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Dyspnea: A Descriptive Study

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Dyspnea: A Descriptive Study

Abstract

Dyspnea is the uncomfortable sensation of feeling breathless. It is not a sign that can be assessed by the observer, such as, rapid respiratory rate or the use of accessory muscles. Perplexingly, an individual may exhibit these clinical signs, associated with breathlessness and yet, may or may not, feel dyspneic. Similarly, the physiological data used to determine inadequate ventilation and perfusion is not always an accurate determinant of perceived breathing comfort.

An exploratory, descriptive study using a semi-structured interview was conducted to determine patients' interpretation of their dyspnea in terms of description, changes in their lifestyle and coping strategies used. A convenience sample of 15 subjects was used; seven had the diagnosis of congestive heart failure and eight had the diagnosis of chronic obstructive pulmonary disease. Activity level was determined by the American Thoracic Society Grade of Breathlessness Scale. Tools to measure levels of social dependency and perceived acuity of breathlessness were also used.

The experience of breathlessness was described by cardiac subjects as having a more spontaneous onset. Breathlessness appeared similar in both groups in terms of trigger mechanisms except that pulmonary subjects listed more irritants and allergens. The most universal physiological correlate that accompanied dyspnea in both groups was dizziness and weakness described by 12 of the 15 subjects.

The major adaptive tasks described by both groups were as

follows: 1) decreasing activity both immediately when dyspneic and chronically, 2) managing feelings of anxiety, guilt and frustration due to inability to perform former roles and losing independence, and 3) managing the fear and anxiety associated with breathlessness.

Adaptive tasks managed by the pulmonary group were more numerous and included managing feelings of anxiety, depression, frustration and isolation. Appearance, personal values and lifestyle were also subject to more change.

Pulmonary subjects described more isolation that functioned not only as an adaption to their breathlessness but also as a means to cope with it.

Cardiac subjects' rating of their usual breathlessness was less than that of pulmonary subjects, although their rating of their worst breathlessness was higher than that of the pulmonary group.

Pulmonary subjects demonstrated greater levels of dependency in areas of physical and social competency.

This study identified variables involved in the experience of dyspnea to be tested in future correlational investigations.

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Chapter I: The Study Problem

Problem Area

Dyspnea is the uncomfortable sensation of feeling breathless. It is not a sign that can be assessed by the observer, such as, rapid respiratory rate or the use of accessory muscles. Perplexingly, an individual may exhibit these clinical signs, associated with breathlessness and yet, may or may not, feel dyspneic. Similarly, physiological data used to determine inadequate ventilation and perfusion is not always an accurate determinant of perceived breathing comfort. For example, there is no single pulmonary function test or arterial blood gas measurement that correlates with how short of breath the person with chronic obstructive pulmonary disease may feel (Comroe, 1966; Frankstein, 1979). Thus, the subjective awareness of shortness of breath for those with cardiac failure does not always parallel the physiological correlates of their disease (Rapaport, 1974).

The pathology responsible for causing shortness of breath may vary from the premature collapse of airways of chronic obstructive pulmonary disease to the engorged pulmonary vasculature caused by congestive heart failure. Many different physiological trigger mechanisms have been hypothesized to cause the sensation of dyspnea.

However, it is the psychological interpretation of the feeling of breathlessness that may differ between individuals regarding how they describe it, how they have coped with it, how it affects their lifestyle and the emotional triggers involved. It is the marked

subjectivity of the symptom which has made it extremely difficult to describe, categorize, measure or predict dyspnea.

Significance

The number of individuals who experience breathlessness is increasing. The American Lung Association estimates that each year approximately 450,000 new patients are diagnosed with chronic obstructive lung disease (COPD). In addition, it is currently estimated that 15,000,000 persons are affected with COPD in the United States. In 1973 over 400 million dollars was paid in Social Security disability to those with COPD. Loss to the economy in illness and death was approximately 8.6 billion dollars a year in 1972 (White, Andrews, Mogan & Downs-Vogel, 1979). The increase in cigarette smoking and air pollution coupled with a growing geriatric population serve to augment the numbers of persons who will experience breathlessness due to lung disease or cardiac disease.

Shortness of breath is a problem frequently encountered by patients. It is difficult to develop effective assessment and intervention methods because of the subjective nature of dyspnea. Typically, the clinical and objective signs of breathlessness are assessed by the nurse and appropriate interventions are planned. However, the nurse possesses few tools with which to assist the patient who complains of feeling short of breath. The problem is compounded when objective data, such as arterial oxygen and carbon dioxide tensions, do not show physiological cause for the discomfort of breathlessness. At the other end of the spectrum is the patient who may exhibit outward signs of respiratory discomfort such as

tachypnea and the use of accessory muscles, but denies feeling breathless.

The precise definition of dyspnea rests upon its subjective nature. It is uncomfortable, difficult, labored breathing that is perceived as unpleasant by the patient (Comroe, 1966; Dudley, 1968; Widdicomb, 1979). The difference in the experience of dyspnea that exists from one person to another needs to be studied further in order to identify the psychosocial or physiological factors that may influence the way one experiences breathlessness.

There exist many unanswered questions regarding the causes of dyspnea. As Widdicomb (1979) noted, there is a need to explore more the psychology of dyspnea, develop quantitative assessment tools, and determine if there are different dyspneic thresholds or breaking points among different conditions in which dyspnea exists. Other authors have suggested correlation between specific patient descriptions of breathlessness and pulmonary function tests (Comroe, 1966; Dudley, 1968; Widdicomb, 1979). Descriptive research would provide clinicians with the precise ways in which patients assess the near onset of dyspnea. Strategies might also be identified which are used by patients to cope with breathlessness caused by acute and chronic pathological conditions.

The differentiation of dyspnea according to underlying pathology has yet to be explored in terms of how it affects a person's lifestyle, how it is experienced and described, and what coping mechanisms are developed and utilized. For the patient in congestive heart failure, the feeling of breathlessness may or may not be

marked. Many of these persons are chronically ill with varying degrees of heart failure either due to valvular dysfunction or ischemic heart disease. Mitral stenosis is a condition in which increasing dyspnea typically prompts the person to seek medical attention. However, the point at which this behavior occurs may vary greatly from person to person. For example, dyspnea may interrupt one person's lifestyle earlier in comparison to other individuals'. This variation could be due to several factors, such as: 1) differences in activity levels, 2) perception thresholds, 3) coping mechanisms, 4) support systems (family or friends) or, 5) the use of denial.

Is the dyspnea that accompanies heart failure the same as that of COPD in terms of sensation, trigger mechanisms and alleviating factors? Are there differences in the day to day strategies used to cope with dyspnea? These are questions whose answers have great implications for improving the care of persons experiencing breathlessness. Systematic, purposefully gathered information describing patients' perception of the experience of dyspnea, will enable health care professionals to better understand, measure, predict, and manage the symptom of dyspnea.

Purpose of the Study

There are two purposes of this study, as follows:

1. The primary purpose of this study is to describe patients' interpretation of their dyspnea in terms of description, changes in their lifestyle and coping strategies used.

2. The secondary purpose is to compare the cardiac patient

with the COPD patient to determine if differences exist.

Specific Aims

Objectives of the study are the following:

1. To elicit patients' descriptions of their dyspnea and its specific surrounding and prodromal circumstances, such as causation, duration and resolution.
2. To identify adaptive tasks used in dealing with their dyspnea.
3. To identify the coping skills used by patients.
4. To compare and contrast the existence of patterns across pulmonary and cardiac disease states in the descriptions of dyspnea, adaptive tasks, and coping skills.

Chapter II: Theory and Review of Literature

Conceptual Framework

A study focusing on the experiences of dyspnea requires a multi-dimensional conceptual framework. Although numerous studies have sought singular physiological correlates or predictors of dyspnea, their findings have been inconsistent. More recently, studies have shown that it is a combination of physiological, sociological and emotional factors that determine how one perceives and experiences dyspnea.

Moos (1977) proposed a conceptual framework for understanding the crisis of physical illness. This framework can be used to examine those variables related to the symptom of dyspnea. Included is an assessment of personal, illness-related, and environmental factors followed by an analysis of perceptual, adaptive and coping skills that all interact to determine the "outcome of crisis". This framework provides a mode for studying the symptom of dyspnea at the descriptive level. Thus the relationship of pertinent variables and individual styles of coping may then be determined through further research across different disease states.

The current acceptance of the important effects of psychological factors on physical illness has evolved through the concepts of behavioral medicine and crisis theory.

Lazarus (1974) examined individual cognitive appraisal of threat. The perception of the threat and its significance was thought to be more important than the threat itself. Both

approaches to the field of coping serve to further emphasize the role of psychosocial factors in the following: 1) etiology of disease, 2) onset of symptoms, 3) illness experience; involving the course, resolution, and response to treatment, 4) utilization of health care; and, 5) compliance with medical regimen (Moos, 1977).

Kaplan's (1964) classic crisis theory is based on a person's need for biopsychosocial equilibrium. A crisis occurs when homeostasis is interrupted and normal responses are inadequate. Anxiety, fear and guilt typically accompany states of disequilibrium and some method of resolution is sought. Resolution may be a healthy adaptive response or a maladaptive one.

Physical illness and its accompanying symptomatology represent a life crisis. It represents a threat to equilibrium which may be acute, chronic or intermittent thereby posing a life crisis. Moos incorporates both theories in his framework which summarizes the events and variables that -determine the outcome of the crisis.

Figure 1 illustrates Moos' conceptualization of physical illness as a life crisis. General determinants of outcome are grouped under three categories. The first is background and personal factors. It includes age, level of intelligence, cognitive and emotional development, religious beliefs, previous coping experience and timing of illness.

The second category includes illness-related factors. Examples are as follows: 1) pathology; 2) type and location of symptoms; 3) painful, disfiguring or disabling effects of the symptom;

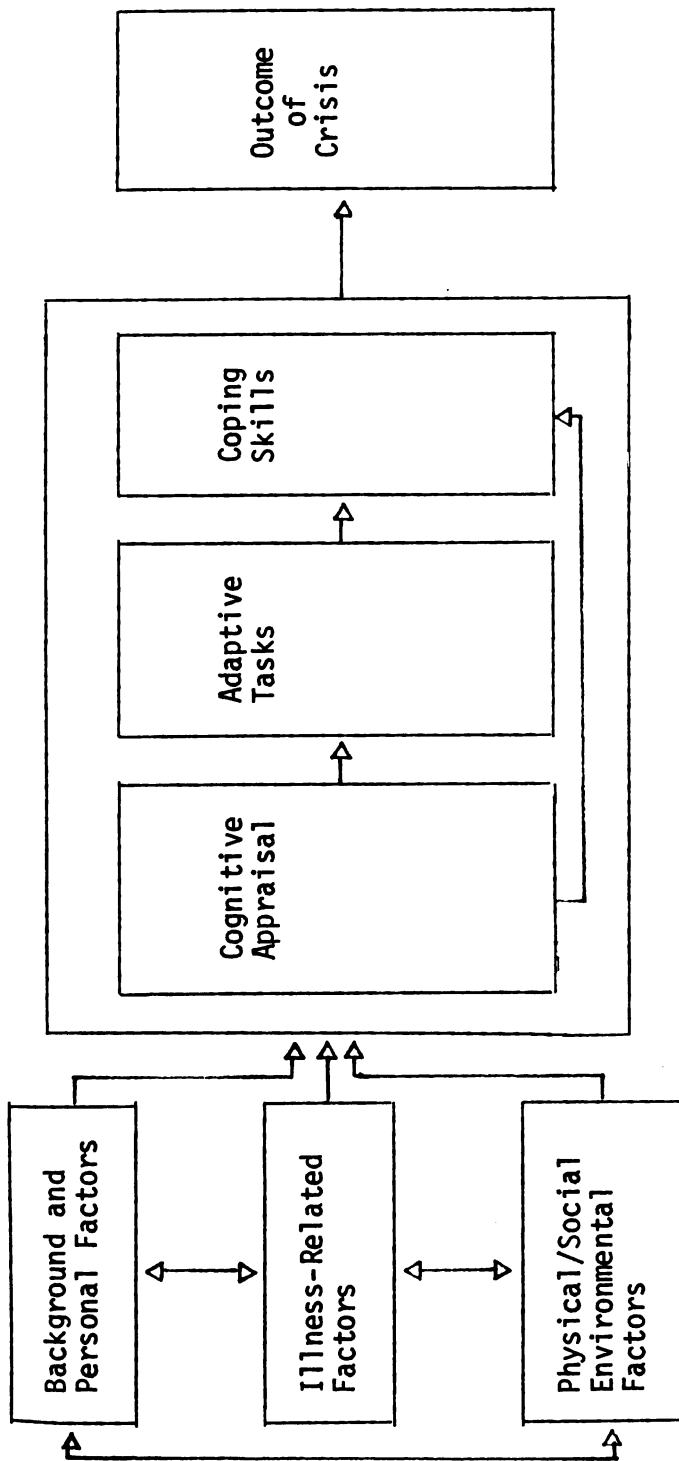


Figure 1. A conceptual model for understanding the crisis of physical illness from: Moos, R., and Tsu, V. The crisis of physical illness: An overview. In R. Moos (Ed.), Coping with physical illness. New York: Plenum Medical Book Co., 1977, p. 16.

4) special importance vested in body region affected; 5) physiological effects that decrease coping ability such as extreme weakness; and 6) rate of onset and general progression of the disease.

Physical and social environmental factors constitute the third category. Important factors include the following: 1) general esthetic qualities of the environment whether it be home or hospital, 2) the amount of personal space, 3) degree of sensory stimulation, 4) family and health professional relationships, and 5) other social support, such as, in the community and the sociocultural norms or expectations.

These three groups of factors may determine variations in individual responses in times of illness. The perception of symptoms, such as dyspnea, adaptive tasks, and coping skills will be affected by these "general determinants of outcome" (Moos, 1977, p. 15).

Following a person's appraisal of the meaning of their symptomatology, adaptive tasks are undertaken. Moos (1977) divides them into seven categories:

1. dealing with an uncertain future
2. maintaining family/friends relationships
3. preserving self-image
4. maintaining an emotional balance
5. establishing relationships with caregivers
6. handling stresses of treatment modalities
7. dealing with the discomforts of the symptom (Moos, 1977, p. 16)

The importance of these tasks will depend upon the personality of the person, the illness-related factors and environmental factors. For example, the dyspneic patient with low self esteem, who has little social support in the way of family and friends, may encounter more difficulty when trying to maintain an emotional balance and handle his own treatment modalities and activities of daily living.

Moos defines coping skills as those strategies, either mental or behavioral, that are utilized to deal with the previously described adaptive tasks. It is the way in which they are used that determines if they are adaptive or maladaptive. Skills appropriate in one situation may be inappropriate in another. Moos (1977) summarizes them as follows:

1. denying or minimizing the seriousness of the crisis
2. seeking relevant information
3. requesting reassurance and emotional support
4. learning specific illness-related procedures
5. setting concrete limited goals
6. rehearsing alternative outcomes
7. finding a general purpose or pattern of meaning to a course of events

This framework provides a broad base from which to study those variables involved in determining how one experiences, adapts, and copes with the symptom of dyspnea.

Review of Literature

The major area of literature reviewed in this chapter will be studies examining illness-related factors of dyspnea, and the adaptive tasks, and coping skills used by persons experiencing dyspnea.

Illness-Related Factors

Pathophysiological basis of dyspnea. There are multiple theories regarding the pathophysiological mechanisms contributing to the multifactorial approach to the study of dyspnea. Proposed physiological mechanisms fall into three major categories: 1) exaggeration of normal respiratory stimuli, 2) stimulation of afferent receptors in the respiratory system, and 3) stimulation of neural receptors in the intercostal and diaphragmatic musculature (Boushey, 1981).

Normal respiratory stimuli that are exaggerated or altered may trigger dyspnea. A change in the hydrogen ion concentration in cerebrospinal fluid or arterial blood accompanied by hypoxemia causes an increase in ventilation that may cause the sensation of dyspnea. Oxygen administration is a widespread practice used to relieve dyspnea. However, Frankstein (1979) noted that hypoxemia induced in normal subjects produced euphoria then central nervous system depression, but not necessarily dyspnea unless in the presence of exercise. He also noted that hypoxemia together with hypercapnia caused dyspnea in all subjects, even in those subjects that did not complain of the sensation with only one alteration in blood gases.

Normal arterial oxygen and carbon dioxide tensions do not ensure respiratory comfort. Persons with total paralysis of respiratory muscles and normal blood gas values may complain of dyspnea until mechanical ventilation is increased 20 to 30% above normal. In these patients lung compliance is decreased due to paralysis so that larger tidal volumes are needed to sufficiently stimulate stretch receptors in lung tissue that, in turn, inhibit the respiratory center (Frankstein, 1979).

Alteration of the normal stimulation of the brain's cortical center may lead to dyspnea. The sensation of breathlessness is characteristic of persons with brain stem lesions. This may be due to the destruction of the pathways linked to structures involved in relaying the sensation of breathlessness. Air hunger has been observed in persons with lesions of the diencephalon despite normal respiratory and metabolic variables suggesting the presence of a "dyspnea center". The sensation of fear arises from within the limbic structure suggesting why respiratory discomfort is so strongly associated with fear (Frankstein, 1979). However, even though some organic brain diseases may cause objective respiratory disorders, they are not always accompanied by dyspnea.

The second category of physiological mechanisms that may trigger the sensation of breathlessness is the afferent receptors located in the respiratory musculature, chest wall, lungs and upper airways. Intrapulmonary receptors may be stimulated to increase ventilation. Pulmonary stretch receptors located in bronchial airway smooth muscle are activated by long distention via the vagal

nerve. Their stimulation serves to terminate the inspiratory effort. In the presence of congestive heart failure, their activity is increased creating rapid shallow breathing (Berger, Mitchell, & Severinghaus, 1977; Boushey, 1977; Raffin, 1980).

