsible for causing fatigue. Generally, fatigue limited the ability of participants to perform physical and social activities as well as desired roles:

I just don't want to be bothered with anything. I just feel wacked out. This is it, and I am tired as if I put in a full day's work when I just wake up. (1001)

Yeah, I was just the living dead really. All I wanted to do was lie down and the act of having to get up and get a cup of coffee was a Herculean effort. (1005)

I feel like I ran five miles you know, and I haven't done anything. (2017)

Some participants identified fatigue as an ongoing presence in their lives:

Fatigue is the devil because... you are tired all the time. (1005)

Everything you do is an effort. If you shave, you get a little bit tired. If you dress, you get a little bit tired. (2015)

Tired. That's what I feel all the time. (2011)

Other participants expressed annoyance, frustration, and anger in response to fatigue:

Oh, I'm frustrated all the time. Frustrated because I have no energy. (1005)

Pissed off sometimes. If you want to know the truth. If I'm going to feel anything I'm gonna say "damn it anyway" and get angry or something. (1007)

Male and female participants as well as those in both stages of disease trajectory experienced fatigue in the same manner.

Participants used several strategies in order to cope with fatigue. Participants coped by preventing or accepting fatigue as a part of their lives. Participants prevented fatigue by undertaking only those activities which required little or no physical work. For example, some individuals engaged in less physically strenuous activities such as watching television. Other individuals limited the number of tasks they performed and paced or rested between activities. When fatigue was unavoidable, acceptance was utilized as a coping strategy. In such cases, participants accepted the presence of this symptom and relaxed, rested, or slept.

In summary, fatigue was ubiquitous in the lives of participants. Fatigue was considered to be annoying, frustrating, and a source of anger. Participants coped by preventing or accepting their fatigue.

Sleeplessness

Both males and females as well as those affected by moderate and severe obstruction identified sleeplessness as a concern. Many participants reported dyspnea and coughing interrupted their sleep:

I just can't sleep that long and if I [get to] sleep early, let's say ten o'clock, I wake up about five, six hours later. Let's say ten o'clock. Let's say I should be in bed for at least six [more] hours but four o'clock I am up already. But lately it's been better because even five or six hours is okay. Better than two or three hours. (1020)

I'd wake up and I'd think I were choking cause I couldn't breathe, cause I couldn't sit upright and [I'd] do some deep breathing and I'd be okay but it makes you very panicky. (1005)

Several participants perceived dyspnea to be life threatening in nature.

Therefore many experienced panic, anxiety, and fear. As a result, some participants were afraid to fall asleep:

What if I go to sleep? Do I wake up? Well that's what was wrong with me. I was fearful of going to sleep. I was fearful that I wouldn't wake up again but that is not the way this disease works. (1001)

Maybe it's just nerves. Oh, I know what it is. I go to bed and then I get up at three and then I start thinking to myself. If hadn't been for that emphysema I would have been sleeping. It's always the emphysema. (1017)

Consequently, while some participants were unable to sleep because of fear and their emotions, others identified dyspnea and coughing as a disturbance to their sleep.

Several participants employed coping strategies in response to their sleeplessness. Participants coped by attempting to promote sleep. This involved preventing or reducing the role of dyspnea, coughing, and emotion in causing sleeplessness. Participants prevented dyspnea during sleep by using inhalers prior to bedtime and/or by sleeping upright. When participants awoke with shortness of breath, strategies were employed to reduce dyspnea. Here, participants used deep breathing and relaxation exercises. When emotions such as panic, anxiety and/or

fear prevented sleep, participants distracted themselves by reading or watching television.

In summary, many participants stated dyspnea, coughing, and choking interrupted their sleep. Other participants identified emotions as a source of sleeplessness. Participants coped with sleeplessness by preventing or reducing the effects of dyspnea, cough, choking, and emotions on sleep.

Concentration

Several participants identified their inability to concentrate during periods of dyspnea as a concern. Participants reported difficulty in initiating and maintaining their ability to concentrate. Specifically, participants stated they experienced a flight of ideas or a forgetfulness in which they became unable to perform tasks or remember names and events:

Yeah...well you see that my mind keeps flitting all over the place. Instead of concentrating on what they are saying, my mind starts thinking about something else when I should be concentrating on what I am listening to or suppose to be [listening to]. (1013)

I mean I couldn't read and concentrate on what I was reading and I mean I am watching T. V. and concentrating and I lost sort of all of the things that I would normally do. [The thoughts] would sort of disappear because of my concentration. (1013)

You become very clumsy. Your mind isn't clear. You can't remember a name, an event, or familiar phrase. (1009)

Participants found their inability to concentrate to be both a source of frustration and anger. Both males and females affected by moderate and severe obstruction expressed difficulty in being able to concentrate.

Participants coped with the decreased ability to concentrate by accepting this concern as a natural result of aging. Other members of the sample chose not to participate in activities that required any level of concentration until a comfortable level of breathing was established.

In summary, several participants experienced difficulty in concentrating. Many stated they experienced a flight of ideas when concentrating on tasks. Participants coped with this concern by accepting it as part of the aging process or avoiding activities that require concentration.

Food Consumption

Several participants were also concerned about their food consumption. Participants stated the ingestion of food resulted in an exacerbation of dyspnea, fatigue, and discomfort. In cases where dyspnea was present, participants described eating as a difficult, labour intensive process:

It's very hard to eat, there doesn't seem to be enough air to allow you to swallow. At the end of your meal, your head is soaking wet with sweat from working so hard at trying to eat. (1009)

It [eating] was such a pleasure, but you think about all these things now. It becomes such a job. (1005)

Participants stated dyspnea decreased their ability to eat. Dyspnea prevented proper food consumption by increasing the level of difficulty experienced in coordinating breathing, chewing and swallowing. Both males and females affected by moderate and severe obstruction expressed difficulty in coordinating the intake of food and distress in response to the experience of fatigue when eating:

I find that if I'm really like that my normal supper will be there and I'll just get tired of [existing] or being (1007)

The consequences of food consumption were also a concern. Participants frequently stated that difficulty in breathing increased following food consumption. Many stated that their diaphragms were being pushed up by the excess food. Additionally, feelings of discomfort were associated with eating too much food. Several members of the sample experienced bloating and dyspnea in response to eating too much food:

I was eating or trying to eat normal. I'd fill myself up and I was losing my breath and feeling heavy. (1001)

Because when I eat too much I have problem breathing. It's too full. Then I can not breathe easily. So you try to eat a little less. (1016)

In summary, the participants identified food consumption as a concern because of the dyspnea, fatigue, and discomfort associated with eating. Consequently, the participants attempted to prevent or reduce the symptoms experienced while eating in order to cope. Participants prevented or reduced the severity of dyspnea, fatigue, and discomfort by pacing meals; several meals were eaten in intervals throughout the day.

Oxygen and Equipment

Participants with severe as well as moderate COPD were concerned about using oxygen and oxygen equipment. Individuals used oxygen on either an intermittent or an ongoing basis. Twenty five percent of the sample (n=5) stated that they used oxygen on an ongoing basis. Ten percent of the sample (n=2) used oxygen intermittently, during hospitalization for disease exacerbation. Individuals who used oxygen on an ongoing basis had arterial blood gas levels below 55mmhg and required oxygen for survival. Individuals with arterial blood gas levels above 55mmhg used oxygen during hospitalization for periods of disease exacerbation. When oxygen was used on an ongoing basis, an oxygen concentrator supplied oxygen in the home and a portable cylinder tank enabled oxygen use outside of the home. Although both groups of individuals used oxygen for varying lengths of time, their concerns were different at times. Those

living with ongoing oxygen delivery described the imposition of the oxygen and equipment on their daily lives, whereas those who used the oxygen and equipment on an episodic basis for disease exacerbation described their concerns regarding the future use of oxygen and the equipment:

I hear that eventually I'll be on the oxygen tank. I think I would rather be dead. (1017)

Participants who expected to use oxygen in the future were concerned with debilitation, powerlessness, and a loss of independence:

I seen the one fella in the hospital. He had oxygen and had to take some kind of other stuff to put on his face and this is what was keeping him going. (1001)

You can't compare plugging you nose with oxygen and carrying the tank if you have it. You can't go down four flights of stairs to open your door or anything. (1017)

Individuals used oxygen on an ongoing basis identified this gas with survival:

It's [the oxygen] that's keeping me living you know so it's [oxygen] got to be good eh. (1005)

Participants considered ongoing oxygen use to be restrictive. The length of the tubing and the amount of time an oxygen cylinder was able to provide a supply of oxygen outside of the home defined the distance an individual could move. As a result, many of the oxygen users felt powerless:

It's just to get there [to a wedding]. That's all. That's hard if I bring my stuff [oxygen and oxygen equipment] and everything. There was a wedding this summer and my son from [another province] put my concentrator in the car and took it to my son's so I could be with them at the [wedding]. (1004)

I know that if sometimes I have by accident pulled the tube off my [concentrator]. I uhh, just a little while I begin to feel light headed and I realize that I can't ignore this. I've got to go back on the oxygen. I have no control. (1005)

Given the physical deterioration associated with this disease, oxygen can also be a means of recovering some aspects of an individual's life. One participant stated that before she used oxygen, her quality of life was poor:

Yeah, I was just a living dead, really. (1005)

All I wanted to do was lie down and the act of having to get up and get a cup of coffee was a Herculean effort. (2005)

Once she received oxygen on an ongoing basis her quality of life improved:

Now that I can see that all these aids [oxygen equipment] are here for people like me to give them more of a meaningful life, I'm uhh. I'm not as angry. I'm not as worried and concerned. I feel that whatever years are left I can [live through them]. That they can have some meaning to them and that I won't have. I won't be uhh...not bored but that I will still be able to do a lot of things that I like to do. And uhh...that was something that really bothered me before I bought the extra oxygen and uhh...I think that's what's done it for me. Really, given me a lot of uhh cheering you know. (2005)

Additionally, opportunities for greater freedom were present provided there was sufficient financial means. Financial ability to store or carry oxygen out of the home was observed to be a key component in improving the quality of life of

individuals. With adequate resources, an individual was able to purchase and fill a portable oxygen cylinder for excursions outside the home. For example, one severely affected female was able to rent an oxygen cylinder which could provide oxygen for a period of five hours rather than two:

As I say that I have five hours of oxygen, but that bothers me... [It] was bothering me until I found I could have it. On account that two and half hours is not enough to do anything. You can't go to a movie for two hours and expect [to have enough oxygen]. Like once you are using up two hours. There's a half hour lost in that. In getting there, going to the washroom, if you have to or buying a bag of popcorn so two and a half hours is uhh. You have to head home long before that so that's not a worry any more and people who don't have this [oxygen cylinder which delivers oxygen for five hours] and I would say most people still don't have this. I don't know what their lifestyle is or what their social functions are, but for me it would have been a set back, if I didn't have that much time at home. (2005)

[The cylinder] gives me more time. My oxygen will be given to me for five hours instead of two and a half. Now I can do the things I've always enjoyed so I'm really feeling very, very hopeful, very cheerful. (2005)

Individuals who paid for their cylinder-stored-oxygen, identified limited financial resources as a barrier to excursions outside the home. If an individual had limited funds, difficulty was experienced when undertaking excursions outside the home. When money was no longer available to support excursions, participants stayed at home. Financial resources and the length of the tubing defined the limits of existence:

It's very expensive. Yes, cause you can only get four hours out of a cylinder and you pay \$28.00 for it. Now they're gonna deliver them [the oxygen cylinders] and take the cost of delivery. They were charging \$10.00 for eight hours delivery. (1004)

Yeah, just the thought of having to pay that much just to have a few hours of fresh air. I can't even. I didn't feel I could afford to sit with the ladies all day in the summertime outside like them. This is all day that they sit out there. Well I couldn't. (1004)

Embarrassment was also associated with the use of oxygen equipment. A few moderately affected males and females found the possibility of wearing a nasal cannula or carrying oxygen equipment to be distressing:

I dread the thought that uhh ahh I'm going to have to carry that [oxygen cylinder] with that little gismo sticking out of your nose. People immediately look when they [see the nasal cannula]. That is embarrassing. (1001)

You are active and one day that one [person you do not want to see] is going to be there and I am going out with my oxygen and my tank. I don't want to face them. A lot of time I feel I just want to hide. (1012)

For those affected by severe COPD, embarrassment was not identified as an issue. Instead, the oxygen equipment's ability to detract from physical appearance was a concern. For example, one severely affected female identified the oxygen tubing and nasal prongs with a poor appearance; the oxygen tubing and nasal prongs left "grooves" in her face:

But it's not. It's just that I feel badly that I have to wear it and I find that I'm always pulling at it [so] it should not leave the ridge on my face that I think it sometimes it leaves. But I'm not embarrassed by it. No I just, I'm just sorry

that it's there because I don't think it adds to my appearance anyway. It doesn't make me a candidate for a beauty contest. (1005)

The oxygen equipment also limited the ability of participants to carry out activities. For example, one participant stated that she was unable to use a blow drier or curling iron. She stated that the intense heat of the blow drier or curling iron and oxygen constituted a fire hazard. As a result, this participant did not style her hair and her appearance was affected:

I can't even think of going to the hairdresser with the uhh drier and the curler. I mean it's all heat. (1005)

The issue of oxygen dependency was of specific concern to men in this sample. Moderately and severely obstructed men who had some experience with oxygen use during acute exacerbations were especially cognizant of the oxygen's ability to raise energy levels and to improve their physical capacity to perform activity:

In the hospital a year ago, they put me on oxygen to see what would happen and it is a silver bullet. There are no two ways about it. That stuff really picks you up so you can see that you are working on it. (1001)

That wasn't healthy so I can see. I seen what this stuff can do and I seen when I did it normally what you come down to so uhh that's why I say it was not me that was doing that [making me walk quickly] it was the oxygen that was keeping me going. (1001)

The "outcomes" of oxygen use led some men to conclude that dependence on oxygen could develop; men were afraid of the oxygen becoming a "crutch". This in turn resulted in a desire to avoid using oxygen on an ongoing basis:

That's right. That's exactly what it [oxygen] is, and I used the word before: silver bullet and that's exactly what it [oxygen] is. It [oxygen] puts life into you like you never believed, but what's happening to your lungs? I have not had a doctor to tell me that, but I mean I am intelligent enough to know that it's [oxygen] stimulating something that should be working on its own. That's why I am fearful of oxygen. (1001)

Well I'm gonna try to make sure that I have [no oxygen yet], but as I say I'm [a] borderline oxygen case. I don't want it [oxygen]. I will do everything possible to stay off the oxygen. Because I know once you get on that [oxygen] you get dependent, and I've seen it [the dependence] in the hospital and this is why I'm very strong willed when it comes to that [to going on the oxygen], and I will do everything in my power [to stay off the oxygen]. (1001)

Safety Issues with Oxygen Use

The oxygen and oxygen equipment was also a participant safety concern.

Severely obstructed males and females identified the tubing as a fall hazard:

Going from the cupboard to the stove and my feet were getting all wound up in the tubing. (2004)

It bothers me because it's [the oxygen tubing] lying on the carpet all the time and it's always a hazard and if anyone [comes] here, they've got to watch it you know. Let's not trip on the tubing. My husband's coming home with crutches you know for three months. A hip replacement.....It is bad enough walking in shoes and I'd say you're all tangled up. Can you imagine? [what is will be like with crutches]. (1005)

One severely affected female stated the oxygen in conjunction with cigarette smoke and/or heat from appliances was a fire hazard:

It's [cigarettes are] not supposed to be good for the oxygen because it [the cigarette] can ignite things. Now it's [the cigarette that is] a menace. It's not that the oxygen won't explode, but smoking is bad because some heat in the air or whatever is created. (2005)

I have a big sign that says no open flames, no smoking uhh. You know. So sure it's always on my mind. (2005)

In summary, oxygen and oxygen equipment use affected the lifestyle of the participants. For the moderately as well as the severely affected participant, the use of oxygen was an embarrassment. Many stated they felt powerless, debilitated, and dependent when they used oxygen. Some of the participants who were affected by severe COPD, identified the use of oxygen with an improved quality of life. Oxygen improved the participant's ability to participate in activities outside the home. This positive quality of oxygen use was limited to those who were financially secure. Those who had sparse financial resources identified the number of oxygen cylinders that could be purchased with the level of activity undertaken outside the home. As a safety hazard, both the oxygen and oxygen tubing was considered to be a risk for combustion and falls respectively.

As one can see, the use of oxygen, and oxygen equipment can be the source of varying different concerns. In response, several participants developed many coping strategies to manage their oxygen related concerns. Participants chose one of two strategies to cope with their use of oxygen: to prevent or to accept the use of oxygen. Those who did not require oxygen on an ongoing basis attempted to maintain a healthy lifestyle by exercising and eating healthy foods. Others accepted the use or possibility of using oxygen. This group of participants coped by educating themselves about oxygen.

Therefore, oxygen and oxygen equipment use involved many issues. Participants who were not using oxygen were concerned with its future use. On the other hand, oxygen dependent individuals noted many issues concerning its use. Both groups developed coping strategies in response to oxygen use.

Summary Biological Secondary Concerns

Participants identified a number of biological concerns during the course of this study: fatigue, sleeplessness, food consumption, and oxygen use. The participants who experienced each of the above mentioned concerns responded by developing coping strategies. Participants attempted to prevent, reduce, limit, fight or accept their concerns in order to cope.

Psychological Secondary Concerns

The participants in this study also identified several psychological concerns namely: powerlessness, self-blame, embarrassment, emotions, death and anxiety.

In this section of the findings chapter, the psychological concerns and coping strategies of participants are presented.

