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The Effects of COPD on Marriage

by

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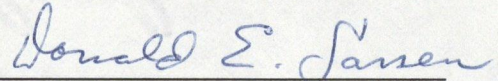
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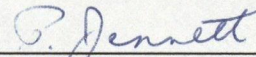
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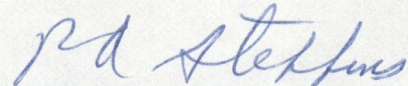
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled, "The Effects of COPD on Marriage" submitted by Gwyneth L. Meyers in partial fulfillment of the requirements for the degree of Master of Science.



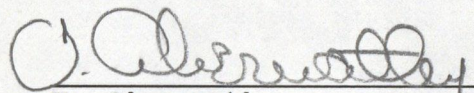
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## ABSTRACT

The purpose of this study was to generate substantive theory on the effects of Chronic Obstructive Pulmonary Disease (COPD) on Marriage. Data were collected and analyzed using theoretical sampling and constant comparative method specific to grounded theory. Self-reported data from 14 couples on the marital partners' perceptions and experiences of COPD were collected using open-ended ethnographic interviews. Findings suggested the following theoretical framework. COPD affected the marriage by creating physical, psychological and social restrictions and losses in a couple's life which in turn create a disequilibrium that potentially threatened the marriage by creating tension, strain and possible conflict within the marital relationship. Couples could experience these changes as a gradual, subtle yet continual process. The degree to which restrictions and losses were perceived to be problematic and intrude upon the marriage depended largely upon the severity of illness, marriage style, a positive marital relationship, management strategies and a couple's perceptions of COPD, especially how COPD is perceived to control their lives. The degree to which marital style ("traditional", "shared" and "companionship") influenced the impact of COPD depended upon a couple's ability to integrate changes in the functional aspects of marriage. The marriage style could eventually require reorganization because of continual change within the marriage. The ability to absorb



change and restructure the marriage was affected by the quality of a couple's marital relationship, particularly their emotional support and interactions. Effective management of COPD, which decreased the problematic nature of its effects, was facilitated by a positive marital relationship. Especially, it involved a holistic approach to the disease consisting of the marital partner's functional, psychological, social and spiritual support for each other. A couple's sense of control over the effects of COPD also influenced their management of the disease and its effects. Individual personalities and psychological resources, such as self-efficacy, self-esteem, self-respect, problem solving and decision making skills, influenced perceptions of control, their marriage, symptoms of COPD and management strategies. Effective management of COPD helped to restore a balance within the marriage and a degree of normalacy which compensated for restrictions and losses and helped to reduce stress in the marriage. The variables of age, general health status and cultural norms confounded the influence the foregoing variables had on restrictions and losses. The practical implications of the findings are discussed in relation to rehabilitation programs and support services for COPD patients and families.

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## CHAPTER 1

### THE RESEARCH PROBLEM

Chronic Obstructive Pulmonary Disease (COPD) refers to a group of diseases which includes bronchial asthma, chronic bronchitis and emphysema. COPD is characterized by increased resistance to airflow in the airways of the lung, usually resulting in variable degrees of dyspnea, fatigue, wheezing and cough producing sputum (Hodgkin, 1979). Petty (1985) suggests that COPD be defined as a pulmonary process characterized by non-specific changes in the lung parenchyma and bronchi which may give rise to one or more of the above symptoms. Airflow obstruction need not be present at all times during the process of the disease.

COPD is an important factor in both male and female mortality, being the seventh major cause of death in Canada (Health and Welfare Canada, 1984). Moreover, COPD is a chronic, degenerative and irreversible disease. Physicians have few medical treatments to alter its course and treatments are for the most part palliative (Strauss, Conrad, LoGofer, Hudson and Bergner, 1986). COPD has a slow, insidious onset and progression, with frequent exacerbations and symptoms that usually manifest themselves in middle or later years. Over time, this has a marked effect on the quality of life of patients and families (Dudley, Sitzman and Rugg, 1985; Sandhu, 1986; Sexton and Munro, 1985).



The patient and family members must both cope with various changes and losses regarding their roles, physical, recreational and social activities, sleep patterns and sexual relations. These changes make it difficult for the individuals involved to continue using their existing coping strategies. For example, physical restrictions resulting from COPD can prevent the COPD sufferer and family members from participating in recreational activities that were previously used to reduce stress or to relax. Changes in both body function and lifestyle can be distressing and lead to depression, anxiety and low self-esteem in the COPD patient. These emotional states can cause difficulties in breathing, and therefore the COPD patient may attempt to avoid them. As well, these emotional states can impede the patient's ability to communicate and this in turn increases tension within the family.

The presence of COPD may exacerbate already existing difficulties in marital or family relationships, such as resentment and ambivalence, or create new interpersonal conflicts. These conflicts may become so burdensome that demands on the patient may eventually lead the patient to withdraw emotionally from relationships with other family members (Sandhu, 1986; Sexton and Munro, 1985). Further, COPD patients may also react to loss of independence and control over their life with anger, despair and anxiety and displace these emotions on the spouse or other family members. Consequently, family members may feel overwhelmed, and react defensively, possibly without being aware of the patient's emotional struggle (Sandhu, 1986; Sexton and Munro, 1985). The disequilibrium and interpersonal conflict experienced within the family may place members under immense strain as they try to maintain communication and support for each other.

Although it has been documented that COPD often has a marked effect on family relationships, only a few studies have systematically studied these effects on the marital relationship. Most of the existing research on the psychosocial effects of COPD has focused on the patient and on quality of life issues. The role of social, cultural or emotional variables in the marital relationship and the coping strategies of marital partners has been largely ignored by researchers.

The effects of COPD on marital relationships are of particular concern in this thesis research. If COPD affects relationships, and medical treatment for it is for the most part palliative, then information about the effects of COPD on marital relationships would be valuable for rehabilitation purposes. That is, information would be helpful for the management of problems that result from COPD and could be used to plan support services for the COPD patients and families.

There are few formal or informal support services within the community or the health care field to assist these people in the management of their illness. Rehabilitation programs, such as the Respiratory Rehabilitation Program at the Holy Cross Hospital in Calgary, play a major role in addressing the need for support services and helping people cope with the effects of COPD.

Information drawn from the chronic illness literature can be used to suggest possible impacts of COPD on the marital relationship. However, since COPD differs in important respects from other chronic illnesses, extrapolations made from other research may not provide a complete or accurate picture of the effect of COPD on the marital relationship. One difference between COPD and other chronic diseases is that the onset of

COPD is gradual while it is often sudden for other diseases, such as stroke or some cardiovascular diseases. Another difference is the profound nature of the symptom of dyspnea in COPD. While the disease is slow and progressive, the dyspnea is insidious and places the patient in continual life threatening situations.

The main goal of the study reported here was to investigate the effect of COPD on marital relationships as perceived by both members of the relationship. The researcher was also interested in exploring the process by which COPD affects the marriage, as well as those physical, psychological and social factors operating in the process.

#### LITERATURE REVIEW

The research commenced with a review of relevant literature dealing with the effects of COPD on the family and marital relationships. This review included psychological and social aspects of COPD, the management of COPD by families and patients, and related literature on other chronic illnesses which focus on family and marital relationships and rehabilitation issues. This review provided the researcher with basic knowledge about the psychosocial dimensions and issues associated with COPD and served as a background for framing the research questions that appear at the end of the chapter.

#### Psychological Aspects of COPD

A distinctive feature of COPD is its psychological component. There is a close relationship between respiratory function and psychological



processes (Nett and Petty 1970). Both involuntary and voluntary control of breathing play a role in the expression and experience of psychological responses. Breathing is involved in the communication with others and the expression of emotion. Variation in respiration rate and depth occurs with laughter, anger, crying, fear and sexual excitement. These become problematic for the COPD patient as they express themselves emotionally. The slightest psychological upset can deplete them of vital but scarce oxygen and create breathing problems. Thus patients become protective, guarding themselves against emotion.

Psychological states may increase COPD symptoms. For example anger, anxiety and happiness increase expenditure of energy and the consumption of oxygen and elevate ventilation and muscle tension. On the other hand, depression, apathy and deep relaxation reduce energy expenditure and decrease ventilation and increase muscle relaxation. The dyspnea produced by either of these situations tends to exacerbate the patient's psychological reaction, which in turn produces more physiological change (Dudley, Glaser, Jorgenson and Logan, 1980). Patients who learn from this experience and attempt to avoid the subjective stress of the dyspnea spiral, may begin to live in an "emotional straight jacket" to protect themselves. This leads to isolation, anger and depression (Dudley et al., 1980; Dudley et al., 1985). A COPD patient's mood, motivation and personality thus can contribute to the patient's disability (Gorman et al., 1984).

Reviews and studies of the psychological aspects of COPD have repeatedly reported findings of depression, anxiety, fatigue, somatic preoccupation, dependency, loss of self esteem, coping difficulties,

impatience, irritability, hysterical disorders, aggressive behaviour and embarrassment (Agle and Baum, 1977; Burns and Howell, 1969; McSweeney, Grant, Heaton, Adam and Timms, 1982; Prigatano, Wright and Levin, 1984; Sandhu, 1986). While these studies have described a distinctive clinical picture of the COPD patient, the findings must be interpreted cautiously because the instruments used to measure the characteristics in this clinical picture may not be appropriate for the COPD population. Findings of depression, anxiety and somatic preoccupation appear to be fairly reliable across studies. But, as McSweeney (1988) points out, this may be, to some extent, because many studies have used the Minnesota Multiphasic Personality Inventory (MMPI). Although the MMPI is a useful measure of psychiatric disturbances, it may not be well suited to measure aspects of COPD patient's quality of life such as psychological well being or social adjustment. McSweeney and Dudley et al. (1980) note that the MMPI scales contain several items concerned with somatic symptoms. For example, items on neurotic scales of the MMPI such as, "I do not tire easily," and "I am seldom short of breath," relate to symptoms likely to be experienced by the COPD patient. Thus, as McSweeney (1988) notes, the findings of hysterical disorder and aggressive behaviour are less reliable. Given the nature of the disease it is understandable however, that findings of depression, anxiety and somatic preoccupation would be common in COPD. Depression has also been documented to be the predominant emotional difficulty for the COPD patient in studies that have used instruments other than the MMPI (McSweeney et al., 1982; Prigatano et al., 1984).

The psychological disturbances associated with COPD include both neuropsychological impairment and emotional responses to COPD. However,

there are differing opinions about the causal factors of emotional disturbances such as depression. Some researchers have suggested that the disturbances may be due to physiological factors, including hypoxxygenation of the limbic system and related brain function (Krop, Block and Cohen, 1973; McSweeney et al., 1982). Others have found that psychosocial factors associated with the loss of pleasurable activities, coping difficulties and economic hardship are important correlates of emotional disturbances (Barstow, 1974; Dudley et al., 1980). Further investigation has shown that while physiological factors play a role in the development of depression, the COPD patient's experience of depression is largely a reaction to their situation (McSweeney, 1988).

The impairment of neuropsychologic function has been reported in COPD patients. Hypoxia and hypoxemia can lead to impairment that results in the limitation of basic adaptive skills. Deficits have been noted in conceptual skills, flexibility of thinking, perceptual motor integration, simple sensory and motor skill, attention, learning and memory as well as verbal skills (Grant, Heaton, McSweeney, Adams and Timms, 1980; Heaton, 1988; Krop et al., 1973). A reduced quality of life has been found to be significantly related to the degree of neuropsychological impairment in COPD and to the disease severity (McSweeney et al., 1982).

Dudley et al. (1980) emphasized that while some similarities in the composite clinical picture of the COPD patient have been established, there is considerable variation in this picture due to personality differences, stages of disease, degree of impairment, and the social, economic, educational and cultural resources of the patient. This

variability among COPD patients may make it difficult not only to describe the dynamics of the illness, but also to compare it to other diseases.

Casselith et al., (1984) have noted that assumptions about the specificity of psychosocial aspects of a disease and psychological responses to a particular disease are often made, as in the case of COPD. A comparison of psychological states in patients with different chronic diseases was conducted. Patients from five chronically ill groups (arthritis, diabetes, cancer, renal disease and dermatologic disorders) were compared with patients under treatment for depression. They found that while some chronically ill patients are depressed and anxious, most remain psychologically intact, similar in their level of mental health to the general public and are distinct from depressed patients.

This suggests that psychological adaptation is effective among patients with a chronic illness and is functionally independent of specific diagnoses. The physical limitations and problems may be unique to a particular disease but the emotional status of a chronically ill patient may not be unique to a particular disease. The uniqueness of COPD patient's emotional responses to the psychosocial consequences of COPD may be questioned based on these findings. While the psychological responses to COPD may not be unique, the fact that COPD affects cognitive and emotional responses and emotional responses affect COPD remains a distinctive feature of the disease.

The psychological component of COPD has a significant impact on a patient and this may be difficult for the patient to cope with in the absence of a diagnosis of disease. COPD is hard to diagnose because of the subjectivity of symptoms and the absence of disease pathology until

later stages of the disease. The experience of symptoms with no sign of disease can be problematic and disturbing to patients. During the early stages of disease the patient can experience dyspnea in the absence of significant changes in pulmonary function during the early stages of COPD (Dudley et al., 1985). The diagnosis is also difficult to make because dyspnea is not a symptom unique to COPD and is also experienced by both healthy people and patients with diseases such as cardiopulmonary disease.

Similar degrees of organ pathology associated with dyspnea may generate different reports of distress or pain among COPD patients, depending on a subjective judgement of their breathing. Dyspnea can accompany emotional change without being associated with changes in blood gas (Dudley, Martin and Holmes, 1968). This type of subjectivity of the symptoms of COPD is problematic for researchers because measurement of the symptoms such as pain, dyspnea or lack of body energy is difficult. Consequently, a clear and accurate picture of the COPD patient is hard to obtain.

#### **Social Aspects of COPD**

The reduction in the quality of life of COPD patients appears to be a complex association between psychological disturbances and the social aspects of their lives. McSweeney (1988) focus on four dimensions of psychosocial issues to define the quality of life of COPD patients. They are: 1) emotional functioning, 2) social role functioning, 3) daily living activity and 4) ability to engage in leisure activities. The reduction in the quality of life can be explained by the physical, psychological and

social losses, whether real or threatened, experienced by the COPD patient.

The ability to carry out vocational, recreational, social and sexual activities and activities of daily living is reduced (Dudley et al., 1980; Dudley et al., 1985; Heaton, 1988; Sandhu, 1986; Sexton and Munro, 1985). These losses increase as the disease progresses. In later or endstages of the illness, COPD patients of necessity focus their attention on dying. Not only have these patients had to deal with these losses but they are also confronted with their mortality.

The losses suffered by the patient are paralleled by those suffered by the patient's family members. Spouses may lose their jobs to care for the patient, their freedom to travel, and their social activities or children may be required to prepare meals or perform additional household chores (Sandhu, 1986). A chronic illness of one member of a family affects all family members and requires the use of a variety of adaptive and sometimes creative innovations to reestablish equilibrium in the family system. A family's response to an individual's illness may influence the course of happiness of the family unit (Litman, 1974). The way in which a family member assumes the role of being ill and the way in which the family responds to it will influence the illness, the health of the family and its equilibrium. The family is involved in defining whether a member is sick or not, providing validation for the sick role of the ill family member and participating in the initial steps in seeking out and using available care.

The ability of the COPD patient to adjust to their psychosocial losses appears to be related to the psychosocial assets of the patient,



such as vital interest in life, adequate financial resources, housing and social support, that is, feeling loved and esteemed (Dudley et al., 1980). These individual characteristics and social support facilitate effective coping or modification of one's environment. Low psychosocial assets have been linked with increased morbidity and mortality, possibly as a result of accompanying emotions of anger, fear, anxiety, helplessness and hopelessness. High psychosocial assets have been correlated with better response to therapy, achieving realistic and appropriate interpersonal behaviour (Dudley et al., 1980; Sandhu, 1986).

According to Barstow (1974), a supportive significant other is probably the single most important factor in adjustment to a chronic illness such as COPD. A marital partner may fill this role but marriage comes under tremendous strain, resulting in disequilibrium caused by change or losses in roles and responsibilities, difficulties in communicating with and supporting each other and struggles with interpersonal conflict (Sandhu, 1986; Sexton and Munro, 1985).

#### Family and Marital Relationships and COPD

Strong evidence exists linking the family system to health behaviour and health outcomes. Family structure and function influence the emergence of health problems, utilization of health services and beliefs families have about illness and how it should be treated (Crawford, 1971). Research on cardiovascular disease provides further evidence of family influences on disease (Sallis and Nader, 1988). Aggregation of risk factors within a family, that is, similarities in health variables among family members, such as blood pressure, serum cholesterol and obesity,

influence the risk of disease within the family. The family environment is also responsible for influencing health behaviours such as dietary habits, smoking and physical activity patterns. This is not surprising given the nature of family interactions. Family relationships, emotional bonds and interactions among family members influence practically every aspect of human life. However, the mechanisms of interaction and influences on health have been less well described and family determinants of behaviours related to the prevention of major chronic diseases have received limited attention.

The interactions between illness, disabilities and the family are increasingly being studied. A few studies have focused on family variables, such as stress and vocation and their influence on the development of specific illnesses such as cardiovascular disease, hypertension and cancer (Jenkins, 1971; Reeder, Scharama and Dirken, 1973). The effect of illness and disability upon family members has received considerable attention. Litman (1974) discusses the family structure and functioning with regard to illness. Family size was regarded as an important variable in predicting the extent of adaptation to role changes as a result of a family member's illness. Larger families were better able to adapt to role change and were less likely to experience role reversal than smaller families. However, family size had no influence on whether or not a member's illness had an adverse effect on family relationships. A family's structure may be modified as the ill member's ability to perform roles is reduced. The extent to which a member's illness may affect role relationships may be a function of the nature of the illness. Family solidity, that is close family ties and

happiness was reported to have little effect against the disruptive impact of a member's illness on family relations. The unity of an extremely close, happy and well integrated family may be severely strained as a result of a member's illness, while an illness may bring a less cohesive family closer together.

Mechanic (1968) has discussed the impact of a mother's illness on the family. Mothers are more likely to seek medical care and advice for their children than for themselves. They seem more reluctant to take on the sick role themselves. This may result from the difficulty she has in maintaining her own roles and responsibilities and fulfilling her obligations to other family members when she is sick.

There is a body of literature that focuses on the impact of chronic illness on marital relationships. Some of the research on chronic illnesses such as pain indicates that role tension and illness in the well spouse occurs as a result of the partner's illness (Flor, Turk and Sholtz, 1987; Klein, Dean and Bogdonoff, 1967). In married couples, the chronic illness of one partner frequently results in increased responsibilities for the well spouse. The well spouse often assumes the role of caregiver in addition to roles the ill partner can no longer maintain. The potential exists for the well spouse to experience burnout. Burnout is physical and emotional exhaustion, involving negative self concept, negative attitude and a loss of one's focus on life (Ekberg, Griffith and Foxall, 1986).

Peterson (1985) found that role adjustment for both partners was the major issue in adapting to home haemodialysis. The psychosocial adjustment of wives who were family oriented, was related to availability

of finances and the adjustment of the patient husband. Some wives had a dual orientation toward career and family. The impact of haemodialysis for these wives was related to role strain encountered when they attempted to fit additional responsibilities associated with illness into their lives.

Another study of the spouse's role in home haemodialysis concluded that the dependence or independence of spouses played an important role in the stability of the marriage and coping with the intrusiveness of a chronic illness. Success in treatment of the illness at home and even the success of the marriage was at risk when the spouse was naturally dependent on the patient partner (Streltzer, Finkelstein, Feigenbaum, Kitsen and Cohen, 1976).

Hafstram and Schram (1984) reported that wives' satisfaction with marriage and with several husband-wife interactions was significantly lower for wives with chronically ill husbands when compared to the satisfaction of chronically ill wives in these areas. Husband-wife interactions included time spent together, understanding and attention from spouse, companionship and roles as parent and marital partner. Chronically ill wives were less satisfied with themselves in their roles of wife and mother. This study did not address the relationship between a husband's marital satisfaction and his own or his wife's chronic illness.

Marital role theory has been used as a framework to examine findings linking marital adjustment and psychosocial functions. (Quick and Jacob, 1973). The theory implies that married couples develop specific role expectations for their spouses. The extent that these expectations are

met, will determine the degree of positive marital adjustment and an individual's adaptive psychological functioning. The absence of satisfying role responses can lead to role strain between the couple, contributing to increased individual psychological distress and affecting marital adjustment (Binik, Devins and Chowanec, 1987). Variables related to marital roles such as division of responsibility and sexuality have been found to be less important in marital disturbance than variables associated with the processes within the relationship (i.e., level of regard, willingness to be known and empathy) (Jacob and Quick, 1973).

The intrusiveness of a chronic illness (the degree to which an illness and its related treatments interfere with normal activities) has also been seen as an important determinant in marital role strain. (Binik et al., 1987). Coping mechanisms previous to an illness and the value a person places on various life activities may determine how disability in one role affects performance or adaptation in other roles (Bruhn, 1977). Thus, how an individual copes with an illness may affect the degree to which an illness intrudes or interferes with normal activities.

Coping successfully with problems resulting from a chronic illness requires substantial effort and adjustment (Bruhn, 1977). To successfully adapt the ill person may have greater need for social supports. Social supports function as a coping resource by facilitating constructive situational change or by helping reduce the ill person's negative emotions.

Spousal criticism and support have been related to the psychological adjustment and coping of wives with rheumatoid arthritis. Patients with a highly critical spouse tend to engage in more maladaptive coping

behaviours and have poorer psychological adjustment. Examples of this includes wanting to escape the reality of the illness, fantasizing or wishful thinking about finding a cure for the illness and reduced self esteem (Manne and Zanna, 1989).

The adjusting to and coping with a chronic illness in a marriage has been related to more than social support. Marital intimacy and love have been considered to be major determinants of effective coping with illness and long term adaptation to the illness (Waltz, 1986). The level of marital problems and role strain appeared to be an important influence on a couple's well-being. An emotionally close, committed, sharing marriage was felt to provide an individual with a secure coherent environment in which an individual may restructure and make adaptive changes to themselves and their environment. A close marriage plays a major role in the maintenance of self esteem and facilitates necessary changes in self concept.

There is small body of literature on the effect of COPD on the marital relationship. The impact of a husband's COPD on the spouse was examined by Sexton and Munro (1985) in a study which used a survey technique. This is the only relevant study located for this review. The wives of COPD patients were shown to assume new roles and responsibilities, relinquish social activities, rate their health lower and experience high levels of subjective stress, low levels of life satisfaction, loss of freedom and sleep and experience a decrease in marital relations. While the study expands the understanding of the impact of COPD on the marital relationship it did not examine the effect of wives' behaviours on their husbands' illness and the effect of the

illness of women with COPD on their husbands. In a more recent study of women's experience of COPD, Sexton and Munro (1988) reported that slightly less than half of the women discussed problems associated with COPD with their spouse. Although both men and women COPD patients are reported to experience similar problems associated with COPD, it would also be of interest to know what coping strategies spouses use to cope with the problems as the disease progresses and how the problems affect a marriage.