Irritant receptors, located in between the bronchial epithelial cells, respond via vagal nerve conduction to histamine release, ammonia or particulate matter in the airway with hyperpnea and bronchoconstriction (Berger, et al., 1977). Nadel (1973) and Gold (1973) suggest that the histamine released during an asthma attack stimulates these irritant receptors via parasympathetic and vagal afferent conduction causing bronchospasm and that the direct effect of histamine on bronchial smooth muscle is relatively small. Responses of these receptors are increased in conditions of pulmonary congestion, pulmonary emboli, and pneumothorax.

"J" receptors have been found in the alveolar interstitium and are stimulated by pulmonary congestion and pulmonary inflammatory disease. These receptors are thought responsible for the dyspnea noted in congestive heart failure, pneumonia, and interstitial fibrosis (Widdicombe, 1979; Widimsky, 1979).

The significance of vagal receptors has been studied extensively. Guz (1966) found that by vagal blockade in normal individuals breathholding time was increased and that there was a diminished response to carbon dioxide rebreathing. He also noted that dyspnea due to infiltrative lung disease, pulmonary vascular obstruction, left ventricular failure, asthma and panacinar emphysema was reduced by vagal blockade. Dyspnea due to chest wall disease or

bronchitis was not affected (Guz, 1966; Guz & Widdicomb, 1970).

The third category of physiological triggers is that of neural receptors in the chest wall muscle. The role of muscle spindles in the intercostal and diaphragmatic musculature has been studied by Campbell and Howell (1963). The elastic and resistive loads of breathing were experimentally increased until detected by the subject. Findings indicated that neither changes in lung volumes nor in muscle tension alone triggered the sensation of breathlessness. However, the change in the ratio of the two parameters resulted in the experience of dyspnea. Campbell and Howell defined this response as the "length-tension inappropriateness" theory. They hypothesize that it is the relationship of the degree of lengthening of the inspiratory muscles (volume of breath achieved) to the tension with which they develop (force needed to achieve the breath) that determines when one feels breathless.

If lung or chest wall resistance changes, the length-tension relationship is therefore altered and afferent impulses are sent to the cord to alter main skeletal fibers and restore "parallel" activity. Any condition which increases work of breathing or decreases compliance would thereby cause a sensation of breathlessness (Boushey, 1977; Campbell & Howell, 1963; Rapaport, 1974; Widdicomb, 1979).

Breathlessness has been found to be caused by metabolites of anaerobic metabolism in the respiratory musculature and this mechanism is labeled the oxygen cost theory (Harrison, 1950; McIlroy, 1959). However, this theory does not account for the dyspnea that

occurs in the absence of any increase in the mechanical work of breathing. In pulmonary vascular disease, for instance, normal cardiac output and adequate perfusion of the respiratory muscles did not alleviate sensations of dyspnea.

In summary, sensory input forming the sensation of dyspnea has been postulated to arise from multiple centers including peripheral and central chemoreceptors, vagal fibers from pulmonary muscle spindles, vascular receptors in the pulmonary vasculature or possibly the right heart, and neurogenic sources such as cortical centers.

The dyspnea that accompanies cardiac failure and obstructive lung disease has been described and differentiated according to the changes in lung mechanics that occur. Obstructive lung disease is marked by increased airway resistance, whereas congestive heart failure creates increased lung stiffness (Raffin, 1980; Raffin & Theodore, 1977).

In the cardiac patient, loss of compliance is a result of increased pulmonary capillary pressures due to left-sided heart failure. Engorgement of the pulmonary vasculature causes a decrease in lung compliance. This, in turn, increases the work of breathing, alters length-tension inappropriateness, and causes possible stimulation of the Hering Breuer reflex. All of these responses result in rapid, shallow respirations (Hugh, May, & Widdicomb, 1958; Rapaport, 1979). Chronic elevation of pulmonary venous, pulmonary capillary and left atrial pressures lead to interstitial and alveolar edema, further decreasing compliance and increasing work of breathing (Dines, 1976; Rapaport, 1971). Airway narrowing may also

occur due to pressure on bronchial walls.

Raffin and Theodore (1977) note that, despite differences in initial pathological origin, stiff lungs due to restrictive lung disease and cardiac failure share the same mechanisms that trigger dyspnea. Stimulation of local stretch receptors and J receptors and length-tension inappropriateness produce rapid, shallow breathing in both disease entities.

Another mechanism proposed to increase the dyspnea experienced with congestive heart failure is reduced cardiac output accompanied by decreased cerebral blood flow. Left-sided failure with decreased output may occur with aortic or mitral stenosis, cardiomyopathy and left ventricular failure due to ischemic heart disease. In contrast, studies have failed to support the occurrence of decreased cerebral blood flow as a mechanism as patients with high output failure may have dyspnea despite adequate cardiac output. However, the possibility of decreased flow to the respiratory center cannot be ruled out (Rapaport, 1971).

Patients with low cardiac output due to noncardiogenic shock may be without dyspnea. Finally, those patients who are dyspneic due to severe failure improve following rapid diuresis even though changes in cardiac output may not occur.

The onset of symptomology has been described in the literature to assist the practitioner in delineating whether the presenting symptom of dyspnea is cardiac or pulmonary in origin. Typically the dyspnea of heart failure occurs initially only on exertion but progresses until occurring at rest. Orthopnea, paroxysmal nocturnal

dyspnea, cough, anorexia, nocturia, right upper quadrant distention, distended neck veins, fatigue and dependent edema may all be accompanying symptoms of heart failure.

The dyspnea of obstructive lung disease may be extremely insidious in onset and may share many accompanying symptoms seen in cardiac failure such as exertion in the early stages, cough, palpitations, wheezing and fatigue. When a patient presents with dyspnea, the differentiation of its origin can be determined by eliciting from the patient when the shortness of breath occurs, its signs and symptoms, and alleviating factors (Raffin & Theodore, 1977; Rifas, 1980).

Rapaport (1971) noted that the absence, presence, or degree of dyspnea cannot be correlated with the physiological status of the patient. This statement was based on clinical observations; for example, there are persons with cardiac disease (and pulmonary disease) who, possibly due to their emotional make-up, fail to complain of breathlessness. At the other end of the spectrum there are those who, in the absence of disease, complain of severe dyspnea.

Physiological correlates of dyspnea. Numerous studies have attempted to correlate physiological measures of lung function to specific levels of dyspnea as perceived by the patient. The continued lack of consistency among findings emphasizes the need to study other biopsychosocial variables. As with other subjective and perception-oriented sensations such as pain and hunger, the objective quantification is difficult.

Hugh-Jones (1958) was first to describe correlations of specific changes in lung function to subjective feelings of breathlessness in patients. He suggested that it might be possible to determine the presence or absence of organic reasons for one's dyspnea. In the clinical setting, such success would allow ruling out of organic causes and point to alternative and more appropriate intervention. Using coal workers as a control group of normal subjects (N=125), a clinical and subjective estimate of the degree of dyspnea (Fletcher, 1958) was made by asking the participants five questions such as "Are you breathless at rest?" and "Are you able to walk and keep up with those persons of your age group?". Each participant was then assigned a grade of breathless, and pulmonary function tests were performed and correlations determined. A dyspneic index was developed which was defined as the ratio of the amount of air needed for a standard amount of exercise to the maximum breathing capacity. Results showed that there were cases of dyspnea occurring when ventilation was only one quarter of the maximum. This finding suggests that it may be altered chest wall or lung mechanics using greater work of breathing to move air.

A Grade of Breathlessness scale was later developed by the American Thoracic Society (1978) based on Fletcher's earlier work (see Appendix C). Five questions ascertain five clinical grades of breathlessness by asking patients to estimate their current activity tolerance in terms of walking ability either on the level or uphill. A study of 921 COPD patients (Hopewell & Turner, 1981) found a significant correlation between an increasing breathlessness score

and an increasing Sickness Impact Profile Score (SIP), a measure of the impact of illness on daily functioning. An increasing breathlessness score was also correlated with the Profile of Mood States (POMS) and a decreasing maximum power output in a one minute incremental exercise test.

McGavin, Martvinli, Naoe and McHardy (1978) correlated exercise tolerance with pulmonary function values and subjective estimates of exercise using simple walking tests. The sample consisted of 44 patients with airway obstruction and 18 with pulmonary infiltrates. Findings indicated a correlation between the distance walked in twelve minutes and the patients' own estimates of performance using an oxygen cost diagram. When shown the diagram, subjects were asked to mark the line at the point at which they felt their dyspnea would prevent them from going any further (McGavin, 1978, p. 241). A significant correlation existed between distance walked and estimates of activity performance using this diagram. The distance walked did not agree with the simple subjective estimates of how far they could walk that was obtained in a clinical history. Distance walked also correlated better with forced vital capacity than with forced expiratory volume in one second in both groups. A variation of results showed that exercise performance could not be accurately predicted from pulmonary function tests or patients' subjective estimates.

Horn (1978) developed a scale to project dyspnea at varying FEV_1 values which could be used to assess rehabilitative potential for those with COPD.

Other researchers' studies have found minimal correlation between measurements of lung function and arterial blood gases. Recently, in a major review, Frankstein (1979) suggested that physiologists have established what clinicians have long known, that is that the extent of hypoxemia and hypercapnia may not correlate in any way with breathlessness or respiratory discomfort. Dudley and colleagues (1968) attempted to identify physiologic and emotional variables associated with the report of dyspnea. No correlation was found between the occurrence of dyspnea and absolute measures of pulmonary function such as respiratory rate, minute ventilation, alveolar ventilation, tidal volume, oxygen consumption and carbon dioxide production.

Burki (1980) studied 24 patients with chronic asthma or chronic airway obstruction. Subjects were divided into two groups based on whether or not they experienced dyspnea at rest. Although results showed that breathless patients had considerably greater airway obstruction, there was a variation in values of FEV_1 , airway resistance, and FEV_1/FVC . In addition, oxygen uptake, minute ventilation and respiratory rate were not significantly different between groups. Mouth occlusion pressures were significantly higher in the breathless group signifying an increased inspiratory neuromuscular drive. The minute ventilation obtained from a given inspiratory neuromuscular output was significantly decreased. These findings support Campbell and Associates' (1961) theory of mechanical inappropriateness as a basis for dyspnea.

Adaptive Tasks and Coping Skills

Illness-related factors combined with personality and environmental factors will determine what types of alterations in lifestyle or adaptive tasks will be necessary. Coping skills will then be drawn upon to deal with the adaptive tasks.

Whether at home or in the acute care setting, one of the most frequently observed adaptive tasks of one experiencing breathlessness is that of maintaining emotional balance. States of anxiety, isolation, repression, denial, anger and despair have been observed in those experiencing dyspnea (Dudley, 1980). States of anxiety may act not only as a trigger mechanism but also as a result of breathlessness and therefore a potentiator of further dyspnea (Dudley, Glaser, Jorenson & Logan, 1980; Grossbach-Landis, 1980; Dudley, 1980; Rapaport, 1974; Rifas, 1980). Grossbach-Landis describes the "domino effect" of the anxiety-shortness of breath cycle. The response of the sympathetic nervous system to anxiety serves only to further increase work of breathing by increasing respiratory rate, muscle tension and bronchoconstriction. Coping with such a viscous circle of events is frustrating to the patient who may not possess adequate tools for self regulation of anxiety states.

Dudley (1968) reported changes of hypoventilation associated with depression and hyperventilation associated with anger and excitement. Recently, Dudley and associates (1980) identified isolation, denial and repression as the classic defenses used by chronic lung patients. The nature of chronic breathlessness affects

all aspects of one's life, for example: vocational, social, recreational, sexual and activities of daily living. Anxiety, dependency and loss of self esteem are therefore not uncommon in these patients. A correlation has been identified between the ability of one to cope with the increasing disability of COPD and the number of psychosocial assets possessed (Dudley, Wermuth, & Hague, 1973; DeAraujo, Dudley, & Holmes, 1973; Pattison, Rhodes, & Dudley, 1971; Agle, Baum, & Chester, 1973). Psychosocial assets has been defined as those qualities or conditions: a vital interest in life; adequate financial resources and housing; social support such as being loved, feeling esteemed, being part of a mutual "defense system"; ability to cope with alterations in one's environment; ability to adapt oneself to unchangeable factors in the environment; freedom from oversensitivity; congeniality, flexibility, reliability, a sense of good judgment, and ability to shoulder responsibility (Dudley, Glaser, Jorgenson, & Logan, 1980, p. 414).

Due to the frequently insidious and invisible nature of increasing breathlessness states of denial are frequently encountered. The ability to identify and measure denial is still being developed by researchers. In research with emphysemic patients, Dudley (1980) stated that denial may serve as a healthy mechanism to give the person time to gather other resources and minimize the perceived severity of his illness.

In a study of 45 patients, Lustig (1972) described COPD patients as highly anxious, socially isolated and lonely. Dudley (1980) refers to this isolationism as an "emotional straitjacket".

Any emotional change whether depression or excitement may produce dyspnea and physiological deterioration. Withdrawal becomes not only emotional but environmental as well as due to restricted mobility. Avoidance of conflict and emotional change only serves to increase the frustration, anger and despair.

In a study of 40 subjects with COPD followed over four years psychosocial assets, as measured by the Berle Index, were found to be as important as physiological assets in the success of treatment modalities (Dudley et al., 1969). The Berle Index assesses quantitatively three areas: 1) family and interpersonal relationships, 2) past performance, personality, structure and attitude of patient toward his illness and 3) objective data. Physiological variables included: vital capacity, maximal breathing capacity, maximal expiratory flow rate, arterial blood gases, respiratory rate, minute ventilation, alveolar ventilation, O₂ uptake and carbon dioxide production. After following subjects for 18 months physiologic and psychosocial values of those deceased subjects were compared to those living or hospitalized. During this time 73% (n=29) of the subjects died. The probability of death was increased in the presence of both low psychosocial and physiologic assets.

Barstow (1974) conducted a field study in which 11 persons with emphysema were interviewed in their home regarding how their disease had changed their lives and how they had coped with it. Alterations in core activities such as bathing, grooming, dressing, and eating were described as the disease and its disability progressed. Such changes included wearing loose clothing, slip on shoes and avoiding

chores that required bending over. Disturbances in mobility and social relations also occurred. Barstow found that the significant other was the single most important factor in determining adjustment to the disease.

Fagerhaugh (1973) interviewed 22 persons with advanced emphysema and identified ways these persons coped with their limited activity capabilities. Isolation was found to be a prominent defense mechanism which was used as a protective mechanism from the dyspnea caused by talking, laughing, crying. In addition, any situation causing anxiety was found to provoke dyspnea.

Mobility problems were handled by "routing" or discovering ways to travel doing daily errands that conserved energy, patients described "puffing stations" to stop and catch their breath.

Strategies utilized by those experiencing dyspnea from cardiac failure have not been studied or differentiated from those that are used by persons with lung disease. In a few selected interviews with patients having undifferentiated cardiac disease, Fagerhaugh identified some of their similarities in the experience of dyspnea with those of the emphysemic patient. Similar routing strategies were found to be used by cardiac patients to conserve energy. However, Fagerhaugh did note that if the cardiac patient misgauged his energy resources for a particular day's activities, it was more likely to be fatal as compared with the emphysemic. A major inference was that cardiac patients experience more anxiety related to misgauging their capabilities for day-to-day activities, and therefore experience different lifestyle changes. Information needs to

be elicited from patients regarding these aspects of their symptomology in order for nurses to assist patients manage dyspnea and promote increased mobility.

Patients with COPD or CHF may learn illness-related procedures in formal rehabilitation programs. These programs provide information describing strategies to relieve breathlessness. In addition, cardiac patients with congestive heart failure are instructed in monitoring their weight and degree of breathlessness so that diuretic therapy can be adjusted accordingly.

The aim of most pulmonary rehabilitation programs is to break the vicious dyspnea-inactivity cycle utilizing various treatment modalities including: breathing retraining, medications, relaxation therapy, biofeedback, behavior modification, goal setting, life change monitoring, education of patient and family and physical reconditioning. Specific panic training is utilized to give patients ways to cope with dyspnea and feel more in control of their symptomology and lives in general. Results of varying programs have shown decreased subjective complaints of breathlessness, decreased anxiety and depression, fewer breathless days, increased activity levels and general improved sense of well being (Beary & Benson, 1974; Nield, 1971; Lustig, Haas, & Castillo, 1972; Petty, Nett, & Finigan, 1969; Fishman & Petty, 1971).

General management strategies for those in congestive failure involves medications, particularly Digoxin and diuretics, sitting upright, narcotics and rest (Rifas, 1980; Rapaport, 1971).

In summary, studies differentiating the experience of dyspnea

in different disease entities remain to be explored. Differences would be expected to exist dependent upon the nature of the dyspnea, the length of time the patient has lived with it, if it is intermittent, chronic or acute and other personal, physiological or environmental factors yet to be studied.

Chapter III: Methodology

Design

An exploratory, descriptive study using a semi-structured interview (Appendix B) was conducted within the hospital setting to obtain patient descriptions of their experience with dyspnea, alterations in their lifestyle and patient management strategies. The design allows for subjective accounts by patients to elicit biopsychosocial correlates associated with the feeling of breathlessness. These correlates can be tested in future experimental studies.

Sample

The study used a convenience sample of 15 persons. Subjects were obtained from the in-patient population of a community hospital located in the San Francisco bay area. For descriptive and comparative purposes, eight subjects had the documented diagnosis of chronic obstructive pulmonary disease and seven had the diagnosis of congestive heart failure. Five of the subjects with CHF had left-sided failure secondary to mitral or aortic valve disease. One of the subjects had coronary artery disease in addition to his mitral valve disease. One subject had left sided failure due to previous myocardial infarctions and cardiomyopathy.

The sample of COPD subjects did not include pure asthmatics as pilot testing of the tools revealed that they were a separate group. Their inclusion would have created a third small comparative group that could not be handled within the scope of this study. There were, however, some bronchitics as well as emphysemics that had an

asthmatic or bronchospastic component to their symptomology. These patients were considered for participation in the study.

Definition of Terms

Dyspnea. Dyspnea is defined as the subjective uncomfortable sensation of feeling breathless.