Powerlessness

The sensation of powerless was identified by many participants as a concern. Participants felt they were powerless because they were unable to control the progression of disease, dyspnea, their ability to perform physical activities as well as social losses:

I don't seem to have any control over it [the emphysema]. It [the emphysema] seems to have taken over me, instead of me trying to control this emphysema, and [the emphysema is the] first thing [I think about] when I get up in the morning. What's my day gonna be like? Is [the] emphysema and my breathing going to be worse? Is my voice going to be worse? This is always on my mind. (2017)

Participants felt more powerless as their disease process progressed:

There are things that you'd like to do that your can't do. I'd like to be able to have company in for dinners because I used to love dinners and have people over for supper, but I can't do that anymore and in that way I am powerless and there's nothing I can do about that. ...That way I feel powerless. I would love to sometimes like...[at] Christmas time ... to go to my daughters but I couldn't do that this year so in that way I would love to go but I can't...I am powerless I can't go. (2009)

Symptoms such as shortness of breath and fatigue increased the participant's sense of powerlessness:

And all you can do is just stand there and it would be you know pretty frightening ...until you could recover enough [breath] to get home. (1007)

As a result, participants stated powerlessness led to frustration, hopelessness, anger and fear.

Your frustration...You get the idea going through. You [think] what are you doing? Why are you wasting your time day in and day out. When it [shortness of breath] does occur...you do get...hopeless sometimes. (1001)

Although both men and women with moderate and severe levels of obstruction experienced powerlessness, some gender and trajectory based differences were present. Severely obstructed women experienced powerlessness in response to social and physical losses. On the other hand, men affected by moderate obstruction experienced powerlessness in response to feelings of frustration, hopelessness, and anger associated with disease. Participants coped with powerlessness by attempting to slow disease progression and limit the severity of shortness of breath; participants learned to take care of their body and to control the severity of their dyspnea.

In summary, powerlessness emerged in response to an inability to perform physical and social activities, prevent disease progression and control dyspnea.

Emotions such as anger, frustration, fear, and hopelessness erupted as a result. Stage in disease trajectory and gender were influential in the experience of powerlessness. Coping with powerlessness involved learning to prevent disease progression and the utilization of strategies to control dyspnea.

Self-blame

Some participants also identified self-blame as a concern. Participants held themselves responsible for smoking or continuing to smoke the cigarettes which eventually led to their development of COPD. Additionally, some participants were critical of their smoking behaviours and blamed themselves for having exposed family members and friends to second hand smoke:

I could have kicked myself for not quitting smoking earlier. (1007)

[You should have] quit smoking years ago or you shouldn't have started. Well, look [at] it. You have subjected your wife or your friends to that second hand cigarette smoke so you start to feel bad. (1015)

Self-blame was also mentioned in conjunction with having listened to health reports on the effects of smoking on the lungs and not heeding them:

But, I am the biggest offender and it's not because of ignorance. It's [I am the biggest offender] because I was down right belligerent and I understand there's people that do have this disease that haven't got the brains enough to stop smoking. (1001)

Both males and females experienced self-blame. Individuals affected by moderate obstruction were more likely to mention their feelings of self-blame in conjunction with their smoking habit. Participants attempted to cope with self-blame by accepting their role in causing COPD. Very few individuals were able to successfully cope with self-blame.

In summary, participants experienced self-blame when they identified their smoking habit as having contributed to their development of COPD. Participants who were able to cope with their feelings of self-blame, accepted the role they played in development of this disease.

Embarrassment

Embarrassment was also a concern. Participants found shaking and using inhalers in public to be a source of embarrassment. As well, some participants experienced embarrassment when they were dyspneic during activities:

The same thing is I lose my breath and right away I reach in my pocket, and you got to shake the darn thing [inhaler]. And right away it draws people see you shaking and your hand draws your attention and you stick it in your mouth. Its uhh embarrassing I find. (2001)

See we go to church Sunday morning. We go to bible class, Sunday school at 9:15 in the morning and church at 10:30. What do I do with my puffers? I was experimenting for about a month, instead of going for six hours I was stretching out my time to seven and eight hours for the one day and it was a pain and it didn't do me any good. (1008)

Participants stated that dyspnea experienced during activities was embarrassing:

I would be climbing the stairs and lose my breath and I'd stop [individuals] in [place of employment] for instance see me right away have ask me if you're okay and stuff like this and other [individuals] and that the same way. Uhhh, I sort of resented it because, I uhh, I just didn't . I felt as if I were embarrassing myself around people you know. I didn't want to show them the sickness. (2001)

I remember many years back in the summer when it is easy to walk even for people with emphysema, and I would walk from my house to the bus stop [with] the lady who was about 20 years older than me. The second neighbour. She can speak [when she reaches the bus stop]. I just kinda trying to speak because I just can't catch my breath. I felt very embarrassed but I didn't know why I was doing that. (1018)

Both males and females as well individuals affected by moderate and severe COPD identified the above stated areas as sources of embarrassment. Participants coped with the embarrassment associated with using inhalers by using the devices in the home or public washrooms. As well, participants avoided embarrassment by shunning activities which would cause dyspnea.

In summary, embarrassment was a concern for several participants. Participants experienced embarrassment when they used their inhalers and/or experienced dyspnea during activities. Participants coped with embarrassment by primarily using avoidance strategies

Emotions

Participants identified emotions as a concern because of their ability to cause dyspnea. Specifically, participants stated that emotional upset, excitement, anger and frustration caused dyspnea:

When it builds up and you lose your breath there is no two ways about it. I find that when I get excited or I am having an argument with somebody.
(2001)

Every little thing bothered me. I was afraid to talk to people. I was afraid to stop [and talk] ... I would just keep right on going. I would pretend I was in a real hurry ... just so [no one would talk to me]. I knew my emotions would catch up with me, and I knew that I wouldn't be able to speak [because of the shortness of breath]. (1013)

If I let my emotions go then I'd be upset and sick again. I can't do that. It [the emotions] would bring attacks [of shortness of breath on]. (2019)

Emotions often occurred in response to events. Events could be unique or special in the participant's life or a part of everyday living. The event itself was an antecedent to an emotional response and the experience of dyspnea:

I am sitting here talking with you now I could talk for hours no problems at all, but if we're having a heated discussion it seems to build up and I guess there may ... a little anger and frustration in there and you get short of breath.
(2001)

I will be working with a boat for instance. The old fashioned sailing ships [models]. What I'm talking about is strings. A lot of strings and little wee eye holes. Very, very, small and you got to use tweezers and yes you will be trying to get that [string through the eye hole] and it just doesn't work cause it

keeps sliding out on you or something like this. And yes you get frustrated and you will lose your breath. (2001)

If I get short of breath, it's not necessarily because of an infection. It may be something else. I am worried about something [or] when I get excited [about something] I notice that [I get short of breath]. (1020)

Participants attempted to cope with dyspnea by controlling their emotions.

Participants controlled their emotions by limiting their emotional responses to provoking situations and by avoiding emotionally charged events. For example, one individual stated he tried to control his emotions when he learned a member of his family was terminally ill. Emotional control was used as a method to limit the severity of experienced dyspnea. In summary, participants stated emotions were a source of dyspnea. Participants coped by controlling their emotions or by avoiding emotion producing situations.

Death and Dying

Death was a significant concern for most individuals interviewed in this study. Issues related to a shortened life span and suffering prior to death were frequently reflected upon and feared by study participants:

People live up to 90 and 100 now, and you can see old guys out there and ladies too...in their 80's. I see them in [the department store]. They are all in good shape. They live in their house and they look terrific and they [are happy]. I'm sure they are doing well. They get their needs [taken care of] there and sometimes when I look at them, I say: One day I thought that I was

going to be like them too. When I get old and [I don't have] many places to go. I'd love it [to live until I am 90]. I would have lots of memories. And now I look at it. It [is] just a sad side that I'll never be able to do it [live until I am 90]. I am not going to live long enough, and I am not healthy like them. (2018)

Some participants were curious as to the type of death they would experience from COPD:

What happens? How do you die? Maybe you just run right out of air or do you fall asleep? You don't wake up or do you choke to death? I don't know. (1013)

Participants feared they would suffer as they died. Fear of suffering prior to death was a source of particular dread. Participants stated they expected to experience the sensation of "suffocation" as they died. A few stated they feared the possibility of mechanical ventilation before death. Others stated they were afraid they would be unable to contact emergency assistance and subsequently would die alone:

I sometimes think about people who die by drowning let's say. They never come back to tell you this but when they are drowning or when someone you know. T. V. has this effect on me. Kids when they put a pillow over you or smother someone and kill them that way. It must be terrible experience to die by suffocation. So this is all the sort of things that kind of haunt your mind when you are having shortness of breath, and that's the feeling you get if you don't breathe. You are gonna [be] finished, and it's not the fear of dying. It's the fear of the process. (2005)

Several participants stated dyspnea exacerbated their fear of death:

Yeah, that's life you gotta breathe. If you can't breathe you are gonna die.
(1004)

The feeling is awfully close to dying. (1004)

Watch somebody gasping their last gasp cause they can't breathe. (2005)

A few participants coped with suffering by seeking out information. None of the participants stated they approached health professionals about their concerns regarding death and dying. Instead, individuals who were living with severe obstruction as well as others who had witnessed a death from this disease were sought out for their ability to provide information. Participants then made observations, and conclusions regarding their own future death.

Other individuals attempted to prevent or delay suffering and death. Here, participants recognized their ability to slow disease process and chose to actively care for their own health in order to limit the progression of disease; for example, taking a flu shot to diminish the likelihood of potential disease exacerbation. Still others, chose to accept the inevitability of death. Such participants accepted their death as an end. Consequently, personal affairs were put in order and in some cases a withdrawal from society occurred. In other situations spiritual coping was utilized to deal with death. Participants spoke of a spiritual being and/or God who

helped them cope with their mortality. Some participants spoke of placing the responsibility of their lives in the hands of a spiritual being. This helped some individuals deal with their dyspnea related fear of death. For participants, coping became a necessary component in learning how to moderate the images of suffering, and death as well as shortened lifespan.

In summary, death and suffering were identified as important concerns for individuals living with COPD. Generally, participants feared their death. Each time participants experienced a perceived life threatening event, fear emerged. Therefore, for some participants, coping with death was a part of living with COPD. Some participants coped by accepting or ignoring death. Others attempted to slow disease progress or seek solace in a spiritual being.

Anxiety

The participants also identified anxiety as a concern. All of the participants stated anxiety was a feeling of discomfort:

But that's the anxiety ... and it's [anxiety is] an odd feeling and it's [anxiety is] a terrible feeling. You know uhh, like if you are waiting for a chandelier to drop. Once it's dropped it's great. That feeling goes, but this feeling doesn't go. That's the feeling and it keeps on and that's a bad day.
(1009)

I don't see it but it [anxiety] feels like I was slightly electrocuted and everything is moving inside and it [anxiety] doesn't leave [me] alone. It gets

worse. And it [anxiety] can get so bad that, I think that emotional pain is more painful than physical pain. (1018)

Many participants stated they became anxious when they experienced dyspnea and/or emotions:

[You get] depressed and you start thinking about your problem and automatically you start breathing faster or trying to breath faster. You become very anxious and the more anxiety that sets in the shorter the breath. (1015)

Some participants stated dyspnea led to anxiety. As well, many of these participants stated anxiety led to dyspnea. Several stated that both dyspnea and anxiety had a cyclical relationship. Participants noted that anxiety would cause dyspnea and dyspnea would in turn cause greater anxiety. In some cases, anxiety would lead to further dyspnea and the cycle would continue. A few participants stated that this cyclic occurrence would continue until they experienced a high level of respiratory distress:

Because I have the anxiety thing which adds to the difficulty again. It's a cycle that grows and grows until things become too [difficult to manage]. Something for the hospital. [For] which there is nothing I can do anymore: anxiety caused by the shortness of breath and also shortness of breath caused by the anxiety, but it's not [so] much the anxiety causing the shortness of breath. It's more shortness of breath causing the anxiety. (2020)

Although males, females, and those affected by moderate and severe disease process experienced anxiety, males and females labelled their anxiety with different words. Females referred to anxiety as anxiety. Males experienced anxiety, but labelled anxiety with the words stress or anxiety:

I guess you get worked up and things don't go the way you'd like them to go: nice and smooth. Then you become tense. And tenseness and stress I think just affect your whole body. I think they do anyway. (1008)

I don't see much difference really. Is there a difference between anxiety and stress. (1013)

When you are emotionally upset, you are worried about things that can cause symptoms in itself. It can may you sick. And you can't help it because it's a strain on the system. (2019)

Participants coped by preventing or reducing their exposure to anxiety producing situations. Situations where dyspnea would occur or emotions would be experienced would be avoided. For example, some individuals prevented or reduced their exposure to dyspnea or emotion producing events by isolating themselves. Others who chose to expose themselves to dyspnea or an emotion producing situation, attempted to reduce the level of anxiety that was experienced. In such cases, participants used relaxation techniques, breathing exercises, and/or distraction to reduce their perceived level of anxiety.

In summary, participants identified anxiety with feelings of discomfort.

Anxiety was caused by dyspnea and emotions. As a result, participants coped by preventing or reducing the level of dyspnea or emotions they experienced in order to prevent or reduce the level of experienced anxiety.

Summary of Psychological Secondary Concerns

Several psychological concerns were identified by the participants in this study. Participants identified powerlessness, self-blame, embarrassment, emotions, death and anxiety as concerns. For the most part, psychological concerns were consequences of dyspnea. Anxiety was both an antecedent and a consequence of dyspnea. The participants coped with their concerns in several ways. For the most part, participants attempted to prevent, reduce, or accept each of their psychological concerns.

Social Secondary Concerns

Participants stated COPD gave rise to several social concerns. Many participants experienced changes in their ability to communicate or speak with others. Additionally, several individuals stated there was a lack of understanding among family, friends, and strangers in regards to the implications of this disease on their social roles and lifestyle. Other participants also found their social roles

and activities had changed or diminished. The following section of this chapter addresses social concerns as described by the participants in this study.

Communication

Participants in this study stated dyspnea acted as a barrier to communication. Dyspnea prevented many from being able to express their views, discuss problems or even complete a sentence. As a result, several indicated they became frustrated and embarrassed by their inability to communicate. Some became reticent to speak at all:

It's just like any debate team. You lose your [ability to talk]. This is just it. It's frustrating on that degree. Especially, if you're arguing with a bank manager or something on a particular point. (2001)

Because my breathing was so bad that I knew I couldn't complete a sentence and then if I went to say something and someone cut in you know, I had to [puffs and pants to illustrate]. It took me too long to get out what I had to say. (2013)

Many of those with moderate COPD stressed that they had found it difficult to communicate because of the dyspnea. Many coped by withdrawing from social activities. By refraining from such activities, many were able to avoid speaking with others. Therefore they did not have to experience feelings of frustration or embarrassment. A few participants continued to engage in social activities.

These individuals limited their physical participation in activities and therefore limited the level of dyspnea they experienced. This improved their ability to talk.

In summary, dyspnea impaired the ability of participants to speak. As a result, many experienced frustration and embarrassment. Some participants coped by avoiding social activities. Others attempted to prevent or limit the level of their experienced dyspnea.

Social Roles

Concerns about changes or potential changes in social roles were also identified as a concern. Participants were quick to identify that they were unable to maintain the roles of shopper, hostess, breadwinner, and/or repairer. The roles of shopper and hostess were roles exclusively identified by females and the role of repairing was identified by males.

Frequent hospitalizations, fatigue, retirement, the inability to perform physically, as well as symptoms of disease were all cited as causes of role loss:

You try to remain in the work force to feel that you are not no pensioner because I am not, and you want to be productive and you want to be out, do your share, but you can't ... something holds you back [is your disease]. It [the disease] creates such an anxiety you get fed up with the whole works, and then you just don't know what to do when you get home. (1018)

I had to leave work at age 62 to go on disability and having been quite active before that. It's been a bit of a shock of course. (1012)

Role loss and limitation were associated with many emotions. Participants cited frustration, sadness, powerlessness, anger, anxiety, upset, irritation, loneliness and depression as the emotions having their origins in role loss and limitation:

They had to take me off [work] and that was an additional cause of worry. I didn't know how we were going to manage financially cause I was the breadwinner and it was causing me to have an awful lot of attacks. Just one after another (2019).

There are things that you'd like to do that you can't do. I'd like to be able to have company in for dinners and have people over for supper, but I can't do that anymore and in that way I am powerless and there's nothing I can do about that (2009).

Participants who identified role limitations and losses as a concern described the use of several coping strategies. Coping strategies varied among individuals. Individuals who were moderately obstructed attempted to deal with their role limitations or losses. Here, individuals employed strategies to reduce the effects of dyspnea on their activities in order to remain productive. Some participants cited exercises such as relaxation, purse lipped breathing and rest as methods of reducing dyspnea. Other participants accepted their role losses as an outcome of their disease. These individuals identified themselves as being disabled and asked others to perform the role.

Individuals living with severe levels of obstruction employed acceptance and a reduction of role responsibilities as coping strategies. In these situations, participants limited their role commitments to only specific roles while others chose not to perform the role entirely.

In summary, several participants identified social role limitations and losses as a concern. Several participants stated they had experienced change in the roles of shopper, hostess, breadwinner and/or repairer. Many experienced emotions such as frustration, sadness, powerlessness and anger as a result. Participants coped by accepting their role limitations or reducing the effects of dyspnea on their ability to perform roles.

A Lack of Understanding From Others

Several participants expressed concern in regards to the lack of understanding that others had toward the impact of COPD on their lives. Participants stated that family, friends and strangers did not understand disease related aspects of COPD. Issues related to disease definition, presentation, treatment, prognosis, and outcome were often mentioned as areas where others were ignorant of the consequences for the participant:

Well, I think the reason for that is that you don't look sick. You feel like you can say, 'There's nothing wrong with you'. They [my friends and family] don't realize what the problem is not even your close family. Like [my wife]

says you don't look like you are sick and there is nothing wrong with you and you haven't changed any. And I say no. I find it more difficult to breathe, but it doesn't show really and to look at a person with COPD you'd never know they had anything. (2015)

My sister. Well how should I put it? She knows what emphysema is, but if you were to ask her what it does to your lungs she doesn't know. To her its just [a disease]. She doesn't know that emphysema can kill you. She just thinks that you can live forever, and then when I mentioned to her that eventually I might be on oxygen. Well, then she says I guess you won't get out in the winter. This is the attitude they have because there is nothing wrong with them. They don't have emphysema. If they had it they would understand it, but she doesn't and very few people understand it. (1017)

Participants noted that their own misleading physical appearance of health, and the lack of public knowledge and understanding of the symptoms and chronicity of COPD contributed to public ignorance. Many concluded that the relative invisibility of COPD led to the false perception among others that one could easily perform many activities or that symptoms of disease were really those of a "cold." Participants found this to be a source of great emotional distress.