### Coping with COPD

There is a multitude of difficulties to which COPD patients and family members must adapt. The patient and family must develop basic strategies to meet them. These challenges include: preventing medical crises, controlling symptoms, carrying out prescribed regimens, either preventing or living with social isolation, adjusting to changes in the course of the disease, normalizing interactions with others as much as possible and maintaining sufficient funds for treatment (Strauss, 1984).

COPD patients manage the stresses imposed by their illness with a variety of psychological adjustments, which may be seen as either adaptive or maladaptive (Agle and Baum, 1977). The use of mental defenses (e.g., denial) is not necessarily maladaptive. The denial of the serious implications of an illness may help a patient maintain hope and avoid serious and incapacitating depression. Any coping strategy, such as denial, that may support hope for continued life, improvement or promote a more comfortable equilibrium which can be considered adaptive. Physical activities carried out within the limitations of the illness can promote positive mental adaptation. The joy and pleasure that COPD patients

experience as they gradually increase their exercise tolerance is an example.

The COPD patient must come to terms with the management of scarce energy (Strauss, 1984). Reduction in oxygen intake means a considerable lessening of available bodily energy. Any exertion or movement that uses oxygen (e.g. laughing, talking, walking) can bring about dyspnea. Another issue that COPD patients must deal with is the visibility of their illness. Respiratory distress is not always visible to others and can be misread. This can lead to problems of legitimizing the illness. Consequently, COPD sufferers are often accused of being neurotic, malingering and manipulative. To the untrained eye even visible symptoms may be misunderstood. COPD patients pausing from shortness of breath in public are often mistaken as being drunk. To avoid social embarrassment they adopt ways to normalize the situation. For example, learning to lean against a wall or sit down in a certain manner.

Coping with a reduction in oxygen intake may, for the COPD patient, require learning to "live on a leash", that is, learning to be dependent on a machine (Strauss, 1984). Some people may be limited to the length of their oxygen hose, others to the length of the oxygen supply in their portable tanks. Adjusting to regimens and symptom control may require COPD patients to redesign their lifestyles. This may involve innovative ideas, such as the patient falling in step behind someone who has more energy to push open heavy doors, or arranging never to be far away for "puffing stations" where a patient can recoup from lack of breath while looking as if their stopping is normal. There has been little research on the progression and course of COPD. It is known in general terms that



individuals move through a process of continual changes in the course of COPD that require both major and minor lifestyle changes. While there have been cross-sectional studies of this process, these time-limited studies are not well suited to reveal in-depth information about the nature of the adaptations to change and the impact the changes have on the individuals involved. Coping strategies of the COPD patients use to manage the course of the illness and the impact these strategies have on the marital relationships require further study.

#### **COPD and Rehabilitation**

COPD is usually first diagnosed in the advanced stages, but medical management of the disease, even at advanced stages, offers hope of an improved quality of life and can be of substantial benefit to patients (Petty, 1985; Woolfe, 1984). Patient education about the disease, breathing and bronchial hygiene techniques, proper use of equipment and physical conditioning all help to improve exercise tolerance, reduce hospitalizations, stabilize the disease process (although it is still progressive) and increase the comfort of living at home. The inclusion of spouses into the rehabilitation process may be important. Through the inclusion of the spouse in the patient's rehabilitation and management plan, caregivers can become more aware of spousal dynamics and interactions. The spouse has an opportunity to understand the COPD patient's therapy, develop self-help and coping skills and gain factual information about COPD. This may facilitate and motivate support and compliance with patient management plans. Information about the marital

relationships of COPD patients would help to clarify the need for and approach to this treatment strategy.

The Respiratory Rehabilitation Team at the Holy Cross Hospital in Calgary have expressed concerns related to the interaction between COPD and the marital relationship. Some of these concerns focused on patients' marital difficulties that surfaced during their participation in the rehabilitation program. In a number of cases, participants in the program required counselling with respect to marital problems. The need to provide counselling revealed that there is a lack of information that would be helpful for the management of such problems. Thus, there appears to be a need to further explore the impact of COPD on married couples. The Respiratory Team is hopeful that with better information about marital problems they would be able to improve their service to COPD patients.

#### SUMMARY

The literature review revealed a significant psychological component to COPD. The COPD impacts patients' emotions which in turn negatively influences the COPD. Both the psychological and social issues that surround the COPD patient have an impact on family relationships that requires the family to develop coping strategies to deal with the disease. The marital relationship is an important part of family dynamics and these family dynamics influence the care of the COPD patient. However, the effects of COPD on the marital relationship and how this relationship responds to those effects have not been widely studied.

## RESEARCH GOALS AND QUESTIONS

This investigation was directed at specific research questions related to the broad research goal which is to explore the effects of COPD on the marital relationship as perceived by the marital partners and the dynamics and processes in that effect. The questions were based on important issues and dimensions highlighted in the literature review. The following questions were investigated:

- 1) How do the partners perceive the cause, nature and scope of COPD?
- 2) How do the marital partners perceive the marital relationship?
- 3) What are the perceived effects of COPD on the marital relationship?
- 4) What changes occur in the COPD illness and the marital relationship in relation to the COPD?
- 5) What situational variables influence the effects of COPD on the marital relationship?
- 6) What management strategies do couples use to cope with the effects of COPD on their relationship?

The research findings based on these questions are reported in the following chapters. The first question is addressed in Chapter 3, questions two through five in Chapters 4 and 5, and question six in Chapter 6. The conclusions drawn from the findings of this study are discussed in Chapter 7.

## CHAPTER 2

### RESEARCH DESIGN AND METHODOLOGY

#### STUDY DESIGN

The Grounded Theory methodology of Glaser and Strauss (1967) was used to address the research questions of this study. There were several reasons why this method was chosen. Grounded theory is a qualitative method that is useful in studies that are exploratory in nature. As previously described, the body of literature on COPD and marital relationships is underdeveloped, thus the area is well-suited for exploratory research. This study was designed to contribute to the development of the literature in three ways: 1) by providing descriptive data related to the research questions (see p. 20); 2) by generating theoretical propositions about the relationship of COPD to the marital relationship; and 3) by identifying relevant issues to be studied in the future. Grounded theory is also a useful method by which to study the dynamic nature of the subject matter. The study attempted to explore processes which are not readily studied through the use of questionnaires.

The grounded theory methodology employs open-ended ethnographic type interviews. It involves a process of formulation, testing and redevelopment of concepts and propositions until a theory is generated

that is integrated and consistent with the data and is operationalized for testing in later quantitative research (Simms, 1980). Grounded theory is not designed to test set hypotheses derived from existing knowledge, but to analyze data in such a way as to generate new hypotheses or theories. Data collection and analysis occur simultaneously. As each interview is completed, it is coded and analyzed.

A constant comparative method is used in the analysis. This consists of comparing incidents to each category developed, integrating categories and properties of categories, and delineating theory. Incidents are the events, behaviours or informant responses in the data that are coded into as many categories of analysis as possible. Tentative explanations for accumulating ideas and knowledge emerging from the data are formulated and reformulated with each interview. The fledgling theories are then reworked or discarded to accommodate new data or negative cases. Gradually, common themes and concepts are identified and merged into an analytical, substantive theory.

## RESEARCH SAMPLE

### Research Participant Inclusion Criteria

Married couples were included in the study if they were: 1) still residing together; 2) both willing to participate in the study; 3) were 40 years of age or older, and 4) one partner had COPD. These criteria were chosen in order to limit the scope of the study, since the topic of marriage is broad and the study necessarily limited by time. Widowed, divorced or separated couples were not included in the study, even though these states

may have been a consequence of the COPD. For example, a married couple may have become separated, due to the severity of the illness, with the ill partner residing in a hospital or nursing home. In this situation, the illness may be very debilitating and possibly endstage, and it would be difficult for the couple to participate in an interview. Obtaining both partners' perspectives of the COPD and the marriage was considered important in terms of exploring the dynamics and changes within the marital relationship. Since COPD tends to manifest itself in middle to later years, the study focused on married couples in that age. Only couples with one COPD partner were interviewed as the illness in both partners would introduce further complications and issues into an already complex subject area. An exception was made in the case of one couple. This two COPD partner couple was interviewed for comparison purposes.

#### The Theoretical Sampling Method and Sampling Frame

The informants for this study were selected from a convenience sample of COPD patients. A theoretical sampling method described by Glaser and Strauss (1967) was used. As the data were simultaneously collected, coded and analyzed, the researcher decided what data to collect next and where to find the data to develop the emerging theory. Criteria for selecting informants were based on their theoretical relevance for furthering the development of emergent concepts. Negative cases (cases that are the exception) were sought to test and challenge the developing concepts and theory. For example, it was found that the issue of restrictions was considered an important problem in relation to the

marital relationship among informants with moderately severe illness. Therefore, informants were sought who were similar in all important variables but had either a low or high severity of illness; to see if the problems of restrictions were still important at these levels.

Through the process of selecting informants with varying degrees of severity, the researcher discovered a couple who did not consider the lung condition a problem or restrictive. This couple was an exception. Outlying or exceptional cases were compared to other cases that had been used to formulate the developing theory. These outliers were eventually integrated into the emerging theory. The analysis of exceptions is important for the development of theory. The exceptions are useful in illuminating properties, showing differences, creating variation, showing new avenues for exploration and challenging existing ideas. If new findings resulting from these outlying cases did not fit the emerging concepts then the concepts were changed and reworked to accommodate the findings. These new findings were then challenged, compared and verified with additional cases, thus step by step, concepts and theory were developed.

Certain criteria were used to select the initial informants for interviewing. The initial criteria were sex and severity of illness. Subsequent criteria for selection were based on the emerging data acquired through the interviews. These included age, diagnosis, oxygen use and socioeconomic status defined by occupation and education.

Sample selection criteria were presented to the Respiratory Disease Specialist who is the Medical Director of the Respiratory Rehabilitation Team at the Holy Cross Hospital. Potential informants filling the

criteria were selected by this physician from a list of COPD patients in his practice. The physician contacted these patients by telephone to inform them of the study. An introductory letter was mailed to the selected couples. This letter described the study's purpose and what was required of those who chose to participate. A reply card was attached to the letter with a return stamped envelope. The letter and reply card also served as a consent form. Those couples who chose to participate were screened by a short telephone interview for variables relevant to the study. This is referred to as sample screening. The purpose of sample screening is to ensure a wide variety of variables in the sample (Glaser and Strauss, 1967). By sample screening, the researcher was able to set up a profile of a variety of potential informants and use this information to determine whether or not respondents met the inclusion criteria. The screening variables included marital status, length of marriage, sex of partner with COPD, age, perceived severity of illness, length of illness, recent hospitalizations, diagnosis, occupation, education and income.

The severity of the COPD illness was determined using an index (Appendix A) which was developed by the American Lung Association (Dudley et al., 1980). The index, based on patient functioning, rated the degree of physical impairment accompanying COPD based on a five-point scale, with level one being the least severe and level five the most severe. Since the severity rating is a subjective measure both the referring physician and the informants were asked to rate the severity of the COPD. The physician rating was based on a medical background, while informants' rating was based on their perceptions of impairment and functioning. Recording the physician ratings was important since medically defined



severity was one of the sampling criteria. Obtaining informant ratings was important as the study explored their perceptions of illness and therefore, it was of interest to know how they rated the severity of the lung condition. Any differences between physician ratings and informant ratings were noted and included in the analysis.

The criterion for judging when to stop sampling potential informants pertinent to a category is referred to as the category's theoretical saturation. Saturation means that no new or additional data are being generated or found by further sampling. To achieve saturation the researcher maximizes the diversity among patients in order to obtain variety in data bearing on a category. To determine when saturation has been obtained the researcher uses her or his knowledge and theoretical understanding of the area to determine when no new data are being generated and whether the generated data are integrated, cohesive and have depth.

#### Characteristics of the Sample

The plausibility, depth and meaning of the research findings was enhanced by the diversity of the study sample. The variation in demographic and situational variables of COPD couples generated by the theoretical sampling is similar to characteristics of this population described in the literature. The following is a description of the sample.

1. NUMBER OF COUPLES. Twenty nine couples were contacted by letter. Sixteen of these couples agreed to be interviewed. Of these 16, 14 were interviewed as two couples were lost due to moves. Of the 14

couples, 13 had one partner with COPD, and in one both partners had COPD. Nine couples refused to be interviewed and four were ineligible for the study.

2. **MARITAL STATUS.** For all but three couples, the present marriage was their first. In three of the 14 couples at least one of the partners had been previously married. The length of the marriages ranged from 8 - 42 years. The mean length of marriage was 29.3 years. Four of the couples married after the partner had been diagnosed with COPD.
3. **SEX.** Among the 13 one-patient couples seven patients were male and six were female. After cigarette smoking and age, the male sex is a risk factor for COPD (Petty, 1985). Males are more likely to die from COPD than women. The higher mortality rates for males can be attributed in part to a higher prevalence of smoking among males (Health and Welfare Canada, 1984). However, Sexton and Munro (1988) report, that an increase in COPD among women is occurring as the cigarette smoking habits of women have closely paralleled those of men and their relative risk of smoking related illnesses have become increasing similar. The experience of COPD is becoming more equally distributed between men and women. The similar distribution of males and females in the sample reflects the smoking trends described in the literature, thus it is relevant the data collected reflect the experiences of both COPD men and women and their spouses.
4. **AGE.** The age of informants in this study ranged from 41 to 82 years. The mean age of COPD partners was 60.3 years and well partners was 56.0 years. The mean age of ill and well partners

when separated by sex was: Males with COPD 66.8 years and well female partners 63.8 years; females with COPD 53.0 years and well male partners 56.3 years. Thus, in this study couples in which the husband had COPD tended to be older than couples where the wife had COPD. This may reflect previous smoking trends in men and women, when men were more likely to smoke than women. Also, men may be more likely than women to leave a spouse who is sick than women (Magidson and Wright, 1978). This may reduce the number of couples with older married COPD wives and so older couples would be more likely to have male COPD spouses than female COPD spouses.

5. **DIAGNOSIS.** The sample in this study reflects a cross section of different lung conditions that are grouped under the term COPD, namely, asthma, emphysema and bronchiectasis (see Table 1).

Table 1. The Distribution of Diagnoses Across COPD Informants

Diagnosis	Sex		Total
	Male	Female	
Asthma	2	2	4
Bronchiectasis	2	2	4
Emphysema	4	3	7
Total	8	7	15

Emphysema was the most common diagnosis, while asthma and bronchiectasis were equally represented. Of the seven emphysema informants one informant had a rare genetic condition,  $\alpha_1$ -

antitrypsin deficiency. This condition is associated with advanced emphysema occurring at an early stage, sometimes even without smoking, and is regarded as a definite risk factor for COPD.

6. **ILLNESS SEVERITY.** Since COPD is a slow, progressive illness the degree of severity and impairment will be quite varied among a group of patients. This is evident for both the physician's ratings and the couples' ratings in the study sample (Table 2). In all couple's, both spouses ratings were in agreement. However, there was agreement between physician and couple ratings in only seven of 15 cases. In the remaining eight cases, the physician's ratings were higher than the couple's rating in four cases, while the couple's rating was higher in four cases. Most of the eight differences in rating between the physician and couples occurred in respect to the more ill COPD patients. The difference in ratings may reflect a possible change in the severity between when the physician saw the patient and when the researcher contacted the informant. Informants reported changes in their level of functioning resulting from exacerbations or fluctuations in their illness. For example, some informants who rated themselves as three felt that at some point they had been a five. Thus, variation in severity also exists within the individual. About two-thirds of the spouses with COPD had a severity rating of either two and three, according to both physicians and couples. No informants rated themselves as five whereas the physician rated three persons at this level. People perceiving themselves as five may have been less likely to participate in the study. The level of severity rating

was evenly distributed between males and females for the physician rating. However, couples rated males higher on the severity index than females. The level of severity rating was also evenly distributed across diagnoses for the physician ratings. However, according to couple ratings emphysema patients had higher severity ratings than the other diagnoses.

Table 2. Rating of COPD Illness Severity

Informants	Couple Rating	Physician Rating	Difference <sup>a</sup>
<sup>b</sup> GAIL/Eric <sub>1</sub> <sup>c</sup>	1	1	0
WENDY/Matt <sub>2</sub>	2	2	0
LEE/Will <sub>3</sub>	2	2	0
KEN/Betty <sub>4</sub>	2	2	0
PAULA/Greg <sub>5</sub>	2	4	P
GARTH/Ulla <sub>6</sub>	3	2	C
MIKE/Mary <sub>7</sub>	3	2	C
SARA/Tom <sub>8</sub>	3	3	0
PHIL/KAREN <sub>9</sub>	3/3	3/3	0/0
JEAN/Peter <sub>10</sub>	3	5	P
BOB/Rena <sub>11</sub>	4	2	C
GRANT/Leonna <sub>12</sub>	4	3	C
EVAN/Susie <sub>13</sub>	3	5	P
JACK/Dora <sub>14</sub>	4	5	P

a. P = Physician higher C = Couple higher 0 = no difference

b. Name in Capital = COPD partner

c. Number = couple number

7. OXYGEN USE. Of the 15 persons with COPD, oxygen was used by five of the COPD spouses. Three of the five COPD spouses were on continuous low flow oxygen, one was on nocturnal oxygen therapy and one kept it in the home just as a back up or in case of an emergency.

8. LENGTH OF ILLNESS. The duration of the illness, as perceived by the informants, was recorded because changes that informants experienced during their illness was an important question in this study. Because the illness progression was slow and insidious the onset of the illness was often vague and it was difficult for the informants to remember events. Thus, it was sometimes difficult for informants to make estimates of length of their illness. The reported length of the illness varied from 4 - 49 years, with a mean of 25.5 years. The degree of severity was not associated with the length of illness.
9. HOSPITALIZATION. Of the 15 COPD informants only two had been recently hospitalized for their lung condition within the last five years. One other informant had made occasional visits to the emergency. Two COPD informants had been hospitalized for other health problems unrelated to the lung condition.

Socioeconomic status was one of the criteria for which informants were selected. Education, occupation, employment and income were used as criteria to define socioeconomic status.

10. EDUCATION. The education levels varied across the couples. Education levels of couples ranged from grade school to post graduate education. Of the COPD informants, three had university education, three had high school and post secondary training, six had grade 12 or some high school and three had under a grade 9 education. Of the well informants, three had university education,

six had high school and some secondary training, three had grade 12 or some high school and two had under a grade 9 education.

11. OCCUPATION AND EMPLOYMENT. The sample varied in terms of occupation for both the COPD and well partners (Table 3). Table 4 shows the

Table 3. Occupations of Well and Ill COPD Partners

Well Parnters	COPD Parnters
Housewife	Principal
Secretary	Machinist
Truck Driver	Housewife
Lawyer	Meat cutter
Operator	Brakeman
Nurse	Bookkeeper
Farmer	Construction Manager
Principal	Secretary
Insurance Broker	Union Leader
Corporate Financier	Small Business Owner
	Engineer

Table 4. Employment Status of Well and COPD Partners by Sex

Employment Status	Male		Female		Total
	Well	COPD	Well	COPD	
Employed	4	1	1	1	7
Part-time		1	1	1	3
Sick leave				1	1
Retired	2	6	4	1	13
Homemaker			1	3	4
Total	6	8	7	7	28

employment status of male and female well and COPD informants. Male informants tended to either employed or retired, while the female informants had a wider variation in employment status. This was evident for the female COPD patient. Almost half of the informants were retired. These informants tended to be older. Five of the seven COPD informants retired due to their illness.

12. **INCOME.** Informants were asked if they felt their income was sufficient to meet their needs. All couples felt that their income was sufficient, but two couples expressed concern about their future incomes. While the couples in this study varied according to the criteria used to define socioeconomic status, the couples could generally be classified as middle class.

#### DATA COLLECTION

The data collection and analysis occurred simultaneously over a period of nine months (October, 1988 to June 1989). The telephone screening interviews were used to gather information on the sample characteristics. Formal interviews were conducted with the informants, using an ethnographic interview format (Spradley, 1979). Early interviews made use of open-ended questions to encourage informants to recount and describe their perceptions and experiences with COPD and its effects on their marriage. An interview guide with topics and relevant questions to be covered in interviews was developed (Appendix B). This guide was revised on an ongoing basis throughout the course of the study. As



analysis proceeded the interview format became more focused and structured.

The purpose of each interview was to identify the general conceptual categories related to the research questions. As the general conceptual categories were identified more specific questions were asked to explore these categories and the relationships between and among the categories. This process continued until the concepts were saturated.

The interviews were tape recorded with the permission of the respondents. The COPD partner and spouse were interviewed separately, except in one case where the couple asked to be interviewed together. The purpose of interviewing the spouses separately was twofold. Firstly, the researcher felt that it would be easier to build a rapport between herself and the informant. This was facilitated by creating a safe environment in which the informant felt more relaxed and willing to talk, and thereby enhanced the quality of the data collected. Secondly, it was easier for the researcher, based on her level of interviewing skills to interview informants individually and subsequently easier to analyze the data collected.

The majority of the interviews were conducted in the informant's home. Some interviews were conducted at their place of work. Interviews ranged from 5 - 90 minutes in length with a modal length of 60 minutes. Variation in interview length depended on the informant's health and willingness to participate. Additional informal interviews in the form of a short telephone call or brief personal interview to clarify a point or elaborate on a concept were carried out with some of the informants.

No contacts were made subsequent to the first interview without prior consent of the informant.

After the interview, the tape recording was transcribed verbatim into a computer file which was used for storage and analysis. The computer program, the ethnograph, was used for the management and sorting of data. All the informants were assigned fictitious names and the interviews stored under those names to ensure confidentiality.

Interim summaries of ideas and information were formulated periodically throughout the data collection process. The purpose of this was to summarize current findings and to note what remained to be discovered. These summaries were used as guides for the revision of the question guide and subsequent data collection.

## ANALYSIS OF DATA

### Analysis of Screening Data

The screening data were analyzed using descriptive summary measures, e.g., proportions and frequency distributions. Spread or variation (i.e., range) and central tendency (i.e., mean) were used to examine the frequency distributions. The results arising from this source of data have been reported in the sample characteristics section.

### Analysis of Interview Data

As discussed, the sampling, collection and analysis of data occur simultaneously in grounded theory methodology. As each case was sampled the interview was coded and analyzed in a specific process. The analysis

process involved coding, and organizing of coded data and categories emerging from the interviews. There are three essential parts in the analytic process: data reduction, data display and conclusion drawing/verification (Miles and Huberman, 1984).

The data reduction stage involved transforming the coded verbatim interviews in such a way that final conclusions could be drawn. This required the abstracting and focusing of raw data into conceptual frameworks. The constant comparative method was used to take the coded incidents within the raw data and develop them into categories and substantive theory. The ethnograph was used in this phase to assist in the sorting and management of the large quantities of coded data.