Congestive Heart Failure. The diagnosis of CHF was based upon the presence of left sided heart failure as documented by cardiac catheterization findings. Three of the cardiac subjects also had some degree of right sided failure as evidenced by catheterization data. Two of the pulmonary subjects had right sided failure documented in their medical records by physical findings and patient history.

Chronic Obstructive Pulmonary Disease. For the purposes of this study the diagnosis of COPD included those persons with bronchitis and emphysema or a combination of both. COPD is defined as an increased lung capacity in conjunction with decreased expiratory flow rates (Comroe, 1962). This diagnosis was documented in pulmonary subjects medical records by physical exam, patient history, chest radiograph, pulmonary function tests (if performed), and arterial blood gases.

Social Dependency. The following definition of social dependency was used for purposes of this study: "the state in which patients require help or assistance from others in performing activities or roles that under ordinary circumstances adults can perform by themselves (McCorkle, 1980, p. 2).

Access to Subjects

Following approval from the Committee on Human Research at UCSF, the proposal was submitted to the Executive Medical Committee of the hospital. Following approval that the proposed research take place within that institution, written consent by one cardiologist and one pulmonary specialist provided the investigator with access to their patients.

Risk to Subjects

Risk to subjects, as noted in the consent form, included loss of privacy and possible breathlessness during the interview. Only hospital numbers were recorded to identify subject information and coded responses were locked separately to prevent loss of confidentiality as much as possible under the law. Signed consent forms were stored in University departmental files.

Procedure

Appropriate participants for the study were identified by the investigator reviewing the census information on appropriate medical floors and approaching the physician regarding the potential participant. The physician then asked verbal permission of his patient to be contacted by the investigator. Following approval by the physician and consent by the patient, the investigator met the patient to describe the study and invite their participation. Appropriate signed consent was obtained at that time (see Appendix A).

The interviews took place at a time preferred by the subject. Most took place either in the early afternoon or early evening. The interview took about one hour to complete. Three subjects with

severe dyspnea were limited in their conversational ability and were unable to complete the interview in one session. In these instances the interview was divided into sessions comfortable to the participant. With subject approval, home follow-up visits were conducted following discharge.

Subjects were not interviewed while in the Intensive Care Unit, Coronary Care Unit, or Transitional Care Unit to minimize stress during the acute stage of their illness.

There was no direct benefit to subjects in the study. However, information gained about dyspnea will be used by nurses and other clinicians to more effectively intervene and help persons to manage their dyspnea.

Instruments

Interview. A semi-structured interview was the major data collection tool. The interview contained open ended questions, such as: "How much of a problem is shortness of breath for you?"; as well as, structured questions, for example: "Does your breathlessness prevent you from doing your own shopping?". In this manner both perceptual and factual information was gathered. The interview took place either in the subject's hospital room or within their home. An atmosphere was created that encouraged personal descriptions and feelings about just how it is to live with breathlessness and how they have coped with its effect on their lives. All interviews were conducted by the investigator.

The interview, developed by Carrieri and Janson Bjerklie (1981), was pilot tested on a small sample to test feasibility. Input from

experts in the field was obtained to assure content validity.

Enforced Social Dependency Scale. The second half of the interview contained the Enforced Social Dependency Scale (ESDS) developed by McCorkle (1978) (Appendix B). The scale was developed in an effort to measure enforced social dependency produced by physical disability that results in a loss of significant roles (McCorkle, 1980). Social dependency is defined by McCorkle as "the state in which patients require help or assistance from others in performing activities or roles that under ordinary circumstances adults can perform by themselves" (1980, p. 22). Through a series of questions two areas are measured: a) physical competence which includes both self-care and mobility competency and b) social competency that includes 11 activities seen as necessary to performing as a normal social adult. These activities include: consciousness, attentiveness and memory, activity with spouse, interest in spouse, contact with spouse, work role activity, work role interest, social contact with work associates, recreational and social activities, interest in recreation and socializing, and social contact in recreation and socializing.

Operationally defined, social dependency is the sum of the individual scores for physical competence, and social competence (McCorkle, 1980). Each activity is rated using a Likert-type scale. Questions are asked about the day-to-day routines of the patient. An Interview Guide provides the investigator with standardized questions that are used to score responses.

The scale was tested on 60 subjects with advanced diseases

such as cancer. Results showed that patients were limited in social competency first, then mobility and lastly self care activities. Results of reliability was based upon an analysis of internal consistency and showed a reliability coefficient alpha of 0.90. Currently a third phase of testing is being done to determine differences in lifestyle changes experienced by patients with cancer and patients with heart disease.

Grade of Breathlessness Scale. In addition to the interview and Enforced Social Dependency Scale (ESDS) which was imbedded in the interview, two other tools were used. The first was the Grade of Breathlessness scale developed by the American Thoracic Society (ATS) (1979) which is a modified version of an earlier one developed by Fletcher (1974) (Appendix C). Five questions ascertain five clinical grades of breathlessness by asking patients to estimate their current activity tolerance in terms of walking ability either on the level or uphill. In a previous study of 921 COPD patients, a statistically significant correlation was found between an increasing breathlessness score and an increasing Sickness Impact Profile Score (SIP). The SIP is a measure of the impact of illness on daily functioning. An increasing breathlessness score was also correlated with the Profile of Mood States (POMS) and a decreasing maximum power output in a one minute incremental exercise test (Hopewill & Turner, 1981).

Dyspnea Descriptive Scale. The third instrument used was the Dyspnea Descriptive Scale (DDS) (Appendix D). It is a visual analogue scale consisting of a 100 mm line marked by increments of 10 mm from 0 to 100. Patients were asked to mark two points on the line. The

first point represents, on a scale of 1 to 100, the point that represents the worst breathlessness that they have ever experienced, whereas, the second point represents their usual, day to day, breathlessness. It is a measure of how one subjectively perceives the severity and degree of their breathlessness. This tool was given to all subjects and took approximately 3-5 minutes to administer.

Guidelines presented by Stewart (1977) for the measurement of pain using visual analogue scales and discussions of reliability and validity were used in the development of the DDS by Carrieri and Janson-Bjerklie (1981). The scale is currently being used in "Dyspnea: Critical Variables from the Patient's Perspective" (Carrieri & Janson-Bjerklie, 1981).

Respiratory Questionnaire. General background or demographic data pertinent to how persons may perceive or cope with dyspnea was collected. In addition, information such as allergies, pets in the home, medications used, smoking history was obtained. A questionnaire developed by the American Thoracic Society Respiratory Questionnaire was filled out by the subject and contained the preceding information. It took approximately thirty minutes to be completed (see Appendix E).

Subject's medical records provided necessary objective data to support the given diagnosis such as available pulmonary function tests, cardiac catheterization results, chest radiographical reports and arterial blood gases.

Data Analysis

Due to its descriptive nature, qualitative analysis was conducted on the data. Ongoing content analysis was done to detect patterns between the two groups as well as to give more specific direction to following interviews.

In addition to the analysis of themes or attitudes pertinent to living with breathlessness, specific responses to questions regarding description, adaptation and coping were sought. Such data was recorded as to the frequency and types of responses in each group. Responses from cardiac and pulmonary samples were analyzed to determine if different patterns appeared.

The theoretical framework described by Moos (1977) provides an organizational scheme within which most of the acquired data was arranged. Using this means of straight description (Schatzman & Strauss, 1973) information will be organized in classifications suggested by the theoretical model of Moos. Analytic descriptions were made to classify acquired data that did not fall within the framework posed by Moos, but instead created new classes and linkages (Schatzman & Strauss, 1973).

Chapter IV: Results

Demographic Characteristics of the Sample

Fifteen persons were interviewed for the study: 8 with chronic obstructive pulmonary disease (COPD) and 7 with congestive heart failure (CHF).

Cardiac subjects. The cardiac sample with CHF (Group C) consisted of five females and two males. Demographic data, presented in Table 1, demonstrates the mean age of 67 years with a range of 58 to 79. Two of the subjects lived alone, four with spouse and one with her two brothers. The investigator did visit two of the homes which, similar to descriptions by other subjects, were in middle class, comfortable neighborhoods. All the subjects had completed high school and roughly half had completed four years of college. All were retired except for one male subject, C7, with ischemic heart disease who was employed 30 hours a week.

Six of the cardiac subjects had valvular disease, as follows: three had mitral stenosis and three had aortic stenosis. All of these subjects had progressed to a point where they reported that their breathlessness was markedly interfering with their daily lives. All were scheduled for surgical valve replacement within two weeks following the interview.

The time between onset of symptoms and formal diagnosis varied. For example, C5 was told she had a murmur of aortic stenosis 14 years ago but remained otherwise non-symptomatic until her hospitalization one week prior to the interview. In contrast, C7 had been

Table 1. Demographic characteristics of Group C

Subject	Age	Sex	Diagnosis	Years Since Diagnosis	Marital & Living Status	Education	Occupation	Smoking History
C1	75	F	mitral stenosis, CHF	21 yrs.	W/alone	high school	retired boot stitcher	non-smoker
C2	71	M	mitral stenosis, CHF, CAD	10 yrs.	M/with wife	high school	ran service station, volunteer fireman	105 pack years
C3	58	F	mitral stenosis	21 yrs.	M/with husband	high school	ret'd dental ass't for 20 yrs.	21 years
C4	79	F	aortic stenosis, CHF	2 yrs.	S/alone	high school	homemaker	non-smoker
C5	61	F	aortic stenosis, CHF	14 yrs.	M/with husband	college education	homemaker	20 pack years
C6	66	F	aortic stenosis, cardio-myopathy	1 yr.	S/with 2 brothers	college education	retired bookkeeper for 30 yrs.	24 pack years
C7	62	M	CAD, CHF	8 yrs.	M/with wife & 3 children	college education	stockbroker 30/hr week	1½ oz. pipe tobacco per week

diagnosed 8 years previously due to shortness of breath and angina and has lived with some symptomology for that length of time.

Within the cardiac sample smoking history varied. Three were non-smokers, one pipe smoker, one previously extremely heavy smoker, and two previously light smokers. All previous smokers stated that they were currently not smoking. The mean pack year history was 24.28 for group C (pack year = years smoked X packs smoked per day).

Pulmonary Subjects. The pulmonary sample (Group P) consisted of 4 males and 4 females. Demographic data is presented in Table 2. The mean age was 72 years with a range of 64 to 82. All were married and living with their spouses except for two of the women who were widows and living alone. One had a live-in housekeeper and one had a daytime housekeeper, who helped with bathing, dressing, housework and cooking.

Educational levels varied among the pulmonary subjects. One had completed college, one had completed 2 years of college, 4 finished high school and 2 had 2 years of less of high school. Careers varied from Navy tool and die maker, auto salesman, bank appraiser, hostess, dental assistant and bank teller. All of the sample were currently retired although P2 was running an informal auto repair business in his backyard and a gunsmith shop in his garage. P2 was also the most active of the pulmonary subjects.

Formal diagnoses of the pulmonary group were as follows: Five had the diagnosis of asthmatic bronchitis, two emphysema bronchitis, and one chronic bronchitis. The length of time since diagnosis varied among the subjects. For example, diagnosis sometimes

Table 2. Demographic characteristics of Group P

Subject	Age	Sex	Diagnosis	Years Since Diagnosis	Marital & Living Status	Education	Occupation	Smoking History
P1	77	F	asthmatic bronchitis, cor pulmonale	5 yrs.	M/with husband	2 yrs. college	dental ass't, 5 yrs. retired	52 pack years
P2	68	M	emphysema bronchitis	2 yrs.	M/with wife	high school	navy tool & dye maker, retired	90 pack years
P3	76	F	asthmatic bronchitis	3 yrs.	M/with husband	high school	bank teller, retired	37 pack years
P4	64	F	asthmatic bronchitis	6 yrs.	W/with house-keeper	2 years high school	clothing clerk, retired	22 pack years
P5	70	F	emphysema bronchitis	15 yrs.	W/with house-keeper	high school	restaurant hostess, retired	64 pack years
P6	68	M	emphysema bronchitis	4 yrs.	M/with wife	high school	bank appraiser, retired	70 pack years
P7	82	M	asthmatic bronchitis, TB, cor pulmonale	27 yrs.	M/with wife	junior high	Southern Pacific Railroad, retired	non-smoker
P8	74	M	chronic bronchitis	10 yrs.	M/with wife	college	auto sales-man, retired	50 pack years

depended on the occurrence of another health problem needing medical attention which provided the opportunity for the diagnosis of lung disease to be made.

Smoking history varied. There was one non-smoker and the lightest smoker had a 22 pack year history. Four subjects had histories of between 40 and 60 pack years of smoking. The remaining two had 90 and 70 pack year histories. The subject who was a non-smoker had a history of tuberculosis and showed some scarring on chest x-ray. The mean pack years for the pulmonary group was 49.4 pack years.

In summary, the pulmonary group was older, had been symptomatic (breathless) for a longer period of time and had a heavier smoking history than cardiac subjects. Education, living and working situations were similar in both groups.

Illness Related Factors

The Symptom

Causation or trigger mechanisms: Cardiac group. Trigger mechanisms (see Appendix F) and aggravating factors were collapsed into six categories: exertion, irritants and allergens, spontaneous, emotional factors, and other.

All seven cardiac subjects reported "any kind of exertion" as a cause of breathlessness. Activities cited included walking, gardening, sexual intercourse, dressing, household chores, reaching overhead, carrying things or doing anything quickly. Specific activities involving bending over were stated as being particularly difficult such as tying or putting on shoes, gardening, and "picking

up". C5 described the progression of her dyspnea as "at first it was only with walking, now it could be any type of movement, especially if a quick one like getting up to answer the door."

Irritants such as strong paint fumes and cigarette smoke were described by two subjects as aggravating their breathlessness. Environmental factors were mentioned by one woman who had recently moved to a higher altitude. With the change in climate, she noted a marked change in her breathing and exercise tolerance. She also said the extremes of weather increased her dyspnea.

Stress and emotional upsets were cited by 4 cardiac subjects as mechanisms that triggered their dyspnea. C1 was diagnosed as having mitral stenosis 21 years ago. At that time mitral valve replacement was recommended but she refused treatment. Now, twenty years later and a week prior to mitral valve replacement, she states "I think I bring it on myself." She talks about her breathlessness happening at night while laying down, "when I worry". She continues: "It's part of getting old, I hate getting old." Another subject, C7, states that the pressures of his job worsens his breathlessness. He also states "and thinking my lifespan is not going to be what I had planned on" may be a factor aggravating his breathing.

Six subjects in the cardiac group stated that, in addition to known triggers, there were many times where it "just comes on" or "it just happens", "sometimes out of the blue that feeling would just come on" or "don't know what brought it on."

Subjects reported other factors contributing to difficulty

breathing, as the following: eating salt, taking in a lot of fluids, gaining weight and eating a large meal.

Causation of trigger mechanisms: Pulmonary group. All eight of the pulmonary subjects reported that any type of exertion could trigger breathlessness. "Anything more than a creep" or "anything more than a plain walk." Other activities listed were showering, brushing teeth, dressing, eating, household chores, vacuuming, making beds, lifting, and mowing the lawn. Bending over was also emphasized, as it was by cardiac subjects, as being particularly difficult and included activities such as tying or putting on shoes, gardening, getting to low drawers and cupboards, and household repairs like working under the kitchen sink.

P4 specified that "social things" worsened her breathing. "Social things" was the term she used to describe all the energy expending activities associated with going out. These included getting ready, getting to the car, walking from the car, talking, eating, and "general excitement."

Irritants or allergens such as cigarette smoke, cold air, perfumes, traffic exhaust, steam from the shower, and dust and pollens were listed by six of the pulmonary subjects. Temperature changes, especially going from one extreme to the other or the oppressiveness of hot weather, were particularly difficult. Environmental change, such as altitude, was cited by 2 subjects who described a dramatic increase in or onset of dyspnea upon arrival to a high altitude city. One woman said her breathlessness usually occurred out of doors.

Dyspnea could be both spontaneous and evoked. Four subjects stated that their dyspnea may happen spontaneously. The other four subjects always cited factors that brought on their breathlessness.

Emotional upsets were dyspnea triggers for four of the subjects. "I think it's a little psychological--we had a tremendous upset at our home." P5 described "fearfulness" as making her more dyspneic. From the descriptions given some depicted the physical nature of getting upset such as hyperventilation and crying or yelling. However, as P5 describes, fearfulness, without such increases in ventilation and energy expenditure, also aggravated her dyspnea.

Other aggravating factors involved eating large meals because they "push up on my diaphragm." Also, "age creeping up on you", chest infections and coughing were cited.

Prodromal Indicators: Group C and P. All seven of the cardiac subjects denied that they had any "feelings that tell you that you are about to become short of breath." C1 answers "can't tell--I know I'm bringing it on...." P4 says "no, just comes on, sometimes just awaken in the morning breathless."

Five of the eight pulmonary subjects reported some indicator of oncoming shortness of breath, such as: "I just begin to notice my breathing", "get a feeling like you're out of wind", and "start panting, have to sit up." P3 stated "sometimes I start to cough and I know a bad time is coming." P7 noted a "tight feeling, a weakness."

Description: Cardiac Group. Descriptions of the feeling or sensation of breathlessness were divided into respiratory

sensations, physiological correlates and emotional correlates.

The respiratory sensations of the cardiac subjects fell into the following four types: 1) difficult breathing, such as "can't take another breath", "fighting for air", or "can't get enough breath"; 2) "chest heaviness", resistance in chest and wheezing; 3) a feeling of chest congestion; and 4) feeling of not being able to get air in or out, or just not being able to get air out. There appeared wide variation experienced in getting air in and out of the lungs. Another subject stated that he had difficulty getting enough breath in. Only one subject described dyspnea as a localized sensation "centered right in the middle" (pointing to chest). Three subjects noted descriptions of changes in ventilation such as "huffin and puffin", "breathing deeper than usual", and rapid breathing.

Accompanying physiological sensations included "weakness", "drained feeling", "rubbery arms and legs" and "dizziness" which were noted by 5 of the seven cardiac subjects. "Tightness and pressure in the head" and "head filling up" were felt by two subjects. C2 was aware of extreme restlessness. Visual sensations such as a "kaleidoscope of colors" was experienced by C6. One subject noted "heart pounding" and one subject complained of tingling in her fingers.