In an attempt to cope with this concern participants utilized two coping strategies: education and avoidance. For some participants this led to attempts to educate family and friends as to the implications of this disease on their lifestyle. For others, it led to an avoidance of those who did not understand the disease and the forging of relationships with those who were also affected by COPD. Several

participants felt they were only understood by others living with COPD because they shared common experiences of the disease. Many stated their membership in support groups was helpful.

In summary, many participants stated family and friends did not understand the impact of COPD on their lives. Participants identified that family and friends were often ignorant of the definition, presentation, treatment, prognosis and outcomes of COPD. In order to cope, participants attempted to educate friends and family, avoided those who did not understand the disease, and developed new relationships with those individuals affected by COPD.

Limitations on Social Activities

Participants stated that COPD placed limitations on their social activities.

Many participants identified the loss of social activities to be a source of concern:

I couldn't perform the way I used to you see. I was a very outgoing person and I liked people, and I used to like to kid and fool around and sit back and joke and all of the good things and then I couldn't do that anymore. (2013)

Many participants stated they were unable to participate in large group social activities:

Well, what it [COPD] does do. It [COPD] prevents me from going out and being part of the party like I would like to be. (2006)

I used to go out with my friends lots for drinking and [to] spend the evening [out]. It was a lovely time, but now [that I have COPD] it's completely different. Everything is different. (2011)

I think its hard its hard to sit and watch. (1007).

Many of the study participants noted dyspnea and the associated physical limitations imposed by this symptom as well as fatigue and cigarette smoke prevented or limited the level of participation in group activities. In some cases individuals stated that group activities with friends and family had been limited or curtailed completely:

My daughter wanted us to go out for pizza and I was determined to go...and it took every bit of effort on my part and I said I wouldn't try it again because it was just. Well I thought I would just expire. I was so close to just falling down. I was so weak and I couldn't breath. I managed the night but I thought that it would be [better]. I wouldn't try it again. (1005)

And after I've been there an hour and a half I'm ready to come home. Everybody else is talking and laughing and drinking, and I'm just sitting there trying to get a breath of air and that makes you feel out of place. Yes, if you can't take part in things well you are not going to enjoy it that's for sure. (1006)

I don't go to the lounge there [in the apartment building] because sometimes I go in there and people are smoking, and I just leave. They even smoke in the lobby. I can go sit in the lobby some time and relax, but if someone comes in and starts smoking then I have to get up and leave. (1013)

Although many of the participants had the same concerns, several gender differences emerged among their descriptions. Both males and females identified

their limited ability to participate in social activities as a concern; however, there was a difference in the type of activity and the feelings that were experienced with the limitation or loss of social activities. For example, males identified their inability to participate in sport related activities as a component of their social concerns. Here, several men stated that they could not play hockey, baseball, golf, or curl with friends. Other males stated that they were no longer able to go to sport events with friends and family. Many men felt that they had been denied or robbed of these pleasurable experiences. Several also experienced feelings of guilt and burden when they were unable to participate in sport activities with friends and family:

I used to play baseball quite a bit in the summer and now I can't. I can go out and catch a little bit [of baseball], but that doesn't last long and I got to sit down. So that restricts me and they [the family are] out there and continue to play. I don't expect them [the family] to stop because I do, but oh yes, it [COPD] definitely restricts you. Your social life with your family. (2001)

On the other hand, women identified their inability to attend cultural events and church as well as to participate in social gatherings with friends as a concern. Women stated that these social limitations and losses diminished their quality of life, and caused feelings of depression, anger, frustration and powerlessness.

I thought I just could not live that way that not being able to get out and be active and have fun and all the things I'm used to out of the home, and I

thought if I can't do that the quality is gone and I might as well not live.
(1005)

In order to cope with these losses and limitations in social activity, many individuals attempted to socialize within the limitations imposed by disease. When barriers to social participation were difficult to overcome, activities were avoided. For example, a few participants chose to not to attend social events where smoking was permitted.

In cases where dyspnea, the physical limitations of disease, and/or fatigue were identified as barriers to participation, participants limited their level of involvement. Here, individuals coped by planning for the event, reducing the level of physical activity during the occasion, or by socializing within the home with friends or family. In planning for social events, individuals rested or limited their physical activity prior to attending. In limiting the level of physical activity during a social event, individuals chose to observe rather than participate. Finally, when social events were planned and dyspnea, physical limitation and/or fatigue proved to be a barrier, friends, and family were invited to visit the family home. Consequently, participants experienced less fatigue.

In summary, the limited ability to participate in social activities was a concern to study participants. Although many moderately and severely obstructed

participants identified similar concerns, members of each gender identified differing contexts in which social losses occurred. Generally, participants were resourceful in developing coping strategies.

Summary of Social Concerns

In this section several social concerns were addressed. As a group, the participants in this study had experienced several changes in their social interactions and roles. Social interaction and role changes resulted in the development of several concerns among participants. Alterations in the ability to communicate, a lack of understanding from others, limitations in social activity and role changes were among the identified concerns. In response to the above mentioned concerns, participants developed coping strategies. Participants learned to cope with social concerns by accepting their limitations, pacing, planning, avoiding or limiting their activities as well as changing their social roles.

Support

Throughout this chapter, concerns and coping strategies of individuals affected by moderate and severe levels of obstruction were presented. The concerns and coping strategies identified by participants were influenced by the presence of supports. In some cases, health professionals, friends, family or other

individuals identified and discussed disease related stressors with the participant. In other cases significant others assisted participants, helping them to cope with their concerns. The following section examines the type of support participants obtained from others, namely: advice and information, emotional, material aid, and social support.

Advice and Information Support

Participants in the study actively acquired support in the form of advice and information from a variety of sources: health professionals such as doctors, nurses, pharmacists and physiotherapists, friends, family, public health organizations, support groups, lectures, pamphlets, books and videos. Depending on the level of disease severity, participants sought out specific types of information. Moderately affected individuals were interested in learning about disease process, prognosis and management. Severely obstructed participants sought out information regarding respiratory medications and coping with dyspnea.

Emotional Support

Participants identified emotional support as an important method of coping with their concerns. Many obtained emotional support from family, friends, health care professionals, support groups, and their spiritual beliefs. For some

individuals, family proved to be a resource which was frequently drawn upon. Several stated that family acknowledgement of disease-related limitations, associated emotions, and concerns was important. A few stated their spouse's emotional support was essential in helping them to cope with their disease. Those participants who did not receive emotional support from family, drew upon other resources. Some utilized support groups or friends diagnosed with respiratory disease. Generally, this group of participants felt that those affected by respiratory disease understood their concerns best. Others sought out health professionals such as nurses and doctors for emotional support. Health professionals were able to recognize and legitimize the concerns of participants. In other cases, spiritual beliefs as well as visits from church members were identified with emotional support. Finally, some individuals stated they felt unsupported. Here, a few participants expressed disappointment in being unable to gather sufficient support from family and friends. Participants stated that COPD was an "invisible" disease. Therefore, they did not appear to look "sick". Participants stated this was a primary factor in influencing the perceptions, interactions and subsequently the levels of emotional support provided by family and friends. In such cases, participants felt that family did not recognize the impact of the disease on their daily living and as a result did not provide an

adequate level of support. The level of emotional support did not appear to vary with disease trajectory or gender.

Material Aid Support

Participants stated they received adequate material support. Among the older participants, many individuals were retired and did not identify their disease as having an effect on their retirement income or material wealth. In cases where a participant had to leave their employment prior to retirement age because of disease related disability, material aid support was a concern. For example, two younger members of the sample stated material aid support was a concern prior to their early retirement from work. It is to be noted that these participants did not perceive a lack of material support following their retirement. Both individuals received material support from other sources subsequent to their leaving work. The participants received monies from a disability pension and social assistance.

Social Participation

Participants engaged in few social activities. Many identified the presence of barriers especially when socializing with family and friends; for example, the inability to communicate, the loss of roles, and limitations in physical ability hindered participant participation in social activities. Although barriers to social activity did exist, some participants attempted to overcome them. Several who

were physically unable to engage in sports chose instead to observe activities. In cases where fatigue, dyspnea and physical limitations were a barrier, rest was undertaken prior to participation. Others chose to avoid social activity outside the home. A few participants invited friends and family into their homes.

Summary of Supports

In summary, the participants received advice and information, emotional, material aid and social support. Support was garnered from family, friends, health care professionals and support groups. Support was an essential component in the lives of those living with COPD. Although many identified several sources of support, others had few or no supports that could be drawn upon.

Summary

In this chapter, the research findings were presented. The concerns, coping strategies and experiences of individuals living with COPD were described as they affected the day to day living of participants. Participants indicated the presence of two types of concerns namely: primary and secondary concerns. All identified dyspnea as their primary concern and the remaining as secondary concerns. Dyspnea was the primary concern because it was described by participants as the antecedent and/or consequence to all the other concerns.

Secondary concerns were varied. Their origins were environmental, functional, biological, psychological or social in nature. As well, the concerns acted as antecedents, consequences, or both to dyspnea. In addition to the concerns, the coping strategies of participants were identified; participants aimed to prevent, reduce, avoid or accept their concerns in order to cope. Finally, this chapter addressed the supports of participants. Participants identified their supports as an important component in helping them to cope with their disease.

CHAPTER SIX: DISCUSSION AND CONCLUSIONS

The findings are discussed in this chapter. Dyspnea, the primary concern, is briefly described and discussed. Next, the secondary concerns and their relationship to dyspnea are discussed. Following this, newly identified concerns, coping strategies of participants, and differences in the relationship of concerns to gender and level of obstruction are discussed in detail. Finally, the relationship of the findings to the conceptual framework, the significance and limitations of the study, as well as recommendations for future research, changes to nursing practice, and education are presented.

Concerns

Participants identified two types of concerns: namely primary and secondary concerns. Dyspnea was identified as the primary concern. All other concerns were considered to be secondary in nature. Dyspnea was observed to be the primary concern because of its central role in the lives of those living with COPD. Dyspnea has been identified as the most troubling and bothersome aspect of living with COPD (Barstow, 1974; DeVito, 1990; Janson-Bjerklie et. al., 1986). Additionally, many have noted dyspnea to be a source of lifestyle alteration (Barstow, 1974; Callahan, 1982; Chalmers, 1984; DeVito, 1990; Gift,

Plaut & Jacox, 1986; Tames, 1991). Existing research has documented dyspnea as both an antecedent and a consequence to several secondary concerns (Barstow, 1973; Chalmers, 1984; Sexton & Munro, 1988; Tames, 1991). Although this study has replicated much of the existing research in terms of the above mentioned attributes of dyspnea, several new characterizations of this symptom have emerged (Barstow, 1973; Chalmers, 1984; Sexton & Munro, 1988; Tames, 1991). Daily-, infection-, and crisis-related dyspnea were identified by participants as three forms of dyspnea that were frequently experienced.

Daily dyspnea was the most common form of shortness of breath described by the participants. It refers to fluctuations in the rate of breathing that may occur on a day to day basis. Daily fluctuations are caused by variations in the level of bronchoconstriction and/or sputum production (Kryger, 1990; Thelan, Davie & Urden, 1990). Infection-related dyspnea, another common form of shortness of breath, refers to breathing difficulties experienced in response to respiratory tract infections. An increased level of bronchoconstriction and/or sputum production in response to infectious processes, alters the rate, depth and quality of breathing (Ostrow, 1990). Finally, crisis dyspnea was a form of shortness of breath that occurred during stressful events or crises; for example, a death in the family. Individuals responded to crisis events with emotions such as

anxiety, anger or fear (Kaplan & Saddock, 1994; Stuart & Sundeen, 1987). In COPD, such emotions cause dyspnea (Lisella, 1993; Sandu, 1986). Therefore dyspnea occurs in response to the emotions present during a crisis.

In summary, participant characterizations of dyspnea indicate that several forms of this symptom can exist. Although many researchers have described dyspnea, none have examined participant or subject characterizations of this symptom (Kryger, 1990; McCarthy, 1990; Ostrow, 1990; Thelan et. al., 1990). More research is needed in order to gain a better understanding of dyspnea and the language of patients. This will improve the ability of health professionals to assess and develop appropriate interventions specific to people living with COPD.

In this study, dyspnea was identified as both an antecedent as well as a consequence to varying secondary concerns. Secondary concerns were environmental, functional, biological, psychological and social in nature. Participants noted the cold, humidity and wind as environmental concerns. Functional concerns consisted of limitations in physical activity. Fatigue, sleeplessness, loss of concentration, decreased food consumption, and the use of oxygen equipment were identified biological concerns. Powerlessness, self-blame, embarrassment, emotions, death, and anxiety were identified as

psychological concerns. Finally, role changes, a lack of understanding among others, and limitations in social activity were noted to be social concerns.

Several secondary concerns which have not been documented in the literature were identified namely: the wind, limited physical activity, oxygen and oxygen equipment use, death and dying, communication, and a lack of understanding by others. The wind was identified as a concern because of its ability to cause dyspnea and fear as well as limit the ability of participant to walk. Evidence suggests the wind increases airflow resistance during breathing. Therefore greater effort is needed to overcome the added airflow resistance to breathe (Gift et. al., 1986; McCarthy, 1990). Essentially, the wind makes breathing difficult. The associated dyspnea causes fear and limits the ability of participants to walk (Barstow, 1973; Callahan, 1982; DeVito, 1990; Janson-Bjerklie et. al., 1986). Existing literature has not addressed the wind's impact on the lives of those living with COPD. More research is needed in order to describe the wind's effect on those with COPD and to aid in the enhancement of coping strategies.

Participants also identified limitations in physical activity as a concern. Many participants expressed anger, disappointment and other emotions when they were unable to perform physical activities and function as a result. Dyspnea was

the primary cause of limitations in physical activity. Increased physical activity lead to increased dyspnea and decreased ability to perform other physical activities. Dyspnea's influence on an individual's physical activities has been well documented in the literature. As well, several researchers have identified the role of decreased physical activity on the lives of those affected (Barstow, 1974; Chalmers, 1984; Janson- Bjerklie et. al., 1986). Few researchers have examined the effect of physical activity limitations in terms of the individual's perspective of his or her function and lifestyle (Bartow, 1974; Chalmers, 1984). Additionally, further research is needed in order to understand the associated emotions and feelings present when an individual's ability to perform physical activities affects their function. This will aid health professionals in understanding the nature of the individual's functional problems.

Participant use of oxygen and oxygen equipment was also noted to be a newly identified concern. Although only a few ($n=5$) participants used oxygen, several issues were raised. Participants stated oxygen and oxygen equipment use were a concern because of safety, body image, and cost-related issues. In terms of safety, some participants stated the use of oxygen and oxygen tubing was a hazard. Participants identified the oxygen tubing as a potential source of falls. As well, several stated smoking or using heat producing appliances was dangerous

because oxygen supports combustion (Thelan et. al., 1990). Participants also identified changes in body image as a concern in conjunction with oxygen and oxygen equipment use. Some participants felt the tubing detracted from their appearance; for example, by leaving grooves on the face where it lay. The cost of using oxygen and oxygen equipment was also a component of their oxygen related concern. Participants with sparse financial resources could only purchase a limited number of cylinder tanks for use outside the home. Consequently, many activities were confined to the home, where an inexpensive ongoing oxygen supply could be accessed. Participants stated this led to feelings of loneliness and isolation. Finally, a few participants, who had used oxygen only during disease exacerbation, stated they felt they could become dependent on the gas. These individuals attempted to maintain their own personal health in order to delay the use of oxygen.

The existing research has addressed the use of oxygen and oxygen equipment in terms of quality of life and technological improvements in delivery of this gas (Anthonisen, 1986; Bergner, Hudson, Conrad, Patmont, McDonald, Perrin & Gilson, 1988; Estaban, Cerda, De La Cal & Lorente, 1993; Georgopoulos & Anthonisen, 1990; Waterhouse & Howard, 1983). Additionally, research has described the benefits of this therapy in prolonging life and

improving clinical outcomes (Dardes, Chiappini, Moscatelli, Pellicciotti, Benedetti & Vulterini, 1990; Elwood, 1990; Georgopoulos & Anthonisen, 1990; Sliwinski, Lagosz, Gorecka & Zielinski, 1994; Petty, 1990; Strom & Boe, 1991). Unfortunately, many patient concerns have not been addressed. Issues relating to the use of oxygen by those affected by COPD have gone unheard. Therefore, research addressing oxygen related patient concerns needs to be conducted. This will help health professionals conduct complete assessments and develop equipment and educational programs that meet the needs of those living with COPD.

Death and dying was also identified as an important participant concern. Participants stated their shortened life span, suffering, and experience with feelings of suffocation, drowning and choking during dyspnea increased their fear of death and dying. Unfortunately, palliative care research, education, and health programs have not addressed the needs of the chronically ill living with COPD. Instead, the focus has been placed upon the dying cancer patient (Broadfield, 1988; Carr, Fischer & Markman, 1994; Foley, Flannery, Graydon, Flintoft & Cook, 1995; Morrison & Morris, 1995; Ross, 1994; Rutman, 1992) and the management of end stage cancer related dyspnea. Essentially, those affected by COPD have been neglected in terms of their disease and symptomatology

(Campbell, 1996; Cumulative Index of Nursing and Allied Health Literature, 1982-1996; van der Molen, 1995); only five articles have addressed the palliative care needs of the COPD patient (Cumulative Index of Nursing and Allied Health Literature, 1982-1996). With the increase in the number of those living with COPD, more research is needed especially in terms of the management of dyspnea, a symptom perceived to be life-threatening by this population. Therefore, disease and symptom specific educational and health care programming can be developed to ensure there is an availability of resources. This will promote patient management of symptoms and feelings related to death and dying (Broadfield, 1988; Foley et. al., 1995). Individuals affected by COPD are among those who need to be researched to ensure their palliative care needs are met (Bailey, 1995; Campbell, 1996; Davis, 1995; Kinzel, 1992; van der Molen, 1995).