Data display required data to be organized and assembled into information that permitted conclusion drawing. The information was displayed through the use of matrices, networks and charts. These assembled and organized information into an immediately accessible, compact form so the investigator could observe any patterns or trends developing.

Describing, explaining and finding meaning in the regularities and patterns observed was the final aspect of analysis process. As conclusions were drawn, verification of the conclusions was made by backtracking through interviews and notes, as well as through subsequent interviews.

#### The Constant Comparative Method

The analysis of qualitative data in grounded theory uses the constant comparative method. Glaser and Strauss (1967) describe four

stages in this method: 1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory, and 4) writing theory.

The comparative analysis began with the coding of each incident observed in the data into as many categories that were relevant. For example, two of the categories included observations on "psychosocial changes that informants labelled as restrictions" (e.g., changes in leisure and household activities) and "factors that informants felt allowed them to manage changes" (e.g., the use of medications and support from spouse). The codes for these categories were noted on the interview transcripts along side the incidents pertaining to the categories. While each incident was coded into a category, it was compared with previous incidents in the same or different groups coded in the same category. For example, sedentary leisure activities were compared to active leisure activities which in time were compared to acceptable and not acceptable activities. Continued comparisons of incidents and observations generated theoretical properties of categories. For example, the data on psychosocial changes in leisure activities that informants called restrictions showed certain common properties such as, "affecting time spent together" and "requiring adaptation". As coding progressed, comparisons of incident to incident changed to comparisons of incidents with category properties. For example, "acceptable activities" would be compared to "time spent together".

Eventually, diverse categories and their properties were integrated. Properties under the category marriage style were related to properties under the psychosocial changes called restrictions. As the theory

solidified there were fewer major modifications in the categories. There was a reduction in the list of original categories. These delimiting features began to curb the need for further data collection and analysis. The theoretical saturation of categories delimited the theory further.

#### STRENGTHS AND WEAKNESSES OF THE METHOD

The findings of this study represent theoretical propositions which are intended to contribute to further development and study of COPD and its effect on the marital relationship. The purpose of the method is to generate theory through a purposeful and systematic way. The investigator should verify the categories, explanations and conclusions with as accurate evidence as possible to reduce bias and enhance the validity of findings. However, the verification should promote the generation of theory that fits meaningfully relevant, rich and complex categories. A focus on testing or verifying emerging propositions can hinder the process of theory generation (Glaser and Strauss, 1967). Unlike quantitative studies in which testing is important for the generalization of findings, the findings in a qualitative study are not meant to be generalized to a particular group or population. The qualitative method uses testing of ideas only to service the enrichment and plausibility of the emerging theory.

The strength of this approach in the present study was that it permitted analysis of the context in which COPD interacts with marital relationships and the meaning of the events for the participants. It serviced the development of substantive theory pertaining to the effect

of a chronic illness on significant relationships. The validity (plausibility and sturdiness) of the findings in this research is an important issue. To confront this, the researcher had to address some methodological problems affecting validity, otherwise the emerging theory may be interesting but have unknown truth and utility. These problems concerned sample representativeness, self-reports, and objectivity in recording and analyzing data.

#### Sample Representativeness

In quantitative studies random sampling is done to obtain accurate evidence on the population studied. Sample representativeness is important for the purpose of generalization. While sample randomization is not an issue in theory generation, it is still important that the sample be theoretically meaningful. Therefore, variation in the sample was needed, particularly in respect to variables sighted in the literature that appeared to be relevant. The sampling parameters used in the sample screening and which are discussed in regard to the sample characteristics, represent relevant variables that were used to address the issue of variation.

#### Validity of Self-Report Data

The researcher was also aware of recall bias problems resulting from the use of self-reported data. The validity of the data may be questioned because people may be unwilling to reveal information or they may be unable to accurately recall previous experiences or perceptions. Despite

these potential problems, the researcher felt that the informants' reports obtained in the interviews were valid for the following reasons:

- 1) One of the inclusion criteria was that both partners be willing to participate in the study. The investigator felt that not only would a more complete and accurate description of the effect of COPD on the marriage be obtained, but also the comparison of experiences and perceptions of both partners would enhance the validity of the information collected.
- 2) The investigator felt that interviewing each partner separately in an environment of their choice would generate more accurate and honest data and create a less threatening environment for that to occur.
- 3) While the subject of marriage was somewhat threatening to informants, the subject of COPD was not. The researcher used this to her advantage by allowing informants to first talk about the COPD. The researcher used this time to build rapport and create a less threatening environment.
- 4) Several informants stated that they enjoyed having someone to talk to about a subject that was of great importance to them but which seemed of little interest to others.
- 5) Informants appeared to trust that the researcher would understand their perspectives and empathize with their concerns. The researcher's personal experience with asthma and the terminal illness of her husband played an important role in this. This was reinforced by comments and feedback from the informants who seemed to relate to the researcher as one would a close confidante.

The researcher's personal experience with her husband's chronic disease and death enabled her to conduct research as an insider. That is,

the researcher had experiences in common with those life experiences or aspects being analysed. With the status of an insider, the researcher was in a better position to ask valid and meaningful questions and obtain information from informants that only such an individual may be privileged to know. As an insider the researcher was less likely than an outsider to impose categories and concepts on informants' descriptions, was better able to describe informants' perceptions and experiences using natural language, meaning and symbolization and was better able to interpret and gain insight into informants' responses (Schwartz and Jacobs 1979).

#### Objectivity in Recording and Analysis of the Data

Validity was a concern with regard to the recording and analysis of subjective data involving informants experiences and perceptions. Tape recording the interviews assisted in the accurate recording of the interview and allowed the researcher to assess and criticize her own interviewing techniques.

The subjective perceptions of the informants could be biased by the researcher's perceptions reflecting her own beliefs, values and experiences. While the researcher's own experience appeared to have a positive effect on the data collected, these same experiences made it difficult for the researcher to be completely objective in both the data collection and analysis.

Consequently, the researcher continually validated findings and perceptions with informants, particularly as the framework developed. The ideas were tested and challenged with new informants. The researcher also engaged the assistance of two other individuals with backgrounds and



experience in social and behavioral science for the purpose of assessing and verifying researcher objectivity. These individuals reviewed the researcher's interviewing techniques, the interviews or excerpts from the interviews and analyzed informants' comments in the interviews. The researcher also discussed emerging categories and findings with these individuals. Positive feedback was given with regard to the interviewing. Observations and analyses of informants' comments were consistent with the researcher's observations and findings. Finally, the discussions of categories and developing theory stimulated new ideas and enhanced the theory development. The validation of findings and feedback from both informants and the two individuals assured the researcher that the emerging categories and theory reflected the perceptions of informants and that researcher bias was reduced.

## CHAPTER 3

### PERCEPTIONS OF COPD

The purpose of this chapter is to describe informants' perceptions and experiences of COPD. This information will provide a context within which to discuss perceived effects of COPD on the marital relationship in subsequent chapters.

COPD can be considered a force which acts upon a couple's marital relationship to create changes in the marriage that result in various consequences. Informants' responses to COPD may be influenced by their perceptions of COPD, their evaluation of symptoms and the illness, and the significance they place on their illness experiences. Therefore, to better understand the effects of COPD on the marital relationship and couples' responses to those effects, knowledge about couples' perceptions and their experience of COPD is of value.

This information was obtained from couples by asking informants these questions about the lung condition: what was it and what did it mean to them? What was it like living with the lung condition and had it changed over time? Further examples of questions used to elicit information from informants are given in Appendix B. Informants were encouraged to explain their comments and provide illustrations.

The different dimensions of informants' responses that are reported in this chapter include; the differences in the COPD experience for ill and well spouses, how informants labelled the lung condition, perceptions of physical and psychological symptoms of COPD, the course, progression and meaning of the lung condition, as well as issues of invisibility, impairment and stigmatization associated with COPD.

#### DIFFERENCES IN THE COPD EXPERIENCE FOR ILL AND WELL SPOUSES

The descriptions of COPD and the illness experience associated with it were generally consistent both within and between couples. Couples described similar perceptions of symptoms, changes in the lung condition, restrictiveness and the problems associated with the condition. Partners described the same or similar events associated with the lung condition, they displayed similar knowledge and understanding of the disease process and physiology, and they appeared to attribute similar meaning and importance to the consequences of the lung condition.

Despite this consistency the researcher noted that several informants made a distinction between an individual who had a disease and an individual who lived with someone who had a disease. Informants consistently made reference to the fact that the experience of COPD was different for the two spouses. The spouses with COPD experienced the illness directly. They would undergo physical changes resulting from the disease and would probably die from this disease or related complications. They were directly affected by the restrictions and limitations placed on

them by their disease. The well spouse on the other hand experienced the lung condition indirectly.

COPD partners often felt that it was more difficult for their well partner to cope with COPD because they did not have the lung condition but had to deal with their ill partner's problem. There was a sense of choice for the well partner while the ill partner had no choice about the lung condition.

Mary<sub>7</sub>: *"I can still go out on my own. His life has changed more than mine."*

MIKE<sub>7</sub>: *"I think the person married to the spouse has got to be prepared or it would be a pretty bad shoe some of the time. When you're short of breath you don't have much patience. So your reactions can be kind of startling at times 'cause you're frustrated yourself. I think in some ways it's probably tougher on the one that doesn't have the problem than the one that's got it."*

Because the well partners experienced the lung condition indirectly, they felt that they could not fully understand what their ill partner was living through, even if they felt empathy and compassion for their partner. They sometimes experienced frustration and difficulty being sympathetic and understanding toward their partner.

Peter<sub>10</sub>: *"It doesn't matter how empathetic you are you can never walk in the other person's shoes."*

Tom<sub>8</sub>: *"You can't conceive of what you would do if you're not the victim. I quite understand that. It's frustrating."*

Leonna<sub>12</sub>: *"I'm not patient with him you see. Because I'm so healthy myself. I have a very difficult time sympathizing with someone who won't push themselves."*

When both partners had a lung condition the differences between them were reduced as both partners shared the experience of having COPD and the problems and limitations that were associated with it:

KAREN<sub>9</sub>: *"I'm lucky 'cause Phil too has a problem and we can sympathize with one another. It's not like he's healthy he'll want to be jiggin' around all night long or hangin' from the chandeliers or he wanted to and I couldn't. Then perhaps it might put a strain on the marriage, but we are both of the same temperaments. We both have the same health standards. You can understand one another's thoughts and feelings this type of thing."*

Because daily life with COPD was experienced differently by the COPD and well partners, they sometimes expressed different concerns or focused on different problems with regard to the lung. Despite the experiential differences between spouses, both COPD and well partners described similar perceptions and experiences, as well, as how they thought the lung condition affected their partner. Some informants however, acknowledged that they felt that they could not speak for their partner and how the lung condition affected them.

KEN<sub>4</sub>: *"I am very cognizant of the fact and basically how it affects her. You'd have to... I have no feeling... its a way of life for her. What that would be, what she would feel, you'll have to ask her about that."*

## LABELLING THE LUNG CONDITION

All informants frequently used medical terms and labels given at the time of the diagnosis, e.g., asthma, emphysema, or bronchiectasis, to describe the lung condition rather than the term COPD. Most informants were not aware of the term COPD. When informants did not use medical terms for COPD they referred to it as their lung condition or lung problem.

KEN<sub>4</sub>: *"I really didn't think I had this COPD thing. I never thought about it but when I read your letter I guess I think I do."*

Int: *"Could you describe your lung condition to me?"*

GAIL<sub>1</sub>: *"Well Bronchiectasis is the term for the disease."*

Informants often described the lung condition by encompassing the medical information they had of the disease with their own descriptions of what they perceived to be occurring in the lungs, and the sensations they experienced or observed:

PHIL<sub>9</sub>: *"As I understand it, the little pockets that are supposed to expand with air.... are bigger pockets than they should be. Is more than a bunch of little balloons, its a bunch of big balloons."*

PAULA<sub>5</sub>: *"I'm conscious of it being there. I can hear it. It feels almost like a bag of ice... and I'm trying to get air all around the ice."*

GRANT<sub>12</sub>: *"Can you remember ever bein' oh say racin' and your fighting for that second wind... your tryin' to catch it and you don't get it right away?"*

## DIFFERENCES IN THE CAUSE OF THE LUNG PROBLEM

While the diagnoses of asthma, emphysema and bronchiectasis are grouped together under the umbrella term of COPD they are medically distinct from one another. Differences between the diagnoses are based on the degree of airflow obstruction, the degree of reversibility of the obstruction, pathogenesis, rate of forced expiration volume in one second (FEV1) and age when abnormality was found (Petty 1984).

Informants identified similarities and differences between the diagnoses. The clearest example of differences existed between emphysema and asthma patients. Differences were perceived in the cause of the lung condition and its manifestation (e.g. its reversibility). Emphysema patients emphasized the differences in the manifestation of the disease while asthmatics emphasized the differences in the cause of the conditions. Asthmatics tended to feel that emphysema patients had themselves to blame for their illness. Asthmatics saw emphysema as a self-inflicted illness, while their's "just happened", the adult onset of asthma being beyond their control. Emphysema patients saw the asthmatic's illness as reversible, involving acute attacks of shortness of breath with periods of respite in between when the asthmatic could function normally. The emphysema patients saw their illness as irreversible and continuous with no respite or chance of achieving a return to normal lifestyle.

Some emphysema patients felt that the cause of their emphysema was not simply some behaviour, but a result of a combination of factors that contributed to the demise of their lungs. However, some emphysema

patients readily pointed to their smoking behaviour as the cause of their lung condition and freely stated that they have no one to blame but themselves. Both emphysema and asthma informants agreed that the acuteness, suddenness and the tendency for attacks of shortness of breath to be unpredictable was more of a problem for the asthmatic, but they questioned the degree of reversibility of airflow obstruction. Some emphysema informants saw asthma as a reversible conditions while asthmatics did not.

Despite some differences in the perceived cause of their lung conditions, there were definite similarities described by informants across all diagnoses. These related to perceived symptoms, description of the lung condition, its progression and the types of problems they experienced with regard to the condition. The remainder of this chapter will discuss these similarities in perceptions and experiences.

#### PERCEPTIONS OF SYMPTOMS OF COPD

COPD informants described and illustrated their symptoms vividly. They frequently described shortness of breath and subsequent feelings of a lack of physical energy, using a variety of adjectives, such as, gasping, puffing, smothering, choking, or drowning. Initially, breathing was an unconscious, automatic, and effort-free activity. As the respiratory system became increasingly burdened due to obstruction of the airways, it became stressed and failed. Breathing became a problem and moved from an unconscious activity to a conscious one. The COPD sufferer had to work to breath and other body systems (e.g. the circulatory and



central nervous systems) became stressed by the physiological abnormality that results from lack of oxygen. Breathing became a focal activity.

EVAN<sub>13</sub>: *"It's very, very difficult to breath. It's an all consuming thing. That's what you spend your time doing, thinking about breathing. And it... well that's what you do, you pace yourself. You gear your whole life to... well if I'm going to walk from here to there I'll get my breath and then I get that far and then I'll stop to breathe. It's all consuming. It's all consuming."*

Feelings of fatigue accompanied the shortness of breath. "Every breath takes effort. Every movement takes effort." Informants felt the biggest problem was not having the energy to carry out daily activities and not having control over the lung condition and subsequent lack of energy. For many informants tiredness and fatigue was felt to be emotionally the hardest aspect of the lung condition to deal with. "Everything has to adjust". Spouses with COPD found they must stop and rest because of their lack of energy. Consequently, more time was required to carry out ordinary, everyday activities. This was considered to be restrictive. Because of limited energy, creative strategies were used to conserve energy and to put it into higher priority activities.

PAULA<sub>5</sub>: *"I can't keep up. I find fatigue tiresome and the biggest hurdle. I don't want to be tired. I don't want to be lying around. I find that emotionally the hardest. That will bring me to tears more than anything because I can't follow through."*

Informants gradually became aware of restricted movement, such as the inability to bend over, lift or walk. Physical exertion became a problem because movement and physical activity caused shortness of breath. Simple activities such as answering the telephone or tying up shoes became a chore. Carrying out housework such as vacuuming or reaching up into a cupboard were problems. Despite the fact that movements and activity were problematic, exercise and physical activity were highly valued by people with COPD. Most informants emphasized the importance of exercise as a method to improve the dyspnea experiences or to slow down the deterioration process of the COPD.

Congestion and chronic cough were other common symptoms experienced by people with COPD. Some pain was associated with congestion and coughing for some informants, as well as wheezing and muscle tension. Associated with congestion was the fear of getting colds, since colds were harder to recover from and they increased congestion, especially when accompanied by a deep chest infection.

Problems of breathing noises and bad breath also accompanied congestion. These concerns proved to be a source of distress for both the COPD and well partners. They were considered to be intrusions on the couple's intimacy. The following excerpts from interviews illustrate some of the concerns related to congestion, such as the inability to breathe, the time required for therapies, odour and noise.

KEN<sub>4</sub>: *"It's just as though you figure you're drowning in mucus."*

MIKE<sub>7</sub>: *"What happens to me is that my lungs fill up with fluid so I spend every morning and every night to drain for half an hour."*

- JEAN<sub>10</sub>: "One thing I must mention that is very disturbing is bad breath with all the medications you take. You get bad breath. And that is another social problem because you don't want to get too close to people so therefore you don't want to even kiss your husband because ooohh... your breath is so terrible. It's because of all the medications you take and all the phlegm. You should see some of the guck."
- Peter<sub>10</sub>: "Its very difficult to concentrate when you have someone coughing. After awhile it can be irritating, down right irritating.... and because she is bringing up phlegm sometimes it's more difficult to kiss her. No doubt about it. I don't want to kiss her on the mouth. I'll kiss her sometimes more on the cheek."
- Susie<sub>13</sub>: "It can be annoying. I don't mean to me. It isn't annoying to me at all you know the oxygen. But the lung condition is. The hacking and hacking. Its just the physical things that go on. Very boisterous sneezes. Always noises. Always breathing noises."

In addition to the symptoms of coughing and congestion informants talked about other body sensations such as muscle tension. Body sensations were considered important cues or signs for breathing. Informants used their body symptoms and sensations to assess their level of oxygen and shortness of breath.

- MIKE<sub>7</sub>: "I feel I am starting to get tense and irritated and I know before I even start because a lot of time I'm making a breathing noise anyways. I just get a feeling and then I start to get tense. To me that is the trigger that I'm getting short of oxygen. You see that's often the only indication I have that I'm getting short of oxygen is that I get irritable."

Body weight was also an important body sensation. Increased weight gain around the abdominal area was noted to make breathing more difficult. The support of weight around the chest area by leaning on something or

floating in a pool, for example, was noted to make breathing easier. While conducting interviews, the researcher not only was aware of sounds of congestion, coughing, breathing and shortness of breath but also that informants, particularly men, repeatedly sat in a particular body position. They would lean the upper body forward, with feet planted squarely on the ground and hands placed on their knees. That seemed to take weight of the chest, allowing the chest to move more freely and ease their breathing.

Informants described psychological symptoms in addition to their physical symptoms. Because the basic fundamental biological process of breathing was hindered, there was an intrinsic panic response to shortness of breath, since breathing was vital to life. The emotional status of the COPD sufferer was affected and responses of fear, panic, anxiety, irritability and frustration resulted. As the symptoms became more pervasive the psychological state became more stressed. When people became short of breath their body and personal space became more important.

MIKE<sub>7</sub>: *"It gives you claustrophobia. You're outside and you can't breathe. You want to go inside where its comfortable. Once inside you still can't breathe so you open a window. Its just panic; you don't know what to do."*

There is a sense of not wanting to be confined and also a desire to withdraw from either physical or psychological interactions with other people:

MIKE<sub>7</sub>: *"You don't want anyone hugging or squeezing you. You just want to be left alone and try to leave every one else alone."*

# "GETTING INTO TROUBLE": THE DYSPNEA SPIRAL

The symptoms described by informants were associated with a significant phenomenon of the lung condition that they described as, "getting into trouble". By this they meant the compounding of physical and psychological effects of dyspnea. Shortness of breath invoked emotional responses, such as fear and frustration, which intensified the dyspnea. This in turn created muscle tension, causing their bodies to become rigid and further compounded the dyspnea.

MIKE<sub>7</sub>: *"I was out this morning for a walk and I can't maintain the speed I was doing a month ago. I just walk whatever I am capable. I've got pretty well now so I know when I am getting into trouble so I quit before I'm in any trouble. This is the whole thing with the problem, is not getting yourself into a panic. If you go far and then you get into a panic and then you don't do anything. Soon as you allow yourself to panic you just get rigid and can't breathe and it compounds the thing and you're a lot worse off than you actually are."*

JEAN<sub>10</sub>: *"Well it gets me uptight and then I can't breathe and then the more I can't breathe, the more uptight and the more uptight the more I can't breathe and it's like a vicious circle. So it's a problem. And it's how shall I say? It's very, very depressing because you don't feel that you can ... you have the control. It seems to take over."*

This cyclic reaction, referred to as the dyspnea spiral in the literature, was profound and problematic for informants. As informants anticipated becoming caught in the spiral, they developed feelings of fear and anxiety. These subjective responses lead some individuals to

develop fears and anxieties about participation in activities and created emotional, physical or social limitations for themselves and their spouses. In response to this, some COPD sufferers would try to avoid or manage the dyspnea spiral by isolating themselves and thereby avoiding emotional arousal. The perception of feeling confined or claustrophobia associated with shortness of breath would appear to contribute to this.

SARA<sub>8</sub>: "I get a little nervous going out in cold weather, particularly if Tom is away or not having family here. I think Oh god! I'll just.... and that's when my friends come to my rescue. But in that cold weather I feel vulnerable trying to do my walking"

GRANT<sub>12</sub>: "You're always afraid you're not going to get the next one (breath). That's the best way I can describe it. You're scared. You're under tension. I can go along and everything will be alright and all of a sudden something seems to ... I don't know what it is. Something comes along and you're breathless."

JEAN<sub>10</sub>: "I was getting to the point that I was afraid to go anywhere. I have to go on a machine every three or four hours and now I have a portable machine and I find that's like a security blanket and if I don't have it, even if I am going out for an hour I panic. I have to have the machine with me and if it wasn't for that machine I don't think I'd leave the house ever, really! It's embarrassment that when you are somewhere that your gonna have an attack and you can't control it."

One of the difficulties associated with getting into trouble was the sense of unpredictability or suddenness of the attack of dyspnea. The dyspnea plight could happen without warning, quickly and unexpectedly, especially in a stressed situation. There was a sense of immediacy associated with the problem of shortness of breath. Medication or medical attention was needed quickly. A sense of fear about the situation accompanied this feeling of immediacy. Situations could be life

threatening. The suddenness and unpredictability of attacks were more apparent in asthmatics. However, unpredictable fluctuations in breathing, were applicable to all types of COPD sufferers. The extent to which fluctuations in breathing occurred and an individual experienced getting into trouble, was dependent upon the stage or severity of the disease, as well as coping and management strategies. Thus, there was variation in fluctuations between informants as well as within the individual informant.