Emotional correlates were only described by two of the cardiac subjects and both were vivid. C5 described it as "apprehensive, numbness in head due to fear, fearful." C6 stated she did not feel dyspneic until after she arrived at the hospital and began to walk

from the car up a grade to the emergency room entrance. She remembers immediately getting extremely breathless and became "frantic, just went crazy, felt like a maniac, gasping and shrieking to get my breath, going to pieces..."

Description: Group P. Descriptions of respiratory sensations by the pulmonary subjects were collapsed into the same four categories. The first category, difficult breathing, included seven subjects' descriptions of "fighting for breath", "felt like I'll never get another breath" and "hard time getting breath". The second area describing chest heaviness and tightness included responses from four subjects, such as "closes right up", "tight feeling", and "the more you suck in the more chest (gets) bogged down." The third category, congestion, was not described by any of pulmonary subjects. The fourth describing movement of air was mentioned by three subjects as follows: "can't get air in" or "can't grasp any air."

Specific sensations in the chest were described by P7 as "it feels awful, as if your lungs are going to turn inside out" and by P2 as "aching in both sides of lungs." Within Group P's descriptions of physiological sensations accompanying their dyspnea, 7 of the 8 subjects used terms describing weakness, dizziness, "rubbery arms and legs" or fatigue. As P6 simply stated: "You know you better stop what you are doing right now, I get slightly dizzy and weak." One subject reported experiencing "heart pounding in eyes and ears." None of the subjects noted tightness or pressure in the head. One subject reported "dots and lightening in front of your eyes."

P3, who experienced great coughing spells that aggravated her breathlessness, always felt "as though your eyeballs are pushed out of your head."

Only one subject in Group P described emotional correlates of her episodes of dyspnea saying she did get "panicky", and "the more ya struggle, the more ya struggle."

Duration. Shortness of breath lasted for no more than "a few minutes" for 4 of 7 of the cardiac subjects. Each of the eight pulmonary subjects answered differently: 1) P8 - few seconds, 2) P2 - 3 to 5 minutes, 3) P6 - 10 to 15 minutes, 4) P3 - about 20 minutes, 5) P4 - about ½ hour after Maximyst, 6) P1 - 1 to 3 hours, 7) P5 - "depends, few minutes or all day," and 8) P7 - varies a great deal, couldn't say. C5 usually experienced shortness of breath for an hour. C6 stated she only experienced breathlessness one night while in the ER for an undetermined length of time.

Pattern: Group C and P. Five cardiac subjects stated the pattern and sensations of their dyspnea were the same each time. C5 said that there was variation in the dizziness, shortness of breath, fear and time of day associated with her feelings of breathlessness. She reported that dyspneic episodes which occurred during the night were accompanied by more fear and apprehension. She also reported an increasing fear that she would not wake up and was overwhelmed by the thought of her husband being alone. She expressed the belief that fear triggered her heart to pound after laying down at night and forced her to sit up and walk about quietly in the night to get fresh air.

All eight pulmonary subjects stated the pattern of their breathlessness was the same each time in terms of sensation, prodromal indicators, trigger mechanisms, and where it occurred. Variations did occur in the length of time episodes would last (see Duration).

Overt indicators of dyspnea: Group C and P. When asked: If you couldn't tell anybody you were short of breath, how would they know? Three cardiac subjects said nobody would be able to tell, one said his wife knows due to his restlessness when he feels dyspneic. Two subjects indicated that others could tell by their increased chest movement.

Three pulmonary subjects reported that no one would be able to know when they felt dyspneic. These subjects gave detailed descriptions of how awful or "ghastly" they look when dyspneic, which included gasping, panting, and coughing. Two stated that (no matter where they are) they frequently have to lean against something when they become breathless, such as a shopping cart or even a wall.

Appendices F through J provide raw data obtained from both groups describing their experience of breathlessness.

Perception of breathlessness. Results obtained from the DDS are presented in Table 4. Cardiac subjects rated their worst breathlessness higher than pulmonary subjects (Group C: $\bar{x} = 850$; Group P: $\bar{x} = 761$). Usual breathlessness was rated highest by pulmonary subjects (Group C: $\bar{x} = 25.0$; Group P: $\bar{x} = 38.4$). These findings indicate that COPD subjects lived with a greater perceived level of breathlessness day to day. In addition the difference between the usual and worst breathlessness was greatest for cardiac subjects

(see Figure 2).

Adaptive Tasks

All subjects in both groups, with the exception of one cardiac subject, reported being confronted with at least one, and usually most of the seven adaptive tasks as described by Moos (1977).

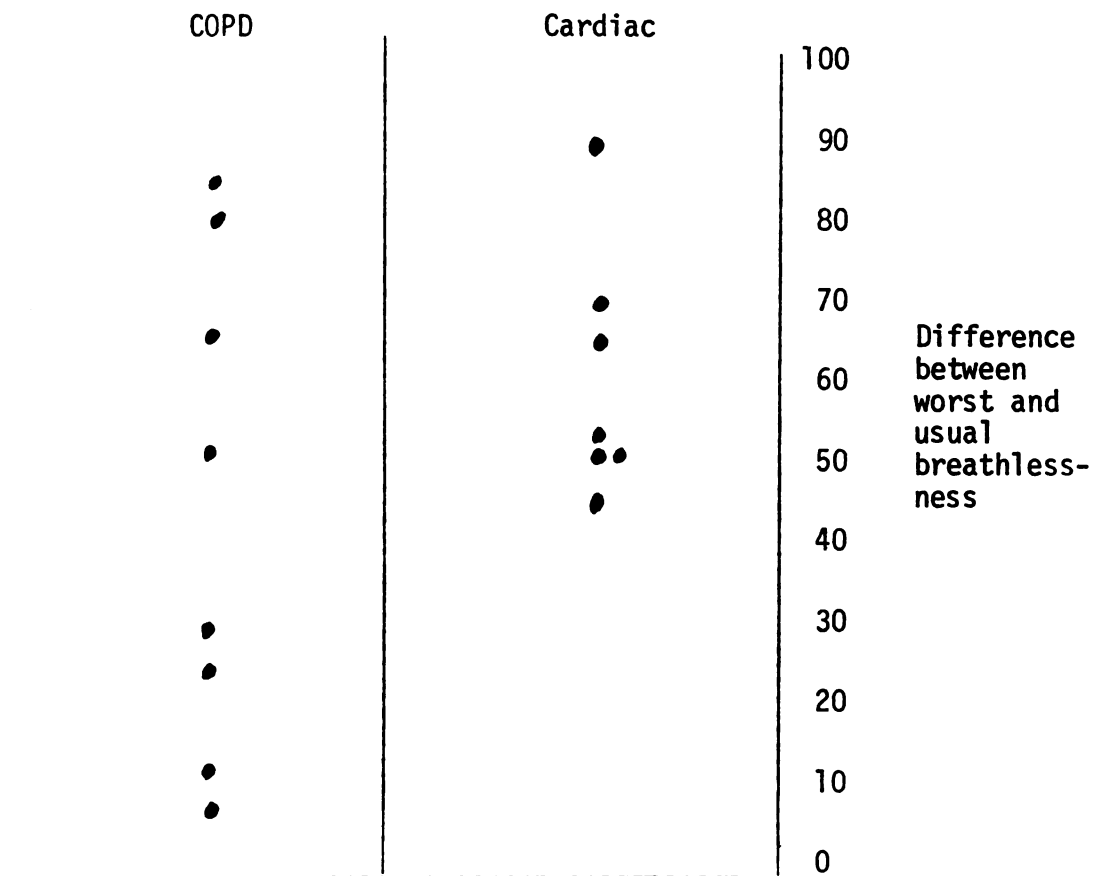
Illness-Related Adaptive Tasks

Dealing with incapacitation. Dealing with the incapacitation of dyspnea in day to day life was universal to all but one subject interviewed. The degree to which subjects were dependent on others for assistance in performing activities of daily living was measured by the Enforced Social Dependency Scale (McCorkle, 1976). Table 3 illustrates the number of subjects within each range of low to high levels of physical and social dependency. Table 4 also summarizes ESDS scores.

In the area of physical competence pulmonary subjects demonstrated a greater degree of dependency, particularly in the area of bathing, traveling and walking. In both groups walking was the physical activity most restricted.

In the area of social competence pulmonary subjects also scored the greatest degree of restriction. Scores within the 2 categories of activity and contact with spouse were high due to the number of subjects in both groups who were single or widowed. A score of 4 was given for 'no activity with spouse' and 'complete loss of contact' with spouse for these subjects. Excluding these 3 categories dealing with activity, interest and contact with spouse; both groups scored the highest levels of restriction in work role activity and

Figure 2. Difference score between perceived worst and usual breathlessness (DDS)



Difference Scores:

Cardiac $\bar{x} = 60.5$ R = 45 - 90

COPD $\bar{x} = 35.5$ R = 5 - 85

Table 3. Frequency of Social Dependency Ratings of Subjects with Congestive Heart Failure (CHF)*or Chronic Obstructive Pulmonary Disease (COPD)†

Activities	Level of Dependency							
	Low (score 1)		(2 to 3)		(4 to 5)		High (score 6)	
	CHF	COPD	CHF	COPD	CHF	COPD	CHF	COPD
<u>Physical Competence</u>								
Eating	7	8	0	0	0	0	0	0
Dressing	3	3	3	3	0	2	1	0
Walking	1	0	5	4	1	3	0	1
Traveling	2	0	4	4	1	4	0	0
Bathing	5	2	2	2	0	4	0	0
Toileting	7	7	0	1	0	0	0	0
<u>Social Competence</u>								
	Low (score 1)		(score 2)		(score 3)		High (score 4)	
	CHF	COPD	CHF	COPD	CHF	COPD	CHF	COPD
Consciousness	6	7	1	1	0	0	0	0
Attentiveness	3	3	4	5	0	0	0	0
Activity with spouse	1	0	0	2	1	2	5	4
Interest in spouse	2	2	4	5	1	1	0	0
Contact with spouse	1	0	4	2	0	1	2	5
Work role activity	1	0	1	2	4	1	1	5
Work role interest	2	1	5	2	0	4	0	1
Social contact/work	6	2	1	6	0	0	0	0
Recreational activities	1	1	2	0	4	6	0	1
Interest in recreation	5	5	2	3	0	0	0	0
Social contact/recreation	5	3	1	0	1	4	0	1

* n = 7 subjects with congestive heart failure

† n = 8 subjects with chronic obstructive lung disease

recreational activities respectively. For those retired or for women that were homemakers, activities performed within the home were considered work role activities.

Overall scores indicated that both groups had greater restriction in areas of social competence as compared to physical competence. For both groups the three most restricted activities (excluding relationship with spouse) were work role activity (most restricted), recreational activity and walking, with pulmonary subjects scoring highest in all three areas.

Another tool utilized to measure physical activity levels of subjects was the ATS Grade of Breathlessness Scale (1979). Results (see Figure 3) indicate lower activity levels of pulmonary subjects due to dyspnea.

Table 4 summarizes group means of all instrument measures.

Dealing with discomfort of dyspnea. There was wide variation in the manner in which subjects dealt with the discomfort associated with dyspnea. When asked: "What helps it (episodes of breathlessness) go away?", the majority of the subjects responded with descriptions of the immediate things that they did to help alleviate or lessen their dyspnea.

All cardiac subjects stated they had to absolutely stop whatever they were doing and sit down or "rest." Two subjects mentioned opening windows and "getting fresh air." When episodes of breathlessness occurred spontaneously, which they reportedly did, cardiac

Figure 3. Activity level of subjects as determined by ATS Grade of Breathlessness Scale

	Group C	Group P
5	0	5 (P1, P6, P5, P4, P7)
4	2 (C5, C2)	1 (P3)
3	3 (C7, C1, C3)	0
2	0	1 (P2)
1	2 (C4, C6)	1 (P8)

Cardiac: $\bar{x} = 2.7$ N=7
 COPD: $\bar{x} = 4.0$ N=8

ATS Grade of Breathlessness Scale

Grade

1. Are you troubled by shortness of breath when hurrying on the level of walking up a slight hill?
2. Do you have to walk slower than people of your age on the level because of breathlessness?
3. Do you ever have to stop for breath after walking at your own pace on the level?
4. Do you ever have to stop for breath after walking about 100 yards (or after a few minutes) on the level?
5. Are you too breathless to leave the house or breathless on dressing or undressing?

subjects stated that they would "use self-hypnosis, try to calm myself down" or "tell my mind 'now just stop' I use some psychology" or "calm myself mentally." All stated they preferred to sit upright and forward, except C3, who preferred to lie down.

Two pulmonary subjects responded by saying they initially tried to ignore it. One subject stated that she tried at first to "just work through it" without doing anything in particular. Similar to the cardiac subjects, all of the pulmonary subjects stated that complete cessation of activity and sitting up was essential to alleviating breathlessness. Again, one female subject, P3, reported that she preferred to lie down (when dyspneic). In comparison to the cardiac group, the pulmonary subjects listed a greater number of alternative strategies which helped alleviate breathlessness. These strategies had either been taught to them or self learned, and included: medications--bronchodilators, specific breathing techniques such as diaphragmatic and pused lip breathing, sips of water either cold or hot, loose clothing, and one said a steamy shower helped. Three mentioned that they also tried to "be calm". One male subject, P7, slept in his chair and P5 spent most of the hours of the day in her recliner.

Table 5 summarizes ways subjects of both groups dealt with the discomfort of the symptom.

Dealing with hospital environment. The second illness-related adaptive task is that of dealing with the hospital environment and its related special treatments and procedures. The interviewer did

Table 4. Summary Group Means for Instrument Measures

	ATS Grade of Breathlessness (1-5)	Enforced Social Dependency (17-79)	Perceived Worst Breathlessness (0-100)	Perceived Usual Breathlessness (0-100)
Group C N=7	$\bar{x} = 2.7$	Total: 32.5 Physical: 10.2 Social: 22.4	$\bar{x} = 85.0$	$\bar{x} = 25.0$
Group P N=8	$\bar{x} = 4.0$	Total: 40.9 Physical: 13.6 Social: 27.3	$\bar{x} = 76.1$	$\bar{x} = 38.4$

Table 5. Subjects' methods of dealing with the discomfort of breathlessness

<u>Cardiac</u>	<u>Pulmonary</u>
C1: I tell my mind 'now just stop'. I use some psychology, rest.	P1: I tell myself to just ignore the problem and be calm, use my Pulmoaid, steam from showers, open windows, I just let it ride. I don't think I pay much attention to my breathing - I guess I don't take it seriously.
C2: have to sit down, sit on edge of bed, fresh air feels good, need O ₂ , change positions, just go slowly.	P2: try to ignore it, must sit down, take it easy, the quieter I am the better like working at my desk.
C3: if walking I must just stop and sit on curb, stop all activity, pull up knees, lay down, don't talk, diuretics, losing weight.	P3: rest, it takes me five rests to make the bed, tried pursed lip breathing but after 75 years I can't learn to breathe differently, usually just lay down, sip warm water, my hand puffer (meds).
C4: sit up with pillows while sleeping, sit down.	P4: I try to work it through but sometimes it just closes up on me, meds, sitting forward and upright, keep my windows wide open, if my treatments don't help then I know it's a bad one, call M.D.
C5: sit up and walk around at night to get fresh air, sit or stand absolutely still, calm myself mentally.	P5: sometimes I just think that the O ₂ is not on the right liter, but it is; use my meds, my Bronko-meter only last about 20 minutes and then those real good breaths are gone; I sit in my recliner, use 2 pillows while I sleep, feet up.
C6: I remember I wanted to lean forward while in the ER and the nurses kept saying "just relax and lean back"-- they were trying to soothe me.	P6: sit down or lean against something, take a glass of water.
C7: self-hypnosis, biofeedback, try to calm myself down.	P7: stop and rest, meds, bronko-meter, fresh air, loose clothing, breathing techniques, I usually sleep in a chair.
	P8: rest, nothing special, just slow down.

not specifically address subjects' adaption to hospitalization. However, questions were asked regarding the extent of education subjects had had concerning their illness, and if they had been taught things they could do to make themselves more comfortable when they were having problems with breathing.

Only one cardiac subject, C2, responded that he had been instructed in physical conditioning and, upon suggestion, purchased an exercycle. He stated that although he is currently too breathless to use it, hopefully he will after undergoing surgery in the near future.

Seven of the eight pulmonary subjects had been taught about their illness or had learned different strategies to handle episodes of breathlessness from respiratory therapists. Two of the seven subjects had completed a "Better Breathers" class sponsored by the lung association.

General Adaptive Tasks

The previous section dealt with 'illness-related' adaptive tasks as described by Moos (1977). The following section addresses what Moos refers to as non-illness related or general adaptive tasks which include: 1) managing those upsetting emotions aroused by the illness, 2) adjusting to a different level of independence, 3) preserving family and friend relationships, and 4) preparing for an uncertain future. Since many of these adaptations are inter-related, they will be addressed together.

General adaptive tasks, Group C. C1 blamed herself for much of her breathlessness. She stated that it was because she was always

pushing herself too far in performing activities that she knew would make her breathless. She said her mind just kept telling her she could do it. She also felt that worrying about problems was responsible for much of her symptomatology. Her greatest adaptation was to change her lifestyle because of limited ability to walk and do gardening, two activities in which she previously had spent the majority of her time.

C1 saw herself as her chief source of emotional support. However, she stated her family was extremely supportive and a source of comfort. She still frequently goes out with her two daughters and to other family gatherings.

C2 felt quite frustrated in regards to his increasing dependence on others. He was greatly perturbed that "even my mother-in-law still mows her lawn" and he couldn't due to his shortness of breath. A sense of anger and frustration at his inability to fulfill his role at home was sensed by the investigator. However, he also stated that he preferred not to discuss his shortness of breath with anyone except his wife who provided him strength and emotional support. He described his wife as "a pretty strong character who did not show her apprehension" which is exactly how this investigator would have described C2. He does not feel that his social and family friendships have suffered due to his increasing breathlessness. Living in a very rural area, he still goes (wife drives) uptown to gamble once a week, shops with his wife and has close neighbors with whom he and his wife regularly play cards. Of all the cardiac subjects, C2 was the only one who stated that his shortness of breath never went away.