Communication was also identified as a new concern for participants. As a society, we have learned to communicate in many ways; for example, through verbal and non-verbal means. When communication becomes impaired, it is difficult to express thoughts and ideas and disability is perceived (Lueckenotte, 1995; Smith, 1986). Some participants stated dyspnea limited their ability to communicate effectively; several stated they were unable to complete sentences

or express their thoughts and ideas when dyspneic. Consequently, many experienced frustration and embarrassment. A few avoided conversation entirely and became socially isolated.

Communication research stresses the importance of speaking with others in the exchange of thoughts and ideas (Smith, 1986). Existing literature has limited its focus to those elderly whose hearing and vision have impaired their communication. This research has identified that the aged who experience such deficits avoid social situations and become isolated (Eliopoulous, 1987; Lueckenotte, 1996). Although this research has aided in identifying the barriers and solutions to communication problems, researchers need to recognize the role of other physical impairments and their effect on communication; for example, the inability to coordinate speech and breathing to communicate verbally (Smith, 1986). In COPD, researchers have documented the effect of dyspnea on communication (Sexton, 1983). None, however, have examined the frustration, embarrassment, social isolation or methods of coping with this concern. Such research is needed in order to facilitate social interaction between those who have a chronic illness such as COPD and others in order to promote social and psychological health (Berkman, 1983; Lueckenotte, 1996; Smith, 1986).

In the past 10 years a vast body of knowledge has accumulated addressing the role of social supports in enhancing the well-being of individuals (Lubben, 1988; Orit & Paul, 1985). Much of the existing research has supported the arguments of researchers that the presence of social supports is positive for the individual. Several researchers have identified the ability of social networks such as family and friends to diminish concerns and facilitate coping, thereby enhancing health (Berkman, 1983; McHaffie, 1992; Norbeck, 1988; Orit & Paul, 1985; Sexton & Munroe, 1988).

Although much of the literature identifies social support as having a positive, protective effect, some researchers have begun to explore the deleterious effects of social support (Berkman, 1983; Cohen & Syme, 1985; Preston & Grimes, 1987; Stewart, 1989; Ulbrich & Bradsher, 1993). New research has emerged that offers an opposing perspective: that social "supports" can negatively influence the individual (Berkman, 1983; Cohen & Syme, 1985). In this study, several participants described their negative experiences with identified social supports. Many stated family, friends and the public did not understand the effects of COPD on lifestyle. Participants stated that people did not comprehend the definition, presentation, treatment, prognosis or outcomes of COPD. Participants noted that their often "healthy" appearance led others to conclude

they were capable of much physical activity. In other cases, a lack of knowledge among significant others led some family members to conclude that the affected individual was suffering from a "cold." Many found this lack of understanding to be distressing and difficult to cope with. Although several attempted to educate their peers and family, many perceived their efforts to be futile.

This concern illustrates that researchers need to better understand both the positive and negative effects of social support (Berkman, 1983; Cohen & Syme, 1985). According to Berkman (1993), although risk for poor health is associated with having few social supports, the intensity and presence of a reciprocal element in the "supportive" relationship may also determine whether the social support is protective or harmful in nature. This leads Berkman (1983) to conclude that the presence of a social support may not be as important as the sense of feeling supported. Therefore there is a need to account for insensitive, strained, and uncaring relationships (Stewart, 1989). In this study, participants identified a lack of support from their family members. This suggests that the quality of support and feelings of being supported are important to those living with COPD. Additionally, it identifies that not all support may be positive in nature. As yet, this component of COPD has not been investigated. Further research is needed in order to understand this multiple role of social supports among specific groups of

individuals including those people living with COPD (Berkman, 1983; Cohen & Syme, 1985; Norbeck, 1988; Preston & Grimes, 1987).

In summary, although many participant concerns identified in this study have been addressed previously in the literature, several new concerns emerged. The wind, limitations in physical activity oxygen and oxygen equipment use, death and dying, communication, and a lack of understanding from others were among those concerns that were newly identified. Further research is needed in order to address these new concerns and thereby facilitate the coping of individuals living with COPD.

Coping

Traditionally, coping has been identified as an important method of enduring, managing, mastering and/or reducing perceived stressors or concerns (Folkman & Lazarus, 1980). Generally, participants used coping strategies to improve their performance of physical and social activities. In this study, participants used prevention, reduction, education, ignoring, avoidance, acceptance and fighting as coping strategies. Coping strategies served many purposes. Prevention averted the occurrence of concerns. Reduction decreased the intensity of concerns. Education enabled the participant to identify strategies that facilitated coping. Ignoring helped the participant to put aside their concerns

and perform physical activities. Avoidance ensured no contact occurred between the participant and the antecedent to the concern. Acceptance enabled the participant to live with a concern, and fighting helped the participant to perform physical and social activities in the face of a concern.

According to the coping literature, many coping strategies can be categorized according to their problem-focused and emotion-focused components (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Problem-focused and emotion focused coping were first described by Folkman and Lazarus (1980). Problem-focused coping refers to the ability of individuals to use problem-solving in managing their concerns (Carrier & Janson-Bjerklie, 1986; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Emotion-focused coping is linked with the use of cognitive and/or behavioural methods to address emotions or decrease emotional discomfort (Carrier & Janson-Bjerklie, 1986; Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). Several researchers have examined both problem and emotion-focused strategies in terms of chronic illness. Many have identified problem focused strategies with positive adjustment to illness (Felton & Revenson, 1984; Felton et. al., 1984; Keller, 1988; Viney & Westbrook, 1984). In contrast, emotion-focused strategies have been associated with maladjustment (Felton & Revenson, 1984; Felton et. al., 1984; Keller, 1988;

Viney & Westbrook, 1984).

Many of the study findings are in keeping with the literature addressing the coping strategies of those living with chronic illness and COPD. Generally, participants who used problem-focused and emotion-focused strategies appeared to cope with their disease. The findings differed from those found in other studies when emotion-focused strategies were examined. Emotion-focused strategies have historically been associated with negative outcomes such as depression, negative affect and low self-esteem in the chronic illness literature (Felton et. al., 1984; Viney & Westbrook, 1984). In this study, emotion-focused strategies facilitated coping with disease. They helped participants participate in both physical and recreational activities. For example, avoidance as an emotion focused strategy served to prevent dyspnea as well as enhance the ability of the individual to perform physical activities (Barstow, 1974; Carrieri & Janson-Bjerklie, 1986; Fagerhaugh, 1986). These findings are in keeping with the work of Fagerhaugh (1986), Carrieri and Janson Bjerklie (1991), McBride (1993) as well as Bombardier et. al. (1991) who identified that emotion focused strategies enhance the ability of an individual to live with chronic illness.

The current findings are also in keeping with the literature specific to coping with COPD. Several researchers have noted that coping strategies prevent

or reduce dyspnea as well as other COPD related concerns (Barstow, 1974; Carrier & Janson-Bjerklie, 1986; Fagerhaugh, 1986; McBride, 1993). According to these researchers, coping as a method of managing emotions, problem-solving, and planning activities, improves the capacity of individual to perform physical and social activities (Barstow, 1974; Carrier & Janson-Bjerklie, 1986; Fagerhaugh, 1986). In this study, coping strategies could be identified as having both cognitive and behavioural characteristics. The study findings are similar to those of Chalmers (1984) who identified that both cognitive and behavioural strategies facilitate problem-solving and planning. The findings differ from those of Chalmers when one considers Chalmers reference to expressive coping strategies. In this study participants did not identify the expression of emotions as a coping strategy. Instead, emotional expression was viewed as being detrimental. Certain emotions acted as antecedents to dyspnea and were therefore avoided or suppressed to facilitate coping.

In summary, the findings in this study are similar to those documented in the chronic illness and COPD literature. The findings differ when emotion-focused strategies are considered. Although some of the chronic illness literature views emotion-focused strategies as a hinderance, participants identified these strategies as a component of coping with their disease.

Gender Differences

Historically, researchers have studied male COPD subjects. Males represented the bulk of those affected by this disease (Barstow, 1973; Sexton & Munroe, 1985). In recent years, the changing trends in the smoking habits of Canadians has led to an increased incidence and prevalence of COPD among females (Health & Welfare Canada, 1982; Semenciw et. al., 1989). The recent rise in the number of female smokers (Health & Welfare Canada, 1982; Semenciw et. al., 1989) in conjunction with the documented evidence suggesting the female response to illness differs from that of males has led many researchers to begin exploring women's experiences with COPD (Emery et. al., 1991; Hahn, 1989; Janson-Bjerklie et. al., 1986; Sexton & Munroe, 1988). Existing research has examined gender differences in terms of the sensation of dyspnea (Janson-Bjerklie et. al., 1986), the experience of anxiety (Emery et. al., 1991) and the perception of body image (Hahn, 1989; Kravetz, 1982).

The present research has identified that most participant concerns were not specific to gender; only a few concerns differed in terms of their gender related attributes: oxygen and oxygen equipment use, anxiety, social roles, and limitations in social activity. In terms of oxygen and oxygen equipment use, only male participants stated they feared developing a dependency upon the gas. In

contrast, only females reported experiencing feelings of powerlessness in response to using oxygen and oxygen equipment. Additionally, females were more aware of fatigue as an outcome of cleaning oxygen equipment. However, caution is needed in drawing firm conclusions because of the small number of participants ($n=5$) who used oxygen in this study. Further research is needed in order to understand the role of oxygen and oxygen equipment in the lives of males and females.

Gender differences were also present in terms of participant descriptions of anxiety. Male and female participants referred to anxiety using differing terminology. Female participants addressed anxiety as anxiety, but males referred to anxiety as both stress and anxiety. In 1986 Janson-Bjerklie et. al. (1986) conducted a study in which she measured the level of anxiety experienced by both males and females. The researchers stated females reported experiencing higher levels of anxiety. The current study suggests the experience of anxiety may be similar for both males and females but the labelling of the emotion may be different. Therefore researchers need to attend to the descriptions participants ascribe to their concerns. Understanding the language of participants will facilitate more valid interpretations of research results.

Social roles were also affected by disease process. Participants from both genders identified traditional roles which had been lost. For example, females described their loss of the shopping and hostessing role. Here, females stated they were unable to shop for goods as well as act as a hostess on social occasions. On the other hand, males cited the loss of the repair role. Males stated they were no longer able to repair the family home. Both males and females experienced frustration, sadness, powerlessness, anger and anxiety in response to their disease related role losses. In recent years the roles of males and females in our society have blurred; both males and females have undertaken many roles previously characterized as specific to only one gender. In this study, many of the roles remained both traditional and gender specific. This may be indicative of the age of the population since the blurring of male and female roles has become more prevalent in the last three decades (Lueckenotte, 1996).

Similar emotions were experienced by both genders when social activities were lost. Emotions such as frustration, sadness, powerlessness, anger and anxiety were experienced by individuals who realized social activity losses. Although both genders identified limitations in social activity as a concern, men and women identified differing forms of social activity losses. Men stated they were unable to participate in sports such as hockey, baseball, golfing and/or

curling. Being unable to participate or attend sporting events with family and friends, led many men to conclude that they had been denied pleasurable activities.

Like men, many women were also cognizant of the increasing number of limitations imposed on their social activity. Unlike men, women identified social activity limitations as the inability to attend social gatherings with friends and family. Consequently, many women stated they experienced feelings of depression in addition to those feelings mentioned above. Generally, very little research has examined the relationship between gender and concern. Only a few researchers have identified gender as having a role in the experience of concerns. More research is needed in order to clearly determine if concerns are influenced by gender. In summary, although this research identifies only a few concerns as being affected by gender, more research is needed in order to clearly define concerns as well as the nature of their influence.

Disease Trajectory Differences

During the course of this study, disease trajectory was identified as having an effect on daily, infection related, and crisis dyspnea. The severity of daily dyspneic experiences varied when comparisons of moderately and severely affected participants were made. Daily experiences with this disease were

categorized by participants as "good days" or "bad days." For example, when participants described a "good day," moderately affected individuals stated they were able to perform physical activities without dyspnea or limitations in physical activity. In contrast, when a severely obstructed individual described a "good day" they experienced lower levels of dyspnea and an increased ability to perform physical activity. Likewise, when the "bad day" was described, a graduated level of symptom severity was noted. For those affected by severe disease process, "bad days" consisted of severe dyspnea and a decreased ability to engage in activities. The experience was similar for those affected by moderate disease process, but less extreme.

Day to day fluctuations in the level of dyspnea were common.

Bronchoconstriction and/or sputum production may vary from one day to another thereby affecting the level of experienced dyspnea (Kryger, 1990; Thelan, Davie & Urden, 1990). As disease progresses, symptoms gradually increase in number and severity. Consequently, the severity of dyspnea and the inability of individuals to engage in activities on a "bad day" as well as a "good day" increases as disease progresses (Kryger et. al., 1990; McCarthy, 1990; Thelan et. al., 1990).

In addition to this, several participants stated they experienced dyspnea in response to crisis events such as a death in the family. Disease trajectory based differences were present, among those participants who described crisis dyspnea. Both moderately and severely obstructed individuals described an increase in the level of dyspnea in response to crisis events, but severely obstructed individuals discussed having experienced an increase in dyspnea in the distant past rather than the immediate past.

According to crisis theory, when an individual perceives a threat and his or her coping strategies are ineffectual, he or she experiences a crisis. The crisis often evokes emotions such as anxiety, anger and/or fear. This occurs because existing coping strategies are underdeveloped or insufficient to meet the challenge of the threat (Stuart & Sundeen, 1987). As the crisis progresses, the individual develops problem and emotion-focused strategies in order to manage the threat and the associated emotions. Later, once the crisis subsides, the individual draws upon developed coping strategies in order to cope with future crises and the associated emotions (Caplan & Saddock, 1994; Stuart & Sundeen, 1987).

Individuals living with COPD also experience crises. As well, they must develop coping strategies in order to manage the threat and the associated emotions. Emotions such as anxiety, fear or anger increase the occurrence of

dyspnea (Lisella, 1993; Sandu, 1986). Therefore, individuals affected by COPD and a crisis must learn to manage the challenge of the threat as well as their dyspnea. Once the individual learns to cope with the crisis, emotions, and dyspnea, he or she is better able to manage future crises and the occurrence of dyspnea.

According to many of the participants a crisis was experienced during the course of their disease. A few participants who suffered from moderate obstruction lived through a crisis in the immediate past. Those who had a severe obstruction experienced a crisis in the distant past. The participants who survived a crisis identified that all subsequent crises were less severe in terms of dyspnea. Essentially, the participants developed coping strategies to manage dyspnea during the initial crisis. Consequently, all subsequent crises were coped with.

As yet, the literature has not addressed the role of a crisis in the lives of those affected by COPD. This study indicates that many individuals did not learn to cope with dyspnea until a crisis occurred. Researchers need to investigate the role of the crisis in accelerating the learning of coping strategies to manage a crisis, the associated emotions, and dyspnea. This study also indicates that health professionals need to identify the origin of the patient's dyspnea in order to plan and initiate appropriate interventions; dyspnea may have its origins in a crisis

rather than a respiratory infection. Once the origin of the dyspnea is identified appropriate coping strategies can be taught.

In summary, disease trajectory influences the experience of COPD. As disease progresses, the level of dyspnea increases and the ability to perform physical activities decreases. Opportunities to learn coping strategies occur throughout the disease process in the form of crises. Individuals who experienced a crisis were better able to cope with subsequent crises. The crisis acted as an opportunity to learn coping strategies. Health professionals need to be able to recognize the physical and psychological manifestations of a crisis in order to facilitate the development of coping strategies.

Conceptual Framework

Symbolic Interactionism (SI) was used as the theoretical basis for this study. SI proposes that human behaviours are shaped by social interactions. Individuals ascribe meaning or value to objects, persons and events through their interactions with others. The following section of this chapter will relate the findings to symbolic interactionist theory.

Symbolic interactionist theory is based on three basic premises (Blumer, 1969; Rose, 1962). The first premise states the individual has a unique concept of the self (Chenitz & Swanson, 1986). The first premise is in keeping with the

findings because each individual in this study had identified concerns that were unique to their lives. The second premise states the individual ascribes values to objects, persons, and events through their interactions with others (Blumer, 1969; Rose, 1962). The findings support this premise. Initially, participants learned to value certain objects, persons, and events through their interactions and communication with other members of society. During the mild stages of their disease, participants were unaware of the presence of a chronic illness. Additionally, few symptoms affected their interactions with others. Therefore no concerns developed. When the disease progressed to its moderate or severe stages, symptoms began to affect lifestyle. Losses, limitations and/or changes in biology, function, psychological health, and social participation resulted in the development of concerns. Essentially, the values ascribed to objects, persons and events were no longer congruent with the changes that had occurred as a result of disease process (Chenitz & Swanson, 1986).

The third premise of symbolic interactionist theory states the individual redefines him or herself through interaction and communication with others (Blumer, 1962; Chenitz & Swanson, 1986; Rose, 1962). Each participant learned about their disease through communication and interaction with their environment, friends, family, health care professionals and society (Blumer,

1969). As a result, participants developed biological, psychological and social concerns in regards to their disease through their own personal experiences with COPD, the experiences of others affected by this disease, and through the illness specific education provided by health professionals. For example, some participants learned that physical activity caused dyspnea when they performed activities too quickly. Other participants learned about the effects of activity on dyspnea by speaking with individuals affected by COPD and health professionals. Consequently, participants developed coping strategies such as prevention, avoidance, reduction and acceptance in order to deal with their concerns. Through this process, participants developed new beliefs, new meanings and values (Blumer, 1969).