SARA<sub>8</sub>: *"Sometimes I'm sort of stressed so it unexpectedly happens."*

JEAN<sub>10</sub>: *"It's a condition that sort of takes over. It comes when you least expect it at times."*

Ulla<sub>6</sub>: *"It's frightening. You've got somebody there who wakes up and all of a sudden its like they can't breathe and you've got to get them to emergency right now. You're scared. You just get moving and do it."*

BOB<sub>11</sub>: *"Sometimes I feel as though I'm smothering. I don't know why. Some mornings I get up and I feel fine. I feel fine for a couple of hours, on top of the world and then I go down."*

KEN<sub>4</sub>: *"A couple of times I'll get up in the morning and all of a sudden it starts in you know. I'll become shorter and shorter of breath."*

In addition to the shorter daily fluctuations of getting into trouble, there was a spiralling up and down in health, that is, a cycling of fluctuations that occurred over a longer period of time, sometimes involving weeks or months.

GARTH<sub>6</sub>: *"You fly along and you never think about it until you're down, down. You can feel yourself slowly day by day just perceptibly going downhill until you hit a point when you know you're going to have to take a heavy dose of medication to dig*

*yourself out of the hole. Throw yourself out of the hole or land up in hospital."*

Ulla<sub>6</sub>: *"Its always there. He could have an asthma attack at any time. When the asthmatic seems to on the up, up in the curve at the top you just try to do all the things and keep your lifestyle going steadily 'cause you know in a couple of weeks he's going to be down at the bottom and you just have to kind of back off with life in that sort of normal pattern."*

#### THE COURSE OF COPD.

The frequency with which informants discussed the progression of the illness suggested that the course of COPD was important and relevant to the way in which the lung condition affected the informants lives. Several words are used to describe the course of the lung condition. These included; progressive, gradual, downward, irreversible and debilitating. Because changes in the illness were subtle informants frequently commented that they did not notice differences or that they had experienced the illness for so long, they could not remember a time without the illness or what life was like before the illness. The illness was considered insidious because the changes were subtle, not always apparent and the changes that were noted were easily dismissed as harmless. The lung condition became a "way of life."

EVAN<sub>13</sub>: *"I always suspected it. I knew the symptoms. I knew it was happening. But I think like everybody else, well it'll only go so far and I'll stop and it'll be okay or else, I'll just smoke another week and things are going to be great and all that sort of thing and you never do it. Because it's going to happen to everybody else but not me. I think that anybody that has an addiction has that problem. I've spent an awful lot of time trying to quit. Many years and lots of dollars on cigarettes that I threw away. But it would be alright if I hadn't bought some others to replace it. I knew it was*



*happening and in fact the doctor that I used to go to used to just shake his head and say, 'I like guys like you Evan, you come into the doctor, please cure my headache but don't tell me to quit butting my head against the wall.' I knew it was happening but I never realized the severity of it. It's hard to say you just never think its going to get as bad because ... well I've got this far. You just don't face facts that's all. I don't know why."*

It was also difficult for informants to perceive change in the illness because the changes were intermingled with exacerbations of the illness and other forces such as age and additional health problems. However, informants appeared to monitor changes in the lung condition by comparing visible signs or cues, such as changes in medications and other therapies, or becoming more conscious of their breathing and their lungs, or noticing that their symptoms were becoming more persistent.

Rena<sub>11</sub>: *"You just adapt gradually, and then when you look back you realize what you're missing, but there is nothing you can do about it, so you just accept it as a matter of course."*

There was a dichotomous relationship in the way in which informants became aware of changes in their health. Awareness occurred either through the gradual development of symptoms or through a crisis experience. Informants often first became aware of their illness when they began to notice a shortness of breath upon exertion. Keeping up with peers in normal activities such as playing tennis, walking, playing with children or grandchildren became more difficult. The symptoms tended to develop after several years of insults from exposure to various factors such as, smoking, chest infections, air pollution. These symptoms could initially be denied, ignored or written off as something else (e.g., aging).

However, in their description of the lung condition, informants often recounted their perceptions of the onset and progression of the illness. These descriptions were like narratives of particular events or series of events that were important or significant to the individuals who told them. These events appeared to be crisis points, that is, points where the lung condition could no longer be ignored or denied. A crisis drew attention and awareness to the lung condition. A crisis event might include a hospitalization, or the inability to carry out a familiar activity such as walking home from a movie or performing some recreational activity (e.g., photography). In the narratives, both marital partners would describe the same events. This indicated that certain critical events influenced and affected both partners in some way.

In the early stages of the illness, the lung condition did not intrude greatly on informants' lives. There were minimal limitations drawing attention to, or creating an awareness of the lung condition. As couples became more accustomed to living with the lung condition they may have become conditioned to it, that is, developed patterns of behaviour that they were unaware of in response to the lung condition. Activities could be curtailed or adjusted to adapt to changes. As the lung condition progressed, more and more activities were adjusted to accommodate the lung condition and to avoid getting into trouble. The problem became harder to deny and people began to seek help or realize that something was not right with themselves or their spouse.

SARA<sub>g</sub>: *"When I came back from abroad, I noticed that my breathing was not what it had been. And I guess I somewhat buried my head in the sand thinking oh well its just one of those things that will improve... I just found I couldn't even..."*

*even in doubles keep up. That's what made me realize I'm pushing it. Gasping for breath when I played and couldn't pick up tennis balls and get back in the game. But I am determined that I am going to do things that are sedentary so I've been playing a lot of bridge... .. When we got back to Calgary I had noticed it (breathing) was quite a bit worse and once again I had not quite faced the fact that I had to go and see a doctor. It happened that I had a business here. It was at a show that I sort of felt terrible one day where I had to have my husband pick me up. And I thought I would be fine tomorrow. Finally I went to the doctor who did a battery of tests and came up with the suspicion of a lung problem."*

#### THE DOWNWARD PROGRESSION OF COPD AND UNCERTAINTY

In describing the lung condition as irreversible, downward and debilitating, informants emphasized that the damage to the lung was not curable and although a person was not always ill or did not always appear ill, the problem was always there. "You have to learn to live with it," they would say. The progression of the illness had a downward course with fluctuations or exacerbations in the symptoms. The disease continued to take over more and more of the lung capacity and continued to impede activity. The condition was disabling and restrictive in that it required a lifestyle change that was permanent. Informants believed that the process could be slowed by taking care of oneself, exercising and keeping active.

While the lung condition was predictable and consistent in its gradual nature and its permanency, some informants experienced a sense of uncertainty about their illness. The uncertainty was brought about by a sense of unpredictability or unknowns about the illness. This experience of uncertainty was more pronounced for asthmatics. Discernment of the cause for their attacks and the placement of meaning on the illness

appeared to be more problematic for this group. However, COPD sufferers from all diagnostic groups and their spouses, experienced a sense of uncertainty about the course of the illness. They were aware of the downward spiral but were uncertain where this spiral would end and what the consequences would be. Other unknowns included not knowing when something would happen (e.g., getting into trouble or shortness of breath), or what caused the symptoms. COPD spouses sometimes wondered, "Is there something wrong with me?" This uncertainty was due, in part, to the hidden nature of the lung condition which created doubt in both ill and well spouses about the existence of the illness and their perceptions of it.

Greg<sub>5</sub>: *"And sometimes you question in your own mind is it really there or is it just me? If I had something like that I'd have more of an appreciation. And something that is more visible makes it easier."*

Informants also expressed uncertainty about when to take medications, when to ask for help and when to go to hospital. The problem of going to hospital centred around "false alarms". Was there really a problem or would the dyspnea attack come under control? Informants did not want to go to the hospital if they could resolve the problem themselves. The indecision was heightened by the perceived extreme life and death nature of the dyspnea attack. COPD spouses and their partners would wonder, "will they get through it?" Having oxygen at home facilitated decision making by allowing time to "wait and see" before couples made a decision. The oxygen provided a security during the uncertain waiting period and thus reduced the stress of unknowns. Not all

couples had oxygen at home. For less severe informants their focus was on having their nebulizer close at hand.

#### THE HIDDEN IMPAIRMENT OF COPD AND ASSOCIATED STIGMATIZATION

The invisibility of the lung impairment was another important feature of the illness. The early symptoms of shortness of breath, lack of oxygen or tiredness were readily hidden by the COPD sufferers and were thus difficult for another individual to see. The hidden nature of the illness allowed both COPD sufferers and others to dismiss or ignore the symptoms and associated limitations. Some informants with COPD had difficulty acknowledging their illness as other people reinforced their tendency to dismiss or hide the illness. The dismissal by these individuals of the lung condition could be considered an avoidance or denial pattern. Although this might be considered a dysfunctional response, it could on the other hand prevent the COPD or well spouse from constantly dwelling on the lung condition or from becoming too absorbed in it. Such behaviours in themselves could potentially become harmful.

GAIL<sub>1</sub>        *"As a matter of fact most people have sort of fed my tendency to dismiss it. They say, 'Well you look healthy. You look athletic and involved in all kinds of things. You don't look like there is anything wrong with you.' And so you just tend to package it away and ignore it."*

Informants reported that as their illness progressed the symptoms and limitations became more visible and the illness harder to hide. There was an increase in coughing and the sounds of breathing and shortness of

breath. In addition, the increased need to use equipment (e.g., oxygen tanks and nebulizers) in public places to manage the illness, served to call attention to the individual and their lung condition. While this was often embarrassing to the individual or their spouse, the need to have the equipment assisted them in making the transition from management of an invisible condition to management of a visible condition.

EVAN<sub>13</sub>: *"At first you're self-conscious about it but I am not any more. I used to go to church and leave the oxygen in the car. Just walk in and sit, but I find that was uncomfortable. So I wear it in. And when little kids say, 'look at that guy', it gives me a chance to give a little speech that they should listen to what they are going to be taught about smoking. Anyway you get over it. I never really did feel self-conscious about it if I thought about it and, well what's the difference between me carrying a little can down the shopping mall and some fellow with a crutch?"*

Closely associated with the invisibility of impairment were issues related to stigma. Negative, incorrect or discrediting judgments were sometimes made either by the individual with the condition or by others.

KEN<sub>4</sub>: *"It's a disgusting disease but I guess all diseases are disgusting."*

SARA<sub>8</sub>: *"When I got the diagnosis of emphysema I obviously thought of old men, yellow fingers, gasping for breath, staggering. I did not find... I did not sense that I fitted that image so it was a bit of a shock."*

MIKE<sub>7</sub>: *"Ah no, not too bad. Like I was going into this place by myself and into a place where everybody knew me and knew what my problem was, so no problem there. What is very disgusting is when your walking along and you get in trouble and you have to stop and cough and freeze and lean up against something. People going by don't know whether to come to your help, think your dying or what your doing. They're looking at you. You just want to be left alone, just fight it through yourself. In time you'll be alright."*

Greg<sub>5</sub>: *"A lot of people's perceptions to the disease and infliction is that it creates a lack of understanding. So you are constantly dealing with the perception that perhaps this is psychological induced and its not really an infliction at all"*

The invisibility of COPD can be both helpful and hindering. Because of the hidden nature of the impairment an individual could withhold information about the impairment. This could be helpful and advantageous to the individual with the impairment. The revelation of information and the creation of awareness about the illness became a matter of individual choice. The choice to reveal information could reflect the level of comfort an individual felt about a situation, as well as their own self-perception with regard to the illness and how they thought others would perceive them.

GARTH<sub>6</sub>: *"People say to you, 'Gee whiz here you're on a pension and there doesn't appear to be anything wrong with ya!' 'Cause you see them when you're out. You don't tell them, 'Well I just came from an inhaler and I've got to go right back to my inhaler.' They don't see what you are using at home. They don't know youknow. Deal with it the best you can. Don't get excited about what they think. Tell them if they ask. Don't be reticent about telling them. That's something you should tell people. Don't hide behind a physical appearance of being fine. You just carry on work. Deal with problems. You don't go out and cry on everybody's shoulder and ask for assistance or support."*

The invisibility was a hinderance for some informants in that the individual's behaviour could be misinterpreted by others and the COPD sufferer may not be given permission socially to be sick and would therefore be labelled inappropriately as a whiner or malingerer:

Ulla<sub>6</sub>: *"He doesn't want to look like he's lazy and people say to him, 'Oh you look healthy.' He's got so much cortisone he's flushed. He looks so healthy and he's feeling rotten."*

PAULA<sub>5</sub>: *"There's a lot of misconception about asthma still. They think you're sort of neurotic. 'Oh its because of your nerves, or its because your emotional.' And I don't like people to perceive me as that kind of person and that's probably more why I hide it."*

#### LOOKING FOR CAUSE AND MEANING

The importance of learning to understand the lung condition and to know the symptoms of the illness became apparent as informants described their illness experience. Knowledge, awareness and understanding of the disease and perceptions of the illness were instrumental in reducing the unknowns associated with the illness, in dealing with issues of visibility and stigma, and in assisting with the management of the lung condition. Informants, however, sometimes expressed difficulty in learning to recognize and understand their symptoms. This was partially due to the subtle changes in symptoms which made it easier for informants to dismiss or deny them and to the gradual nature of the disease. In addition, there were confounding factors that made it difficult to discern symptoms of the lung condition. These included, aging, other health issues, cultural norms, and such external stresses as finances.

In an attempt to reduce the sense of uncertainty surrounding the lung condition and to understand it, informants searched for meaningful explanations for the cause of their lung condition. This search may have influenced their descriptions and perceptions of the progression of the lung condition. Informants attributed various factors both in the past



and present to the cause of the lung condition. Work conditions and the environment were the two main causes cited. Exposure to different elements such as asbestos, paint, fumes, smoking, stress and health problems were mentioned. Not all informants discussed their past smoking behaviours or childhood illnesses, such as whooping cough, in their explanations of the cause and development of their lung condition. These informants were often aware of these factors but mentioned them only in passing or not at all.

Other causes mentioned included tuberculosis, allergies and "adult onset" (in the case of asthmatics),  $\alpha_1$ -antitrypsin and "weakness" through heredity. These were all perceived to be contributing factors in the past to the development of the lung condition. Often an accumulation of causes or several factors were seen to contribute to the development of the lung condition.

Informants often had one primary factor in mind as well as several secondary ones. Bob felt that his smoking was the primary cause of his emphysema but he also felt that environmental factors contributed to it. He blamed the lung condition on "bum" air from trains or locomotives. Informants made associations between events that bothered them in the present with events that had occurred in their past. For example, Grant saw that cold air bothered him in the present. In the past he had worked in refrigerated areas and had been exposed to cold air. He felt this was the cause of his lung condition. His wife however, focused on Grant's smoking as the cause of his emphysema.

The denial of the cause of illness lead some informants to attribute different factors to the cause of their illness or to its onset and

progression, as in the case of Grant described above or in the case of Lee. Lee attributed her emphysema to the development of her ear problem and the poisons from it which passed through her lungs leaving them with a weakness.

Informants referred to causes of the lung condition and factors which influenced exacerbations of the lung condition as triggers. Triggers were often factors that continued to insult the lung in the present. The triggers can be divided into the following groups:

- 1) Environmental e.g., cold and windy weather, humidity fumes, crowds, smoky areas, poor ventilation and dust.
- 2) Biological e.g., allergies, heredity factors,  $\alpha_1$ -antitrypsin, colds, flu, diet.
- 3) Physical e.g., physical exertion and exercise, muscle tension body and position i.e., lying down.
- 4) Psychological e.g., excited states of emotion, anger, laughter, stress and anxiety.
- 5) Unknown. Some people do not know what causes or aggravates their condition.

## SUMMARY

The informants experience of COPD was profound. Although informants pointed out that there was an experiential difference between partners with regard to living with the disease, partners' perceptions and descriptions of the lung condition and its associated problems were similar. The descriptions of the lung condition included physical and

psychological symptoms and the course and progression of the disease. The progression had a significant effect on informants' lives. The subtlety of change made discernment of symptoms and changes difficult. This consequently impacted on how informants responded to the changes. Although the changes were subtle, they were significant because they eventually invaded the informants' lives more and more. Initially, informants could hide their symptoms as they were for the most part invisible. As the disease progressed the symptoms became more persistent and visible. The permanence of such changes ultimately demanded the attention of the informants and thus they had to learn how to incorporate the lung condition into their lives. This was not always an easy transition. The symptoms and impairment of the COPD produced limitations and restrictions that were problematic for informants.

## CHAPTER 4

### THE EFFECTS OF COPD ON COUPLES' DAILY LIVES

This chapter focuses on restrictions that COPD places on the daily lives of patients and their spouses. Differences among informants and factors that give rise to restrictions and that make it difficult for informants to identify the extent of the effect of COPD on their lives will also be described.

#### THE CONCEPT OF RESTRICTION

Informants frequently described various physical, psychological and social restrictions or limitations that accompanied their disorder. These included the physical and psychological symptoms of the disease (e.g., lack of energy, shortness of breath, fear and anxiety), the changing nature and severity of the disease, the triggers which exacerbate the lung condition, arranging social life around the illness, and the timing of therapies and medications. Negative psychological reactions to restrictions could in themselves become limitations, as illustrated by Wendy and Leonna.

WENDY<sub>2</sub>: *"When the doctor said, 'I think you have emphysema'! then I thought what the hell's the sense? What I am going to do?"*

*I'm going to go around miserable or wanting to smoke, because I don't know why. I can't seem to knit or I don't have the energy for anything. What am I going to do? Do I want to be tied up to a lung machine or a breathing machine, or smoke and take my chances you know? Am I going to be tied up to a machine anyway? You know its just crazy, crazy thinking maybe. But the only reason I want to quit is because it stinks so bad and smells up everything so bad and its so dirty. Its not on account of my lung condition that I want to quit"*

Leonna<sub>12</sub>: *"He is pessimistic. He's never been an optimist. He just feels he'll never be better and I'm hoping that this therapy is going to make him better. He feels discouraged that he can't do anything. As I said he feels like he'll never get better. But he's gonna be!"*

Both Wendy and Leonna's husband Grant had a response of hopelessness and defeat to their lung condition. These attitudes and resulting behaviours could ultimately become self-defeating and cause them to give up and not deal with their lung condition. Wendy's emphysema was the least of her problems. While her lack of energy may have resulted from the lung condition, it may also have been due to the burden of other problems and her lack of inner personal resources to cope with them. Grant was depressed. The depression could prevent him from attempting to improve the lung condition or his quality of life. His wife had a sense of hope, which was potentially unrealistic, but her hope could have a positive influence on Grant by encouraging him to work on his lung condition.

Such restrictions set boundaries or parameters that reduced the scope of an individual's or a couple's activity, performance or behaviour. However, these restrictions were not necessarily or uniformly seen as problematic. Greg's and Jack's comments serve to illustrate the concept of restriction.

Greg<sub>5</sub>: "Well, its a very disabling disease. It certainly alters your lifestyle. Its a permanent infliction. Its unsettling. So as long as you understand the parameters in which you have to work with... as long as you understand the parameters Gwyn. Really, what I am saying is if you don't understand the parameters and think that its no big deal you're in for a surprise because its progressively the modifications. Like she is taking an increasing amount ... the dosage has been increasing. Hopefully they will provide a new drug or she may reach a level that is of no value to her. It is a progressive disease but it will eventually kill her."

JACK<sub>14</sub>: "Well, I find I am being inconvenienced by walking up stairs. We do a lot of travelling and as a matter of fact I have my trailer up for sale now. I have done everything I can do to make it more convenient for me on the highways. Everything is electric. Electric jacks, bending over and everything is a problem for me. So I am limited in that way. And am limited in just walking fast, walking stairs and every so often I just run out of wind and I don't like carrying oxygen but I know I have to. I have to be attached to it and they say you should be on it about 18 hours a day. I try to fight this. I want my lungs to do the breathing to do my exercises and I do my exercises but I am just limited. So I have my trailer up for sale now and my truck cause I can't do anything on it. So that's annoying to me. I'm retired and being retired now I can't do that much."

Initially, the lung impairment and limitations were minimal and thus the restrictions in informants' lives were minimal, temporary, easily compensated for, ignored or covered up. Gradually, as the lung condition progressed the restrictions became more persistent, irreversible, invasive, and influenced more areas of the informants' lives. To accommodate the restrictions, lifestyle modifications were eventually required.

Table 5 shows that some informants did not see the limitations as a problem. Informants who perceived the lung condition to be no problem were less ill and had fewer restricted areas in their lives. Some degree

of restriction was noted across all severity levels. However, because of the temporary nature and limited effect of the condition the restrictions in some informants' lives were not seen as problematic and were felt to be inconsequential.

Table 5. Couples' Perceptions of the Lung Condition: Problems and Restrictions

Couple	Severity	Couples' Perception of:			
		Restriction <sup>a</sup>		Lung Problem	Affected by Restrictions <sup>b</sup>
		COPD	Well		
GAIL/Eric	1	1	0	No	L
WENDY/Matt	2	1	0	No	M
LEE/Will	2	1	0	No	L
PHIL/KAREN	3	2	2	No	M
KEN/Betty	2	2	2	Yes	M
PAULA/Greg	2	2	2	Yes	M
GARTH/Ulla	3	2	2	Yes	M
MIKE/Mary	3	3	2	Yes	H
SARA/Tom	3	2	2	Yes	H
JEAN/Peter	3	3	3	Yes	M
BOB/Rena	4	3	2	Yes	H
GRANT/Leonna	4	3	2	Yes	H
EVAN/Susie	3	3	2	Yes	H
JACK/Dora	4	3	2	Yes	H

a. 0 = Not restricted  
 1 = Slightly restricted  
 2 = Somewhat restricted  
 3 = Very restricted

b. L = Slightly affected  
 M = Somewhat affected  
 H = Highly affected

The degree to which a restriction was considered important or problematic appeared to be influenced by such factors as the value an individual placed on the affected activity, whether or not informants' felt they were able to keep up with peers and lead a normal life, whether they were prevented from doing what they wanted or needed to do, and

whether they had learned to live with whatever inconveniences or limitations that were present. This is illustrated by the following responses:

JEAN<sub>10</sub>: "Your whole life is your illness it seems you know that everyday is focused on what you can do. The quality of life is not the quality of life that I would have wanted. I don't foresee myself not being able to work to 65 and lead a full active life and I feel that because of my COPD. It has restricted me and limited me."

Eric<sub>1</sub>: "Well clearly it tends to complicate a person's life in that someone you are relying on to do certain things isn't capable of doing them. But she is in the enviable position that she was going to school and the worst thing that happened was that she stopped going to school so it was not disruptive at all to her. The thing is, I don't know its too long ago for me to have a vivid recollection of it or have an impact on me. Its my assessment that it's no different than having one kid at home sick. It's a minor inconvenience but perhaps there are things to do that didn't get done. Or things happen that you don't expect to happen so that's a particular routine that you may be in that gets modified for a period of time but I wouldn't say that it's so disruptive so as to be uncomfortable. But you can adapt ultimately and carry on till the matter gets straightened out."