He said he was always aware of his breathing.

C3 did not describe or exhibit any adaption to emotional changes from her dyspnea except that she simply missed doing those things she enjoyed most, such as walking and gardening. She seemed to adapt well to her inability to do many of her household tasks because her husband was very helpful with cooking and cleaning. Those more strenuous recreational activities that she could no longer do were replaced by "quieter" ones such as writing letters to her family in Europe and needlework.

C3 did not feel that her increasing breathlessness affected her personal relationships in any way. Her neighbors were her and her husband's most frequent and sole social contacts. She said she and her husband were very close and described him as her best friend.

C4 was a very independent 79 year old woman who lived alone and walked daily the 2 to 4 miles roundtrip to town and back both for enjoyment and necessary shopping. C4's largest concern was adapting to her increasing breathlessness which she saw as a threat to her independence and ability to walk. Not being able to walk to the senior citizen club and see friends deprived her of much of her socialization although she did have neighbors and two sisters whom she saw at least weekly and usually more often.

C5 experienced a great deal of fear, apprehension and anxiety with her episodes of breathlessness. Her most difficult adaptive task was her attempt to conceal her breathlessness and accompanying apprehension from her family, friends, and co-workers. C5 usually accompanied her husband on walks. Soon, however, she could not

tolerate the walking and would tell him to go on ahead, she'd catch up. Fortunately she said, during the past months he had traveled a lot so she would simply come home from her part time job and go straight to bed.

During the past months she was awakened "the majority of nights" out of a dead sleep and would quietly slip out of bed and walk about the house for "fresh air". When these episodes would occur on a social evening out to dinner with friends she describes how she would sit "absolutely still" at the table, talk only if absolutely necessary and smile so nobody would notice anything. Simply walking into the restaurant and being seated would leave her breathless and feeling dizzy. As soon as she had to walk any distance back to the car her breathlessness would re-occur. She tried to casually suggest someone bring the car around as "it was too cold" or she was "just too tired."

At work during the Christmas season she always tried to have the younger girls carry the packages that needed gift wrapping and also to do any necessary reaching to high areas as that increased her breathlessness.

The day prior to her emergency admission to CCU she had "awakened in the A.M. breathless, went (50 miles roundtrip) to visit my mother (in convalescent hospital), went to dinner with relatives and the whole time I had a numbness in my head, fear, apprehension, very short breathing--working harder, sat quietly at dinner--stayed calm--walked from car straight to bed but in middle of night I woke my husband to call my physician."

C5 also said she experienced guilt when thinking about the possibility of not being able to work and contribute financially.

The biggest alteration in her lifestyle was having quieter evenings, earlier dinners and a generally "subdued" approach. This change had occurred gradually over the past year. She did not feel her increasing breathlessness affected relationships with friends and family except that their social life was quieter.

C6, although admitted to the ER in acute CHF, denies ever feeling breathless previous to that time and, upon interview, did not describe any changes in her lifestyle or activities that may have illustrated any problems with her breathing.

C7 describes his most significant adaptive task as his change in work role both at home and in his job. He currently is working part-time and does not know how long he will be able to handle that amount. At home, he used to do all sorts of repairs and now depends on his family to help with them. He is very open about the frustration he feels at his inability to perform these tasks.

The greatest change in his lifestyle has been not being able to do "anything athletic". Their social life is also "quieter" although he does not feel his relationships with family and friends has been affected.

Tasks involving preparing for an uncertain future were particularly significant for the cardiac sample in that 6 of the 7 subjects knew at the time of interview that valve replacement surgery was planned within the next week. Many spoke of their coping with the possibility of living with their breathlessness forever before they

fully realized exactly what was wrong and/or that surgery could correct the problem. C1 stated "it's part of getting old, I hate getting old". C2 said "you wonder what the hell is gonna happen-- maybe some will come up with a solution." C3 said that she absolutely could not face another hot summer in high altitude. C5, when describing the apprehension that accompanied her breathlessness, said her greatest fear was going to sleep and not waking up.

General adaptive tasks, Group P. Adaptive tasks identified in the pulmonary sample were generally reflective of the increased incapacitation as was also measured by the Enforced Social Dependency Scale.

P2 reported that his breathlessness never goes away. "I just live with it; I just know what I can do". He says "thinking about it doesn't bother me but I don't like talking about it". He sees his biggest sacrifice as giving up his favorite hunting spots which were in high altitude areas. He has developed many hobbies at home. Old friends streamed in and out of the house during the interview. The role he performs at home demands that he do a lot around the house because his wife is weak due to an old CVA. His wife frustrates him a great deal because she always tells him to quit panting and that he's breathing too heavily. He sees himself and God as chief source of strength.

P3 had difficulty managing the emotional stress of the panic that occurred with her breathlessness even though she tried to utilize strategies that she had learned from respiratory therapists

to help her manage and control her dyspnea. In addition to the panic she also associated a great deal of embarrassment with her need to raise thick or copious sputum during her frequent coughing spells. "I know it sounds awful to other people, just nasty and nauseating." "I just want to be left alone. If we're among people I leave. We always sit on the outside theater seats, or we don't go."

P3 was confronted with tasks of preserving her self image which was changing since her illness began. She was very embarrassed about the fact that "I really don't care what I look like and I never have. Isn't that terrible? My poor husband says 'if we go out, you're not wearing those thongs.'" However, slip on shoes and loose fitting clothing were her preference. She also said that picking up lipstick and applying it increased her breathlessness so that she no longer wore it when they went out. She called herself lazy because she is "just too coked out" to perform household tasks.

She described her husband of 51 years as a great guy who did all the cooking and cleaning. The only impact she felt her breathlessness had on their relationship was that he was bothered by her episodes of coughing, especially at night when he'd tell her to "shut up".

The biggest change in her relationships with other family and friends was decreased socialization. She did go to the Senior Citizens club and played cards once a week. She rarely went out shopping as "there is no place to sit down. I either lean on the

cart or sit in the car."

At home she spent increasing time reading. She had an exercise cycle that she rode off and on at her own pace with O₂ every day on and off during her soap operas.

When having problems breathing or coughing, P3 just wanted to be left alone. In addition, she absolutely could not stand to have people "hit her on the back" and preferred not to have anyone touching her or hovering around her during episodes of breathlessness.

P4 was very bothered by thinking about her breathlessness and its effects on her lifestyle. "I wish I didn't have it, it makes me so slow--I'm always holding up everyone--it just wears me out to try and go out. I just slow everybody down. There are times when I'm not good but I just push myself--I try not to lay around. My daughters really push me..."

She no longer performed any household tasks except perhaps cooking very simple meals. A housekeeper and her daughters helped her bathe, dress, and keep house.

She did not like discussing her problems with anyone except her physician or her daughters. Other friendships she felt suffered because she was so slow. She said she really had given up social activities because any kind of excitement and movement made her dyspneic. She usually did not feel up to socializing outside her home.

P5 had similar adaptive tasks to P4 and P3 in terms of the following: a) dealing with increasing dependence on others and

decreasing mobility, b) having less interest and energy in her outward appearance, and c) having less social interactions.

P5 was very bothered by her appearance. "I hate to see myself with this thing (O₂) in my nose. I always prided myself on looking perfect all the time--I can't stand not having hair done and make-up on. Socially, friends don't come around because they know they can't smoke and with all this equipment, I won't go out." She goes further to say "I wish I didn't have so many visitors--it interrupts my routines--IPPB treatments."

She also had family who pushed her to get out of the house. She said it hurt her feelings because she didn't think they realized how breathless she was. On the other hand, she always tried to hide any respiratory discomfort (e.g., "as long as I'm sitting, I'm O.K.") so, she shouldn't expect them to know that she truly was dyspneic. Most of her socializing took place within her apartment building where she used to be manager.

Thinking about the future was a current concern as she faced the possibility of going to a nursing home. She also felt extremely guilty that her youngest son not only always had a sick mother but also bore the financial burden of her care.

P6 was very frustrated with increasing disability due to his breathlessness. He had no "stamina". "Your breath is so important to you--I used to do so much." His dyspnea was to the point where he had to wait one hour in between putting on his socks and his shoes. Around the house he was unable to perform most all his former tasks such as gardening and vacuuming. He still attempted to

mow the lawn a little at a time even though it made him extremely dyspneic. His wife was very active and provided much support for him. Their social life was quite limited and most all activities took place at home. His recreational activities consisted of T.V. sports, seeing family and shopping which he enjoyed because he could take his time and lean on the cart as needed to rest.

P7, 82 years old, was admitted with the diagnosis of dyspnea. After evaluation, however, his most significant complaint was depression. He was increasingly limited in his activity level and he recently had talked a lot about dying as he thought his wife should be prepared for this. He worried a great deal about his wife being alone. He spoke casually yet very quietly about death saying his family reacted so seriously to him discussing the subject although he thought that it was quite appropriate.

His recreational time was spent quietly listening to music and taping it. He missed his friends and wished he could get out to see his neighbors more frequently.

P8 described very few adaptive tasks to manage. Although he was limited in his activity levels, he had never had to do anything around the house because they had always had maids and a gardener. In addition, his wife was very active. He did not see his breathlessness as a problem except that he could no longer travel to high altitude areas and when he got a cold, he remained ill for a long time. Otherwise he saw no changes in his lifestyle or personal relationships.

Coping

Cardiac Group: Coping Skills

Denial. The use of denial or minimization of the seriousness of the illness is frequently utilized as a self-protective device to cope with illness (Moos, 1977). Although denial was not directly measured in this study, interview findings revealed that some subjects did use this mechanism to deal with their adaptive tasks.

C1 stated that she knew her activities brought on her breathlessness and that she "used denial." When she became breathless while doing something she would just keep telling herself that she could do it and continue the activity as long as possible. She also felt that the breathlessness she experienced while laying down at night was primarily due to her worrying.

Subjects C3 and C4 both appeared to have a very realistic understanding of their symptomatology. They had accepted their limitations and looked forward to feeling more energetic following their valve replacement surgery. They both appeared somewhat anxious regarding their upcoming surgery but had good support from close family and friends.

C5 knew in 1968 that she had a heart murmur but did not experience breathlessness until one year prior to valve replacement. She saw her physician and began diuretic therapy at that time. Subsequently she experienced increasing episodes of dyspnea during which she described feeling fearful, apprehensive and breathless. Not only did she try to hide this episodes from others, but she frequently attributed them to being out of shape and smoking.

She also verbalized thinking that there was something wrong in her head, such as a tumor, because she sometimes experienced dizziness. She frequently used the word fear in describing these episodes and was particularly fearful of not waking up after going to sleep at night. She said that had she known that all her symptoms were due to her heart that she would have seen a physician much earlier. It seemed that she connected feelings of breathlessness with her heart problem but her other sensations such as fear, apprehension and dizziness she thought were due to something going on in her lungs or head.

C7 had increasing left ventricular failure and was not a surgical candidate. He was facing a shorter life span and described losing his work role capabilities both at work and at home.

Seeking relevant information. None of the cardiac sample demonstrated an acute need to seek out information about their illness beyond what they had been told by their physicians. Some did mention they felt that inactivity, growing old, eating too much or smoking may have had something to do with their symptoms.

Requesting reassurance and emotional support. Two subjects, C1 and C4, lived alone. However, they described having either children or other family members and friends as providing them with comfort and support. C7 lived with her two brothers and had many other neighbors who were very supportive during her hospitalization. The other 4 subjects lived with their spouses. These subjects described other people in their lives that they saw as a source of comfort and emotional support.

Rehearsing alternative outcomes. Only C5 discussed the possibility of dying as an alternative outcome. She describes letting her husband know that "if anything should ever happen to her" she did not want him to bear the burden of her family's needs. Other subjects facing surgery did not spontaneously discuss any possibilities of their not surviving. Two subjects did comment that they couldn't go on the way they were. The interviewer did not probe in this area unless subjects spontaneously discussed it.

Learning illness related procedures. This coping skill was not described in any of the interviews except for managing medications--for example, increasing diuretics if a weight gain occurred.

Setting goals. Goal setting was talked about by all subjects except C7. The subjects expected or hoped that they would again be able to perform certain specific activities. C1, C3, and C4 spoke about being able to garden and walk again. C2 said he would like to hunt again, however, how realistic that goal is, is questionable. C7 was especially aware that, in terms of goal setting, his activities and capabilities were only decreasing over time. It seemed that it was becoming increasingly difficult to accomplish goals. He was becoming less able to work at his job and would probably soon be working even less. Home-related activities, for example, taking out the garbage, were impossible tasks. This goal setting seemed only to remind him of his limited functional abilities.

Finding a general purpose or pattern of meaning to life. This was not pursued by cardiac subjects. None mentioned a belief in a divine purpose or spirit as directing their lives. C1 appeared to

question or search why his life included his illness and its discomforts. He said, "you wonder what's gonna happen--maybe someone will come up with a solution."

Pulmonary Group: Coping Skills

Denial. Many of the pulmonary subjects either overtly or covertly described denial techniques they used to cope with their breathlessness.

P1 commented regarding her shortness of breath: "I just let it ride. I don't think I pay much attention to it--I guess I don't take it seriously--I try to ignore the problem and be calm."

P3 reported that she still constantly attempts to do activities that she knows she cannot accomplish, for example, making beds. She also commented that thinking about her shortness of breath does not bother her.

In the case of P4, it seemed as though her daughters attempted to minimize the seriousness or incapacitation of their mother's breathlessness. They were very active and energetic and always pushed P4 to go out and be more active. Despite all the limitations in her day to day life, P4 described her breathlessness as "only being a problem when I get sick, everybody copes with something." She also said she could probably walk "two blocks unless I was sick". However, when responding to the ATS questionnaire she said she was too breathless to leave the house and breathless upon dressing. Some of her denial was apparent when, after being hospitalized for increasing shortness of breath, there were no changes in her chest x-ray, arterial blood gases, pulmonary functions or

sputum cultures. She could not understand why she felt so poorly without evidence of a physical change in her condition.

P7 also was admitted due to complaints of increasing dyspnea but had no respiratory infection or other objective changes. He was seen by the psychiatric nurse specialist who identified that he was depressed dealing with the terminal phases of lung disease.

P5 said she was very aware of her illness, poor prognosis and the fact that she may soon have to have full-time nursing care. She stated that "you realize that it's not going away." She would frequently awaken in the morning and say to herself "today I'll clean out that closet." However, she repeatedly would fail in whatever small goal she had set for herself and would become even more discouraged. When she would become breathless she often thought that she was not receiving the proper level of oxygen, which was rarely the case.

P6 really thought a large part of his symptomatology was "age creeping up on you." He said his breathlessness was only a problem "with exertion or infection." However, as the interview progressed, it was obvious his functional ability was very limited. He was overweight and did no regular exercise. On the ATS questionnaire he stated that he was too breathless to leave the house or breathless on dressing. Two breaks were taken during the one hour interview because he was short of breath. Even so, he said he was planning to try and mow their lawn that afternoon.

Seeking relevant information. This was common among the pulmonary group in that two had attended the Better Breathers classes.

Others had learned about their pulmonary disease through respiratory therapists.

Requesting reassurance and emotional support. Requesting support sometimes proved difficult for the pulmonary subjects. All except two of the subjects lived with their spouses. The other two had live-in housekeepers that also helped them with bathing, dressing and breathing treatments. Most pulmonary subjects found that activities such as socializing, talking, and entertaining at home or going out to see friends and family all served to increase their dyspnea. Consequently, many subjects had an isolated day to day existence with few people around them. With the exception of two subjects, many preferred not to discuss their breathing problems with others.

Subject P3 credited her pulmonary physician as being a chief source of strength and emotional support along with her husband. He had recommended that she talk with another person with a similar diagnosis. She stated that regular "chats" with this person "really helps" her and lets her know that there are others managing problems like hers.

P5 commented that, "I wish I did have someone like me to talk to about it." P5 had developed a fairly isolated lifestyle. She didn't like visitors as they interrupted her routines of treatments, etc., and the talking would wear her out. She looked primarily to her son and physician for support.

P4 also was withdrawn from socialization because of her dyspnea. Her primary source of emotional support was her daughters and physician. She did not see other friends because she was so slow

and it increased her breathlessness. Other pulmonary subjects noted decreased support from friends of family simply because all types of socialization increased their shortness of breath.

Rehearsing alternative outcomes. In contrast to the cardiac sample, most pulmonary subjects realized there was no alternative outcome to the progression of their illness. Some vacillated between attempting to do things they knew they couldn't accomplish and facing the fact that the only course was decreasing lung function and increasing disability.

Learning illness related procedures. This was found to be important for pulmonary subjects in order to maintain independence. In addition, their disease process was associated with many more procedures and equipment than was that of the cardiac sample. Three subjects were receiving continuous oxygen and breathing treatments every 3-4 hours. None of the three were able to clean and set up their equipment without the help of their spouse or housekeeper. Two others had attended a Better Breathers course. These subjects attempted to practice the breathing retraining techniques, proper coughing and postural drainage and some physical reconditioning. All subjects stated that if they followed their prescribed regimen it could help prevent respiratory infections. However, medical compliance could not be determined after one interview with these subjects.

Setting goals. None of the pulmonary group described goals they had specifically set for themselves. Most had accepted the downward course of their disease. Specific activities that they

would like to do were described, however failure to accomplish these activities resulted in further discouragement.

Finding a general purpose or pattern of meaning to life. It was difficult for this group to answer this question. Two stated that God was their chief source of emotional support although they never referred to any divine purpose of their life or that their illness was God's will. Many subjects asked "why me"? Guilt regarding their smoking was frequently mentioned.