In summary, SI theory was used as the conceptual framework for this study. Theoretically, SI effectively explained the relationship between concerns and coping strategies. It provided an overview of the actions and events that underlie the development of concerns and participant responses in the form of coping strategies. Therefore, SI describes the role of interactions and communication in how an individual learns to redefine him or herself.

Limitations of the Study

Rigor in qualitative research is important. Rigor functions to increase the probability of producing credible findings (Lincoln & Guba, 1989). The credibility of the findings can be affected by researcher bias and interpretation (Lincoln & Guba, 1989). As well, disease related, environmental, participant and sample specific factors can affect the quality and transferability of the collected data (Polit & Hungler, 1991; Sexton, 1983). In COPD, individuals are hypoxemic or hypercapnic. They suffer from a decreased oxygen supply to bodily tissues such as the brain (Sexton, 1983). This can lead to functional and personality changes (Sexton, 1983). Poor oxygen delivery to the brain can lead to forgetfulness as well as fatigue (Grant, Heaton, McSweeney, Adams & Timms, 1980). This can diminish the quality of interview data (Sexton, 1983). In the study hypoxemia may have altered the quality of the participant responses; some participants may forgotten to describe certain aspects of their disease or become too fatigued to provide a full description of their concerns.

The environment can also affect the quality of the research data. In this study, verbal comments by a spouse, the sounds made by a pet, and the ringing of a telephone disrupted participant interviews; the participant's attention was drawn away from the interview to the source of the noise. In some cases the participant

stopped the interview to attend to a telephone call or to a spouses's needs. When the interview began again, the researcher had to summarize the earlier comments of the participant in order to re-focus the interview. Some of the participants' thoughts and subsequent comments at the time of the disruption may have been forgotten when the interview resumed. Consequently, interruptions disrupted the communication of thoughts and ideas (Smith, 1986; Tappen, 1995).

The situational experiences of the participants also influenced the quality of collected data. Participant descriptions of concerns included both past or present experiences with other illnesses (Polit & Hungler, 1991). For example, one participant defined her COPD related encounters with dyspnea in terms of the shortness of breath she experienced when one of her lungs had collapsed. In another case, an individual who had strained his arm prior to an interview described his COPD related concerns in terms of his sore arm. Consequently, caution must be taken in interpreting the findings of this research as other illnesses may alter the attributes of participant COPD related concerns.

Researchers also need to be cognizant of the potential influence that family members can have on the quality of the interviews. Ideally, interviews should take place with only the researcher and the participant present (Sexton, 1983). Unfortunately, in this study many participant homes and apartments were

small. Therefore, a spouse was often nearby. A few spouses developed an interest in the interview questions as well as responses of the participants. A small number of spouses attempted to comment on the participant's responses. In such a cases, the spouse was asked to refrain from making comments during the interview and invited to speak at the end. In comments at the end of the interview, a few spouses reflected on the effects of this disease on the participants lifestyle especially in terms of the limits it has placed on physical activity. Unfortunately, caregiving interest in the spouse's responses may have influenced the quality of interview responses; participants may have disclosed only limited descriptions of all of their concerns because they did not want to upset their caregivers (Cossette & Levesque, 1991; Sexton., 1983; Sexton & Munroe, 1985).

Finally, sample related issues need to be considered in reviewing the findings of this research. Qualitative research utilizes a small sample of individuals who represent an experience with a specific phenomenon (Polit & Hungler, 1991). Therefore, collected data is specific to the participants and is situational in nature. Although the findings are representative of the sample's experiences, the results are transferrable in this research. The researcher's use of two interviews provided a rich data base. Therefore the data base was sufficient to allow for the effective transfer of findings to other research situations (Lincoln

& Guba, 1989).

In summary, several factors influenced the quality of the collected qualitative research data and the transferability of the results. Disease related, environmental, and participant related factors can affect the responses of participants and, in turn, the quality of the data and findings. Additionally, one must be cognizant of the role of qualitative research. The intent of qualitative research is to yield rich descriptive, narrative data. Such data may not be transferable to other individuals or settings.

Implications for Future Research

Historically, dyspnea has been extensively researched. Although the body of knowledge addressing dyspnea has grown, much needs to be examined in terms of the characteristics of this concern. Earlier in the study, the researcher identified the key role of dyspnea in the lives of those living with COPD. Participants stated dyspnea was a distressing and life threatening symptom that acted as an antecedent or consequence to varying other concerns. The role of dyspnea in regards to concerns needs to be more fully documented. Although this study has described dyspnea, additional research may be necessary.

Institutional study is also required. The support received from friends and family in the community differs from the support which is available from health care professionals in an institution. The knowledge of health professionals, institutional policies and the ready accessibility of devices to support oxygenation may alter some of the concerns of obstructed individuals. Individuals may perceive the institutional setting as being less stressful than that of living in the community (Lueckenotte, 1996).

Dyspnea itself needs further study. Participants were able to characterize dyspnea according to its daily, infection related and crisis forms. The research illustrates the need to describe the language of participants in order to assist practitioners in their assessments and the development of programs specific to this population. As a result, practitioners will be better able to understand as well as communicate educational initiatives to this population. Finally, a greater understanding of the expression of dyspnea is needed. This is especially needed in response to stressful situations. Many of the participants discussed an increase in the severity of their dyspnea when experiencing a stressful situation. Presently, COPD patients are frequent visitors to both hospitals and emergency wards. Understanding the link between stress and dyspnea may help some clinicians to differentiate between those who are experiencing disease exacerbation and those

who are responding to stress. This would lead to a more appropriate treatment of the underlying cause of dyspnea.

In terms of treatment alternatives, research addressing the palliative care of COPD patients is urgently needed. At present, no palliative care research has been conducted in this population. Instead, much of the research has addressed the palliative care needs of terminally ill cancer patient (Broadfield, 1988). In the present study, several participants identified their fear of death and dying. Many individuals affected by both moderate and severe obstruction discussed this concern with great distress. Several associated death and dying with dyspnea, a common symptom of COPD. As a result, many lived in constant fear of dying when they experienced dyspnea. A new branch of COPD research needs to be developed, specific to the palliative care needs of this group. Investigators need to examine the palliative care needs, coping strategies, treatment issues, educational initiatives and programs that would best address this expressed concern.

From a patient perspective, another area of research that needs to be addressed is the use of oxygen and oxygen equipment. Research examining the role of oxygen and oxygen equipment is necessary in order to develop more portable, life-style friendly methods of delivering oxygen in order to help

individuals lead productive lives. Several participants referred to the inadequacy of equipment in terms of its portability, the delivery of oxygen, the cost, and safety. Additionally, oxygen and oxygen equipment quality of life issues should be identified and examined (Sliwinski, Lagosz, Gorecka & Vulterini, 1990). Individuals affected by COPD would like to live active fulfilling lives (Tames, 1990). Attempts need to be made in order to improve the safety and portability of equipment while decreasing the costs involved in its use.

Much of the existing research has done little to examine the role of oxygen and oxygen equipment in affecting quality of life. Instead, research has described the benefits of this therapy in prolonging life, improving clinical outcomes and delivering oxygen (Anthonisen, 1986; Bergner, Hudson, Conrad, Patmont, McDonald, Perrin & Gilson, 1988; Estaban, Cerda, De La Cal & Lorente, 1993; Georgopoulos & Anthonisen, 1990; Waterhouse & Howard, 1983). Also, little research has examined the concerns of individuals using oxygen equipment; for example, their limited ability to participate in activities outside the home, the cost of maintaining equipment, the cosmetic implications of using tubing, as well as the potential danger for combustion (Dardes, Chiappini, Moscatelli, Pellicciotti, Benedetti & Vulterini, 1990; Elwood, 1990; Georgopoulos & Anthonisen, 1990; Sliwinski et. al., 1990; Strom & Boe, 1991).

Additionally, only a few studies have investigated the psychological status of oxygen dependent individuals. These studies have measured psychological variables rather than quality of life, and day to day living concerns that arise from using such equipment (Lee, Graydon & Ross, 1991; Sliwinski, Plasecki & Zielinski, 1991).

From a practice perspective, both the communication patterns and the lack of understanding persons with COPD derive from others need to be researched. Participants in this study were extremely cognizant of their inability to communicate with others because of dyspnea. In some cases this led to a complete withdrawal from participation in social and recreational activities. In our society verbal communication is a primary form of expressing thoughts and ideas (Smith, 1986; Tappen, 1995). When one is unable to communicate, social needs are unmet (Lueckenotte, 1996; Smith, 1986). Researchers need to better describe the process of communicating with others during periods of dyspnea and the methods used to overcome this barrier to communication. This will aid clinicians in helping individuals to communicate. Consequently, obstructed individuals will be better able to identify their needs and health care professionals will be able to provide a more comprehensive assessment.

In summary, many initiatives must be undertaken in order to gain more knowledge regarding the concerns of individuals affected by COPD. Although the existing research has documented the concerns of individuals living with this disease, more study is needed.

Implications for Nursing Education

Historically, nursing research and education have been responsible for the development of practice. Nursing research has led to curriculum design and content changes and thereby furthered practice. This study, like other research, offers a guide to nurse educators in the revision of theoretical and clinical course content (Baumgart & Larsen, 1992; Brink & Wood, 1990; Polit & Hungler, 1991; Roberts & Burke, 1989. From a theoretical perspective, this research suggests symbolic interactionism be used to illustrate the role of the individual and society in the development of concerns and coping responses. The symbolic interactionist perspective states the individual's interaction and communication with others results in values being ascribed to individuals, persons and events. This, in turn, shapes the development of participant concerns and the selection and use of specific coping strategies (Blumer, 1962; Blumer, 1969; Chenitz & Swanson, 1986; Folkman & Lazarus, 1980).

From a practice perspective, this study illustrates the importance of teaching research based, respiratory specific course content to student nurses. Course content specific to the needs of the respiratory patient will enhance nursing assessment of concerns, as well as planning, implementation and evaluation of nursing interventions that facilitate patient coping. Additionally, the ongoing review and use of research based content by nurse educators will ensure that new findings are incorporated into the existing curriculum content; for example, newly identified concerns, the role of dyspnea as both an antecedent and consequence to all other concern as well as the importance of assessing concerns according to gender and stage in disease trajectory. Finally, nurse educators need to encourage student interest in studying the concerns of people with COPD. This research identifies several gaps in the current knowledge. Many concerns need to be described and coping strategies need to be promoted in order to help people live with their disease.

In summary, this study identifies the need to revise the nursing curriculum and course content to reflect the current research. As well, it also notes the need for nurse educators to encourage student nurses to pursue research in the field of respiratory nursing.

Implications for Nursing Practice

Currently, individuals affected by COPD frequently interact with nurses in a number of settings. Nurses are in a unique position to utilize their skills in assessment, planning, intervention and evaluation to both identify concerns and teach coping strategies because of the frequency of their patient contact. This study has presented several participant concerns. Many are environmental, biological, psychological and social in nature. Nurses need to be aware of their role in identifying the concerns of obstructed individuals and the importance of conducting a thorough assessment of the health of individual's. Consequently, this will ensure the development of plans and interventions that have meaning for the individual and, in turn, facilitate compliance and promote effective coping.

The present study also identifies the need for a comprehensive patient centred approach to assessing concerns and promoting coping among individuals living with COPD. Earlier, in chapter one, the researcher identified that health professionals assess, diagnose and treat disease related problems according to a medically defined perspective. The current research illustrates that although many concerns have been identified by health professionals, several still remain undocumented and unstudied. Therefore, nurses must maintain a patient focus in order to ensure comprehensive assessments and to promote and enhance coping.

This research also identifies a need to establish programs and educational strategies specific to those concerns which have not been described in the literature. For example, palliative care programming for those patients concerned about death and dying and educational strategies to help individuals cope with oxygen and oxygen equipment use.

Nurses also need to be availed of the implications of gender and disease trajectory in their practice. This research suggests that there are differences in the experience and labelling of some concerns. Nurses need to be aware of the differences and probe for them in their assessments in order to meet patient needs. Additionally, nurses must develop an awareness of the terminology that is used in the description of concerns. The current research identified that males and females have labelled anxiety in two different ways. The terminology that is used may lead to a misleading assessment as well as inappropriate interventions.

Finally, this research describes the importance of communicating with the patient. Several participants described their inability to communicate their thoughts and ideas because of dyspnea. Nurses need to be able to conduct patient interviews and assessments in a concise manner that will lead to the expression of concerns in an atmosphere which is unrushed..

In recent years nursing research has taken great strides in developing a knowledge and practice base that supports the coping of individuals (Janelli et. al., 1991; Roberts et. al., 1987). Nursing has described, classified and incorporated into its practice the coping strategies of individuals affected by COPD (Barstow, 1974; Carrieri & Janson-Bjerklie, 1986; Chalmers, 1984; Fagerhaugh, 1986; McBride, 1993). As a profession, nursing has the ability to promote health and facilitate optimal wellness and coping with chronic illness (Burckhardt, 1987). Nurses need to take the time to conduct thorough assessments in order to effectively support, promote and maintain the ability of the individual to cope (Clarke, 1984; Panzarine, 1985; Roberts et. al., 1987). This research illustrates the importance of taking time to assess the needs of the individual to better help them cope.

Summary

In this chapter, the findings were discussed. Participant concerns and coping strategies were described and discussed in terms of the current literature. Differences in the attributes of concerns as they relate to gender and level of obstruction were also discussed. Finally, the relationship of the findings to the conceptual framework, the significance and limitations of the study as well as recommendations for future research, changes to nursing practice, and education

were presented.

Summary of the Research Process

In summary, the purpose of this study was to explore and describe the concerns of people living with COPD according to stage in disease trajectory and gender, and the relationship of concerns to stage in disease trajectory and gender. This study was motivated by the current approach of health care professionals towards patient care: to define patient concerns in terms of a disease specific, medical perspective. Symbolic interactionism was used to describe the development of participant concerns and coping strategies. Through purposive sampling and ethnographic analysis, the concerns of participants were identified and examined.

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Appendix A

Risk Factors of COPD

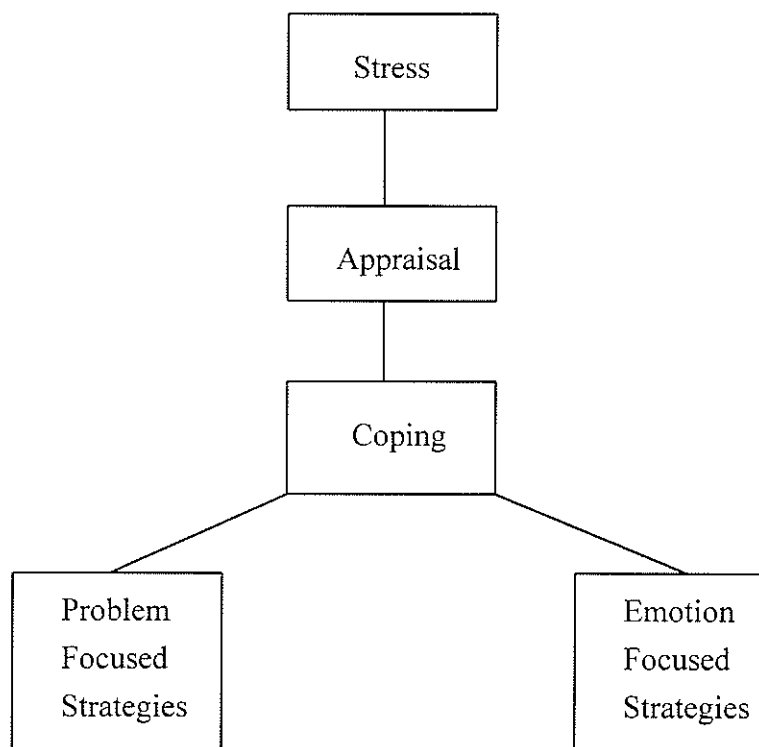
"Although the presence of these factors is associated with the development of COPD, limitations of current knowledge precludes a precise prediction that any one patient will develop COPD" (Tames 1991). The following is a list of risk factors of COPD:

Risk Factors

1. Smoking.
2. Occupational exposure to organic dust.
3. Air pollution such as chemicals and dusts.
4. Socioeconomic status.
5. Heredity; for example, a homozygous deficiency in alpha-antitrypsin in the lungs.
6. Bacterial or viral infection
7. Climate
8. Alcohol consumption
9. Allergies

Note: From Breathing to Live: A Physicians Companion to Managing COPD Counseling Patients (pp. 19-23) by Tames, 1991, Toronto: Grosvenor House PressAdapted.

Appendix B
Folkman and Lazarus's
Diagrammatic Relationship of Stress, Appraisal and Coping



Note: From "An analysis of Coping in a Middles-Aged Community Sample" by S. Folkman and Lazarus, R. S., 1980, Journal of Health and Social Behaviour, 21(9), pp. 219-239. Adapted.

Appendix C

Alterations in Activities of Daily Living in COPD Patients

Activity of Daily Living	Changes
Morning Toilet	Dressing done in stages. Rest periods taken during activities.
Bathing	Showers perceived as suffocating. Therefore baths taken. Baths are tiring. Few are taken or assistance is required.
Dressing	Loose clothing is worn. Such clothing is easier to get on and off. Bending is avoided with slip on shoes.
Meal Preparation	Heavy lifting is avoided with use of light weight utensils. Energy is conserved with organized kitchens. Energy is conserved with consumption of easily prepared food.
Sleeping	Frequent position changes occur during the night. Sleep is interrupted through coughing, dyspnea or restlessness.
Mobility	Climbing stairs and running is stopped. Lifting, pushing, pulling and stooping, are done slowly to conserve energy. Electrical equipment is used to conserve energy. Objects are placed at arm level to avoid stooping and lifting.