GAIL<sub>1</sub>: "I don't perceive it as a problem per se, except that there are occasions where it limits my activities but not very much. I could almost ignore it except when I occasionally got pneumonia and then you just deal with it like anybody else who has pneumonia and it passes on. So until the age of 40 I ignored it and then a few things happened that made me realize that I probably need to encompass it as a part of my existence and pay attention to it so that it doesn't limit me as I get older. It doesn't feel like a threat to me right now. I mean it's not like I've got a terminal illness although in the end it will be my terminal illness. It doesn't you don't have the same impact because I still keep up with my peers and lead a normal life. It's not a problem for me. It hasn't become so severe that it interferes with my daily life."

PHIL<sub>9</sub>: "I know she thinks it's pretty serious, but I don't think she thinks it's that serious. It doesn't prevent me from doing anything that I want or need to do. I've had it so long that I've learned to live with whatever inconvenience there is. I don't see it as that much of an inconvenience."



KAREN<sub>9</sub>: *"I've always had bronchitis or pneumonia every year so its something I have learned to live with and it doesn't bother me. Obviously I can't do the same as I used to be able to, youknow like going up and down stairs. I don't have the stamina."*

Gail and Eric, and Phil and Karen are two couples who do not see the lung condition as a problem. However, as couples they differed between each other in that Phil and Karen had more limitations than Gail and Eric. As a couple, Phil and Karen had begun to modify their lifestyles, and were similar to couples who considered the lung condition to be a problem. Their limitations were more persistent and permanent, yet like Gail and Eric they did not report themselves to be restricted in many areas. This may in part be explained by the fact that both Phil and Karen have COPD. They both had the same severity of illness and they both had experienced similar limitations and boundaries that had required them to modify their lifestyle together. This differed from all other couples in which only the COPD partners had to modify their lifestyle.

Both Phil and Karen had created lifestyles that allowed them to live within the boundaries set by the illness, thus they did not feel restricted and that the lung condition was a problem. Their lifestyle and the acceptance of it may have been facilitated by the nature of their marital relationship as well as the fact that they both have COPD. Phil and Karen were an exception to other couples in terms of the differential illness experience between partners that was discussed in Chapter 3. Both Phil and Karen felt they had an understanding of each others' problem because they both had a lung condition.

The different experience of the lung condition between partners in one-COPD couples could be problematic. The modification of lifestyle in one-COPD partner couples could result in more tension, strain and conflict within the relationship than within a two-COPD partner couple. There could be a greater disequilibrium within one-COPD partner couples as they cope with the widening gap between the illness of one partner and the health of the other. This disequilibrium could contribute to a sense of restriction in lifestyle. The extent to which restrictions of one-COPD partner couples were problematic appeared to be modified by their marital relationship and their level of acceptance of the lung problem and the subsequent restrictions.

Other factors also influenced whether or not the restriction was considered a problem for partners, such as other health problems, or previous existing marital difficulties. These problems sometimes overshadowed the importance of COPD and made it difficult for informants to distinguish between the effects of COPD and other existing problems. The vagueness surrounding effects of the lung condition could facilitate denial of the realities of the lung condition and could contribute to viewing it as non-problematic.

Some informants used other problems to ignore or discount the importance of the lung condition. They focused their attention on these problems to draw attention away from the problems of the lung condition. The expenditure of energy on other problems would leave them with less energy to deal with their lung condition, thus they appeared to be less aware of the condition and the potential gravity of its effect on their lives.

The limitations defined the boundaries or scope within which informants could live their lives. As the disease progressed, these boundaries changed and they became more restrictive. Informants modified their lifestyles in an attempt to live within these boundaries.

Some of the boundaries for the COPD spouse included the time required to perform an activity or when an activity could be performed, the types, length and frequency of activities or tasks that could be performed, the environment that informants could be exposed to, and the psychological responses to COPD that informants experienced. The well spouse was also exposed to the same limitations and boundaries imposed on their ill partner. However, the well spouse could choose whether or not to modify their life to accommodate or respond to their ill partner.

Mary<sub>7</sub>: *"I can still go out on my own. His life has changed more than mine."*

Dora<sub>14</sub>: *"Well it doesn't bother me. I mean it hurts me to see him like that but I mean as far as it bothers my life I just.... he's got it and I try to work with him."*

#### SPOUSES' PERCEPTIONS OF RESTRICTIONS

Table 5 shows the perceived degree of restriction for both ill and well spouses. At lower severity levels the well spouse usually did not perceive restrictions, while their COPD partner perceived slight restrictions. Spouses usually perceived restrictions the same way at moderate severity levels and at higher illness severity, the COPD spouse tended to feel more restricted than the well spouse, because as the impairment of the lung increased, more personal areas of the COPD spouse's

life were affected as the struggle to breath became all-consuming. Activities of daily living such as mobility, self care and eating were affected. In general, well spouses tended to modify their life patterns to meet those of the COPD spouse to some extent, although well female spouses were more likely to adapt their lives to meet the needs of their partner than well male spouses. Table 6 shows the degree of lifestyle modification of both ill and well partners and the well spouse satisfaction with that modification.

Rena<sub>11</sub>: *"Well I've slowed down to keep pace with him. I go out alone sometimes if you don't you get cabin fever."*

Mary<sub>7</sub>: *"He's still well enough to get up and travel some and I find it easier going away with out him. I haven't done that for more than a few days at a time and I don't expect that I will. I don't have the desire to. For awhile I figured I couldn't because I was doing therapy on him but now he has a vibrator. So I lost my job. Not that I complained when I was doing therapy on him twice a day for eight years. Do you felt committed there you had to be around."*

Well male partners expressed more dissatisfaction with regard to the modification of their lifestyles. These well males were more likely to adopt a traditional husband role, such as family provider, thus they were more likely to carry the financial load. Financial stresses could contribute to the tension and dissatisfaction expressed by males. While all couples felt their incomes were sufficient to meet their needs, the majority of informants emphasized the importance of adequate finances with regard to their illness. The cost of being ill in terms of lifestyle modifications and earning power was considered to be high. In addition,

Table 6. Couples' Lifestyle Modification:  
Degree & Satisfaction

Couple	Severity	Modification of Lifestyle by Spouse			
		Degree <sup>a</sup>		Sex of Well Spouse	Satisfaction of Well Spouse
		COPD	Well		
GAIL/Eric	1	1	0	Male	Yes
WENDY/Matt	2	1	1	Male	Yes
LEE/Will	2	1	0	Male	Yes
PHIL/KAREN	3	2	2	-	-
KEN/Betty	2	2	3	Female	Yes
PAULA/Greg	2	2	2	Male	No
GARTH/Ulla	3	2	3	Female	Yes
MIKE/Mary	3	3	3	Female	Yes
SARA/Tom	3	2	2	Male	No
JEAN/Peter	3	3	2	Male	No
BOB/Rena	4	3	3	Female	Yes
GRANT/Leonna	4	3	2	Female	No
EVAN/Susie	3	3	3	Female	Yes
JACK/Dora	4	3	3	Female	Yes

- a. 0 = No modification  
 1 = Slight modification  
 2 = some modification  
 3 = High Degree of modification

couples with well male spouses tended to be younger and subsequently were in a different phase of the life cycle than couples with well female spouses. These younger males were still involved with their careers as illustrated by Greg's comments. Well male partners who expressed satisfaction with their lifestyle had made either no lifestyle modification or only slight or temporary modifications.

Greg<sub>5</sub>: "I've tried to discount it, to pooh pooh the whole thing. We've got three young kids. I've got a fledgling business that I am trying to nurture requiring an awful lot of time. I can't be burdened with what if. You don't want to burden yourself down with what would we do in this situation. I

*think we both know where the end is but you don't want to park the hearse in front of the door. And maybe that's burying your head in the sand but you've got so many other people relying upon you, the lifestyle and situation you don't tend to bury your head in the sand but you tend to get on with life. That's important."*

The modification of a well spouse's lifestyle was necessary if the well spouse wished to accommodate their ill partners restrictions and subsequent widening separation between themselves and their ill partner. The extent to which a partner modified their lifestyle and was satisfied with that modification appeared to be related to personality, values and gender. The need for lifestyle modification became problematic if a difference existed between partners in terms of their attitudes, values, priorities and expectations within their marriage. For example, the priorities of a well spouse could lead them to modify their activities drawing them away from their ill partner instead of keeping them together.

JEAN<sub>10</sub>: *"I can't curl any more. He likes to curl so he curls all winter and so therefore we're not doing the things together that we would normally do, that we used to do. So there's sort of a separation there. It alienates you because you have to find other things you might be able to do. You do your own thing and they do their own things and so you don't do what you want to do together."*

Tomg: *"I think that with the advent of the constrictions, restrictions of our own activities I am becoming more and more emersed with what I am doing in my own activities. With the demise of our social life if you like then my interests or time I am spending in that area are greater and that causes a great deal of resentment."*

## AREAS OF LIFE AFFECTED BY COPD

Table 7 shows the degree to which couples perceived the lung condition to be restrictive in various areas of their life. The areas of leisure activity, household tasks, and sexual activity were most often cited as being affected. The areas of sleep, mobility and work were next most often cited, followed by self-care and diet as the least often mentioned areas affected. Changes in leisure activity were noted across all severity levels and it was the first area perceived to be affected. Changes in the ability to care for oneself occurred only as the illness became more severe.

The most affected areas involved functional, task oriented activities. There were perceived as restricted because of the inability of informants to perform the tasks required by the activities or because informants had to modify the activity in some way. This lead to a sense of loss of control over their lives and a loss of spontaneity in their ability to carry out activities.

Planning specific activities became an important coping strategy to accommodate changes. However, despite careful planning the lung condition could still interfere with the performance of activities. Couples would sometimes have to wait to see if the COPD partner was well enough to participate in an activity even though it had been carefully planned. Sometimes couples would spontaneously take an opportunity to do something during the COPD partners well periods. Thus, activities or situations whether planned or spontaneous were governed by the condition of the lung problem at the time.

Table 7. Areas of Life Restricted by COPD

Couple	Severity	Leisure Activity	House hold	Sex	Sleep	Mobility	Work	Self Care	Diet
GAIL/Eric	1	1	1	0	0	0	0	0	0
WENDY/Matt	2	1	1	0	1	0	0	0	0
LEE/Will	2	1	1	1	1	1	0	0	0
KEN/Betty	2	2	2	1	2	0	0	0	0
PAULA/Greg	2	2	2	2	1	1	2	1	2
PHIL/KAREN	3/3	1	1	1	0	0	0	0	0
SARA/Tom	3	2	2	2	1	1	1	0	0
MIKE/Mary	3	2	1	2	1	2	2	1	0
GARTH/Ulla	3	2	2	2	1	0	2	1	1
JEAN/Peter	3	2	2	1	1	1	2	1	2
BOB/Rena	4	2	2	2	0	2	N/A	1	0
GRANT/Leonna	4	2	2	2	1	2	N/A	1	0
EVAN/Susie	3	2	2	2	2	2	2	2	2
JACK/Dora	4	2	2	2	2	2	N/A	0	2

0 = Not affected

1 = Partially affected

2 = Affected a lot

N/A = Retired before lung condition was a problem

### Leisure Activities

The range of perceived reduction of leisure activity varied across couples. Some informants perceived restrictions as slight or temporary while others perceived them as very limiting and permanent.

The leisure activities were closely associated with couples socialization patterns, (e.g., travelling or going to dances with friends). Changes in leisure activities often resulted in changes in socialization patterns. Leisure activities were often activities that couples did together. Changes in these activities affected the nature and the way partners spent time and socialized with each other.

A couple's preference for different types of leisure activities varied from highly physical to sedentary activities. Highly physical



activities included, bicycling, hiking and skiing. Moderately physical activities included yoga, travelling, driving, mall walking and gardening. Sedentary activities included knitting, watching television, reading, playing cards and writing. Those couples who socialized less and enjoyed more sedentary activities did not see the lung condition as intrusive or restricting as those couples who valued exercise and enjoyed highly physical activities and whose activities involved socializing with friends.

As the illness progressed couples gave up activities. There was a movement from more active to sedentary activities. If an informant had a strong preference for a certain type of activity adjustment to different activities was more difficult. Some informants were planning for their future and were developing interests in both sedentary and active pursuits. While the leisure activities were modified or replaced by more sedentary activities, many informants still placed a high value on exercise and the maintenance of activity as a way of managing the illness or to slow its progress. The maintenance of social contact was viewed as important part of keeping active and for preventing self-pity, isolation and losing what ability one had to perform activities.

SARA<sub>8</sub>: *"Most of my friends are golfers and tennis players and what not, so it has affected me. But I am determined to do things that are sedentary so I've been playing a lot of bridge. I've also started painting classes."*

GRANT<sub>12</sub>: *"You can get pretty tired sitting around feeling sorry for yourself. I can't get interested in any of the shows. Reading, I can't. If it's a how to do article maybe I can. But just up and read a fiction or anything like that I just can't."*

EVAN<sub>13</sub>: *"In this condition you have to commit yourself to exercise if you don't you're going to sit and deteriorate considerably. You use it or lose it."*

Factors that influenced reductions or replacements in activities included: shortness of breath upon physical exertion, crowds, difficulties interacting with people, environmental concerns such as smoke and cold or dry air, the time required to perform the activity, a need to escape from problems, and emotional responses to the lung condition (e.g., fear, anxiety or embarrassment).

#### Household Activities

The types of activities viewed as household tasks varied from vacuuming to mowing the lawn to house management and the scheduling of social events and entertainment. The COPD spouse's ability to perform activities and tasks around the house was affected as the severity of the lung condition increased. The well spouse began to take on more and more of the household responsibilities. Role reversals or sharing of activities often occurred in response to this change.

BOB<sub>11</sub>: *"I've given up an awful lot. I used to help Rena out a lot. I used to do the vacuuming but now I don't. I do get up and bake bread once in a while and I used to do a lot more cooking."*

Some of the reasons COPD spouses gave for sharing tasks or reversing roles included: "doing your share around the house", "it's good exercise", reducing burden on the other spouse, preventing boredom, or for the enjoyment of doing an activity. The lack of ability to perform household

tasks resulted from lack of energy and shortness of breath. Activities such as vacuuming required physical exertion. The inability to lift, reach over ones head or bend were also limitations.

Not all couples shared household tasks, or shared them easily. Those couples with a more traditional role arrangement had more difficulty making role changes. Philosophical, cultural and stigma issues also influenced some informants' ability to adjust to role changes.

Ulla<sub>6</sub>: *"I tend to find it easier to get out and cut the lawn, to do the gardening. Garth feels he's always previously been able to do that and it's the sort of thing he should do and if the neighbours see me out cutting the lawn and see Garth sitting on the step... he doesn't think that looks too good."*

The adaptation to different roles seemed to be easier for those couples who have always shared or mixed roles as a part of their relationship. The lung condition, however, could modify the nature and mix of that sharing.

JACK<sub>14</sub>: *"We both help each other out. House cleaning we both do house cleaning. Washing, who ever decides to do the laundry will do it. We've always done it that way."*

Well female spouses in traditional roles were more likely to take on extra roles than were well females in mixed relationships. As the COPD progressed, however, all the well female spouses took on more and more of the tasks. Although well male spouses in traditional relationships took on extra tasks, they were less interested in doing so. Women in general,

whether they were the ill or well partner, were likely to shoulder more of the house hold tasks and responsibilities than the males.

SARA<sub>8</sub>: *"I think we grew up in those times. I think partly he came from a family with sisters. I don't see the roles changing where he's the nurturer and housekeeper. No and I haven't gotten to that stage. If I was on oxygen and in a wheel chair that would have a big effect but role reversal no."*

Leonna<sub>12</sub>: *"I have to pretty well do everything now. Like even now I have to put the rack up in our son's room and it would be so handy if he could come and help me hold it. But he can't so I just had to learn."*

GAIL<sub>1</sub>: *"I mean it isn't a lot of fun around here when I'm sick and out of commission 'cause I do a lot and they notice it."*

#### Financial and Economic Tasks

Informants employment situations and finances were complicated by COPD. Some couples retired before major complications from the lung condition occurred and so they were not greatly affect by COPD in this area. Some informants with COPD spent most of their time at home and were not or had not been in the work force. This group consisted primarily of COPD housewives who were supported by their husbands. The group most affected in the area of employment were those couples in which the COPD spouse was forced to retire due to their illness caused by the lung condition. Work and retirement was influenced by both health and finances. Alternative arrangements at work were often tried before retirement. Work was sometimes modified to include more sedentary activities or to accommodate oxygen on the work site. Work hours were rearranged so that the ill partner could go home for treatments or therapies at required times. Financial concern was an influential factor

in the attempts to remain at work. Financial strains were sometimes stressful. This stress in turn impacted the lung condition and complicated the situation further.

As in the household tasks, the work load could be shared by couples. The well spouse sometimes modified work patterns (e.g. change from full-time to part-time or take on full-time work) to accommodate their COPD partner's illness and need to retire.

Mary<sub>7</sub>: *"When he first got sick and was working.... that went on for quite a few years, and just gradually got worse and it was hard to work for him. I was working then too and then once he got to where he couldn't work and he was not very good and I was still working. Then after awhile he got his Alberta Workmen's Compensation as well as his pension so financially we settled down and then about a year after that I retired. I think for a few years there he was having so much trouble trying to breath and work and he was worried about finances and what not and his disposition was not the greatest. He was getting very depressed which I found hard to handle 'cause there's so little you can do about it. But that has improved. But then after I retired and relaxed then financially we were okay and he started to improve why things got much better."*

Informants emphasized that finances were important concerns associated with the lung condition. Although none of the informants perceived it to be a problem in their lives, they were very aware of the costs of medications, applicators, oxygen and other medical therapies and changes to the home that were required. The loss of the ability to work reduced both income and quality of life for couples. Expenses also used up retirement savings. Financial strain was considered to be a factor that could compound existing problems and would possibly be "the straw that breaks the camels back with regard to the marital relationship".

## Sexual Activities

The lung condition was seen to affect the sexual activity of couples in terms of both quality and quantity. This change in sexual activity was not always perceived as a problem. Other factors sometimes existed in the relationship which also affected sexual activity. Marital problems, other health problems, age and satisfaction with sex were mentioned by informants. In these cases where other factors influenced sexual activity the COPD was not perceived to be problematic. The importance of sexual activity contributed to whether or not the change in sexuality was seen as problematic or a weakness in the relationship.

- Tom<sub>8</sub>: *"Since the other medical concern came along that was the beginning of the end of her desire to have a sexual relationship and that certainly is a minus point for us as far as I am concerned. I've made advances and suggestions but there is no interest. That is an aspect that has undergone major changes. I've only enjoyed that relationship with her but I like sex."*
- Rena<sub>11</sub>: *"One weakness would be our sex life, which is.... might as well say is practically nil, because after three transurethrales there's not much left. But as far as I'm concerned that's a minor detail. It doesn't bother me. It does bother him to a point, but it isn't a disturbing factor."*
- Dora<sub>14</sub>: *"Its not like it was but that doesn't bother me. To be honest with you sex to me was never great anyway but to him it was. It was something I felt had to be done I guess for our marriage."*

While sexuality was viewed as important to the relationship it was considered to be only a small component of the relationship. The presence or absence of sex was not necessary to demonstrate the depth of love or caring that a couple had for one another.

Betty<sub>4</sub>: *"I think is a slow reduction in virility. You know his breathing has a lot to do with it. We've had more than our share so I don't feel that either of us has suffered for the lack of it and at this stage of our lives it's a very unimportant part. You know you care deeply and I don't think we need sex to prove it so its not a problem."*

Sexuality in the relationship was not only affected at the physical level of the sexual act but also in terms of the intimacy a couple shared. For example, the lung condition affected the ability to go out for a romantic dinner. There could be time constraints as to how long a couple felt they could be away from home. There could be concern about being in a public place and coughing. The lung condition affected the personal care and hygiene of the ill partner, consequently, concern over matters such as odours from incontinence or bad breath reduced the desire for physical closeness. Also, oxygen hoses could become barriers to physical closeness.

Partners sometimes felt anxiety, embarrassment or guilt in response to these concerns. These affective responses in turn affected the level of intimacy. As well, emotional expression or fear of affective responses during sexual activity could also be problematic and could lead to the avoidance of the activity. Medications, lack of oxygen, coughing and body posture all contributed to difficulties during sexual activity.

The desire for sexual intimacy may still exist although the ability to participate was no longer possible or greatly reduced. This could create conflicting feelings for both the COPD and well partners. The well partner could have feelings of guilt for seeking or desiring sexual pleasure when their partner was ill or because they felt less attracted to their COPD partner because of the illness. COPD partners could also

feel turmoil about not being able to perform but still having the sexual desire. Acceptance of the situation, remembering the past with enjoyment and satisfaction, or finding ways to work around situations were seen as solutions to resolve some of these sexual issues.

Mary<sub>7</sub>: *"Well your sex life changes to a certain extent because when he's not breathing well sex is exercise. It gets him breathing hard and he coughs and he coughs and he coughs when he isn't feeling well and that kind of turns you off. When you think that's what's causing it, a lot of coughing, well that doesn't encourage you as far as that goes. That's one thing I've noticed as far as my feelings are concerned. I'd rather not because mostly for that reason because afterwards I'm lying in bed and he's standing in the bathroom coughing his head off. Well that isn't right."*

#### Activities of Daily Living

Mobility and range of motion. The lung problem became very intrusive and personal for the COPD sufferer when it affected many normal daily activities such as mobility, self-care, sleeping and eating. This intrusion affected the well spouse as the COPD spouse required more care and became less able to help out with other daily tasks. Walking was an important activity that was required for many other activities. Housework, leisure activities and self-care became more difficult. Functional activities, such as answering the telephone, became more difficult.

JACK<sub>14</sub>: *"If I walk too fast if the phone was to ring and I'd have to take three fast steps .... I can't answer the phone 'cause I can't say hello."*



Informants with severe COPD found they had to pace themselves when walking. They could not just get up and walk a short distance. Everything became planned, even where to stop and catch a breath.

EVAN<sub>13</sub>: *"I'd have to sit 10 or 15 minutes in a chair before I could walk out to my car and your car's from here to that wall and your sitting there looking at it and you want to get to it and you can't. You can't move and you say just walk over there but you can't move."*

Some days informants found they were able to walk better than others. Informants related this variation to such factors as fluctuations in the illness, exposure to triggers, the quality of rest or sleep, the amount of energy they had, steep grades or inclines, and wind and cold weather.

Mobility not only is the ability to walk but the freedom to move. COPD sufferers had decreased ability to reach above their heads or to lift. This kind of restriction prevented them from sharing in simple pleasures such as picking up a grandchild or carry out physical tasks.