Summary of Findings

The Symptom

The experience of breathlessness was described by cardiac subjects as having a more spontaneous onset. Only one cardiac subject cited a prodromal indicator as opposed to 5 pulmonary subjects who described signals of oncoming dyspnea such as changing sensations in their chest or changes in their breathing patterns. Breathlessness appeared similar in both groups in terms of trigger mechanisms except that allergens and irritants were noted by 6 pulmonary subjects as compared to only 2 cardiac subjects. Respiratory sensations were similar with the exception that two cardiac subjects described "chest congestion" which was not noted by any of the pulmonary subjects. The most universal physiological correlate that accompanied dyspnea in both groups was dizziness and weakness described by 12 of the 15 subjects. The duration of dyspneic episodes was the same each time for 5 cardiac subjects but varied a great deal among pulmonary subjects from a few minutes to all day. The pattern and sensations of breathlessness were usually the same

each time for all subjects and overt behavioral indicators were similar between groups.

Adaptive Tasks

The most significant adaptive tasks needed by cardiac subjects were the following: 1) decreasing activity both immediately when dyspneic and chronically as described by all subjects as developing "a quieter lifestyle", 2) managing feelings of anxiety, guilt and frustration due to inability to perform former roles and losing independence, and 3) managing the fear and anxiety associated with breathlessness. No one subject felt that significant relationships with family or friends were affected by his shortness of breath.

The adaptive tasks managed by the pulmonary group were more numerous and affected more aspects of their lives as compared with the cardiac sample. Similar to cardiac subjects, the pulmonary group all reported quieter lifestyles, feelings of anxiety, guilt and frustration due to inability to perform former roles and loss of independence. Many subjects described anxiety and panic as accompanying their breathlessness. However, it was different than that of the cardiac subjects. For example, pulmonary subjects did not describe having experienced such acute levels of fear and apprehension. Emotional adaptation was related more frequently to the feeling of anxiety, depression, frustration and isolation.

Tasks of maintaining self image were more prominent in pulmonary subjects. Appearance, personal values and lifestyle were subject to more change.

Preservation of friendships and a social life was different

between the two groups. Pulmonary subjects experienced more isolation as compared with cardiac subjects who in general did not feel their interpersonal relationships had suffered. This isolationism functioned not only as an adaption to their breathlessness but also as a means to cope with it which shall be further discussed in the following section on coping skills.

Coping Skills

Denial was described in both groups. Techniques to hide breathlessness were described more frequently in the pulmonary group. Pulmonary subjects also demonstrated a greater need to learn information about their illness and the procedures involved such as breathing treatments and ways to prevent infection.

Requesting reassurance and support from others was difficult for pulmonary subjects due to their increasingly isolated lifestyle.

Cardiac subjects were more future oriented in that they looked forward to an improvement in their energy levels following surgery. It was easier for these subjects to set future goals. There was also, however, the anxiety of facing open-heart surgery and some spoke of dying as a potentially imminent alternative outcome.

It was more difficult for pulmonary subjects to set goals and describe a pattern of meaning to their lives. Anger, guilt and frustration arose from their increasing disability and dependency.

Perception of Breathlessness

Results obtained from the Dyspnea Descriptive Scale are presented in Figures 2 through 5 along with the ATS Grade of Breathlessness findings. Table 6 summarizes findings of the DDS, ESDS, and ATS.

Chapter V: Discussion

Significance

Fifteen subjects' descriptions of their experiences of breathlessness has provided a beginning look at variables involved in the phenomenon, adaptive tasks undertaken, and the utilization of coping strategies.

The symptom. Subjects' descriptions of their episodes of breathlessness identified physiological and emotional correlates. For example, pulmonary subjects were able to describe prodromal indicators of their episodes of breathlessness. The indicators included changes in chest sensations and breathing patterns. Cardiac subjects, however, described their breathlessness as sudden in onset and without any preceding indicators. If these prodromal indicators could be taught to patients and clinicians, appropriate interventions could be instituted at an earlier time. Such intervention might enable the difficult dyspnea-anxiety cycle (Grossbach-Landis, 1980) to be treated at an earlier stage. It may be that pulmonary patients would benefit most from such teaching as cardiac subjects in this study did not describe prodromal indicators.

The Dyspnea Descriptive Scale (DDS) enabled subjects to rate the acuity of their usual and most severe breathlessness. Results showed that the mean usual level of breathlessness among the pulmonary subjects was 38 (scale: 1-100) compared to cardiac subjects' mean level of 24. A greater degree of adaptation for pulmonary subjects described in interviews plus ESDS findings of greater social

dependency are consistent with these DDS results. These findings indicated that the pulmonary subjects lived with a greater degree of perceived usual breathlessness. Consistency between these tools showing a relationship between increased social dependency (ESDS), lower activity levels (ATS Breathlessness Scale) and higher levels of usual breathlessness provides beginning concurrent validity for the Dyspnea Descriptive Scale as a tool to assess levels of breathlessness and accompanying disability. Future studies utilizing larger samples are needed to establish a significant correlation between ATS grades of breathlessness and perception of breathlessness as determined by the DDS.

Chronic versus acute dyspnea. Within this study, subjects' descriptions of the sensation of breathlessness that accompanied cardiac and pulmonary disease states did not reveal distinctly different patterns, except in terms of the absence or presence of prodromal indicators. However, the subjects' perception of their acuity of usual and worst breathlessness provided information in terms of expected adaptation and coping patterns. One initial assumption of this study was that the experience of breathlessness, adaptation and coping patterns would vary between different specific disease states. However, findings in this study of higher levels of usual breathlessness associated with greater social dependency and lower activity levels suggests that it is the frequency and intensity of episodes of breathlessness as opposed to the specific disease entity that determines what adaptive tasks and coping skills are needed.

Whether one's dyspnea is due to restrictive, obstructive or

vascular lung disease may not determine respective differences in sensation and lifestyle changes. More importantly it may be whether one's dyspnea is acute, chronic or intermittent. This study's findings indicated that pulmonary subjects rated their worst breathlessness lower than did cardiac subjects. Those pulmonary subjects experiencing chronic dyspnea may have developed coping skills over time that allowed them to more effectively deal with their acute episodes of dyspnea.

Social acceptability and isolation. Adaptive tasks managed by the pulmonary group were more numerous and affected more aspects of their lives as compared with those of the cardiac sample. Similar to cardiac subjects, pulmonary subjects reported quieter lifestyles and feelings of anxiety, guilt and frustration due to their inability to perform roles and increasing dependency.

Although similar adaptations were described by both groups, the Enforced Social Dependency Scale (ESDS) showed that the pulmonary group was more restricted and dependent in both physical and social competency categories. The advanced age of the pulmonary (P) group ($\bar{x} = 72$ years), in comparison to the cardiac (C) group ($\bar{x} = 78$ years), may account for some increased disability.

The combination of restrictions in mobility and a high degree of breathlessness result in physical deconditioning in addition to oppressive emotional correlates (Dudley, 1980). Pulmonary rehabilitation programs are aimed at breaking this dyspnea-inactivity cycle. The revolving door syndrome of frequent hospitalizations due to recurrent respiratory infections and increasing dyspnea is a large

focus of such programs. Patients are taught day to day management strategies to preserve energy, increase their socialization, increase their exercise tolerance and decrease the incidence of respiratory infections. Such interventions can assist with the successful development of adaptive behaviors among these patients (Moos, 1977).

Two specific tasks were described more frequently by pulmonary subjects in this study: maintaining self-image and preserving friendships. The two tasks were described in an interrelated manner by pulmonary subjects who described experiencing stigma because they were frequently separated from smokers at social functions. Three were on continuous O₂ and rarely socialized outside of the home. Others stated that they knew their coughing and frequent expectoration was nasty and nauseating to others.

Activities such as grooming, bathing and dressing were sometimes relinquished as they simply were too exhausting. These activities were gradually altered unless a significant other or housekeeper could provide assistance. Inability to complete activities of daily living contributed to a poorer self-image. An understanding of functional alterations is essential in providing nonjudgemental care to patients with COPD.

Descriptive findings of alterations in self image in conjunction with findings that socializing increased dyspnea resulted in a more isolated lifestyle. These findings lend support to Dudley and associates (1980) who described severely disabled COPD patients as living in an "emotional straitjacket" (p. 414). Withdrawal into the home and avoidance of social interactions insulate the COPD patient

from encountering situations which may trigger dyspnea and lead to physiological decompensation.

Social relationships are also affected by the increasing amount of time spent on medical regimens and symptom control (Strauss, 1975). Subject P5 actually stated that she resented visitors because getting up to answer the door made her extremely breathless. Furthermore, visitors interrupted her routine of treatments and medications.

In addition to the patient withdrawing, friends and family may also withdraw because of their inability to face the sick person (Strauss, 1979). Two subjects stated that they had lost certain friends who no longer visited because they couldn't smoke around them. One woman gave up her bridge club because she was always seated away from smokers. She believed that her presence made the smokers feel uncomfortable.

The changes in self-image, social acceptability and isolationism experienced by individuals with COPD contribute to feelings of anxiety, dependency and loss of self-esteem (Dudley, 1980).

Management strategies. Adapting to decreased resources of time and energy as described by Fagerhaugh (1973) was also noted by subjects in this study. The use of 'routing' as discovering the least exertive means of getting from one place to another as well as finding 'puffing stations' to recoup their breath was described by most COPD subjects. In addition, wearing loose clothing, slip on shoes, modifying bathing patterns, relinquishing activities involving bending over were also described as found by Barstow (1974) in her interviews with emphysema patients.

Denial, anger and frustration. Moos (1977) identifies denial, or minimization of the seriousness of a crisis, as one method of managing the adaptive tasks involved in physical illness. Coping skills, such as denial, may be appropriate and essential in one situation and maladaptive or detrimental in another. Based on interview findings, this study identified that denial was used as a coping mechanism by the subjects. Pulmonary subjects who faced an irreversible diagnosis such as emphysema faced adaptive tasks different from those of the cardiac group whose diagnosis was potentially reversible. The use of denial was described by pulmonary subjects as a way of dealing with the irreversibility of their illness.

Although an instrument to measure denial was not used in this study, pulmonary subjects' interview data contained descriptions which suggested their use of denial techniques. Attempting tasks which the subjects knew they could not complete resulted in increased feelings of anger and frustration. This was particularly evident with tasks associated with changes in roles which had to be relinquished such as cooking for homemakers and working for the breadwinners.

Strauss (1975) describes normalizing as a basic strategy used by those that are chronically ill. Normalization encompasses those efforts of symptom control and regimen management that result in leading as normal an existence as possible. This was illustrated by one cardiac subject, C5. She described the intricate strategies used to hide breathlessness from her family and work associates

until the night of her emergency hospital admission for acute congestive heart failure. As Strauss describes, the psychological costs to those who successfully manage to conceal their disability may be high. Subject C5 did describe her fear and anxiety when thinking of her family handling her inability to work or the possibility of her death.

Because CHF subjects were scheduled for corrective surgery they may not have seen themselves as suffering from a chronic illness. In contrast, pulmonary subjects were forced to accept a lower level of normality without any hope of improvement in their symptoms. Barstow describes "hiding techniques" used by emphysemics to disguise their breathlessness from others. Hiding techniques described in this study included leaving others presence to cough and expectorate, looking "o.k. if I'm resting in a chair (P5)", and trying to look nonchalant when stopping on a stairwell in a department store.

Subjects in both groups reported quieter lifestyles due to increasing breathlessness and decreasing energy. However, socialization resulting in emotional support from others was particularly difficult for COPD subjects as described previously. It was difficult for pulmonary subjects to decide between losing social contacts or to withstand the breathlessness brought on by socialization. For example, one man still played cards with close friends who smoked, even though the evening usually left him severely dyspneic. Encouraging socialization is an important component of pulmonary rehabilitation programs. Better Breathers Clubs are also available for persons with COPD to be among others faced with similar problems.

Spouses or significant others are also able to share problems and ways of coping.

Dudley (1980) discussed the difficulty of chronic lung patients to express their feelings and thereby gain emotional support from others. Crying, laughing or talking may lead to increased dyspnea and physiological decompensation (Dudley, Weimuth & Hauge, 1973). The resulting suppression of emotions may impede successful coping.

General determinants of outcome. Within the conceptual framework used for this study there are three categories of determinants of outcome: 1) background and personal characteristics, 2) illness related factors, and 3) features of the physical and sociocultural environments. These factors influence the meaning the illness carries for the individual, adaptive tasks and coping skills (Moos, 1977; Lipowski, 1970).

Features of the physical and social environment include social support systems such as health care givers, community social support systems and immediate family. Variables that influence the perception of breathlessness also include social support, disease pathology, and the length of time one has lived with or experienced the symptom (Moos, 1977). In addition, Dudley (1980) identified past experiences associated with dyspnea as a variable determining one's perception of the symptom.

Barstow (1974) identified the presence of a significant other in the home as the most important factor in successful coping among emphysemics with progressive dyspnea. Subjects in both groups of this study identified many day to day tasks taken over by either

their spouses or other family members. One pulmonary subject's perception of illness changed a great deal when faced with the loss of her "significant other".

Although some cardiac subjects' dyspnea was not at the same disabling level, similar descriptions of the role played by significant others were given regarding the day to day assistance provided by significant others.

The two groups of subjects selected for this study were appropriate for purposes of examining the experience of dyspnea. Both the pulmonary and cardiac subjects provided examples of dyspnea that had progressed to a level which interfered with daily activities. Different physiological mechanisms were responsible for the breathlessness in each group, and therefore, patterns across disease states could be explored. The pulmonary group faced an irreversible diagnosis and the cardiac group faced potentially corrective surgery, therefore there existed basic differences in the meaning that each illness carried with it and its effect on coping and adaptation.

The findings raised the question that perhaps it is not the pathology responsible for the shortness of breath that determines the "outcome of crisis". Instead, it may be the chronic or acute nature of the illness. Patients with chronic left-sided failure as in cardiomyopathy or coronary artery disease may have been a more appropriate group in terms of comparing adaptation and coping. The finding that the pulmonary group was older and dealing with irreversibly progressive dyspnea may have accounted for some subjects' responses.

Timing and environment of the interview process varied somewhat among the sample. Three pulmonary subjects' interviews were split into two sessions because of their breathlessness. Interviews were begun in the hospital and continued at home after discharge. One cardiac subject and two pulmonary subjects were interviewed only at home following their discharge from the hospital. It is assumed that variability in data could occur in perception of one's dyspnea, adaptation, and coping dependent on the stage of acute illness at which data is conducted. However, interview questions did focus upon how it was to live with breathlessness and therefore included coping with all levels of acuity.

Limitations

Limitations of this study included: 1) a small convenience sample and therefore lack of generalizability, 2) use of a non-standardized interview and a Dyspnea Descriptive Scale lacking reliability and validity testing, and 3) data obtained by self report only without direct observation or reinforcing data from other family members.

Implications for Nursing

The symptom. This study identified physiological sensations and emotional correlates which subjects described as accompanying their dyspnea. Dizziness, weakness, visual disturbances, shakiness, numbness, fear and poor memory were among them. Nursing interventions used when assisting patients to manage their dyspnea must acknowledge these frightening sensations. This is especially important when dealing with intubated patients who are unable to communicate

verbally. The agitated, intubated patient who complains of dyspnea needs concise, clear, calm, explanations of what is happening. Simple questions or acknowledgement of other accompanying sensations such as visual disturbances or uncomfortable chest sensations may calm the patient. One cardiac subject admitted in acute CHF described her anxiety and frustration from repeatedly being told by nurses to "just relax and lie back". She stated that she really didn't think that they realized how breathless she was. Precarious hemodynamic states may prevent patients from being allowed to sit up. However, simple verbal acknowledgement by the nurse of the patient's feelings and needs may help alleviate anxiety. A patient should be told that, following intubation or improvement in blood pressure, he or she will be able to sit up. Acknowledgement of a patient's needs is more effective than global, ineffective statements such as "just relax". Visual disturbances, poor memory, foggy hearing and numbness in the extremities would certainly add to the anxiety experienced by a dyspneic patient. Nurses should be aware of these sensations to allow them to more effectively intervene.

Because nurses are at the bedside managing dyspneic patients, they are also in a position to detect breathlessness that may indicate the presence of undiagnosed pathology. Barstow (1974) describes the nurse as being instrumental in the early detection of lung disease during the period she defines as "emerging awareness" when patients' breathlessness becomes difficult to disguise. It is not unusual that cardiopulmonary disease is diagnosed during hospital admissions for surgical procedures or respiratory infections.

A patient history of increasing dyspnea on exertion may be a clue to other underlying disease processes such as heart failure or lung disease.

Adaptive tasks and coping skills. Implications for nurses at the bedside involve identifying interventions that are specifically tailored to assisting patients manage dyspnea and its accompanying biopsychosocial correlates. Moos (1977) identifies areas in which staff members should be competent to assure effective and appropriate interventions. One is the need for care givers to "know the major adaptive tasks and typical coping strategies, so that they can respond to the adaptive efforts which their patients make (Moos, 1977, p. 18). This study has begun to identify adaptive tasks and coping skills at the descriptive level. If greater fear and apprehension is described by those whose dyspnea is intermittent and acute in onset, nurses must include this in their assessments and knowledge base. Approaches to chronic breathlessness would also differ as these patients may be confronted with different adaptive tasks. There is a need for correlational research in these areas to establish the existence of such relationships.

The adaptive task most frequently described in both groups was that of managing decreasing energy levels. Nursing care of dyspneic patients should be purposeful and allow for regular periods of rest. Having essential items within reach was important to subjects with Grade 5 (ATS) dyspnea.

It is essential to understand the feelings of a COPD patient. Suppression of emotions to prevent dyspnea may result in sudden

outbursts of anger and frustration directed at health care givers.

Feelings of guilt and frustration were mentioned by subjects in both groups. Some subjects described their illness as a form of punishment or as a result of smoking or lack of exercise. It is important for nurses to know patients' understanding of their disease in order to correct misconceptions that they may have.

Future Research

This study has identified variables to be tested in future correlational research. There is the need to replicate this study and include a larger sample size, for example, 50 cardiac subjects and 50 pulmonary subjects (n=100).