Note. From "Coping with Emphysema" by R. E. Barstow, 1982, Nursing Clinics of North America, 9, pp. 140-142. Copyright 1974 by R. E. Barstow. Copyright 1974 by R. E. Barstow. Adapted.

Appendix D

Problem and Emotion-focused Coping in Dyspnea

Immediate Strategies

Problem-focused Coping

- positioning and slowing motion.
- breathing techniques
- avoiding aggravating factors
- medication treatment use
- seeking support

Emotion-focused Coping

- isolationing self.
- reducing tension
- seeking support

Long-term Strategies

Problem-focused Coping

- change in activities of daily living
- activity modification
- health oriented behaviour
- treatment use
- preventing SOB
- seeking social support

Emotion-focused Coping

- maintenance of a positive attitude
- seeking social support

Note: From "Strategies Patients Use to Manage the Sensation of Dyspnea" by V.

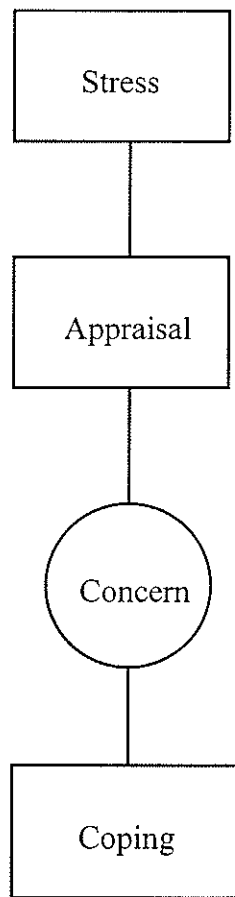
K. Carrieri and S. Janson-Bjerklie, 1986, Western Journal of Nursing Research, 8,

pp. 288-297. Copyright 1986 by V. K. Carrieri and S. Janson-Bjerklie.

Adapted.

Appendix E

Stress, Appraisal, Concern and Coping Framework



Appendix F

Complete List of Concerns and Sresses

<u>Author</u>	<u>Clinician or Patient Identified</u>	<u>Stressors and Concern</u> (Stressors are identified by clinicians and concerns are identified by patients.)
Agle & Baum, 1977	Clinician	Anxiety
Agle, Baum, Chester & Wendt, 1973	Clinician	Anxiety
Barstow, 1974	Clinician	Anxiety
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Anxiety
Dudley, Wermuth & Hague, 1973	Clinician	Anxiety
Emery, Leatherman, Burker and MacIntyre, 1991	Clinician	Anxiety
Fagerhaugh, 1986	Patient	Anxiety
Fuhs & Stein, 1976	Clinician	Anxiety
Gift & Cahill, 1990	Clinician	Anxiety
Gorman & Uy, 1987	Clinician	Anxiety
Hargreaves, 1968	Clinician	Anxiety

McSweeney, Grant, Heaton, Adams & Timms, 1982	Patient	Anxiety
Moody, McCormick & Williams, 1991	Clinician	Anxiety
Post & Collins, 1981-82	Clinician	Anxiety
Prigatano, Wright, & Levin, 1984	Clinician	Anxiety or Tension
Sandu, 1986	Clinician	Anxiety
Shekleton, 1987	Clinician	Anxiety
Trask & Cree, 1962	Clinician	Anxiety
Traver, 1975	Patient	Anxiety
Agle & Baum, 1977	Clinician	Body Image
Barstow, 1974	Clinician	Body Image
Carrier & Bjerklie, 1986,	Patient	Body Image
Dudley, 1981	Clinician	Body Image
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Body Image
Hahn, 1989	Patient	Body Image
Hargreaves, 1968	Clinician	Body Image
Kravetz, 1982	Clinician	Body Image
Shekleton, 1987	Clinician	Body Image
Fishman, 1971	Clinician	Congestive Heart Failure
Khaja & Parker, 1971	Clinician	Congestive Heart Failure

Openbrier, Hoffman & Wesmiller, 1988	Clinician	Congestive Heart Failure
Rao, Cohn, Eldridge & Hancock, 1968	Clinician	Congestive Heart Failure
Barstow, 1973	Clinician	Cough
Callahan, 1984	Clinician	Cough
Carrieri & Bjerklie, 1986	Clients	Cough
Kinney, 1967	Clinician	Cough
Traver, 1975	Patient	Cough
Pet, Speizer, Cochrane, Moore, Fletcher & Tinker, 1983	Clinician	Cough
Webster & Kadah, 1991	Clinician	Cough
Agle & Baum, 1977	Clinician	Depression
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Depression
Fuhs & Stein, 1976	Clinician	Depression
Gift & Cahill, 1990	Clinician	Depression
Chalmers, 1984	Patient	Depression
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Depression
Dudley, Wermuth & Hague, 1973	Clinician	Depression

Light, Merrill, Despars, Gordon & Mutalipassi, 1985	Clinician	Depression
McSweeney, Grant, Heaton, Adams & Timms, 1982	Clinician/ Client	Depression
Prigatano, Wright, & Levin, 1984	Clinician	Depressed
Sandu, 1986	Clinician	Depression
Sandu, 1986	Clinician	Depression
Sexton & Munro, 1988	Patients (Females)	Depression
Shekleton, 1987	Clinician	Depression
Traver, 1975	Patient	Depressed
Webster & Kadah, 1991	Clinician	Depression
Agle & Baum, 1977	Clinician	Dyspnea
Archibald & Guidotti, 1987	Clinician	Dyspnea
Barstow, 1973	Clinician	Dyspnea-
Callahan, 1982	Clinician	Dyspnea
Carrieri & Bjerklie, 1986, 1986	Clients	Dyspnea
Callahan, 1984	Clinician	Dyspnea
Chalmers, 1984	Patient	Dyspnea
DeVito, 1990	Patient	Dyspnea
Dudley, 1981	Clinician	Dyspnea
Dudley, Wermuth, & Hague, 1973	Clinician	Dyspnea

Friedman, 1968	Clinician	Dyspnea
Fuhs & Stein, 1976	Clinician	Dyspnea
Gift & Cahill, 1990	Clinician	Dyspnea
Gift, Plaut & Jacox, 1986	Clinician	Dyspnea
Hargreaves, 1968	Clinician	Dyspnea
Janson- Bjerklie, 1986, Carrieri & Hudes, 1986	Patient	Dyspnea
Kravetz, 1982	Clinician	Dyspnea
Lee, Graydon & Ross, 1991	Clinician	Dyspnea
Mahler, 1992	Patient	Dyspnea
Moody, McCormick & Williams, 1991	Clinician	Dyspnea
Pet, Speizer, Cochrane, Moore, Fletcher & Tinker, 1983	Clinician	Dyspnea
Renfro, 1988	Clinician	Dyspnea
Sandu, 1986	Clinician	Dyspnea
Sjoberg, 1983	Clinician	Dyspnea
Traver, 1975	Patient	Dyspnea
Webster & Kadah, 1987	Clinician	Dyspnea
Chalmers, 1984	Patients	Prevention of exacerbation's
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Emotions

Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Emotions
Dudley, Wermuth & Hague, 1973	Clinician	Emotions
Fagerhaugh, 1986	Patient	Emotions
Hanson, 1982	Patient	Emotions
Janson- Bjerklie, 1986, Carrieri & Hudes, 1986	Clinician	Emotions
McSweeney, Grant, Heaton, Adams & Timms, 1982	Clinician	Emotions
McSweeney, Grant, Heaton, Adams & Timms, 1982	Clinician	Emotions
Renfroe, 1988	Clinician	Emotions
Sandu, 1986	Clinician	Emotions
Carrieri & Bjerklie, 1986, 1986	Patient	Environmental Pollutants
Fagerhaugh, 1986	Patient	Environmental Pollution
Fuhs & Stein, 1976	Clinician	Environmental Pollutants- airborne
Sexton & Munro, 1985; 1981	Patient (Female)	Environmental Pollutants
Sexton & Munro, 1988	Patient (Females)	Environmental Pollutants
Shekleton, 1987	Clinician	Environmental Pollutants

Agle & Baum, 1977	Clinician	Emotions
Dudley, Hague & Wermuth, 1973	Clinician	Emotions
Carrieri & Bjerklie, 1986, 1986	Patient	Emotions
Anthonisen, Manfreda, Warren, Hershfield, Harding, & Nelson, 1987	Clinician	Exacerbations
Callahan, 1982	Clinician	Fatigue
Chalmers, 1984	Clinician	Fatigue
Dudley, 1981	Clinician	Fatigue
Dudley, Wermuth & Hague, 1973	Clinician	Fatigue
Fagerhaugh, 1986	Patient	Fatigue
Sexton, 1983	Clinician	Fatigue
Sexton & Munro, 1988	Patient (Female)	Fatigue
Small & Graydon, 1992	Clinicians	Fatigue
Webster & Kadah, 1991	Clinician	Fatigue
Barstow, 1974	Clinician	Finances
Fagerhaugh, 1986	Patient	Finances
Sexton & Munro, 1988	Patient (Females)	Finances
Post & Collins, 1981	Clinician	Frustration

Dudley, Wermuth & Hague, 1973	Clinician	Hopelessness
Callahan, 1984	Clinician	Hypoxemia
Fishman, 1971	Clinician	Hypoxemia
Harris & Cournand, 1957	Clinician	Hypoxemia
Krop, Block & Cohen, 1973	Clinician	Hypoxemia
Grant, Heaton, McSweeney, Petty & Timms,	Clinician	Hypoxemia
Prigatano, Wright, & Levin, 1984	Clinician	Hypoxemia
Trask & Cree, 1962	Clinician	Hypoxemia
Agle & Baum, 1977	Clinician	Isolation
Fuhs & Stein, 1976	Clinician	Isolation
Post & Collins, 1981	Clinician	Isolation
Sexton, 1983	Clinician	Loneliness
Sexton & Munro, 1988	Patient (Females)	Loneliness
Hanson, 1982	Patient	Marriage
Barstow, 1973	Clinician	Nutrition
Chalmers, 1984	Patient	Nutrition
Webster & Kadah, 1991	Clinician	Nutrition
Wilson, Rogers & Openbrier, 1986	Clinician	Nutrition
Chalmers, 1984	Patient	Powerlessness

Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Powerlessness
Sandu, 1986	Clinician	Powerlessness
Shekleton, 1987	Clinician	Powerlessness
Barstow, 1974	Clinician	Recreation
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Recreation
McSweeney, Grant, Heaton, Adams & Timms, 1982	Clinician/ Patient	Recreation
Sandu, 1986	Clinician	Recreation
Agle & Baum, 1977	Clinician	Role Changes
Agle & Baum, 1977	Clinician	Role Changes
Barstow, 1974	Patient	Role Changes
Barstow, 1974	Clinician	Roles Changes
Chalmers, 1984	Patient	Role Changes
Chalmers, 1984	Patient	Role Changes
Chalmers, 1984	Patient	Role Changes
Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Role Changes
Hanson, 1982	Patient	Role changes
Kravetz, 1982	Clinician	Role Changes
Sandu, 1986	Clinician	Role Changes
Sandu, 1986	Clinician	Role Changes
Shekleton, 1987	Clinician	Self-esteem
Agle & Baum, 1977	Clinician	Sexuality/ Sexual Function

Dudley, Glaser, Jorgenson & Logan, 1980	Clinician	Sexuality/ Sexual Function
Hahn, 1989	Patient	Sexuality
Hanson, 1982	Patient	Sexuality
Katzm, 1991	Clinician	Sexuality
Kravetz, 1982	Clinician	Sexuality
Sandu, 1986	Clinician	Sexuality
Agle & Baum, 1977	Clinician	Sleeplessness
Barstow, 1974	Patient	Sleeplessness
McSweeny, Grant, Heaton, Adams & Timms, 1982	Clinician/ Patient	Sleeplessness
Task & Cree, 1962	Clinician	Sleeplessness
Fagerhaugh, 1986	Patient	Social Isolation
Shekleton, 1987	Clinician	Social Isolation
Sandu, 1986	Clinician	Social Isolation
Chalmers, 1984	Patient	Sputum
Webster & Kadah, 1991	Clinician	Sputum
Hargreaves, 1968	Clinician	Sputum
Traver, 1975	Clinician	Sputum
Hanson, 1982	Patient	Symptoms (Physical)
Small & Graydon, 1992	Clinician	Symptoms (Physical)
Fagerhaugh, 1986	Patient	Weather
Shekleton, 1987	Clinician	Weather
Sexton, 1983	Clinician	Weather

Fuhs & Stein, 1976	Clinician	Wheeze
Pet, Speizer, Cochrane, Moore, Fletcher & Tinker, 1983	Clinician	Wheezing
Webster & Kadah, 1991	Clinician	Wheezing

Appendix G

Access Letter

Winnipeg, Manitoba
R

October 1993.

Dr. Lewis Oppenheimer
Director of Research, Health Sciences Centre
820 Sherbrook Street, Room MS 754
R3A 1R9

Dear Dr. Oppenheimer,

My name is Elizabeth Borycki and I am a graduate nursing student currently undertaking studies towards a Master of Nursing Degree at the University of Manitoba. Presently, I am in the second year of my studies and have developed a proposal to conduct research as part of the thesis component of the university program.

My research is qualitative and exploratory. It is my intent to study the concerns of patients affected by chronic obstructive pulmonary disease (COPD) in order to develop a greater understanding of this population. I am specifically interested in examining the concerns of COPD patients, and the relationship of concern to stage in disease process and gender. Individuals wishing to participate in this study will be:

1. medically diagnosed with chronic obstructive pulmonary disease in the form of emphysema, chronic bronchitis and combinations of asthma, chronic bronchitis and emphysema.
2. able to read, write and comprehend English.
3. live within the city of Winnipeg.
4. give written, informed consent.
5. eighteen years of age and older.
6. not be in a stage of disease exacerbation.
7. able to complete an interview without developing an uncomfortable level of respiratory distress.

Each individual who will take part in the study will be asked for permission for the investigator to examine his or her chart to identify information about their respiratory disease, complete a demographic form, and participate in two interviews each lasting for approximately one hour. The patient's chart will be examined in the clinic. The interview will be held at a time and location convenient to both the individual and investigator. This is likely to be in the patient's home. At this time, the individual will also be asked to complete the demographic form. Information collected in the study will be kept confidential. The individual's participation in the study will be voluntary and withdrawal from the study may take place at any time. In the initial contact with the individual in the clinic, the investigator will explain the study to the individual and obtain verbal consent. Prior to the interview, the investigator will obtain written consent.

My research is being supervised by faculty members of the University of Manitoba: Dr. Karen Chalmers, Associate Professor, Faculty of Nursing, Professor David Gregory, Assistant Professor Faculty of Nursing and Dr. Barry Trute, Professor Faculty of Social Work. Dr. Karen Chalmers, is the chairperson of my thesis committee. She may be contacted at 474-9315 or in writing at the Faculty of Nursing, University of Manitoba, Winnipeg, Manitoba, R3T 2N2.

I am seeking access to the Respiratory Outpatient Clinic, Respiratory Hospital, Health Sciences Centre. I have had the opportunity to meet with the nursing staff in the outpatient clinic during the previous year as part of my Community Health component of the Master of Nursing Program and have discussed my intention to utilize the clinic for my thesis work with the Head Nurse. The nursing staff has been very supportive of my endeavours.

I am approaching your agency for access because of your involvement with this particular population of individuals, your research excellence in the community, and interest in providing quality health care to individuals within the province of Manitoba. I am requesting access to the individuals affected by COPD served by the Respiratory Outpatient Clinic. This process will only involve the indirect cost of Respiratory Outpatient Clinic staff initially approaching individuals to ask them if they would consider speaking to me about the study and my examination of patient charts. I am willing to acknowledge the support of the Health Sciences Centre in future publications in relation to this study and provide you with a summary of my research findings.

Confidentiality of research data will be maintained at all times. Patient charts will only be accessed in the Respiratory Outpatient Clinic. Only data about pulmonary function values and respiratory diagnosis will be obtained from the charts. The interview data will be maintained in locked cabinets. The patient's names will not appear in any of the transcribed materials. Only the researcher and committee members will have access to the data. Only code numbers will appear on the transcripts. These code numbers will also appear on a corresponding list of names, addresses and phone numbers to maintain confidentiality. This list will be kept in a separate locked cabinet by the researcher to ensure confidentiality. Only the researcher will have access to this cabinet.

I am currently seeking ethical review at the University of Manitoba. I have included a copy of my proposal, the documentation required by your organization, and the documentation for ethical approval. Thank-you for your time and consideration of my request. Should you have any further questions or concerns, you wish to discuss with me please feel free to call me at my phone number ***** I look forward to your response.

Sincerely,

Elizabeth Borycki RN., HBSN

Appendix H

Assistant Head Nurse Approach for Participation in Study

Hello, my name is ----- . There is a Master of Nursing degree student, from the University of Manitoba here. She is a nurse. Her name is Elizabeth Borycki. She is interested in studying the concerns of people with chronic obstructive pulmonary disease (COPD). She is interested in speaking with you because you have this breathing problem. Would you consider speaking with her? If you speak with her, you are under no obligation to be part of the study.

Appendix I

Verbal Explanation of the Study

Hello, my name is Elizabeth Borycki. I am a nurse and I am currently studying at the University of Manitoba to obtain a Masters of Nursing Degree. I am interested in understanding the concerns of people with chronic obstructive pulmonary disease (COPD). I have done a lot of reading in the last year about individuals who are affected by your disease. In doing this reading, I have learned that health professionals have identified many concerns among individuals who have COPD, but there is little information about what individuals with COPD themselves think. What I would like to do is to interview you to find out what concerns you have about your disease and how the disease affects your life. Should you want to participate in my study, you will be asked to participate in two interviews that will each last one hour. Since shortness of breath or being tired is sometimes a problem for people with your disease, if during the interview I see you are becoming short of breath or tired, I will stop the interview for you to rest or to arrange to spread the interviews over three sessions. If during the interview, you feel tired or short of breath, please tell me so I can stop the interview for you to rest or arrange to spread the interviews over three sessions.