Although exercise was seen as essential for the maintenance of mobility and movement, walking or movement was difficult because of the shortage of oxygen. Thus, walking for exercise or leisure became difficult and unenjoyable, but a sense of achievement and pleasure was received when informants increased the distance they were able to walk. Often informants would go mall walking (i.e., walking around shopping malls), especially in the winter when the weather inhibited walking outdoors. Walking often became a leisure activity that couples could do together and derive pleasure and enjoyment from each others' company.

Self-Care. Because of limited mobility informants found that self-care became more difficult. Walking to the bathroom or standing in the shower became problems. Coughing also affected the bladder and could lead to problems of incontinence. This could cause embarrassment for the ill partner, especially if it occurred in a public place. Incontinence resulted in more frequent showering or washing to prevent odours and maintain hygiene. Informants with this problem would use aids, such as pads or adult diapers, to assist them with this problem. A sense of loss of control and dignity accompanied these types of problems as well as feelings of anxiety and depression.

Because of the increased activity associated with the upkeep of personal hygiene more energy and time was required for personal care. Informants developed daily routines to accommodate the management of their self-care. Sometimes the well spouse would assist in dressing and taking care of medications or therapies. When the area of self-care was affected the well spouse would often take on the role of caregiver. This role was more frequently assumed by women than men.

Susie<sub>13</sub>: *"There are other conditions that have gone on with his lung condition that he's had to face. This is incontinence. That is a big one. We have found that adult diapers are good. I don't molly coddle him. I feel he should do what he can for himself. But there were times when he didn't think he would get out of the shower. It's (a chair)been a big help so he can sit in the shower and take his time. But the incontinence has been hard because it can happen in public. But its hard for a person to accept. It's his dignity and I am very aware of odours so I let him know."*

BOB<sub>11</sub>: *"It takes me all day to get up. Like you were coming so I kinda got ready for you. Usually I'm sitting here still waiting to go swimming at 11:00. That's about when I finally get around to dressing, when I come up from swimming. Just getting clothes on, like these modern socks. They won't*

*stretch properly and of course I have to rest between putting a pair of socks on. So it's not very nice."*

Sleep. Because of decreased energy and lack of oxygen COPD informants felt they required more sleep. As a result, they would go to bed earlier or take more rests. Sometimes sleep was used as a means to relax if they were becoming uptight. For some COPD informants sleeping was irregular and obtaining a good night's sleep was difficult. Coughing, congestion and laboured breathing associated with lying down were seen as factors affecting sleep. For those informants using oxygen, sleeping with an oxygen hose could be difficult as the hose would sometimes get wrapped around their necks. Poor sleep was associated with being tired which was associated with feeling more ill, a decrease in mobility, low energy and a general decrease in psychological well-being. Not all COPD informants, however, reported sleep difficulties.

The COPD spouse's irregular sleep patterns sometimes affected the well spouse's sleep patterns. Not all the well spouses reported difficulties in sleeping. Sleep was considered a problem if the well spouses felt that they did not get enough sleep. Some well spouses felt they did not require much sleep and were not bothered by disturbances or found that they slept soundly and were not affected by their partner. For other well spouses sleep was a problem and this problem was complicated if sleeping together was valued as part of their relationship and expectations in their marriage. This would put a strain on the relationship. For those informants who did not highly value sleeping together, sleep disturbances were accommodated for by sleeping in another room.

Betty<sub>4</sub>: "I don't mind if he has some trouble at night. I want to be up. He doesn't want to bother me but that's foolish, losing a little sleep isn't going to hurt me. It has a calming effect when I am there. But I've always been one that I can drop off and go to sleep anywhere anytime. I can cat nap and be fully rested."

Peter<sub>10</sub>: "I go to bed and am tired and I sleep and yet I guess every time she gets up I am awakened and as long as I get my five hours sleep I am okay but if I don't get my five hours I can get a little irritable because she does a lot of coughing at night."

Diet. Diet and food consumption were considered to be affected by the COPD by some informants. These effects varied. Food allergies were a major concern for asthmatics and so diet was altered to avoid foods that triggered asthma attacks. In addition, diet was important because some medications and the illness itself were felt to deplete the COPD partner of nutrients. A well-balanced diet was considered important. Weight was also a concern as increased weight around the abdomen resulted in greater discomfort around the diaphragm and made breathing more difficult. A full stomach after eating was considered undesirable. Smaller and more frequent meals were preferred to three meals a day by some informants. The effort to conserve energy played a role in eating smaller meals. Digestion requires oxygen and energy. Smaller meals were seen as a means to manage the scarce energy and lack of oxygen.

#### CONFOUNDING FACTORS: AGE AND HEALTH.

While informants saw COPD as a force affecting various aspects of their lives, as described above, other factors, predominantly, age and

health sometimes confounded these issues. It was sometimes difficult for informants to distinguish outcomes that were a result of COPD as opposed to those that resulted from normal aging processes. Some informants felt that illness was just a part of aging. You do not feel as well when you get old. Consequently, restrictions resulting from tiredness and lack of energy were considered normal rather than the effects of COPD.

Age also influenced the perceived intrusiveness of COPD. The restrictions and changes that resulted from COPD were not perceived as restrictive or problematic for older couples. Due to normal life cycle changes or other health issues which older people are at higher risk for, modification had already begun in areas such as leisure activity, work, house hold tasks and sexuality. Comparisons by older informants with peers did not reveal large discrepancies in lifestyles as it did with younger couples.

Rena<sub>11</sub>: *"I've slowed down with age so there's a factor there, that you slow down period you know. It hasn't actually affected me too much physically I don't think. I do the washing or ironing or house cleaning. I haven't got to the stage where I've got anybody in with house cleaning but the day is coming. The day is coming. I do more in the line of housework and stuff because he can't help me and that takes more than a day now but I think it's also the ageing process that you normally slow down."*

Younger couples were more likely to consider changes in their live as restrictive and problematic compared to older couples. Younger couples still had children at home and had the stress of raising and supporting them. Financial obligations and stress were different from those of couples who had retired. Older couples felt financially less stressed.

When younger couples compared themselves to their peers, the pace of their lifestyle seemed to be slower to accommodate the illness. Younger informants felt that it is not age appropriate to be sick,

PAULA<sub>5</sub>: *"I can't keep up, but I don't want to tell him that, because I don't want to be viewed as a crippled person at 41 years old. I haven't got arthritis you can't see that I'm.... I can't. I don't want everybody to know how I feel so I keep doing things where I should be resting. And I hate saying when the kids say 'What are you doing tonight mum? Well I'm parking myself tonight because I'm tired. Oh I want to do this. I want to do that.' And I feel really bad and I do the same to Greg. And I know that he is looking forward to retirement 'cause we can have time together, and I think I don't know what shape I'm going to be in by then. I find that hard to talk about."*

Regardless of age the lung condition posed problems for couples in a variety of ways that were invasive and difficult. It was difficult for some informants to distinguish effects from COPD from effects arising from other health problems. For example, arthritis could be very restrictive and considered more of a problem than the lung condition. It was often difficult to distinguish how much fatigue and lack of energy was due to the arthritis rather than the COPD.

Other health conditions were sometimes used to avoid dealing with the COPD. In these cases, informants saw the lung condition as non-problematic and not affecting them to any great extent in the various areas described earlier. More focus and emphasis was placed on the other health problems.

Common illnesses, such as colds and flus, also made it difficult for COPD informants to distinguish whether or not they were experiencing

COPD related symptoms. A cold or flu could exacerbate the lung conditions, so informants were wary of catching such diseases.

The changes and effects of COPD also become problematic if the COPD spouse's partner had a health problem. The extent to which the COPD partner could rely on support from their partner and the way in which activities became modified reflected the nature and degree of the severity of the other spouse's health problem.

#### SUMMARY

Although informants sometimes had difficulty discerning the extent of the effects of COPD, they were clearly able to identify certain frequently observed changes in functional or task-oriented activities. Whether or not informants experienced restrictions or considered the lung condition to be problematic, depended on various factors, such as severity of the lung condition, importance of activities, beliefs and attitudes and behaviours, as well as individual coping skills.

The restrictions in couples' lives required changes in order to modify or adapt to the lung condition. This required the reorganization of the way in which couples had structured their marriage in terms of tasks, responsibilities and role division. The ease with which couples were able to effect reorganization reflected the couples' lifestyle, personalities and expectations of their marriage.

The restrictions experienced by the well partner reflected the experiences of their ill partner and the degree to which they modified

their life to accommodate that of their ill partner. Gender appeared to play a role in the degree and satisfaction of modification.

The effects of the lung condition on functional areas of the marriage also appeared to affect the intimacy and sharing aspects of a couple's relationship. These relational issues appeared to be indirectly affected by the lung condition through changes in the functional areas. The nature and dynamics of the direct and indirect effects of COPD in couple's marriages are described and discussed further in Chapter 5.



## CHAPTER 5

### PERCEPTIONS OF MARRIAGE AND THE EFFECTS OF COPD ON THE MARITAL RELATIONSHIP

One of the central questions of this research was the impact of COPD on marriage. This question was difficult to address because informants were unaccustomed to thinking about the nature of their marital relationship and about the impact of COPD on that relationship. To overcome this barrier, the researcher explored with the informants their perceptions of marriage in general and their own marriage in particular. They were then asked to focus on their feelings toward their spouse and how COPD affected their spouse. Through this information the link between COPD and the marriage was drawn.

This chapter first focuses on informants' descriptions of their marriage in terms of their expectations, needs, conflicts and congruencies. The analysis then shifts to different marital styles that were inferred from their descriptions. The impact of COPD on those styles and different areas within the marital relationship are reported next. Finally, factors that modify the impact of COPD on marriage are described.

## INFORMANTS' PERCEPTIONS OF MARRIAGE

The informants tended to view marriage as a system in which two subsystems, the partners, operated. The partners brought with them their personalities, needs, expectations and life experiences to that marriage. Individual personalities were commonly considered to be an important part of a couple's marital relationship. Personalities were related to socialization and past experiences that were brought to the relationship and affected the way in which an individual perceived the illness and influenced how they reacted to it within their relationship. Thus, the style of marriage and the dynamics of their relationship were a reflection of the individuals within the marriage. Informants also distinguished the relationship a couple developed between themselves from their marriage. The relationship was considered to be only a part of the marriage.

Eric<sub>1</sub>: *"When people meet it's the kind of people that get together, a match of types of people. Some are like doting husbands. I'm not that type. I couldn't take it if she were that type."*

GAIL<sub>1</sub>: *"I think you often get a personality type associated with disease and I think that the pattern develops over a lifetime. When I was growing up, my mother was very protective of me and I think I ended up marrying to get away from that so I entered into the marriage with a very strong determination not to depend on anyone else for anything, so I was very independent. So as a result you end up with certain patterns and problems in the marriage. It's a lot to do with my socialization as a child and I think a lot to do with my personality."*

The marital system (the relationship and marriage) was seen to exist within a larger biopsychosocial environment which has forces (e.g., financial and medical) that act upon the marital system. Marriage and the marital relationship were considered to be naturally dynamic, that is, the changes in the marriage were considered to be a normal part of life and not always related to the COPD. Different forces were seen to influence change in the marriage. Informants saw changes in their marriage as their children grew up. Factors associated with finances, such as business, employment and retirement, were also seen to create change and place stress on a relationship. Death and illness, such as the lung condition, were other forces that were felt to influence marriage.

Peter<sub>10</sub>: *"If commitment is your underlying philosophy then you are going to make it work regardless of the circumstances. Regardless of the financial setbacks. Regardless of illness. Your wife becomes not only your lover but your best friend and confidante. The whole thing. I mean this is whether you are healthy or not. It's nothing to do with COPD. If you have that philosophy, then the moment things don't go right I'm gonna bail out, then COPD is an easy excuse to bail out very quickly and I can't put up with that."*

Many informants felt that changes due to these forces stimulated the growth and development of their relationships, particularly in the areas of communication and expression of intimacy. Several informants considered the length of their marriage as important to this growth. The time they had spent together increased the sensitivity and understanding of each other's behaviour and habits. This facilitated the maturation of their relationship.

- Eric<sub>1</sub>: *"There is always room for improvement. I would see good communication on an ongoing basis. In the initial years of our marriage, my role was a dominant one, then for a period of four or five years rather turbulent and in the last three or four years I would describe it as being more of a partnership."*
- JACK<sub>14</sub>: *"We've been together 43 years now and I think we are just one person. We seem to think alike. Its just strange and hard to explain. I can be thinking of something and she'll mention it or vice versa. We just work together. But from the beginning to now has been quite a change. And there had to be change 'cause when you're younger you start to raise a family and you're at the other end of the spectrum now. Your family is all gone and you're back to square one again. Just the two of us. Well we're enjoying ourselves more. We're financially sound and satisfied."*

Through descriptions of their marriage informants identified dimensions of their marriage that could be considered to be a marital contract. This marital contract involved the informant's expressed or unexpressed, conscious or unconscious, obligations in their marital relationship. The obligations included different aspects, from sexuality, leisure activities, finances to achievements. The terms of a contract appeared to be determined by deep needs or wishes of the partner that the marital relationship was expected to fulfil.

The issue of needs and expectations in the marital relationship emerged in the course of the informants' description of three aspects of their marriage, namely, 1) expectations of marriage, 2) needs and desires that affected their marital relationship, and 3) external features of their relationship, such as communication and roles, where conflicts or congruencies in the relationship were apparent. The impact of COPD on their marriage could be identified within areas of conflict or congruence that couples described.

### Expectations of the Marriage

Informants' expectations of marriage centred on the ideas of commitment, companionship, sex, family, and an economic or social unit. The idea of commitment, which was commonly referred to, involved loyalty and the acceptance of the good with the bad, or staying with the partner regardless of circumstance. Loyalty included a sense of duty that was expressed in relation to the fulfilment of an individual's expectations. A husband may feel a sense of duty or loyalty to his wife since she raised his children, cared for his house and fulfilled his expectations of her as wife and mother.

Tom<sub>8</sub>: *"The marriage will continue because of loyalty. She brought up my children and all those other things but frankly sometimes I wonder why?"*

Most informants expected their marriage to be dynamic and to fluctuate between both good and difficult periods. It was considered normal to have disagreements in marriage and that marriage was a balance of strengths and weaknesses, commonalities and differences between partners. Marriage was a process of give and take that required adaptation to the strengths and weaknesses of the partners.

PHIL<sub>9</sub>: *"It's basically give and take and nobody is in the same mould as you otherwise you would be marrying a twin I guess. I think you probably compliment one another in character over the years. You kind of adapt to one another and realize one another strengths and weaknesses and blend in together."*

### Individual Needs and Expectations

Partners' expectations of their marriage arose from their needs and desires that emerged from their physical and psychological make up. These needs involved issues of dependency, power, control and love within the relationship and were associated with an individual's feelings of fear, abandonment or loneliness. Often the needs of one partner reflected the characteristics which that partner desired in their spouse in terms of love, feelings, attitudes, role requirements, sexuality, acceptance and cognitive attributes. The dynamics of a couple's relationship, that is, their roles and interactions appeared to be played out through these issues. The nature of the interactions in a couple seemed to be designed for the purpose of fulfilling and satisfying their needs and expectations within the marital relationship.

Informants expressed several needs and expectations associated with COPD and the marital relationship. The lung condition was a disruptive force in a couple's relationship as it created a disequilibrium within the relationship. The imbalance occurred as new needs in the partners were created or existing needs were exacerbated by the illness. These changes were threatening to the relationship and created strain and anxiety, particularly if the needs remained unmet.

Informants identified changing needs in the areas of dependency, sharing and togetherness and the fulfilment of roles. The existing dependency states of a relationship were threatened as the COPD spouse became more dependent on their well partner. The maintenance of the COPD spouse's independence was valued by most couples.

The ability of a couple to share and experience each other was reduced by the lung condition as partners experienced a separation from each other in terms of how and when they were able to spend time together. Because of this growing sense of separation, the needs for companionship, friendship, understanding and love were felt to be threatened and tested by the lung condition. Love between a couple that survived the strain of the lung condition was considered to have endured, having been tried and tested by time.

Finally, the lung condition threatened a couple's needs and expectations as the COPD spouse's ability to fulfil role requirements was affected. The issues of dependency and sharing are associated with the need to fulfil roles. With a decrease in ability to function in roles ill spouses became more dependent and felt themselves becoming a burden on their partner. By no longer performing certain roles, the COPD spouse was unable to share in the same way with his or her marital partner.

In each of these areas COPD poses a common underlying threat, that is, the loss of a partner and the subsequent loss of a relationship. This loss touches the basic underlying human fears of feeling abandoned or alone which stem from the deep human need to be loved. The following two experts from the interview with Tom, serve to illustrate these points.

Tomg: *"Her bedroom was always immaculate. Everything was always in it's place and now things are thrown on the floor and the cupboard and maybe once a week she cleans up or maybe once a week I clean up. But that's a very clear manifestation of her inability to cope mentally or cope physically. It's affected our social life greatly because we don't have people in as frequently and we used to and there is a noticeable decline in our invitations out. If you don't ask somebody back they don't ask you out. It's very hard for her to adjust. When*

*I am with her I try harder but sometimes to be frank you don't give a damn and think how long is this going to go on."*

Tom8: *"Sara is determined to proceed down the path as defined by the medical world. As far as her belief or attitude to the spiritual side, she had condemned herself to a path of prediction which is normal for the medical side. I personally don't believe that. I think you can overcome things to a large degree. I view life as a field trip and you are given the opportunity to understand your spiritual side and grow and work with it and Sara had rejected that. Her view is that I am living with the dead and she is living here and now and that I am negating some of life and it's a strong resentment for her. I think that with a lot of these things you can plateau and normalize with limitations, but I don't think Sara will achieve that and it's bloody disappointing."*

In these illustrations, the growing dependency of the COPD partner can be seen as her inability to perform tasks and carry out roles increased. This changed the way in which the couple could share together. The COPD was seen as a threat to the relationship and to the COPD partner's life. This in turn threatened the well partner because his wife could no longer fulfil the roles and consequently his needs and expectations within the relationship. The well partner responded to the treats in an attempt to restore or maintain some balance in the relationship. Tom did this by attempting to control the disease and his partner's approach to handling the disease. The inability to control his spouse and the unsuccessful attempt at controlling the disease lead to feelings of anger, frustration and disappointment. These emotions increased conflict between the partners and the well partner was left feeling powerless and threatened.



### Conflict and Congruence in External Features of the Marriage

The way in which a partner responds to their unmet needs and the effectiveness of their response will influence the degree of conflict or congruence experienced by marital partners. The conflict or congruencies that result from affective, cognitive or behavioural responses manifest themselves in the external features of the marital relationship, including role division, communication, money, values, friends, interests and lifestyle.

Spouses whose needs and expectations were not met in their marriage and experienced higher levels of conflict in their relationship often assessed their marriage as fair or tolerable. Those informants whose needs were generally met or had adapted to unmet needs and had more congruence in their relationship generally evaluated their marriage as good although not perfect. These dynamics within a couple's relationship served to define a style of marriage developed by the couple that reflected their personalities and psychological make-up.

LEE<sub>3</sub>: *"We were all brought up that love and marriage is....but as you get older perhaps you need more things or see more things, you expect more things and it isn't there. Well many people just walk away from it, but others say well you just carry on and the older you get it's just, there's that situation and you make the best of it. Whatever, you can't change it. You gradually accept that fact. You look back with fond memories. If you haven't got something now your not going to make an issue out of it."*

Will<sub>3</sub>: *"Well I guess it's fair. I guess."*

Mary<sub>7</sub>: *"I would say its been a very good marriage. My son thinks we have a wonderful marriage and that's because we do. We like doing so much of the same things. Our interests are similar. Well they are and they aren't."*

## MARRIAGE STYLES

In this study, there was a wide variation in the nature and dynamics of couples' marriages and their relationships. Each marriage could be described as having a unique flavour that reflected the personalities of the individuals within the marriage. However, several components of the marriage were consistently discussed by informants that helped to describe their marital system. These included communication, role division, sexuality, finances, beliefs and values, interests, companionship and togetherness. The way in which couples lived out these aspects of their marriage indicated or described a type or style of marriage that the couple had developed between them.

The couples were grouped into three broad categories of marriage styles that were developed on the basis of the above components. Three of the aspects (sexuality, role division and companionship) were emphasized the most by informants and were predominantly used by the researcher to define the styles. By using these features to define the styles, some of the observed dynamics and effects of the lung condition were more easily described. Three marriage styles were identified: 1) traditional 2) shared and 3) companionship.

Most of the marriages described by informants did not fit precisely into one style or another. Rather, the marriages appeared to fall along a continuum of marriage style that ranged from traditional to shared. The companionship style appeared to be a subset of the traditional and shared styles.

### The Traditional Marriage Style

Traditional marriages were defined by traditional role divisions and rigid role boundaries. In these marriages the husband was the provider and the wife the homemaker who was in charge of housework and raising the family. Housework included organizing the social calendar and managing household activities. As a homemaker, the wife was more likely to take on the role of nurturer and caregiver. The level of sharing was often lower in these types of marriages. However, companionship and intimacy were still valued. Sexuality was considered important in this type of marriage. The following excerpt illustrates this style of marriage.

PAULA<sub>5</sub>: *"He has hired a cleaning lady but that was probably selfish. He doesn't like the way I keep house. He wants it immaculate. But I'm not that way, digging around in the dust bothers me. I think we have a good relationship with the kids, but he doesn't do a lot of the nurturing. I find I have to do my volunteer work. I need that. I think it's really important to me, but I can't do that and run my kids everywhere they need because he's not that involved. He comes home when he's finished his work."*

### The Shared Marriage Style

The role division and responsibilities were shared by partners in this style. The spouses tended to help or had helped each other out in most aspects of their marriage. The role boundaries were more flexible and there was generally a high level of intimacy, companionship and togetherness in the relationship. Sexuality was also generally considered to be an important aspect in this style of marriage. The following excerpt for an interview with Betty helps to illustrate this style.

Betty<sub>4</sub>: *"Since I'm out working permanently he'll just pitch in. He always has. He's always been that type of husband. He'll automatically pitch in. He'll cook and clean up when I'm away with some of the office work. He has a small business that he still runs."*

Despite the shared nature of this type of marriage, women still seemed to take a leadership role in the home, coordinating and taking on the responsibility of running the home as well as assuming added responsibilities such as employment and caring for the ill partner.

KEN<sub>4</sub>: *"When we were first married we were both working. Betty was working at a good job. I was working and we finally got two kids six years later and she took time off for awhile. But she's always been the glue that holds the works together as far as I'm concerned. I don't think that's changed over the years because I've become more useless than I used to and just because I'm older. Maybe I'm too damn old."*

#### The Companionship Marriage Style

The companionship style of marriage could be either traditional or shared in terms of role division. Companionship was valued highly although the level of intimacy and togetherness appeared to vary. Sexuality was not highly valued and was dominated by the importance of companionship. Those couples who had companionship style marriages tended to be older, in second or third marriages, had a higher degree of illness affecting the relationship or had marital problems in the past. This style of marriage is illustrated in the excerpt from an interview with Wendy.