The symptom. The findings raised the following questions: Are patients' descriptions of prodromal indicators and chest sensations significantly different between restrictive, obstructive, vascular pulmonary disease and cardiac disease? Is it experienced differently within restrictive disease states such as pulmonary edema or idiopathic fibrosis? Implications of such findings would include teaching patients and nurses assessment skills to enable early detection and effective intervention. The inclusion of asthmatics in future studies would provide descriptive data of breathlessness that may be completely absent for a period of time and then has an acute onset.

Adaptation and coping. Correlational studies of general determinants of outcome (Moos, 1977) are needed to direct symptom management. Such determinants include background and personal characteristics, illness-related factors and environmental factors.

Further research focusing on the area of adaptation and coping may reveal commonalities between groups. Identification of successful coping strategies would enable scientific testing of these by researchers and teaching of these by clinicians.

The conceptual framework utilized for this study has provided a feasible way in which to organize findings. It is not a theory but instead is a way to arrange information so that variables may be identified, scientifically tested and theory developed.

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APPENDICES

Appendix A: Consent to Be a Research Subject

Susan Jacobs, R.N. a graduate student in the nursing program at University of California, San Francisco is doing a study to learn more about shortness of breath, a problem I may or may not have as a result of cardiopulmonary disease. She has invited me to participate in the study.

1) I will fill out a short questionnaire during a one hour interview. The questions will be related to shortness of breath such as what makes it better or worse and what it feels like.

2) The interview could momentarily increase my shortness of breath and at any time I can stop the interview and continue on another day if I would like to do so .

3) My name will be given a code number to identify the information that I give.

4) If any questions are uncomfortable for me to answer I do not have to do so.

5) The interview will be tape recorded only with my consent.

6) There will be no direct benefit from me participating in this study. However, nurses hope to learn more about shortness of breath which may help patients like me in the future.

I have talked with Susan Jacobs, R.N. about this study and have had my questions answered. If I have other questions I may call her at 595-3921. I have a copy of the consent form and the Experimental Subject's Bill of Rights. I also have the right to refuse to participate or to withdraw without any jeopardy to my medical or nursing care at this hospital.

Date

Subject's Signature

Dyspnea Interview Schedule

Interviewer: _____

I. Perception of Shortness of Breath

Structured Questions

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

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

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

3. What did you do about it?

4. Did you talk to someone about it?

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

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

7. Tell me about the last time you were short of breath. (if no answer, elicit responses with one of the following situations: exercise, psychological factors, anger, fear, depression, daily hassels, infection).
8. For any situation described, determine the following:
Aggravating factors: What brought on the shortness of breath?
9. Description: Can you describe in your own words how it felt?
10. Prodromal indicators: (onset) Do you have any feelings that tell you that you are about to become short of breath?

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

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

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

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

15. Adaptive mechanism: What helps it go away? (actions and positions, needs, other). What are the little things you do that you might not even tell people about that help your shortness of breath? What kinds of things help you live with or cope with your shortness of breath? Probe
16. Is this situation you've just described typical of most of the times when you've felt short of breath? Can you tell me about other times and how they have differed?
17. Does your shortness of breath ever go away? When? (constant or sporadic)
18. How much of a problem is shortness of breath for you?
19. Does thinking about your shortness of breath bother you?

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

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

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

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

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

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

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

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

Enforced Social Dependency Scale
(McCorkie, 1981)

II. Activities of Daily Living

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

1. What about eating, for example? How do your present eating habits differ from what was normal for you before your illness?
 - a. Do you need help from other people to eat? To fix your meals?
Do people bring food to you?
e.g. Are you able to cut your own food?
Is pouring milk or coffee a problem for you?
 - b. Are there any special eating utensils, such as enlarged fork handles or nonskid plates, that you use and find helpful?

(Dressing)

2. Do you have any problems dressing yourself now that you didn't have before your illness?
 - a. Do you need help in putting on some of your clothes--fastening buttons, for example, or lacing your shoes?
 - b. Do you wear special clothing, or use special equipment, to make dressing easier?
 - c. Are there days you don't get dressed, but wear your bedclothes? About how many days a week, would you say?

(Walking)

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

a. Do other people assist you in getting about?

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

e.g.

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

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

Do you use a cane or a crutch?

e.g.

Do you wear braces or special shoes?

(Travel)

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

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

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

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

(Bathing)

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

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

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

showers?

sponge baths?

c. Are you assisted in bathing by other people?

Are water and equipment brought to you?

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

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

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

Perhaps a long-handled brush?

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

Do you have grabrails around the tub?

(Toileting)

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

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

Does someone assist you in walking to the bathroom?

e.g.

Does someone bring you a bedpan when you require it?

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

(Attentiveness and Memory)

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

a. How do you keep track of appointments?

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

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

d. Do you find you are forgetful?

(Relationship with spouse)

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

- a. Are there things around the house that you used to do (e.g., yardwork, cooking) that you can no longer do? Who does these things now?
- b. Do you spend as much time together -- with your spouse -- as you used to?
- c. Do you still eat all your meals together?
- d. Do you still sleep in the same room?
- e. Has your illness had an effect on how well you and your spouse are able to share things with each other?

(Work role)

- 12 - 14. a. How has the kind of work you do changed over the course of your illness?
- b. Do you do your work in the same way now?
- c. Do you still think about work-related things as much as you used to? Do they seem important to you now?
- d. How often do you see the people you know at work? Did you used to see them more often than this? (For home-makers, you might ask about neighbors, shopping companions, etc.)

(Recreation and socializing)

- 15 - 17. a. What kind of things do you do for recreation or just for fun?
- b. Has this changed in any way since your illness?
- c. How much contact do you have with people outside your family, and where does this occur?
- d. Do you keep in touch with your friends like you used to?
- e. Are there things you'd like to do in the way of recreation or entertainment that you just can't do anymore because of shortness of breath?
- f. Are there friends you haven't seen for a while that you'd really like to see again?
- g. What did you do (do you plan to do) on the most recent (upcoming) major holiday?
- h. How do you spend spare time now compared to before your illness?
- i. Do you find yourself reading more or less now than you used to?

RESPIRATORY QUESTIONNAIRE

IDENTIFICATION NUMBER: _____

NAME: _____

ADDRESS: _____

(zip code)

TELEPHONE NUMBER: _____

INTERVIEWER: _____

DATE: _____

- INTERVIEW SITE: 1. _____ hospital
 2. _____ home
 3. _____ clinic

1. Date of Birth: _____
 Month Day Year

2. Place of Birth: _____

3. Sex: 1. Male ____
 2. Female ____

4. What is your marital status: 1. Single ____
 2. Married ____
 3. Widowed ____
 4. Separated/Divorced ____

5. Race: 1. White ____
 2. Black ____
 3. Oriental ____
 4. Other ____

6. What is the highest grade completed in school? _____
 (For example: 12 years is completion of high school)

7. Living situation: (check one)

1. ____ alone 2. ____ with spouse or partner
3. ____ with family members 4. ____ other

8. Residence: (check one)

1. ___ private home 2. ___ apartment 3. ___ hotel 4. ___ nursing home

COUGH

9A. Do you usually have a cough? 1. Yes ___ 2. No ___
(Count a cough with first smoke
or on first going out-of-doors.
Exclude clearing of throat.)
(If no, skip to Question 9C.)

B. Do you usually cough as much as 1. Yes ___ 2. No ___
4 to 6 times a day, 4 or more
days out of the week?

C. Do you usually cough at all on 1. Yes ___ 2. No ___
getting up, or first thing in
the morning?

D. Do you usually cough at all during 1. Yes ___ 2. No ___
the rest of the day or at night?

IF YES TO ANY OF ABOVE (9A, B, C, or D),
ANSWER THE FOLLOWING.
IF NO TO ALL, CHECK DOES NOT APPLY
AND SKIP TO NEXT PAGE.

E. Do you usually cough like this on most 1. Yes ___ 2. No ___
days for 3 consecutive months or more
during the year?

8. Does not apply ___

F. For how many years have you had
this cough? _____
number of years

88. Does not apply ___

PHLEGM

10A. Do you usually bring up phlegm from your chest?
(Count phlegm with the first smoke or on first going out-of-doors. Exclude phlegm from the nose. Count swallowed phlegm.)
(If no, skip to 10C)

1. Yes ___ 2. No ___

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

1. Yes ___ 2. No ___

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

1. Yes ___ 2. No ___

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

1. Yes ___ 2. No ___

IF YES TO ANY OF THE ABOVE (10A, B, C, OR D), ANSWER THE FOLLOWING.
IF NO TO ALL, CHECK DOES NOT APPLY AND SKIP TO NEXT PAGE.

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

1. Yes ___ 2. No ___

8. Does not apply ___

F. For how many years have you had trouble with phlegm?

_____ Number of years

88. Does not apply ___

EPISODES OF COUGH AND PHLEGM

11A. Have you had periods or episodes of (increased*) cough and phlegm lasting for 3 weeks or more each year?
*(For persons who usually have cough and/or phlegm.)

1. Yes ___ 2. No ___

IF YES TO 11A:

B. For how long have you had at least 1 such episode per year?

_____ Number of years

88. Does not apply ___

WHEEZING

12A. Does your chest ever sound wheezy or whistling:

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

- 1. Yes ___ 2. No ___
- 1. Yes ___ 2. No ___
- 1. Yes ___ 2. No ___

IF YES TO 1, 2, or 3 in 12A:

B. For how many years has this been present?

_____ Number of years

88. Does not apply _____

13A. Have you ever had an attack of wheezing that has made you feel short of breath?

- 1. Yes ___ 2. No ___

IF YES TO 13A:

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

_____ Age in years

88. Does not apply _____

C. Have you had 2 or more such episodes?

- 1. Yes ___ 2. No ___

8. Does not apply _____

D. Have you ever required medicine or treatment for the(se) attack(s)?

- 1. Yes ___ 2. No ___

8. Does not apply _____

BREATHLESSNESS

14. If disabled from walking by any condition other than heart or lung disease, please describe and proceed to Question 15A.

Nature of condition(s): _____

15A. Are you troubled by shortness of breath hurrying on the level or walking up a slight hill? , 1. Yes ___ 2. No ___

IF YES TO 15A:

B. Do you have to walk slower than people of your age on the level because of breathlessness? 1. Yes ___ 2. No ___
8. Does not apply ___

C. Do you ever have to stop for breath when walking at your own pace on the level? 1. Yes ___ 2. No ___
8. Does not apply ___

D. Do you ever have to stop for breath after walking about 100 yards (or after a few minutes) on the level? 1. Yes ___ 2. No ___
8. Does not apply ___

E. Are you too breathless to leave the house or breathless on dressing or undressing? 1. Yes ___ 2. No ___
8. Does not apply ___

CHEST COLDS AND CHEST ILLNESSES

16A. If you get a cold, does it usually go to your chest? (Usually means more than $\frac{1}{2}$ the time)

1. Yes ___ 2. No ___
3. Don't get colds ___

17A. During the past 3 years, have you had any chest illnesses that have kept you off work, indoors at home, or in bed?

1. Yes ___ 2. No ___

IF YES TO 17A:

B. Did you produce phlegm with any of these chest illnesses?

1. Yes ___ 2. No ___

8. Does not apply ___

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

___ Number of illnesses
___ No such illnesses

8. Does not apply ___

PAST ILLNESSES

18. Did you have any lung trouble before the age of 16?

1. Yes ___ 2. No ___

19. Have you ever had any of the following?

1A. Attacks of bronchitis?

1. Yes ___ 2. No ___

IF YES TO 1A:

B. Was it confirmed by a doctor?

1. Yes ___ 2. No ___

8. Does not apply ___

C. At what age was your first attack?

___ Age in years

88. Does not apply ___

2A. Pneumonia (include bronchopneumonia)?

1. Yes ___ 2. No ___

IF YES TO 2A:

B. Was it confirmed by a doctor?

1. Yes ___ 2. No ___

8. Does not apply ___

C. At what age did you first have it?

___ Age in years

88. Does not apply ___

PAST ILLNESSES (cont'd.)

19. 3A. Hay fever? 1. Yes ___ 2. No ___
- IF YES TO 3A:
- B. Was it confirmed by a doctor? 1. Yes ___ 2. No ___
8. Does not apply
- C. At what age did it start? ___ Age in years
88. Does not apply ___
- 20A. Have you ever had chronic bronchitis? 1. Yes ___ 2. No ___
- IF YES TO 20A:
- B. Do you still have it? 1. Yes ___ 2. No ___
8. Does not apply ___
- C. Was it confirmed by a doctor? 1. Yes ___ 2. No ___
8. Does not apply ___
- D. At what age did it start? ___ Age in years
88. Does not apply ___
- 21A. Have you ever had emphysema? 1. Yes ___ 2. No ___
- IF YES TO 21A:
- B. Do you still have it? 1. Yes ___ 2. No ___
8. Does not apply
- C. Was it confirmed by a doctor? 1. Yes ___ 2. No ___
8. Does not apply ___
- D. At what age did it start? ___ Age in years
88. Does not apply ___

PAST ILLNESSES (cont'd.)

22A. Have you ever had asthma? 1. Yes ___ 2. No ___

IF YES TO 22A:

B. Do you still have it? 1. Yes ___ 2. No ___

8. Does not apply

C. Was it confirmed by a doctor? 1. Yes ___ 2. No ___

8. Does not apply ___

D. At what age did it start? ___ Age in years

88. Does not apply

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

88. Does not apply

23. Are you allergic to:

- | | | |
|----------------|--------------|----------------------|
| 1. ___ animals | 3. ___ smoke | 5. ___ certain foods |
| 2. ___ pollens | 4. ___ wool | 6. ___ dust |

24. Do you have pets?

- | | | |
|------------|--------------|-----------------|
| 1. ___ dog | 3. ___ fish | 5. ___ horses |
| 2. ___ cat | 4. ___ birds | 6. ___ chickens |

25. Have you ever had?

A. Any other chest illness? 1. Yes ___ 2. No ___

If yes, please specify _____

B. Any chest operations? 1. Yes ___ 2. No ___

If yes, please specify _____

C. Any chest injuries? 1. Yes ___ 2. No ___

If yes, please specify _____

26A. Has a doctor ever told you that you had heart trouble? 1. Yes ___ 2. No ___

IF YES TO 26A:

B. Have you ever had treatment for heart trouble in the past 10 years? 1. Yes ___ 2. No ___

8. Does not apply

PAST ILLNESSES (cont'd.)

27A. Has a doctor ever told you that you had high blood pressure? 1. Yes ___ 2. No ___

IF YES TO 27A:

B. Have you had any treatment for high blood pressure (hypertension) in the past 10 years? 1. Yes ___ 2. No ___
8. Does not apply ___

28. Current Medications:

- | | | | |
|--------------------|-----|---------------------|-----|
| 1) bronchodilators | ___ | 5) diuretics | ___ |
| 2) steroids | ___ | 6) Digoxin | ___ |
| 3) allergy shots | ___ | 7) antihypertensive | ___ |
| 4) oxygen | ___ | 8) anti-angina | ___ |

OCCUPATIONAL HISTORY

29A. Have you ever worked full time (30 hours per week or more) for 6 months or more? 1. Yes ___ 2. No ___

IF YES TO 29A:

B. Have you ever worked for a year or more in any dusty job? 1. Yes ___ 2. No ___

8. Does not apply ___

Specific job/industry _____ Total years worked ___

Was dust exposure: 1. Mild ___ 2. Moderate ___ 3. Severe ___?

C. Have you ever been exposed to gas or chemical fumes in your work? 1. Yes ___ 2. No ___

Specific job/industry _____ Total years worked ___

Was exposure: 1. Mild ___ 2. Moderate ___ 3. Severe ___?

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

1. Job occupation: _____

2. Number of years employed in this occupation: _____

3. Position-job title: _____

4. Business, field, or industry: _____

E. Are you presently:

1. ___ employed (30 hours per week or more)

2. ___ employed part-time (less than 30 hours per week)

3. ___ temporarily unemployed

4. ___ retired

TOBACCO SMOKING

- 30A. Have you ever smoked cigarettes?
(No means less than 20 packs of cigarettes or 12 oz of tobacco in a lifetime or less than 1 cigarette a day for 1 year.) 1. Yes ___ 2. No ___
- IF YES TO 30A:
- B. Do you now smoke cigarettes (as of 1 month ago)? 1. Yes ___ 2. No ___
8. Does not apply ___
- C. How old were you when you first started regular cigarette smoking? ___ Age in years
88. Does not apply ___
- D. If you have stopped smoking cigarettes completely, how old were you when you stopped? ___ Age stopped
Check if still smoking ___
88. Does not apply ___
- E. How many cigarettes do you smoke per day now? ___ Cigarettes per day
88. Does not apply ___
- F. On the average of the entire time you smoked, how many cigarettes did you smoke per day? ___ Cigarettes per day
88. Does not apply ___
- G. Do or did you inhale the cigarette smoke? 1. Does not apply ___
2. Not at all ___
3. Slightly ___
4. Moderately ___
5. Deeply ___

TOBACCO SMOKING (cont'd.)

31A. Have you ever smoked a pipe regularly? (Yes means more than 12 oz of tobacco in a lifetime.) 1. Yes ___ 2. No ___

IF YES TO 31A:

FOR PERSONS WHO HAVE EVER SMOKED A PIPE:

B. 1. How old were you when you started to smoke a pipe regularly? ___ Age stopped

2. If you have stopped smoking a pipe completely, how old were you when you stopped? ___
Check if still smoking pipe ___

88. Does not apply ___

C. On the average over the entire time you smoked a pipe, how much pipe tobacco did you smoke per week? ___ oz per week
(a standard pouch of tobacco contains 1½ oz)

88. Does not apply ___

D. How much pipe tobacco are you smoking now? ___ oz per week

88. Not currently smoking a pipe ___

E. Do you or did you inhale the pipe smoke? 1. Never smoked ___
2. Not at all ___
3. Slightly ___
4. Moderately ___
5. Deeply ___

TOBACCO SMOKING (cont'd.)

32A. Have you ever smoked cigars regularly? 1. Yes ___ 2. No ___
(Yes means more than 1 cigar week
for a year.)