The interviews will be tape recorded. You will also be asked to answer few

short questions so I can fill out a short form that gives me some background information about you. As well, I will look briefly at your chart to gather some information about your breathing tests and your disease.

The study will be of slight risk to you, since in some cases shortness of breath or being tired is sometimes a problem for people with your disease. If during the interview I see you are becoming short of breath or tired, I will stop the interview for you to rest or to arrange to spread the interviews over three sessions. If during the interview, you feel tired or short of breath, please tell me so I can stop the interview for you to rest or arrange to spread the interviews over three sessions.

I hope to be able to compile the information from all the people I speak to and present it to health professionals such as doctors, nurses and physiotherapists. In doing this, health professionals may be more aware of what concerns people with COPD have. If at any point you feel uncomfortable with any of the questions I ask, you may chose to refuse to answer the question, or ask to have the tape recorder turned off.

At the end of the interview, the tape recordings will be made into notes. Your name will not appear on any of the notes, tape recordings, or forms you fill out. Codes will be assigned to each set of information. All the information which will be gathered will be kept in a locked cabinet. My research supervisors may request

to see the interview notes or information I have gathered from the forms or your chart.

The findings of the study may be published. Any information that is published will be written in a manner so that what you have said will not be linked to you.

Your participation in this study is voluntary and you may withdraw at any time without any penalty or risk to any care you receive. Should you agree to participate, you will be asked to sign a consent form prior to the interview. I will give you a copy of the consent form now for you to review. If you are interested in the results of the study, I will send you a summary of the findings.

Do you have any questions you would like to have answered about the study? If you are interested in volunteering, may I review the requirements of the study with you? In order for you to volunteer for the study you must be:

1. medically diagnosed with chronic obstructive pulmonary disease in the form of emphysema, chronic bronchitis or combinations of asthma, chronic bronchitis and emphysema.
2. able to read, write and understand English.
3. live within the city of Winnipeg.
4. give your written, informed consent.
5. eighteen years of age and older.

6. feeling well at the time of the interview
7. able to talk with me without becoming too short of breath

If you are still interested in participating in my study, I would like to arrange a time and place where I can meet with you. Thank-you for your time and consideration. If you develop any further questions or concerns, please contact me.

Appendix J
Consent Form

I _____, volunteer to participate in a study entitled " A Study of the Concerns of People with Chronic Obstructive Pulmonary Disease". I have been given a verbal and written explanation of the study.

Elizabeth Borycki, R. N., a student in the Masters of Nursing program in the Faculty of Nursing at the University of Manitoba is conducting a study in order to explore the concerns of people with COPD living in the community. The study is being supervised by faculty from the University of Manitoba: Dr. Karen Chalmers (474-9315), and Professor David Gregory (474-9317) of the Faculty of Nursing and Dr. Barry Trute (474-9798) of the Faculty of Social Work.

I understand that Elizabeth Borycki will examine my chart for information regarding my breathing tests (pulmonary function tests) and will interview me twice for a total period of approximately two hours regarding the concerns I have about my disease and how my disease has affected my lifestyle. The interviews will be tape recorded, and our conversation on the tape will be typed up. I will answer a few short questions in order to complete a short form that asks for background information about myself.

I understand that the information I provide will be kept strictly confidential and only Elizabeth Borycki will have access to my name and information which may identify me. My name will not be used in relation to the information gathered in the study report or any publications from the study. All notes, tapes and forms will be kept in a locked cabinet.

I realize that I may become short of breath or tired during the interview. If I become short of breath or tired, I understand that I can tell the researcher to stop

the interview for a rest or continue the interview at another date and time. I am aware that if the researcher believes I am short of breath or tired, she will stop the interview for a rest or continue the interview at another date and time. If I feel uncomfortable in answering any questions during the study, I am free to have the tape recorder turned off, refuse to answer any questions, or withdraw from the study at any time without any repercussions or effects on my health care.

The findings of the study will be summarized and may be published at some future date. I can receive a summary of the findings.

I understand I can call Elizabeth Borycki, by telephone, at ***-****, or write to her at ***** at any point in the study. I understand I can ask Elizabeth Borycki questions about the study at any time and will receive answers.

I understand that I will not personally benefit from the study, but that the information gathered in the study may help health care professionals to care for other individuals affected by COPD in the future. I understand that my participation in this study is voluntary and I am free to refuse or withdraw from the study at any point without risking any care I will receive.

I have received a copy of this consent form. My signature indicates my willingness to participate in the study.

Date

Participant

Researcher

.....
I would like a summary report of the findings:

_____ Yes _____ No

Please mail the summary of my findings to:

Name: _____

Address: _____

Appendix K

Demographic Data Form

Administered at the end of the first interview.

I have a short form I would like to you to help me complete. This form will tell me a little background information about yourself. If you do not feel comfortable with answering any of these questions, I can skip the question and move on to the next question.

Could you please answer the following questions.

1. What is your age? _____

2. Are you:

Retired _____ Employed _____ Full-time _____ Part-time _____

3. What is (was) your occupation? _____

4. What is your highest education?

less than high school _____

high school diploma _____

community college _____

university _____

other _____

5. Are you:

Married_____ Single_____ Divorced_____

Who lives in your home with you?

Can you please list the individuals and their relationship to you?

1.

2.

3.

4.

6. How long have you been diagnosed with your respiratory disease?_____

7. Do you presently smoke?

Yes_____ No_____

8. Did you smoke in the past?

Yes_____ No_____

9. If yes, to either of the above questions:

10. How long have you been smoking or have you smoked?_____

11. Do you presently use oxygen?_____

12. If yes:

What is your prescription for oxygen?_____L/min

13. What is your annual household income?

less than \$10 000

\$10 000-19 999

\$20 000-29 999

\$30 000-39 999

\$40 000-49 999

\$50 000-59 999

\$60 000-69 999

\$70 000-79 999

\$80 000-89 999

\$90 000-99 999

\$100 000 and over

14. Source of Present Income:

15. Do you have enough financial resources to meet your needs?

All my needs are met_____

I sometimes find all my needs are not met_____

I find my needs are not being met_____

Demographic Data Form

Literature Support for Questions Asked

Administered at the end of the interview.

I have a short form I would like you to help me to complete. This form will tell me a little background information about yourself. If you do not feel comfortable with answering any of these questions, I will skip the question and move on to the next question.

1. What is your age? _____

COPD is primarily diagnosed when the individual reaches his or her middle to late fifties (Kanner, 1989, p. 173), but with advancing age disability increases (Kanner, 1987; Tames, 1991).

2. Are you:

Retired _____ Employed _____ Full-time _____ Part-time _____

Typically, a diminished respiratory reserve restricts activity forcing many individuals to seek part-time employ or early retirement (Agle & Baum, 1977; Barstow, 1974; Chalmers, 1984; Dudley et. al., 1980; Prigatano et. al., 1984; Sandu, 1986; Sexton, 1981; Sexton, 1983). Forced retirement causes more emotional distress than being able to work until retirement age (Chalmers, 1984; Dudley et.al., 1980)

3. What is (was) your occupation?_____

Occupational exposure to lung irritants can be a source of chronic obstructive pulmonary disease (Holland, 1988; Tames, 1991)

4. What is your highest education?

less than high school_____

high school diploma_____

community college_____

university_____

other_____

Level of education may allow an individual to work in a position suited to the individual's physiologic capacity to do work (Barstow, 1974). This may prevent the distress associated with early forced retirement and offset possible financial problems (Agle & Baum, 1977; Barstow, 1974; Chalmers, 1984; Dudley et. al., 1980; Prigatano et. al., 1984; Sandu, 1986; Sexton, 1981; Sexton, 1983).

5. Are you:

Married_____ Single_____ Divorced_____

Who lives in your home with you?

Can you please list the individuals and their relationship to you?

- 1.
- 2.
- 3.
- 4.

Social supports can minimize or maximize the stressors experienced by affected individuals. Families who care for individuals affected by COPD can minimize the impact of physiological, psychological, and sociological stressors on the lifestyle of the individual (McNett, 1987; Sexton, 1981; Sexon & Munro, 1985). In contrast, the loss of specific roles and changes as a result of the significant others illness can prove to be a source of strain to the caregiver (Leahey & Wright, 1987; Sexton & Munro, 1985; Sexton & Munro, 1988; Shekleton, 1987)

6. How long have you been diagnosed with your respiratory disease?_____ Duration of illness serves as a means of classifying individuals affected by this disease (Sexton, 1983).

7. Do you presently smoke?

Yes_____ No_____

Smoking has been established as a primary cause of chronic obstructive pulmonary disease (Canadian Thoracic Society Workshop Group, 1992; Gross, 1990; Petty, 1990; Tames, 1991; Thurlbeck, 1990)

8. Did you smoke in the past?

Yes_____ No_____

9. If yes, to either of the above questions:

10. How long have you been smoking or have you smoked?_____

11. Do you presently use oxygen?_____

If yes:

12. What is your prescription for oxygen?_____L/min.

Oxygen has been noted to decrease the impact of several physiologic stressors and improve activity tolerance (Georgopoulos & Anthonisen, 1990; Waterhouse & Howard, 1983).

13. What is your annual household income?

less than \$10 000

\$10 000-19 999

\$20 000-29 999

\$30 000-39 999

\$40 000-49 999

\$50 000-59 999

\$60 000-69 999

\$70 000-79 999

\$80 000-89 999

\$90 000-99 999

\$100 000 and over

Note. From Perspectives on Labour and Income (p. 54) by Statistics Canada,

1993, Ottawa: author. Adapted.

14. Source of Present Income: _____

15. Do you have enough financial resources to meet your needs?

All my needs are met _____

I sometimes find all my needs are not met _____

I find my needs are not being met _____

A lack of financial resources can increase the complexity and number of concerns (Barstow, 1974; Fagerhaugh, 1986).

Appendix L

Interview Guide

Thank-you for taking the time in assisting me with my study. I will ask you to discuss your concerns and at the end of the interview I will ask you some additional questions in order to complete a short demographic form. The interview will be tape recorded. If you feel uncomfortable with any questions, you can choose not to answer the question, or you can ask to have the tape recorder turned off. If you become short of breath, tired or you feel you cannot complete the interview today, please tell me and I will stop the interview and we can arrange another time and place to complete the interview.

Interview Guide

Chronic obstructive pulmonary disease can cause many changes in an individual's life which may become concerns.

1. Can you tell me what chronic obstructive pulmonary disease (COPD) means to you?
2. Can you think back to when you were diagnosed? When was this?
3. Tell me how COPD has altered your life since you were first diagnosed?
4. What do these changes mean in your life?
5. How do you feel about these changes?

6. Can you tell me about some key concerns you have in relation to COPD?

Probes:

Shortness of Breath

Can you tell me about your shortness of breath ?

Tell me about how you feel when you become short of breath?

Does the shortness of breath prevent you from participating in activities you did
before you were diagnosed?

Tell me how you feel when you cannot participate in activities?

Does the shortness of breath prevent you from going out with your family and
friends?

Tell me what it means to you if you cannot go out with your family and friends?

How does this make you feel?

Work Role

Did the shortness of breath interfere with your work?

What does retiring because of a shortness of breath mean to you?

How did (do) you feel about that?

Financial Problems

Did you find that financial problems became an issue for you and your family
after you developed your disease?

What does having financial problems mean to you?

How did you feel when this occurs?

Dietary Habits

Have you ever found the shortness of breath affects your eating habits?

What are some of the ways in which shortness of breath affects your eating habits?

Can you explain some of the changes which have occurred?

How have they affected your life?

How do you feel about your change in eating habits?

Anxiety

Are you ever anxious about your disease?

Do you ever become anxious when you are short of breath?

How has this anxiety affected your life?

Can you tell me what the anxiety means to you?

Tell me how you feel when you become anxious?

Frustration

Do you ever become frustrated in living with your disease?

Can you tell me what aspects of your disease make you frustrated?

Tell me what happens when you become frustrated with your disease?

What feelings do you have when you are frustrated?

What does frustration mean to you?

Powerlessness

Do you ever feel you have no control over your disease?

When do you feel you have no control?

What makes you feel as if you have no control?

How does not having control make you feel?

Emotions

Have you ever felt you could not express your feelings because you would get
short of breath?

When does this happen?

How does this make you feel?

Can you tell me what it means to you not to be able to express your feelings?

Limitations on Social Activity

Do you spend a lot of time going out with family and friends?

What kinds of activities do you participate in?

Since your diagnosis are there some activities you no longer participate in?

What are those activities?

How did you feel when you could not participate in activities with friends and family?

Tell me what this has meant to you?

Fatigue and Sleep

Do you find yourself getting tired more often since you have been diagnosed?

Can you tell me about some situations in which you become tired?

How has this affected your life?

Tell me what this has meant to you?

Have you experienced sleeplessness since you have been diagnosed?

Tell me what happens when you experience sleeplessness?

Tell me how it affects your life ?

How do you feel when you experience sleeplessness?

Cough

Do you have a cough?

Can you tell me when your coughing occurs?

How does it make you feel when you cough?

Wheezing

Does wheezing ever bother you?

Tell me about it?

How does it make you feel?

Sputum

Does sputum ever bother you?

When does sputum bother you?

Can you tell me about how sputum makes you feel?

Exacerbations

Do you find your symptoms worsen following colds or infections?

How has a worsening of your symptoms affected your life?

How does this makes you feel?

What has a worsening of symptoms meant to you?

Hypoxemia

Have you ever experienced trouble doing tasks requiring a lot of thought?

When does it happen?

Tell me about these experiences?

How did it make you feel?

What has it meant to you and your family?

Body Image

Do you use any special equipment or medications?

Can you tell me about them?

Can you tell me what it means to you to use special equipment and medications?

How do you feel when you have to use them around strangers or family?

Has your appearance changed since you have been diagnosed with COPD? If so,
in what way?

What has this meant to you?

Can you explain to me what you feel when you see the changes in your
appearance?

Roles

Can you tell me about the responsibilities you have at home and at work?

Have any of your responsibilities changed since you have been diagnosed?

Can you tell me what responsibilities have changed your home and in your
family?

Tell me about what it has meant to you to have your responsibilities change?

How did you feel when you were no longer able to perform your responsibilities?

How do you feel now when you see others performing the responsibilities you
once did?

Support Networks

Can you tell me who you seek out for support or help?

For each individual:

How often does this person provide you with support or help when you ask?

What kind of support does this person give you?

Types of support to probe:

Emotional Support

Material Aid Support

Advice and Information

Physical Assistance

Social Participation

Sexuality

Has your sexual function changed while you have had your disease?

What kind of changes have occurred?

How has this affected your relationship with your spouse or friend?

Tell me what this has meant to you?

How has this made you feel?

Depression

Have thoughts about COPD ever depressed you?

Can you tell me when you become depressed?

What happens when you become depressed?

Why do you think you become depressed about your disease?

Tell me what depression means to you?

7. Are there any concerns we have not discussed that you would like to mention and discuss?

Literature Support for Questions Asked

Interview Guide

Thank-you for taking the time in assisting me with my study. I will ask you to discuss your concerns and at the end of the interview I will ask you some additional questions in order to complete a short demographic form. The interview will be tape recorded. If you feel uncomfortable with any questions, you can choose not to answer the question, or you can ask to have the tape recorder turned off. If you become short of breath, tired or you feel you cannot complete the interview today, please tell me and I will stop the interview and we can arrange another time and place to complete the interview.

Interview Guide

Chronic obstructive pulmonary disease can cause many changes in an individual's life which may become concerns.

1. Can you tell me what chronic obstructive pulmonary disease (COPD) means to you?
2. Can you think back to when you were diagnosed? When was this?
3. Tell me how COPD has altered your life since you were first diagnosed?
4. What do these changes mean in your life?
5. How do you feel about these changes?

6. Can you tell me about some key concerns you have in relation to COPD?

Probes:

Shortness of Breath

Can you tell me about your shortness of breath?

Tell me about how you feel when you become short of breath?

Does the shortness of breath prevent you from participating in activities you did
before you were diagnosed?

Tell me how you feel when you cannot participate in activities?

Does the shortness of breath prevent you from going out with your family and
friends?

Tell me what it means to you if you cannot go out with your family and friends?

How does this make you feel?

(Barstow, 1974; Callahan, 1982; Chalmers, 1982; Carrieri & Janson-Bjerkle,
1986; DeVito, 1990; Gift et. al., 1986; Mahler, 1992; Parsons, 1990; Pet et.
al., 1983; Traver, 1975)

Work Role

Did the shortness of breath interfere with your work?

What does retiring because of a shortness of breath mean to you?

How did (do) you feel about that?

(Barstow, 1974; Chalmers, 1984; Dudley et. al., 1980)

Financial Problems

Did you find that financial problems became an issue for you family after you
developed your disease?

What does having financial problems mean to you?

How did you feel when this occurs?

(Barstow, 1974; Chalmers, 1984; Davis, 1981; Dudley et. al., 1980; Fagerhaugh,
1986)

Dietary Habits

Have you ever found the shortness of breath affects your eating habits?

What are some of the ways in which shortness of breath affects your eating
habits?

Can you explain some of the changes which have occurred?

How have they affected your life?

How do you feel about your change in eating habits?

(Gift et. al., 1986; Webster & Kadah, 1991; Wilson et. al., 1986)

Anxiety

Do you ever anxious about your disease?

Do you ever become anxious when you are short of breath?

How has anxiety affected your life?

Can you tell me what anxiety means to you?

Tell me how you feel when you become anxious?