WENDY<sub>2</sub>: *"I would say our marriage is comfortable. We've been in separate beds for three years now and that's on account of my*

arthritis. He's very quiet. We're sort of two different personalities and I'm the one to be talking all the time. But sometimes I want to be left alone so it works out alright 'cause he's very, very quiet and I have a TV in my room and I can go in there and watch the soaps. He has to do more around the house now on account of my arthritis so he gets the meals. And he's retired and he'd sooner get the meals than do wood work. He's that type."

Table 8: Groupings of Couples According to Marital Style: Relationship to Marital Issues

Couple	Severity	Marital Style <sup>a</sup>	Elements of Style				Marital Issues <sup>c</sup>		
			Role Relationship <sup>b</sup>	Companionship <sup>b</sup>	Sharing	Import of sex <sup>c</sup>	Marital Problems	Needs met	Satisfaction
GAIL/Eric	1	T	T	H	L	1	1	2	1
PAULA/Greg	2	T	T	M	M	1	1	2	2
GARTH/Ulla	3	T	T	H	H	1	2	1	1
SARA/Tom	3	T	T	M	L	1	1	2	2
GRANT/Leonna	4	T	T	H	L	1	1	2	2
EVAN/Susie	3	T	T	H	H	1	2	1	1
KEN/Betty	2	S	S	H	H	1	2	1	1
MIKE/Mary	3	S	S	H	H	1	2	1	1
PHIL/KAREN	3/3	S	S	H	H	1	2	1	1
JEAN/Peter	3	S	S	H	M	1	1	2	2
JACK/Dora	4	S	S	H	H	2	2	1	1
WENDY/Matt	2	C <sub>s</sub>	S	H	H	2	1	2	2
LEE/Will	2	C <sub>t</sub>	T	M	L	2	1	2	2
BOB/Rena	4	C <sub>s</sub>	S	H	H	2	2	1	1

a. T = Traditional  
S = Shared  
C = Companionship

b. H = High  
M = Medium  
L = Low

c. 1 = Yes  
2 = No

The grouping of couples into the three styles is shown in Table 8. The presence of conflict and dissatisfaction varied among the marriage styles. Couples with traditional or companionship style marriages were more likely to experience conflict and dissatisfaction in their

relationship. These couples often described unmet needs and expectations in their marriage. The couples with shared marriage styles expressed the most satisfaction and least degree of conflict or problems within their relationships.

#### THE IMPACT OF COPD ON THE MARRIAGE

COPD impacted the marriage on two levels; a functional level and a relational level. Both levels were part of the marital system that couples had developed. The functional level included the areas described in Chapter 4, such as leisure activity, sexuality and household activities. COPD restricted these aspects of the marriage, resulting in problems for the couple. The relational level included psychological aspects of the marriage, such as the feelings couples had for each other, their attitudes, reactions and behaviours to one another, and individual personalities.

There appeared to be a relationship between the functional and relational levels of the marriage. As already noted, the COPD directly affected the tasks which were performed by partners within the marriage, resulting in greater awareness of these effects. The inability to carry out functional activities in the marriage changed the way in which couples could participate in the relational aspects of the marriage and express their intimacy. Because COPD usually affected the relational level indirectly, informants were less aware of effects at this level. COPD, however, could directly affect the relational level by impacting the ability of the COPD partner to communicate because of lack of oxygen, or

by affecting changes in cognitive, affective or behavioural functions of the COPD partner, also because of a lack of oxygen. The direct effects at the relational level were alluded to only by a few informants because these effects are more likely to occur in later stages of illness and this type of patient was under-represented in this study. The relational aspects of the marriage could influence the functional areas. For example, care, love and support from a well spouse may provide encouragement for an ill spouse to continue to work at maintaining physical and mental activity and this in turn was considered important for the maintenance of the ability to perform functional tasks.

Betty<sub>4</sub>: *"When I was working he would sort of go into a slump. Do a little work or something but I'd come home and find him asleep in the middle of the day. I guess with my being there I encourage him to be more active. He's more inclined to do things on his own 'cause I'm around. But I think it's communication and having someone to talk to."*

#### Strengthening and Weakening Effects of COPD on the Marriage

The lung condition was seen to have both a positive and strengthening, and a negative and weakening effect on the marriage relationship. Most informants felt that marriage was normally a balance between strengths and weaknesses and that the effects of COPD on the relationship were also a balance between positive and negative effects. The effects of COPD were considered to be predominantly weakening at the functional level of the marriage, but both strengthening and weakening at the relational level of the marriage.

Ulla<sub>6</sub>: *"You need the support of the person. You protect them to no end. It's strengthened. You try to really understand how they feel. You sort of protect them from the outside world so it possibly does strengthen but then it kind of weakens it too, because of just the little incidents in life and physical relationships. There's a change in the relationship. It's weakened it on one hand and strengthened it. There are two different weights there."*

COPD strengthened the relationship between partners by increasing the partner's appreciation and acceptance of each other, and by causing them to no longer take each other for granted. Strengthening of the relationship developed by a process of sharing, helping each other, working and spending time together, and trying to understand each other. For instance:

GRANT<sub>12</sub>: *"Well I think that you respond to concern. In reflection you think back to how your wife has accepted and helped you and you are more appreciative. I think that helps solidify the relationship. I think we do more things together. I think that sort of deepened our relationship. It has strengthened it or held it together."*

The restrictions and physical disability caused by COPD were considered to weaken the marriage. As noted in Chapter 4 restrictions affected the ability to carry out functional tasks. This in turn could cause tension and strain within the relationship. Some informants felt a sense of incompleteness about their marriage as they could no longer be together with their partner in the way they desired and they also experienced an inequality in their sharing. The lung condition made it difficult for partners to be intimate with one another and couples experienced a feeling of growing separation. Partners frequently felt that



their relationship if not presently, would ultimately be threatened by separation due to death.

A few partners described how they sometimes found themselves developing priorities and plans different from their partner. This apparently was due to the fact that the lung condition influenced the partners in different ways. This is exemplified by the excerpt from the interview with Ulla. The changes that occur in the ill partner may cause partners to respond differently to one another. Many of these changes, plus the threats created by COPD, and the strain and undesirable psychological responses, such as fear and anxiety, were seen to be the weakening effects of COPD.

Susie<sub>13</sub>: *"I don't think it's changed that much it's just that I don't find it obnoxious or abhorrent. It's just that it's there. We never were that lovey dovey but you're just not.... you've got all this stuff hanging around and the whole shmeal."*

Dora<sub>14</sub>: *"I think he's gradually getting worse 'cause he seems to be relying on the oxygen more. I'm glad he's got it. He may not be here if he didn't."*

Ulla<sub>6</sub>: *"We've certainly had sometimes when there are frustrations. Thinking down the same paths and its gets frustrating for me. 'Cause I don't know what I'm believing when we plan trips. I've probably got other things that are first priority now. There's lots of little things that come up. I'll be wanting to do some situations and it's not the time for him. It's just a little more difficult and you hope for more positives. Any two people are not always planning down the same path. I guess priorities and pressures are sort of different. You can't be as open. Garth's not the same as he used to be because of his asthma and I'm not the same in the way I react because of the asthma. They're not ...well you don't treat them the same."*

## Togetherhness

A couple's sense of togetherhness was an area where informants saw the lung condition to be both strengthening and weakening. The idea of togetherhness meant the feeling of belonging together which couples achieved by sharing in activities, tasks or feelings. The lung condition affected a couple's togetherhness by both increasing and decreasing the way and time that they spent together.

A couple's togetherhness became more centred around the lung condition. The lung condition may have forced retirement and this resulted in a couple spending more time together. As well, as the lung condition increased in severity, couples spent more time together involved in the ill partner's therapy. Couples who had supportive relationships and spent time together working on the lung problem saw the lung condition as increasing their togetherhness and strengthening them.

Ulla<sub>6</sub>: *"You deal with each thing you've got planned. You have to solve things of value. You don't just sit there and watch. We both agree that's not what life is. We do things together and we enjoy them. Some couples kind of walk past one another. We always plan together. Hopefully we remember each other so we don't have conflicts but we plan to do certain things together. He retired early so he has more independence. He's got lots of outlets which are good. He just goes off and does his thing and when your tired you tend to be more together. So when he's feeling not all that well, well just try and do things that you can do comfortably."*

Betty<sub>4</sub>: *"I can't say that its proven a rift at all. If anything its brought us closer together. 'Cause we naturally have fought together. Its brought us closer emotionally because we care what happens to either of us. Its not a negative thing for us."*

While more time was spent together focusing on the lung problem, less time was spent together on activities that the couple used to do together which had increased their sense of togetherness. Despite the lack of being able to do these things together, some informants still valued the presence of their spouse and the companionship in terms of just having someone there, someone to talk to. Some togetherness was better than none at all. However, the lack of togetherness and increasing sense of separation was a source of conflict or tension and anxiety in a couple's relationship. In this way the lung condition was seen as decreasing a couple's togetherness.

Greg<sub>5</sub>: *"It inhibited the lifestyle we enjoyed. For example, going out and having a bottle of wine. Can't do that any more. Or going out and going hiking. Can't do that. That really got to me."*

Leonna<sub>12</sub>: *"We don't spent a lot of time together. He lies down a lot. We don't spend much time together. We watch T.V. together, but that's about all we do together. for instance if there is a hockey game we watch the game and sort of talk about it. It's nice to have someone to talk to when you feel like talking, whether he's lying down or not I can still go talk to him. I don't suppose we have a lot of companionship any more but he is here."*

JEAN<sub>10</sub>: *"I'm up and down and up and down all night. Well he needs his sleep. He has to work in the morning. He gets frustrated. He gets upset and we end up in an argument. Well maybe we should have separate beds. You know and I don't want that. I think what's the point of being married if you can't sleep together so there is an ongoing animosity there."*

A sense of togetherness was an important part of a couple's marital relationship. For several informants, togetherness and feelings of belonging came from a familiarity and understanding of each other. The togetherness provided a sense of comfort, support and security for the ill

spouse. For the well spouse togetherness helped reduce worry and concern for the ill spouse.

#### FACTORS THAT MODIFY THE EFFECTS OF COPD

##### Supportive and Non-Supportive Relationships

Whether or not COPD was perceived to strengthen or weaken a relationship depended on the nature of the couple's relationship. The coping skills that a couple used in their marriage were also reflected in the way the couple dealt with the lung condition.

Marital relationships can be divided into two types: one that is supportive, that is, caring, loving, and close, with low spousal criticism and one that is non-supportive, that is, more critical, and less intimate. Those couples in a relationship that was supportive seemed to be better able to accommodate the impact of the effects of COPD at both functional and relational levels, and to more readily accept and incorporate the condition into their lifestyle. This type of relationship seemed to transcend the lung problem and was strengthened by it. Couples in a non-supportive relationship seemed to be weakened under the strain and struggles associated with the lung condition.

**Supportive Relationships.** Informants in a supportive relationship described the bond they had with their partner in terms of feelings of love and affection, regard, admiration, trust, caring, compassion, empathy and understanding. These couples took the time to show their affection and love for each other. Their feelings were felt to come from a process of learning to know and understand one another which resulted in an

acceptance of one another and consequently an acceptance of the presence of the illness in the COPD partner. Closeness was considered an important factor in keeping the marriage together.

PHIL<sub>9</sub>: *"I guess I love her more than I ever did. She's just a great person and a great organizer and totally unselfish, about the nicest human being I know I guess."*

KAREN<sub>9</sub>: *"I've been with him for 28 years and I wouldn't change it. I love him more than when I first married him. He's a great guy. He's wonderful. I love him."*

JEAN<sub>10</sub>: *"Marriage is the bonding, the caring and sharing. I think we're starting to realize there is more to life. It means more. Sometimes I think where would I be now if I didn't have him. I'd be worse off, maybe dead."*

Good communication was an important factor in the development of this kind of relationship as it appeared to facilitate an openness and a sharing between partners. This type of relationship seemed to help create a sense of physical and psychological well-being for the partners and create a relaxed supportive environment which provided spouses with the autonomy to change and develop in response to the illness. Partners changed not only because of the illness but also because they interacted with each other on an emotional and behavioural level as they adjusted to the influences of the COPD.

While a supportive relationship may become less physically intimate due to the lung condition, the bond of sharing, caring and commitment and love remained strong. Sometimes it appeared that simply the presence of a well spouse was important emotionally for the ill spouse. The presence of the well spouse appeared to have a calming and reassuring effect on the COPD spouse. Likewise, the presence of the ill spouse appeared to be

important for the well partner. Ill partners could provide compassion and support for the well spouse as the well spouses struggled to deal with their own responses and changes to the lung condition and their ill partner.

Mary<sub>7</sub>: *"I think that a lot of the time Mike has really struggled to keep breathing for my benefit. He'd have given up along time ago if it had just been himself."*

Susie<sub>13</sub>: *"Its a companionship and closeness with two people and a putting up with one another for a long time, with one another's foibles and a closeness. I know when I'm not there Evan finds it hard. Not because he doesn't cook but because it's lonely. It's lonely with out someone so its nice to have their companionship."*

JACK<sub>14</sub>: *"You have to keep going, but you need your partner there to help out and you have to help your wife because she's going through a change too. She's watching on me the same time I'm watching on her to see if there is any change with her regarding my condition."*

In supportive relationships consideration for a spouse was regarded as important. Consideration extended from the love and care that partners had for each other to the well partner including their ill partner in plans and decision making. Consideration also involved recognizing the difficulties experienced by the ill spouse, and sensitivity to that person's needs and feelings. This required that the well spouse be aware of the lung condition and often required changes in lifestyle.

The COPD spouse could also take the well spouse into consideration through awareness of the well spouse's needs, feelings, changes and problems that they experience with regard to the COPD. The inclusion of the well spouse in their illness experience and decisions was considered

an important aspect of consideration. In addition, the ill spouse could take the well spouse's healthiness into consideration and encourage them to carry on with other activities.

GARTH<sub>6</sub>: *"Well I think she has to consider me more that she did before. She has to consider the social calender. She has to say yes or no to various things depending on where I am at on the impairment scale."*

Greg<sub>5</sub>: *"I have a great deal of sympathy for her and understanding. You don't try and go outside of the lifestyle you have established. You don't want to do that because the consequences are far worse than the enjoyment you have doing that."*

Non-Supportive Relationships. Couples in a non-supportive relationship also experienced love, strong feelings and bonding, but they appeared to be less supportive and more critical and conflicting. The well spouse in this type of relationship could be psychologically abusive and this did not encourage COPD spouses to change and grow. Instead, negative and undesirable feelings and behaviours could exist that would inhibit sharing and openness. In this kind of relationship there appeared to be a lack of trust, fear, feelings of insecurity and non-affirmation with regard to the ill partner's experiences. As well, changes that resulted from the lung condition appeared to be more threatening and increased feelings of fear and frustration. This caused the partners to respond with various psychological defenses, such as anger, blame, and denial, to protect themselves and to try and restore a balance within their relationship.

PAULA<sub>5</sub>: *"He's demanding and he recognizes that, but he's not easy to live with, because he's demanding. I feel in some way he's a bit of an emotional abuser. I have to be careful how he handles me. How I feel about him? Pick a day. It depends on the state I'm in how I am feeling. I can be really angry at him and I find I'm running him down. I love my husband but I feel he's been immature in our marriage. I think he respects me. I know he loves me and I don't think he's mad at me because I'm not healthy but he'd rather it not be there. I don't think it's that bad but it does keep you on your toes. I think that when my lung problem does interrupt it must make him frustrated but I don't blame him. But for my feelings, I try to carry all the load and try to make it so that it doesn't interrupt."*

COPD was more problematic for couples who had troubled relationships. The lung condition could exacerbate existing difficulties in a relationship. Feelings about the lung condition seemed to be intermingled with feelings about the marriage. Discontent and anger with regard to restrictions and impositions placed on the spouse because of the lung condition were interconnected with the feelings of discontentment about unmet needs and expectations of the marriage. Fears of the illness and of death could parallel fears of marriage breakdown.

Lee and Will provide an example of a couple in a non-supportive marriage, who experience problems coping with both their marital problems and the lung condition. Lee and Will tended to use denial mechanisms to deal with both the lung condition and issues and problems in their marriage. They had difficulty communicating their feelings about the lung condition or discussing problems of their marriage. When they talked about issues related either to COPD or their marriage they did so in very concrete functional terms. The following responses from Lee and Will illustrate their dissatisfaction about the lung condition and their marriage.



- LEE<sub>3</sub>: "We didn't know each other well before we got married."
- Will<sub>3</sub>: "I saved her life. I took her out of the city and brought her to the farm in the clean air."
- LEE<sub>3</sub>: "Ya and I was sicker for the first 15 to 20 years of marriage."
- Will<sub>3</sub>: "Ya but it wasn't your breathing."
- LEE<sub>3</sub>: "We live two different lives. Now Will's a very independent person but I don't think that there's either one of us that has thought about separating or divorce."
- Will<sub>3</sub>: "As you get older you can't go around shopping any more. You might get rid of a used car and get hold of another one that's worse or just as bad if you look at it from that angle. I help out a lot. I think that without me things would go down hill pretty fast. There's lots of things to think about, repair work etcetera."
- LEE<sub>3</sub>: "Well repair work! Well that's house repairs, mechanical repairs, not human repairs!"

Supportive relationship appeared to be better able to buffer the impact of the effects of COPD than non-supportive relationships. Couples in supportive relationships had developed coping skills and qualities such as, love, acceptance, and effective communication which helped them to manage changes and crises arising from the lung condition and to incorporate the lung condition into their lifestyle. This is illustrated by responses from Jack and Susie:

- JACK<sub>14</sub>: "The lung condition hasn't put a strain on us. We are just going out and doing everything we can and by God we have! We realize that I have a problem and we have incorporated it into our lifestyle, but, I don't think there has been much of a change between us. If there has I haven't noticed it."
- Susie<sub>13</sub>: "The lung condition is a gradual thing and it just comes along and once you get used to being on oxygen and the conditions

*that carries with it, you just live with it. You're used to it and it isn't like having major surgery or things like that happened. This is ongoing and its gradual and there's lots of sickness involved."*

As Susie stated, the lung condition carried with it conditions that required continual adaptation, such as the use of oxygen or the problem of incontinence. Marriages with non-supportive relationship had difficulty managing these problems. These marriages continued to storehouse, that is, accumulate unresolved problems, rather than deal with them. The problems would accumulate until some maximum tolerance point was reached, at which a crisis within the relationship would occur which brought about change, be it positive or negative. Figure 1 illustrates this idea of marital buffering capacity by the different relationship types.

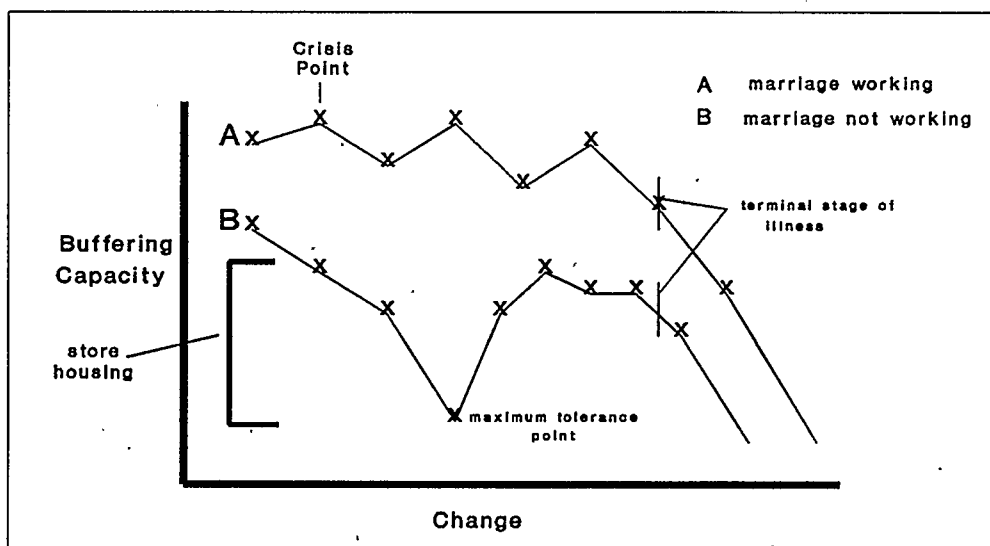


Figure 1. Marriage Buffering Capacity

## MOVEMENT OF MARRIAGE THROUGH DIFFERENT STYLES

As the lung condition became more intrusive in the area of functional tasks, couples were faced with the need to reorganize the structural arrangement of their marriage and move into a more shared marital arrangement. This could be difficult in a traditional marriage because of the more rigid and well-defined role boundaries, and particularly so if there is little intimacy and communications in the marriage. Traditional relationships could cope effectively with the impact of the lung condition if the partners had a supportive relationship or the COPD spouse was male. The traditional marriage with a COPD wife appeared to have the most trouble with adjustment to COPD, because males in traditional roles appeared to be less willing to share their wife's role and modify their lifestyles.

The movement of a traditional style marriage into a shared type of marriage could be facilitated by good communication between partners and a supportive relationship. Both traditional or shared marriages could gradually move into a companionship style. The movement to a companionship style occurred mostly when the illness became severe. Companionship styles were less likely to work if the role divisions remained rigid, the female spouse was ill, or the severity of illness increased. An increase in severity of illness would eventually impact all the marriages regardless of style. The illness would intrude so much that the well partners who provided care would eventually reach a point where they could no longer support the ill partner. This would most likely occur at endstages of the illness, as shown in Figure 1.

## COMMUNICATION: ANOTHER MODIFYING FACTOR IN RELATIONSHIPS

Communication appeared to be an important determinant of adaptation to the effects of COPD. Effective communication between couples was more commonly associated with successful responses by couples to the influences of COPD, including the view that the lung condition did not affect the relationship. This applied to slightly more than half of the couples. Couples who communicated effectively considered this to be a strength in their relationship. It reduced frustration and increased happiness between partners. Effective communication facilitated a greater understanding of the lung condition and enabled couples to discuss and talk about their feelings and problems in relation to the lung problem. It helped them to make decisions, resolve problems and work together.

PHIL<sub>9</sub>: *"We've always been able to communicate fairly well I think. She does most of the talking but if there is something I need to say I don't hesitate to say it. She's pretty smart actually. She's very sensitive. Much more so than I. She'll pick up things that I with out saying anything and she'll start saying things like something's bothering me and try to find out what it is and correct it if she can."*

Slightly less than half of the couples tended to have ineffective communication. This included argumentative and destructive types of discussions and difficulties in communicating thoughts, feelings or ideas. Ineffective communication was a barrier to understanding the effects of COPD on the partner and to developing a positive marital relationship. Couples had difficulties discussing unresolved problems and their unmet

needs and thus experienced a higher level of dissatisfaction in their marriage. Couples with poor communication saw this as a weakness in their relationships. Communication difficulties were more likely to occur in traditional or companionship styles of marriage.