IF YES TO 32A:

FOR PERSONS WHO HAVE EVER SMOKED CIGARS:

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

2. If you have stopped smoking cigars ___
completely, how old were you when Age stopped
you stopped? Check if still

smoking cigars ___

88. Does not apply ___

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

88. Does not apply ___

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

88. Check if not smoking cigars currently ___

E. Do or did you inhale the cigar smoke? 1. Never smoked ___
2. Not at all ___
3. Slightly ___
4. Moderately ___
5. Deeply ___

FAMILY HISTORY

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

	FATHER			MOTHER		
	1. Yes	2. No	3. Don't Know	1. Yes	2. No	3. Don't Know
A. Chronic bronchitis?	_____	_____	_____	_____	_____	_____
B. Emphysema?	_____	_____	_____	_____	_____	_____
C. Asthma?	_____	_____	_____	_____	_____	_____
D. Lung cancer?	_____	_____	_____	_____	_____	_____
E. Other chest conditions?	_____	_____	_____	_____	_____	_____
34A. Is parent currently alive?	_____	_____	_____	_____	_____	_____
B. Please specify _____ Age if living	_____	_____	_____	_____	_____	_____
_____ Age at death	_____	_____	_____	_____	_____	_____
8. Don't know _____	_____	_____	_____	_____	_____	_____
C. Please specify cause of death.	_____	_____	_____	_____	_____	_____

Following information to be completed by interviewer: (if chart available)

35. Primary Pulmonary Diagnosis:

- | | |
|------------------------------|--------------------------------|
| 1)asthma _____ | 5)pulmonary emboli _____ |
| 2)emphysema _____ | 6)pulmonary hypertension _____ |
| 3)bronchitis _____ | 7)sarcoidosis _____ |
| 4)bronchitis-emphysema _____ | 8)pulmonary fibrosis _____ |
| 10)other _____ | 9)pneumonia _____ |

36. Primary Cardiac Diagnosis:

- | | |
|------------------------------|---------------------------------|
| 1)mitral valve disease _____ | 4)coronary artery disease _____ |
| 2)aortic valve disease _____ | 5)cardiomyopathy _____ |
| 3)congestive failure _____ | 6)congenital defect _____ |

37. Pulmonary Category: 1.Obstructive __ 2.Restrictive __ 3.Vascular __ 4.Comb __

38. Severity: 1.Acute __ 2.Chronic __ 3.Acute-Chronic __

39. Primary Disease Category: 1.Cardiac __ 2.Pulmonary __ 3.Cardiopulmonary __

40. Secondary Diagnosis:

41. Pack Years: __ __

42. Hollingshead Classification: ____

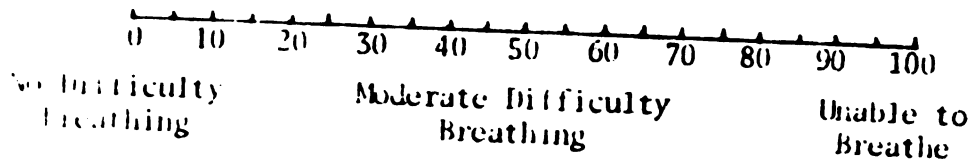
Adapted from:

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

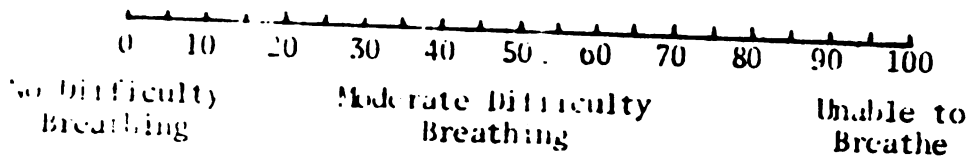
Dyspnea Descriptive Scale

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

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



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

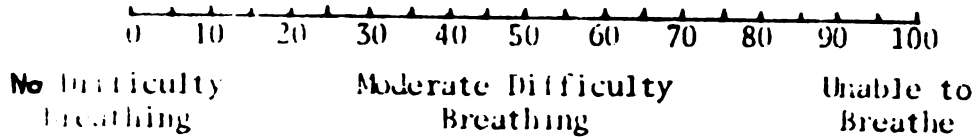


From: Carrieri, G., & Janson-Bjerklie, S. Dyspnea: Critical Variables from the Patient's Perspective, Unpublished manuscript. University of California, San Francisco, 1981.

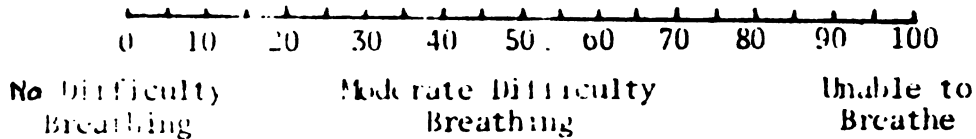
Dyspnea Descriptive Scale

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

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



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



From: Carrieri, G., & Janson-Bjerklie, S. Dyspnea: Critical Variables from the Patient's Perspective, Unpublished manuscript. University of California, San Francisco, 1981.

Appendix F: Causation, Raw Data

Cardiac

D.F.: any exertion, gardening, bending over, walking, stress, worry, getting upset, keep pushing myself to do things even tho I get pooped, just keep going. I think I bring it on and then I use denial. My mind keeps telling me I can do it. Happens at night, laying down, when I worry and then it's without any exertion, excitement, talking, eating (esp. if too much salt). Part of getting old - I hate getting old.

D.E.: sexual activities, any exertion like walking, household chores, just getting dressed, bending over to tie shoes. Sometimes I feel like a million dollars and the next day it all goes to pot.

I.H.: bending over, gardening, housework, picking up, mopping. Weather or air temperature changes will bring it on. Different times--coming and going too much fluid in my system, eating too much, sex, walking in Paradise (hi altitude) became real problem, that's what brought it all on was the move to hi altitude and hills; paint fumes, worse in hot weather, sometimes it just happens, Las Vegas too, happens more outside than inside.

J.R.: walking, cold weather while walking; not a problem with housework; sometimes just happens at night, sometimes spontaneous, just comes on.

Pulmonary

G.H.: I think it's a little psychological, we had a tremendous upset at our home. It comes and goes, sometimes seasons make it worse, I don't think I pay much attention to my breath.

C.L.: exertion, or really upset, working on my cars, hi altitude, eating a large meal, my smoking.

W.H.: dressing, moving quickly, anything except a plain walk, anything more than a creep; leaning over for shoes, standing a long time, coughing, any exertion brings the same pattern, dressing.

E.F.: dressing, walking, hard to answer because it varies, weather changes, sometimes I just wake up in the morning feeling closed in; sometimes there is nothing specific that causes it - I just wake up that way; social things, excitement, starting off quickly for anything, any 'cold'.

R.P.: any exertion, shower, brushing teeth, fearfulness, cig. smoke, making bed, cooking, can't vacuum, fumes, perfumes esp. MUSK, strong smells, certain fruit.

W.G.: fumes from deisel buses, traffic, exhaust, cig. smoke, age creeping up on you, lifting, walking, can't cut lawn, with infection like a cold, putting shoes on, shopping (lean on cart), can't vacuum.

Appendix F (continued)

Cardiac

E.C.: at first it was only with walking, now could be any type of movement esp. if a quick one like getting up to answer the door; reaching overhead, carrying things, sometimes out of the blue that feeling would just come on, varied a great deal, getting dressed, housework like vacuuming, worrying at nite.

M.C.: don't know what brought it on; my brothers noticed my breathing but I didn't feel worse but when I had to walk up a slight hill I just went crazy and couldn't breathe. Has only happened to me twice, once on admission and once in the CCU but that was not bad (following Swan Ganz removal pt. reportedly had short episode of bronchospasm).

M.K.: anything exertional like emptying the garbage, walking, sometimes just happens, in evening, being around alot of cig. smoke; pressure from my job (stock-broker) and thinking my life-span is not going to be what I had planned on, can't imagine not working, would increase financial problems.

Pulmonary

J.K.: getting dressed, talking, over-heated, too warm makes my breathing heavier, any exercise like walking, I may have a very good then begin to wheeze then next day I'm worse; household duties.

R.C.: doing anything quickly, swimming one lap, walking upstairs, bending over, upset may trigger it, high altitude travel, may just come on suddenly, when I get bronchitis, I've never done house or yardwork; we have always had maids.

Appendix G: Prodromal Indicators, Raw Data

Cardiac

D.F.: can't tell, I know I'm bringing it on, my mind just keeps telling me that I can do it.

D.E.: none, sometimes I feel like a million dollars and the next day it all goes to pot.

I.H.: no - it just happens, sometimes a weight gain precedes SOB.

J.R.: none.

E.C.: no, just comes on, sometimes just awaken in A.M. breathless.

M.C.: no.

M.K.: no.

Pulmonary

G.H.: just begin to notice my breathing.

C.L.: get a feeling like you're out of wind.

W.H.: sometimes I start to cough and I know a bad time is coming.

E.F.: start panting, have to sit up.

R.P.: it's such a normal thing to me, sometimes I just don't notice.

W.G.: none.

J.K.: get a tight feeling, weakness.

R.C.: none.

Appendix H: Description, Raw Data

Cardiac

D.F.: you just can't take another breath, no dizziness, sort of weak, get out of breath, extra congestion.

D.E.: huffing and puffing, congestion inside, bloated stomach, wheezy, fighting for air, restless, have to sit down, need O₂, changing positions, always aware of my breathing.

I.H.: pressure in my head, resistance in chest, couldn't get air out, dizziness sometimes, heavy chest.

J.R.: breathing deeper than usual, can't describe it, just can't get enough breath.

E.C.: apprehensive, numbness in head due to fear, dizziness, fearful, head filling up, tight head, drained feeling, rapid breathing, heart pounding, tingling in fingers, lips feel drained of color.

M.C.: frantic, just went crazy, felt like a maniac, gasping and shrieking to get my breath, brilliant kaleidoscope of color, going to pieces, rubbery arms and legs, centered right in the middle, couldn't get it in, couldn't get it out; originally I had just noticed that my breathing hadn't been as good as it had been.

Pulmonary

G.H.: hard time getting breath, dizzy, fingers shaky, dots and lightening in front of eyes, feels tight, can't breathe up as far as I want to go, poor memory, closes right up.

C.L.: fighting for breath, out of gas, out of wind, can't get enough air in, aching in both sides of lungs, rubbery legs, really fighting for that ol' breath.

W.H.: heavy chested, hard to breathe, panicky the more you struggle, the more you have to struggle, eyeballs pushed out of your head, beat out, just want to flop down on the bed.

E.F.: closing right up, whole chest bogged down, can't get air in, shakey, the more you suck in the more chest bogged down, tired.

R.P.: heart pounding hard, heart pounds in my eyes and ears, feel like I'll never get another breath, not gasping, not problem getting air out, it's getting air in.

W.G.: no pain, just know you better stop what you are doing right now, slightly dizzy, weak.

J.K.: feels awful, as if lungs are going to turn inside out, can't grasp any air, high up in chest, tight feeling, weakness, heavy breathing.

Appendix H (continued)

Cardiac

M.K.: just feel short of breath, doing anything exertional, alot of coughing.

Pulmonary

R.C.: suddenly I just get SOB after exertion, it just grabs me, tired, I have to rest and then it's over, stiffness over R. chest, maybe it's neurotic, I don't know.

Appendix I: Duration, Raw Data

Cardiac

D.F.: few minutes.

D.E.: takes awhile, more than
 $\frac{1}{2}$ hour.

I.H.: couple of minutes.

J.R.: just a few minutes.

E.C.: about one hour, the
worst times it lasted all
evening.

M.C.: since it has only hap-
pened once I don't really know,
I don't remember how long it
lasted that time.

M.K.: couple of minutes.

Pulmonary

G.H.: 1 - 3 hours.

C.L.: 3 - 5 minutes to get
back to normal.

W.H.: about 20 minutes.

E.F.: about $\frac{1}{2}$ hour after IPPB
or about 5 minutes after
inhaler.

R.P.: depends, few minutes or
all day.

W.G.: 10 - 15 minutes.

J.K.: varies a great deal,
couldn't say.

R.C.: few seconds.

Appendix J: Pattern, Raw Data

Cardiac

D.F.: same each time.

D.E.: always the same.

I.H.: bending over produces more discomfort in head with SOB whereas the SOB due to walking is a heavy chest but each is same each time.

J.R.: same each time.

E.C.: some episodes had more dizziness than others along with SOB; breathlessness at night when laying down accompanied by great deal more fear and apprehension.

M.C.: n/a.

M.D.: same sensation over and over.

Pulmonary

G.H.: usually the same.

C.L.: the same.

W.H.: same pattern.

E.F.: always typical.

R.P.: never different.

W.G.: same.

J.K.: same.

R.C.: always feels the same.

Appendix K: Overt Indicators or Behavioral Correlates of Dyspnea

Group C

D.F.: none.

D.E.: restlessness, changing positions.

I.H.: mouth open, increased chest movement.

J.R.: increased chest movement.

M.C.: don't know.

M.K.: none.

Group P

G.H.: by my gasping.

C.L.: it's obvious, my mouth is open, face changes color to white or red; I sit or lean against anything, even the wall.

W.H.: I look ghastly; breathing hard and coughin.

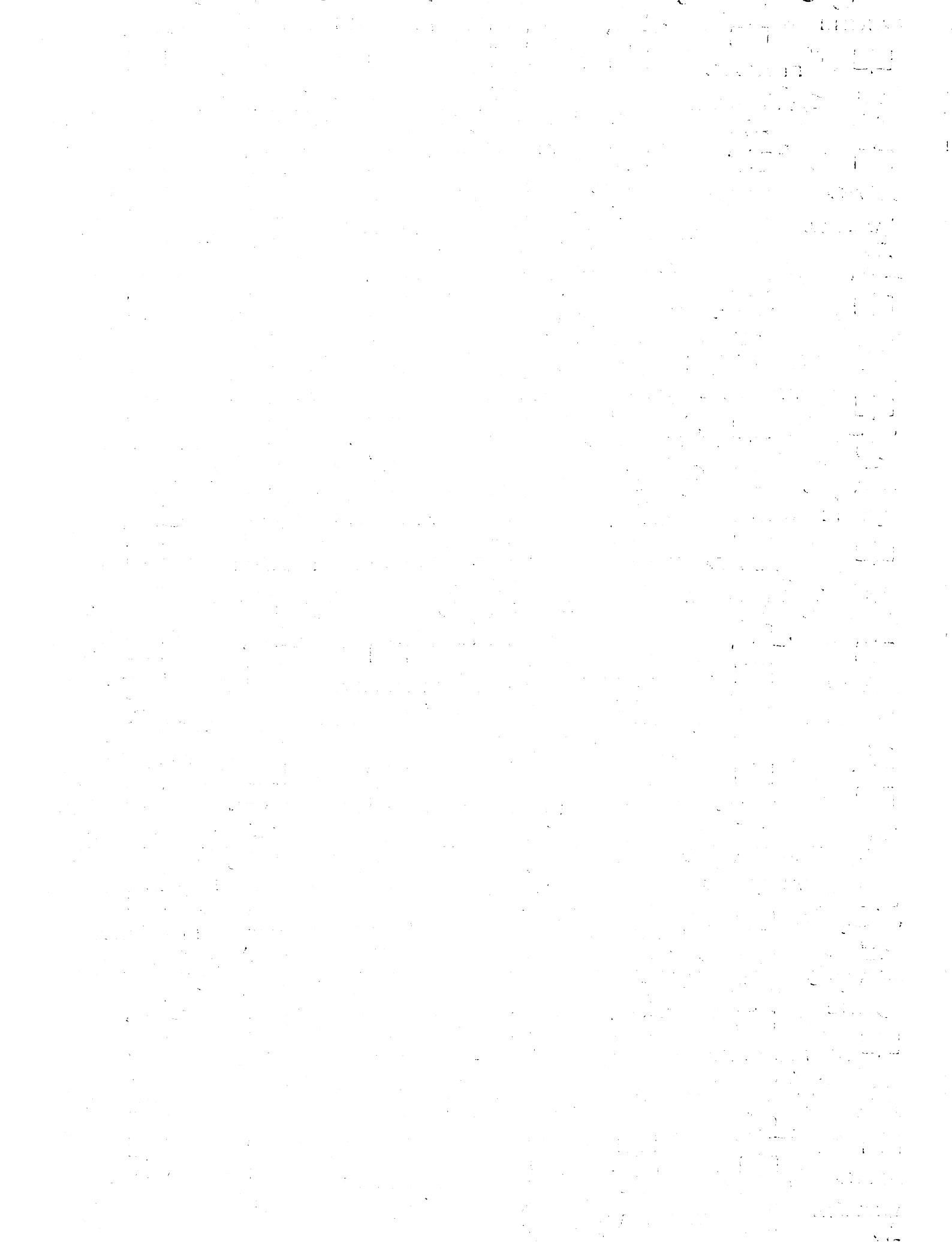
E.F.: panting, gasping, my daughter can tell by talking to me on the phone.

R.P.: couldn't tell; I usually have to tell people.

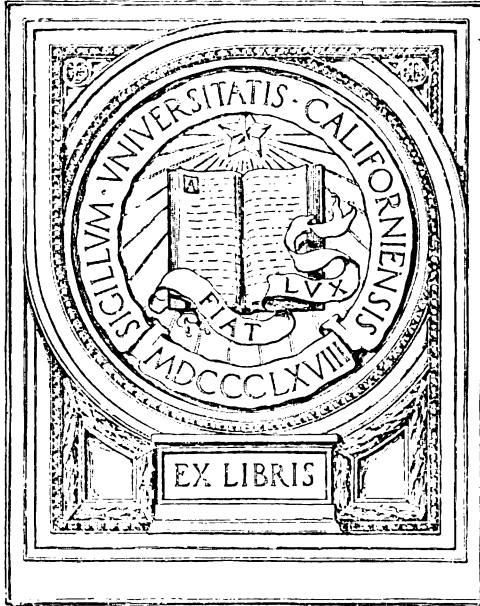
W.G.: by my sitting or leaning against something.

J.K.: wouldn't know.

R.C.: when I talk I have to breath between words--maybe wouldn't be able to tell.



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