(Agle & Baum, 1977; Agle et. al., 1973; Barstow, 1974; Chalmers, 1984; Carrieri

& Janson-Bjerklie, 1986; Janson-Bjerklie et. al., 1986; Dudley et. al., 1973;

Dudley et. al., 1980; Fagerhaugh, 1986; Gift et. al., 1986; Mahler, 1992;

Parsons, 1990; Sandu, 1986; Traver, 1974)

Frustration

Do you ever become frustrated living with your disease?

Can you tell me what aspects of your disease make makes you frustrated?

Tell me what happens when you become frustrated with your disease?

What feelings do you have when you are frustrated?

What does frustration mean to you?

(Chalmers, 1984)

Powerlessness

Do you ever feel you have no control over your disease?

When do you feel you have no control?

What makes you feel as if you have no control?

How does not having control make you feel?

(Chalmers, 1984)

Emotions

Have you ever felt you could not express your feelings because you would get
short of breath?

When does this happen?

How does this make you feel?

Can you tell me what it means to you not to be able to express your feelings?

(Agle et. al., 1973; Carrieri & Janson-Bjerklie, 1986; Dudley et. al., 1980; Dudley
et. al., 1964; Dudley et. al., 1973; Fagerhaugh, 1986; Post & Collins, 1981-82;
Sandu, 1986)

Limitations on Social Activity

Do you spend a lot of time going out with family and friends?

What kinds of activities do you participate in?

Since your diagnosis are there some activities you no longer participate in?

What are those activities?

How did you feel when you could not participate in activities with friends and
family?

Tell me what this has meant to you?

(Agle & Baum, 1977; Agle et. al., 1973; Fagerhaugh, 1986; Prigatano et. al.,
1984)

Fatigue and Sleep

Do you find yourself getting tired more often since you have been diagnosed?

Can you tell me about some situations in which you become tired?

How has this affected your life?

Tell me what this has meant to you?

Have you experienced sleeplessness since you have been diagnosed?

Tell me what happens when you experience sleeplessness?

Tell me how it affects your life ?

How do you feel when you feel sleeplessness?

(Barstow, 1974; Chalmers, 1984; Carrieri & Janson-Bjerklie, 1986; Dudley, 1981;

Dudley et. al., 1973; Fagerhaugh, 1986; Kinsman et. al., 1983; Mahler, 1992;

Parsons, 1990; Sexton, 1983; Sexton & Munro, 1988; Graydon & Small,

1992; McSweeney et. al., 1982; Prigatano et. al., 1984; Trask & Cree, 1962;

Traver, 1975)

Cough

Do you have a cough?

Can you tell me when your coughing occurs?

How does it make you feel when you cough?

(Callahan, 1984; Kinney, 1967; Kniesl & Ames, 1987; Pet et. al., 1983; Traver, 1975; Webster & Kadah, 1991)

Wheezing

Does wheezing ever bother you?

Tell me about it?

How does it make you feel?

(Fuhs & Stein, 1976; Pet et. al., 1983; Webster & Kadah, 1991)

Sputum

Does sputum ever bother you?

When does it occur?

Can you tell me about how it makes you feel?

(Dudley, 1981)

Exacerbations

Do you find your symptoms worsen following colds or infections?

How has a worsening of symptoms affected your life?

How does this makes you feel?

What has a worsening of symptom meant to you?

(Anthonisen et. al., 1987; Friedman, 1968; Rhodes, 1987; Sherman et. al., 1991)

Hypoxemia

Have you ever experienced trouble doing tasks requiring a lot of thought?

When does it happen?

Tell me about these experiences?

How did it make you feel?

What has it meant to you and your family?

(Krop et. al., 1973; Krop et. al., 1977; McSweeney et. al., 1982)

Body Image

Do you use any special equipment or medications?

Can you tell me about them?

Can you tell me what it means to you to use special equipment and medications?

How do you feel when you have to use them around strangers or family?

Has your appearance changed since you have been diagnosed? If so in what way?

What has this meant to you?

Can you explain to me what you feel when you see the changes in your
appearance?

(Agle & Baum, 1977; Agle et. al., 1986; Barstow, 1974; Dudley, 1981; Dudley et.

al., 1980; Hahn, 1989; Hanson, 1982; Hargreaves, 1968; Kravetz, 1982)

Roles

Can you tell me about the responsibilities you have at home and at work?

Have any of your responsibilities changed since you have been diagnosed?

Can you tell me what responsibilities have changed in your home and in your family?

Tell me about what it has meant to you to have a change in responsibilities?

How did you feel when you were no longer able to perform your responsibilities?

How do you feel now when you see others performing your responsibilities?

Tell me about your feelings?

(Barstow, 1974; Chalmers, 1984; Post & Collins, 1981-82)

Support Networks

Can you tell me who you seek out for support or help?

For each individual:

How often does this person provide you with support or help when you ask?

What kind of support does this person give you?

Types of support to probe:

Emotional Support

Material Aid Support

Advice and Information

Physical Assistance

Social Participation

Note. From "The Perceived Support Network Inventory" by E. J. Oritt, S. C. Paul
& J. A. Behrman, 1985, American Journal of Community Psychology, 13(5),
pp. 579-580. Adapted.

Sexuality

Has your sexual function changed while you have had your disease?

What kind of changes have occurred?

How has this affected your relationship with your spouse or friend?

Tell me what this has meant to you?

How has this made you feel?

(Agle & Baum, 1977; Dudley et. al., 1980; Hahn, 1986; Hanson, 1982; Kniesl &
Ames, 1987; Sandu, 1982; Sexton & Munro, 1981)?

Depression

Have thoughts about your disease depressed you?

Can you tell me when you become depressed?

What happens when you become depressed?

Why do you think you become depressed?

Tell me what depression means to you?

(Barstow, 1974; Chalmers, 1984; Dudley et. al., 1973; Light et. al., 1985;

McSweeney et. al., 1982; Prigatano et. al., 1984)

7. Are there any concerns we have not discussed that you would like to mention and discuss?

Appendix M

The Perceived Support Network Inventory

Perceived Support Network Inventory

The support we receive from family, friends, professional helpgivers, and others during times of stress seems to play an important role in determining our reaction to that stress. The interaction that we have with support individuals appears to help us

feel better faster after flunking an exam, losing a job, or experiencing conflict with someone. This questionnaire attempts to gather information about your perceptions and experiences with your support network in response to stressful events that have occurred in your life.

SUPPORT NETWORK

Write the first name and last initial of all the people you would go to if you needed support or help during a stressful time in your life. Check the appropriate column that describes

your relationship with each person¹. You do not have to fill out this list in any order. You do not have to use all the spaces available.

First name, last initial	Spouse or Partner	Family Member	Friend	Co- Worker	Professional Helpgiver	Religious Leader	Self-help group member

HELPING BEHAVIORS

Support from people during stressful times can be broken down into five categories of helping behaviors:

- a) Emotional support - someone listening to your private thoughts and feelings regarding a stressful event and/or giving you physical affection.
- b) Material aid support - someone lending you money or the use of some valuable object like a car or an appliance during a stressful event.

- c) Advice and information - someone suggesting what to do or where to get needed information during a stressful event.
- d) Physical assistance - someone helping with jobs around the house, errands, or favors you might need during a stressful event.
- e) Social participation - someone offering you the opportunity to engage in pleasant social activities during a stressful event.

SUPPORT NETWORK INFORMATION

On the following pages are questions about the people whose names you wrote down on the Support Network list. Please write the first name and last initial of the first person you listed and answer the questions about him/her. Then write the first name and last

initial of the second person you listed and answer the questions about him/her. Go through your entire Support Network list.² Each set of questions for each person takes less than a minute to answer, so the following pages will not take you long.

First name, last initial _____

Rate the extent to which you agree with the following statements by circling the appropriate numbers:

	Almost never		Sometimes		Usually		Almost always
<u>During times of stress:</u>							
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support or help	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support

_____ d) Physical Assistance

_____ b) Material Aid Support

_____ e) Social Participation

_____ c) Advice and Information

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

¹When the model of perceived social support was being developed, the authors considered including a proportion of relationship category as a component variable. However, there was little research supporting its relevance to the model. It was included in the instrument to test exploratory hypotheses about its relationship to perceived social support and other constructs in future studies.

²There are twelve groups of statements, one for each network member listed. For brevity's sake, only one group of statements has been presented here. Copies of the entire instrument are available from the first author.

Note. From "The Perceived Support Network Inventory" by E. J. Oritt, S. C. Paul

& J. A. Behrman, 1985, American Journal of Community Psychology, 13(5), pp.

579-580. Adapted.



UNIVERSITY OF MANITOBA

Appendix N

Ethical Approval

FACULTY OF NURSING

Room 246 Bison Building
Winnipeg, Manitoba
Canada R3T 2N2Tel.: (204) 474-8202
FAX: (204) 275-5464

November 3, 1993

Elizabeth Borycki

Winnipeg, MB

R

Dear Ms Borycki:

The Faculty of Nursing Ethical Review Committee reviewed your thesis proposal, "A study of the concerns of people with chronic obstructive pulmonary disease (COPD)," at the November 1, 1993, meeting. No major concerns of an ethical nature were identified. Two minor points of an ethical nature were identified:

- (1) explanation/invitation to participate is very thorough and complete, but a little repetitious and lengthy. Recommend that this be combined with consent and abbreviated. Given the fact that these subjects have particularly limited energy resources due to dyspnea--simple and brief communication exchanges are encouraged, and
- (2) please indicate in explanation/consent that project has been approved by the Faculty of Nursing Ethical Review Committee.

I leave these minor changes to you and your Committee to address. Enclosed, you will find a form granting formal ethical approval.

The Ethical Review Committee asked me to commend you for a thorough and well presented proposal. We wish you well with your research.

Yours sincerely

Linda Kristjanson, RN, PHD
Chair, Ethical Review Committee

cc: Dr. Karen Chalmers

50th Anniversary Celebrations - May 25 - 30, 1993.



The University of Manitoba

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FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#93/33Proposal Title: "A Study of the Concerns of People with Chronic Obstructive
Pulmonary Disease"Name and Title of
Researcher(s):ELIZABETH BORYCKI, R.N., HBScN
MASTER OF NURSING GRADUATE STUDENT
FACULTY OF NURSING
UNIVERSITY OF MANITOBADate of Review: NOVEMBER 01, 1993.APPROVED BY THE COMMITTEE: NOVEMBER 01, 1993.

Comments:

Date: Nov. 2/43Linda J. Kristjansson, PhD, RN
Associate Professor
University of Manitoba Faculty of Nursing

Chairperson

Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

University of Manitoba Faculty of Nursing Ethics Chair

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Revision Recruitment Request

Winnipeg, Manitoba
R

February 14, 1994.

Dr. L. Kristjanson
Co-Chair of the Ethical Review Committee
Faculty of Nursing
Bison Building, Room 245
University of Manitoba
R3T 2N2

Dear Dr. Kristjanson:

RE: A Study of the Concerns of People with Chronic Obstructive Pulmonary Disease

I am requesting a revision of the method to recruit participants in the above named study. Recruitment of participants has been slow for the following reasons:

1. The cold, an irritant to individuals affected by respiratory disease, prevents affected individuals from attending the clinic.
2. Those individuals who attend the clinic are seeking attention for exacerbations of disease. Therefore, they do not meet the study criteria.
3. The frequency with which certain prospective participants are attending clinic is limited; for example, those males and females affected by moderate forms of COPD attend the clinic less often than those affected by severe COPD.

I would like to alter the method of sample recruitment to the following:

The Assistant Head Nurse will telephone those individuals she identifies as meeting the study criteria and the needs of the sample. The Assistant Head Nurse during her phone call will briefly describe the intent of the study, the extent of required participation, ask if the individuals would consider discussing the study further with the researcher, and consider the release of their name and phone number to the researcher (See Appendix H). The Assistant Head Nurse is agreeable to identifying and telephoning possible study participants.

Subsequent to this initial telephone call, the researcher will contact the possible participant and describe the study (See Appendix I). Appendix I is essentially the same with some minor editing to reflect the change in recruitment strategy; for example, the deletion of the statement "I will give you a copy of the consent form now for you to review". If the potential participant agrees to participate, the researcher and participant will decide to meet at a mutually

agreeable time and place. The written consent of the participant will be obtained prior to beginning the first interview. At this time, the participant will also be provided with a copy of the consent form for his or her personal records. My thesis chair, Dr. Karen Chalmers, has approved these changes.

Thank-you very much for your time and consideration of this change. If you have any further questions you wish to discuss with me please call me at my home phone number *****

Sincerely,

Elizabeth Borycki

Appendix H

Assistant Head Nurse Approach of Potential Participants

The Assistant Head Nurse will telephone those individuals she has identified as meeting the study criteria and the sample needs.

The study criteria are as follows:

1. medically diagnosed with chronic obstructive pulmonary disease in the form of emphysema, chronic bronchitis or combinations of asthma, chronic bronchitis and emphysema.
2. able to read, write, and understand English.
3. live within the city of Winnipeg.
4. give you written, informed consent.
5. eighteen years of age and older.
6. feeling well at the time of the interview.
7. able to talk with me without becoming too short of breath.

The sample needs will consist of:

1. women diagnosed with moderate COPD
2. men diagnosed with moderate COPD
3. women diagnosed with severe COPD
4. men diagnosed with severe COPD

Hello, my name is _____. May I have a moment of your time to speak with you. I am calling behalf of a graduate nursing student from the University of Manitoba named Elizabeth Borycki. Elizabeth is nurse who is studying the Concerns of People with Chronic Obstructive Pulmonary Disease. She is interested in learning about the concerns of people living with chronic obstructive pulmonary

disease and the effect of this disease on their lives. Participants in the study will be asked to participate in two interviews that will each last about one hour. The interviews will be tape recorded and will be made into notes. As well participants will be asked a few questions about some background information. The participant names will not appear on any of the notes, tape recordings, or forms that will be filled out. The interviews will take place in a time and place that is convenient to both the participant and the researcher; for example, the researcher can come to your home to conduct the interviews.

Would you be interested in learning more about the study from Elizabeth.

You are under no obligation to participate. If you are interested, may I release your name and phone number to Elizabeth so that she may call you to provide you with more information about the study.

If the potential participant responds with a yes, the Assistant Head Nurse will note his name and phone number.

If the potential participant responds with a no, the Assistant Head Nurse will state that it is okay and she will thank him or her for their time.

Appendix I

Verbal Explanation of the Study

Hello, my name is Elizabeth Borycki. I am a nurse and I am currently studying at the University of Manitoba to obtain a Masters of Nursing Degree. I received your name and telephone number from -----(Assistant Head Nurse name) at the Respiratory Outpatient Clinic. Is this a good time for you to talk?

If no the individual will be asked if they would like to be called at another time.

If yes the following will explanation of the study will occur.

I am interested in understanding the concerns of people with chronic obstructive pulmonary disease (COPD). I have done a lot of reading in the last year about individuals who are affected by your disease. In doing this reading, I have learned that health professionals have identified many concerns among individuals who have COPD, but there is little information about what individuals with COPD themselves think. What I would like to do is to talk to you to find out what concerns you have about your disease and how the disease affects your life.

If you want to participate in my study, you will be asked to participate in two interviews that will last about one hour. The interviews will be tape recorded. You will also be asked to answer few short questions so I can fill out a short form that gives me some background information about you.

The study will be of slight risk to you, since in some cases shortness of breath or being tired is sometimes a problem for people with your disease. If during the interview, I see you becoming short of breath or tired, I will stop the interview for you to rest or to arrange to spread the interviews over three sessions.

If during the interview, you feel tired or short of breath, please tell me so I can stop the interview for you to rest or arrange to spread the interviews over three sessions.

I hope to be able to compile the information from all the people I speak to and present it to health professionals such as doctors, nurses, physiotherapists. In doing this, health professionals may be more aware of what concerns people with COPD have. If at any point you feel uncomfortable with any of the questions I ask, you may choose to refuse to answer the question, or ask to have the tape recorder turned off.

At the end of the interview, the tape recordings will be made into notes. Your name will not appear on any of the notes, tape recordings, or forms you fill out. Codes will be assigned to each set of information. All the information which will be gathered will be kept in a locked cabinet. My research supervisors may request to see the interview notes or information I have gathered from the forms or your chart.

The findings of the study may be published. Any information that is published will be written in a manner so that what you have said will not be linked to you.

Your participation in this study is voluntary and you may withdraw at any time without penalty or risk to any care you receive. Should you agree to participate, you will be asked to sign a consent form prior to the interview. If you are interested in the results of the study, I will send you a summary of the findings.

Do you have any questions you would like to have answered about the study? If you are interested in volunteering, may I review the requirements of the study with you? In order for you to volunteer for the study you must be:

1. medically diagnosed with chronic obstructive pulmonary disease in the form of emphysema, chronic bronchitis or combinations of asthma, chronic bronchitis and emphysema.
2. able to read, write, and understand English.
3. live within the city of Winnipeg.
4. give you written, informed consent.
5. eighteen years of age and older.
6. feeling well at the time of the interview.
7. able to talk with me without becoming too short of breath.

If you are still interested in participating in my study, I would like to arrange a time and place where I can meet with you. (Arrangements to meet will be made at this point if the participant agrees). Thank-you for your time and consideration. If you develop any further questions or concerns, please feel free to contact me at my home address ***** or the telephone number



Revision of Recruitment Approval

THE UNIVERSITY OF MANITOBA

FACULTY OF NURSING

Room 246 Bison Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel.: (204) 474-8202
FAX: (204) 275-5464

February 25, 1994

Elizabeth Borycki
Winnipeg, Manitoba
R

Dear Ms. Borycki:

RE: A study of the concerns of people with chronic obstructive pulmonary disease

Thank you for your recent letter updating the Ethical Review Committee regarding the proposed revision to your subject recruitment procedure. I have reviewed the proposed changes and note no problems of an ethical nature. The prior ethical approval granted remains in effect.

I wish you well with the study and hope that subject recruitment will proceed smoothly with this change.

Yours sincerely,

Linda J. Kristjanson, RN, PhD
Chair, Ethical Review Committee

cc Dr. Karen Chalmers