PAULA<sub>5</sub>: *"I can't talk to him but I keep hoping that I will be able to. But as soon as I start to talk about the asthma he immediately has a look (makes a facial expression) like I don't want to hear this. We've always had trouble communicating about finances. I get on the defensive because of the way he approaches it. Because when he has a problem with his staff he sits down and talks with them and that's why they all like him but when it comes to us and I think the boys would express the same because there's not a lot of communication about feelings and all kinds of things with Greg."*

The lung condition also directly affected communication for some informants. Some people with COPD found it difficult to communicate when short of breath or under stress. The lack of breath could make it difficult to talk generally or to communicate about emotional or stressful subjects which would feed back into the dyspnea spiral, making the breathing more difficult and communication worse. Thus, the COPD itself affected the quality of communication between a couple.

JACK<sub>14</sub>: *"Dora always tells me hey cool it and I've got a gravelly voice when I talk and it seems when I am getting low on oxygen, my voice is going higher and for talking I am trying to push the words out and I'm yelling and I don't realize I'm doing this."*

Ulla<sub>6</sub>: *"There is no sense in trying to communicate with a person under extreme stress. If they had the ability to talk to you that would be okay but when they can't breath they really haven't the energy to try and talk to you"*

## SUMMARY

The type of marriage and relationship between partners influenced their perceptions of the impact of the lung condition on their relationship and marriage. Informants' perceptions of their marriage were related to their expectations of marriage which in turn reflected their individual needs and desires in respect to marriage. The extent to which spouses' needs and desired were met was manifest in the conflicts or the congruency exhibited in a couple's marriage. The conflicts and congruencies could be seen, for example, in a couple's communication pattern, role division and level of togetherness. Although each couple's marital organization was unique to some degree, different marital styles were apparent, namely, traditional, shared and companionship. As the COPD continued to intrude on the marriage couple's were forced to reorganize their marital structure. This could involve the movement into a different marital style. The COPD was seen to affect the marriage at both functional and relational levels. The extent to which informants perceived the COPD to impact their marriage at these two levels was modified by the quality of a couple's relationship and their ability to communicate with each other. These qualities could facilitate marital changes and adaptation to the COPD and determined the level of satisfaction and happiness within a marriage. Satisfaction and marital congruency was most commonly observed in the shared marriage style. These marriages showed higher levels of support, companionship, sharing and togetherness and appeared to facilitate adaptation to the lung condition. Adaptation involved the incorporation of the illness into a couple's lifestyle and marital

organization. The strategies that informants use to respond to the changes in their marriage s a result of COPD are described in Chapter 6.

## CHAPTER 6

### THE PROCESS OF CHANGE AND MANAGEMENT STRATEGIES AS RESPONSES TO THE EFFECTS OF COPD

This chapter describes the change process created by COPD and informants' reactions to the changes and to the effects of COPD. Informants described the insidious, progressive course of COPD that created a change process which impacted their lives. The slow changes appeared to be part of the problem of COPD because informants were not always aware of the changes. Consequently, they did not react to them or they were not always aware of their reactions because the reactions themselves were subtle and gradual.

Management strategies of a functional, psychological, social and spiritual nature that informants used to cope with the changes in their lives and marriages are also described in this chapter. Many informants used these strategies in a holistic approach to management. The description of informants' responses and their management strategies provide a better understanding of the impact of COPD on their marriage.



## THE PROCESS OF CHANGE

The extent of change that resulted from COPD occurred along a continuum from no change to high levels of change. The extent of change was associated with the degree of severity of the illness. The changes in early stages of the disease, were slower, short term, temporary and reversible, while changes in later stages were more invasive, long term, permanent and irreversible. The extent to which changes were seen to invade informants' lives depended on the significance and importance they placed on the changes and subsequent outcomes of those changes.

Changes could also be considered positive or negative. Negative change involved changes that threatened informants, created conflict in their marriage and generally weakened their relationship. Positive changes were changes that produced growth and development in informants' lives as well as strength and maturity in their marital relationship.

Leonna<sub>12</sub>: *"Its probably not too bad to adjust to. As I say it's hard to know 'cause as I say these things happen so gradually and you just don't remember what it was like before. It surprises you when you realize how things have changed."*

## RESPONSE TO CHANGE

Informants could react consciously or unconsciously to change. A conscious response implies an attempt to deal with change and to achieve a positive outcome. Such a response reflects an attempt to maintain or achieve a level of homeostasis within informants' lives. That is, it

attempts to halt or slow the change process and to return to previous activity levels or lifestyle patterns.

SARA<sub>8</sub>: *"I think exercise in particular, that if I don't keep that up, I'm going to deteriorate quite quickly. I try to meditate and in some way that helps. I try to do positive imaging about my lungs. It all sounds idealistic and I'm not always successful in these things but you know this is what I try to do. I feel rather determined that it's not going to get worse at least. Hopefully."*

The response to change involved an adaptation and modification of informants' behaviour patterns to accommodate the COPD and integrate it into their lifestyles. Both temporary and long term modifications could be made depending on whether the changes were temporary or long-term. Informants' ability to modify and adapt to change was influenced by their attitudes, personality and personal skills and inner resources (e.g., problem solving and decision making skills). The excerpts from Jack's and Leonna's interviews illustrate different attitudes which influenced the approach to coping with the lung condition.

JACK<sub>14</sub>: *"Anytime I have a problem I have to assess it. I am restricted so I have to experiment. And what I did to work under my truck and my car, I built a skidder so that I can get underneath. And I have to use jacks to jack it up and I block and I can slide all underneath so it keeps me going."*

Leonna<sub>12</sub>: *"I believe there is somebody guiding us all the time. We don't have a choice in how we live our life."*

### Choice and Control Issues

Most informants acknowledged that they had no choice over the presence of their lung condition because the damage to their lungs was permanent and irreversible. Consequently, to incorporate it into their lives informants felt they must learn to live within certain parameters defined by the disease and their perceptions of it if they did not want to suffer severe consequences that could be life threatening.

GARTH<sub>6</sub>: *"You're always dealing with it. I don't think you worry about it. It's just like approaching old age it's there. You deal with it. I think it's like any illness you automatically deal with it. It's that or die or become depressed."*

Rena<sub>11</sub>: *"Well he copes with it or tries to cope with it by doing things that are supposed to help him breath or help like you know swimming every other day or doing his breathing exercises. He copes with it because it's a necessity. You don't have a choice. So you do what you can or he does what he can."*

MIKE<sub>7</sub>: *"If I do all the things I need to I've got a pretty comfortable living, if I don't I struggle."*

Although informants agreed that they had no choice over the presence of the lung condition, their opinions varied as to their influence on the effects of the lung condition. Some informants felt powerless and a lack of mastery or control over the effects of the lung condition, that is, either to overcome or reduce the effects. The lung condition seemed to take over their lives.

JEAN<sub>10</sub>: *"Its very, very depressing because you don't feel that you have control it seems to take over."*

Other informants displayed a greater perceived control or mastery over the effects of the lung condition. These informants felt that they could make alternative choices to manage the effects.

Ulla<sub>6</sub>: *"You have to change some of the things you do because one week you can go out and dance , another week you can't. We've had to change our lives in an emotional capacity. You just have to alter."*

The difference in perceptions of control and mastery over the effects of the lung condition seemed to reflect informants' perceptions of the extent to which the lung condition controlled their lives. Informants who saw the lung condition as a predominant controlling force in their life tended to submit to the disease. These informants were more likely to feel defeated, powerless and helpless. Informants who perceived the lung condition in this way had difficulty coping with it. These informants tended to have a non-acceptance of the disease. That is, they were more likely to engage in unrealistic thinking, such as wishing that the lung condition was not there or use such ineffective strategies of avoidance or denial as mechanisms to deal with the lung condition. These types of reactions tended to be counter-productive to the management of the lung condition because they further perpetuated feelings of frustration and helplessness that in turn could feed back into the dyspnea spiral and worsen the lung condition.

Other informants did not see the lung condition as predominately controlling their lives but rather as one of many factors that influenced their lives. These informants accepted the lung condition and saw it as

an element of life to be integrated into their lifestyle and marital system. The management strategies these informants used facilitated more effective coping with the lung condition. The following two excerpts illustrate the differing perceptions of the controlling influence of the disease.

Leonna<sub>12</sub>: *"I think Grant would like it if I would be more sympathetic. I think he resents the fact that I'm not. I can be almost cold, but I just can't help it. I don't like it but I can't help it. You can't change. You can try but you really can't change. I go my own way. I wish things were different, don't get me wrong but you can't change it so you go along the best you can. I've always been a stubborn independent broad. I'm worse than that. I'm more independent than I used to be. I just don't ask for help. It's probably that I'm not quite willing to face facts. But I have to. I probably don't dwell on the fact that there is an illness. I think that's my way of coping. I don't face it. I just try and go on and let him fend for himself."*

PHIL<sub>9</sub>: *"The lung condition is not something you can cure, but most other things that come up are something you can deal with and there's either a solution to the problem or like the lung condition, if it's not a problem and there no cure for it, it becomes a fact you have to live with. I think that everything in your life is controlled by your basic attitudes to life. Certainly your general attitude controls how you handle any given situation. That's the way I think anyway."*

The difference in the extent to which COPD was seen as controlling also reflected a difference in informants' personalities, inner resources and personal skills. Those informants who had a higher sense of self-efficacy, self-esteem, knowledge, awareness and effective problem solving skills, were more likely to have a higher sense of mastery over the lung condition and were more able to effectively respond to and manage the lung condition.

The process of change in informants' lives and marital relationships could in itself create the need for individuals to develop their inner resources. The need to respond to changes may cause individuals to seek help and develop their inner resources so that they can deal with the lung condition more effectively.

JEAN<sub>10</sub>: *"I think that going to the program has given me an understanding of my disease and has helped me cope. It changed my understanding."*

MIKE<sub>7</sub>: *"You've got to talk with each other to learn what the other guy is doing. It's finding out."*

#### NORMALIZATION

COPD informants talked about wanting to be normal or to do normal activities in their lives and their relationships. They attempted to achieve some level of normality by compensating for the losses they have experienced and by achieving a sense of mastery over the effects of the lung condition.

Int: *"What is important to you in terms of your illness and your relationship with your wife?"*

GRANT<sub>12</sub>: *"Being a normal person again. In that.... well just acting like whatever the word normal is supposed to represent. That you could get out and enjoy a breath of fresh air. You could get out and meet people and with me get in the car and go to Kananaskis and see if I could see some nice picture possibilities."*

An effort was made to halt or counteract changes by making a change which would return their life to a level that they considered normal or by

creating a different level of normal living. For instance, if informants perceived they could no longer function in one activity that they considered normal then they might substitute it with activity that they also perceived to be normal. As the illness progressed on a downward course, informants created or attempted to maintain new levels of what they perceived to be a normal lifestyle. The movement from highly physical activities to more sedentary activities is an example of this.

SARAg: *"I'm looking down the road and thinking well I sure can't play tennis but its very important to see people and keep active and to get out and not cut yourself off. And I look down the road to those things I will always be able to do. I can always sit at a bridge table. I can paint."*

As the ill partner progressed downward, the well partner may or may not choose to make changes to accommodate their ill partner and to close the widening separation between them. The well partner had a choice to move between two levels of lifestyle dictated by their well health and their partner's ill health (see Figure 2).

In addition to changing activity patterns, informants tried to normalize changes by de-emphasizing the changes and attributing them to normal factors such as age, thereby minimizing the presence of the lung condition and the significance of the changes. For example, informants would consider symptoms such as lack of energy, difficulty in movement and sickness to be attributes of old age. Some considered the lung condition to be part of the aging process and thus was a normal occurrence. Since an increase in age meant an increase in the likelihood of acquiring an

illness, the lung condition was seen as just a part of life to be treated like other issues in life.

GARTH<sub>6</sub>: *"I can't do much in a day. I can accept a lot of that as old age, approaching old age. You aren't as energetic. Some days I'm not feeling well. My legs are aching 'cause of the seemingly lack of oxygen. I just have to go home and sleep in the afternoon. That's general with old folks."*

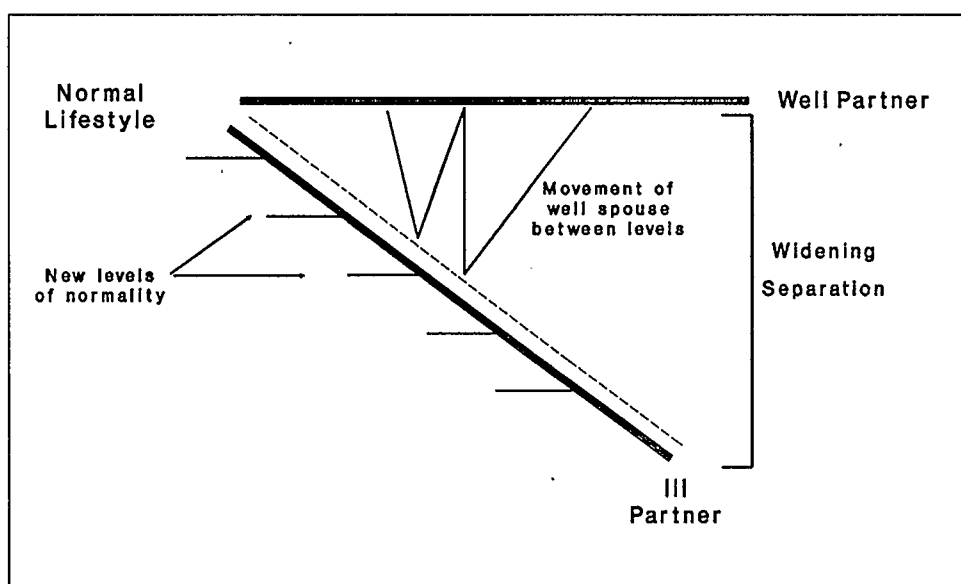


Figure 2. Normalization and Lifestyle Modification for Ill and Well Partners



## MANAGEMENT OF THE LUNG CONDITION

Management strategies were developed as responses to change and because the management of the lung condition became necessary in order for the COPD patient to survive. The lung condition was continually present and required continual management on a day to day or possibly hour to hour or minute by minute basis.

GARTH<sub>6</sub>:       *"You're always dealing with it."*

JEAN<sub>10</sub>:       *"People just don't realize the difficulties coping with it everyday. Day to day."*

The effective management of the lung condition required that informants address the lung condition, work with it and integrate it into their lives. To do this, couple's needed to seek information, understand the lung condition, acknowledge changes and effects of the lung condition, learn to know the limitations set by the illness and the impact the limitations had on a partner. The development of management strategies required experimentation and creativity on the part of informants.

JACK<sub>14</sub>:       *"Something I experimented with is I used to come down here to do my exercises and walk upstairs and pass out. I found an easier way, back up the stairs. Do you know why?"*

Int:           *"No!"*

JACK<sub>14</sub>:       *"Walking up you're bending forward and collapsing your lung and if you back up your perfectly straight!"*

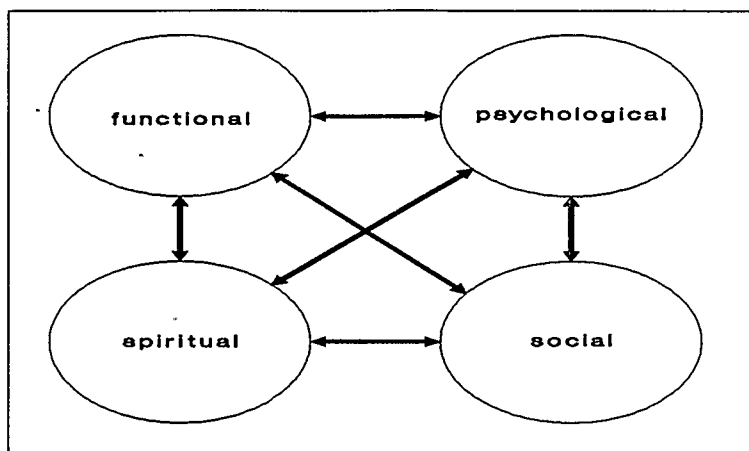


Figure 3. The Dimensions of Management

The COPD has been shown to affect couples' lives on various dimensions. Informants' management strategies responded to this variation by being varied themselves. Informants described their management strategies on functional, psychological, social and spiritual levels (see Figure 3). While some informants focused their management of the lung condition on a particular level (e.g., functional level), many informants approached the management of the lung condition holistically, integrating their management at all levels. Management at these different levels will be described in the remainder of this chapter.

#### Management of the Lung Condition at the Functional Level

The management of the lung condition at a functional level involved the reshaping of the functional tasks described in Chapter 4 and giving consideration to both the illness and lifestyle.

Management of illness. Because informants were aware that there were was little they could do in terms of disease control, they focused on symptom control. The management of symptoms would not change the lung condition but there was hope that the management would slow or arrest the disease process. The control of symptoms influenced the degree of restrictions the lung condition placed on informants' lives.

The management of symptoms included taking medications, following therapies, learning effective breathing techniques, watching diet, maintenance of activity through exercise, and improvement of the environment in which informants lived. The management of symptoms through these various strategies required knowledge and understanding of the symptoms. This included learning the pattern of their symptoms, such as duration, onset, triggers and consequences of the symptoms, loss of energy and emotional responses.

GARTH<sub>6</sub>: *"I really feel I have it under much better control now than then. I guess it is the different types of medications. My wife, many was the day she had to help me into my clothes and see me off out into the car and I would go to work."*

SARA<sub>8</sub>: *"I can tell when my oxygen's depleted. Its as simple as a sign of the hand. The blueness of your fingers or a little light headedness and sometimes in the shopping centre a little disorientation."*

The use of medications and therapies helped to bring breathing under control and to reduce the number of trips to the emergency department. Learning effective breathing techniques such as pursed lip breathing and diaphragmatic breathing was important. When informants learned the

correct way to breath they found it assisted them in relaxation and speeded the recovery from a dyspnea attack.

Informants managed changes in their functional activity and symptoms by watching their diet and exercising. Proper nutrition and avoiding excess weight around the abdomen were seen as important and helpful in the maintenance of good physical condition and symptom control. The maintenance of good physical condition was also achieved through exercise, which in turn improved breathing capacity. The exercise and efforts to control symptoms were integrated with life style patterns and incorporated into couple's leisure activities.

MIKE<sub>7</sub>: *"Cold air and wind affects my breathing. I get out like today I went walking and walked down in the park through the trees out of the wind, going through the trees and coming back with my back to the wind. I couldn't have walked into the wind. I've got an exercise bicycle. I try to ride it or go the shopping centre but one of the things I have found that I have an oxygen mask without oxygen. Just wear the mask and put the hose down inside my coat and just breath warm air. That makes a lot of difference. I did that the last two winters to get from my car and then to the shops. It worked quite well."*

The development of a controlled environment was important for symptom control and illness management. A controlled environment was perceived to be a more protective and safe environment for the COPD partner. Informants modified their environments so that they could regulate the elements that would affect their lungs, such as the level of humidity and exposure to triggers. This was achieved through the use of humidifiers, air cleaners on furnaces, air conditioning, the removal of carpets and avoidance of problem-causing substances in the house, such as cigarettes and oil paints. The creation of a safe environment helped

informants to maintain better symptom control which in turn allowed for better management of the lung condition.

MIKE<sub>7</sub>: *"Now I have an environment where I can molly coddle myself at home. It makes an awful lot of difference not havin' a lot of exposure."*

Greg<sub>5</sub>: *"We have things like air cleaners on the furnace cleaned on a regular basis. Tearing up carpets in certain parts of the house because of dust and lint. We have a house cleaner who comes in and keeps house up to speed. Windows are closed. The house is now fully air conditioned. I can't smoke in the house and I don't allow people to come into the house to smoke."*

**Lifestyle modification.** Several informants developed daily routines as a part of in their management strategy. This was more prominent among more severely ill informants who found their lives centred around their therapies. Not all informants lived with routines. Some preferred to have no routine. These informants were either less ill or tended to ignore their illness.

Time management was an important reason for the development of routines. It allowed therapies to be followed regularly and also assisted in the management of scarce energy. The development of routines involved the redesigning of lifestyles which were becoming limited and restricted by the lung condition because many activities required more time to carry out and informants found they had to rest in between activities. This meant they had to plan and structure daily activities. The organization of daily activities helped informants to accomplish valued activities, manage symptoms, as well as develop a lifestyle that was considered to

facilitate a more controlled environment in which to live with a lung condition.

JEAN<sub>10</sub>: *"I do exercise all the time and I do them three times a week so that takes me about an hour to do. So I have to get up in the morning and have my medications, breakfast then I do my exercises. By the time I shower its lunch time. So that's half my day gone already. There are some days when I can't get out of bed. I am just really zopped, completely exhausted so I just don't do it. And to do house work takes me all day cause I have to rest in between. Its very strenuous. You have to do time management type of things. You have to say okay I'll go to the dentist by not until one or two o'clock because I have to do this in the morning and I have to have my lunch and then a treatment before I go to the dentist."*

Informants' lifestyle modification involved a change in the pace at which they lived life. For example, Mike and Mary lived an active life but at a slower, more relaxed pace. The pace with which couples lived their lives (lifepace) appeared to reflect their attitudes, beliefs, personalities, level of acceptance of the lung condition and severity of the illness. The lung condition influenced the lifepace by forcing couples to slow down and relax because the ill person was more restricted and limited by their illness. The well spouse might slow down as well to keep pace with their ill partner. It was sometimes difficult for informants to distinguish between normal adjustments in life due to age and changes in lifepace due to the lung condition.

Mary<sub>7</sub>: *"We don't go out a lot. I don't know if we would if he didn't have the problem or not. It's changed our lives a little, a little slower paced than we probably would have although we're still pretty active. Part of the things we don't do are because we're getting older too. I don't make a lot of demands a fancy house or anything. I don't want one. So that didn't create any pressure financially. We try to have a*

*pretty ordered life, having our meals at the same time. Not exactly the same time just a fairly calm, relaxed atmosphere is what I try to keep as much as possible. I think it does help."*

Doing. A concept of doing was associated with lifepace. Doing meant keeping active through the maintenance of various functional or physical activities in relation to recreational, leisure, work, or household tasks. Keeping active was important whether the lifepace was slow or fast. Those informants who had a slower lifepace still saw activity as important and organized their lives and routines to include activity.

The purpose of doing appeared to be the management of the lung condition. Keeping active was considered by many informants to be a way to maintain a positive attitude toward life. The maintenance of activity was a source of encouragement and hope for many informants and provided with a sense of working on their problem. It kept people involved with life and sharing with others. Keeping active was considered healing and important for the body, mind and spirit.

GARTH<sub>6</sub>: *"You keep doing things to keep positive. Do as much as you can at the level you can do them."*

EVAN<sub>13</sub>: *"I don't want to sit around and feel sorry for myself. That's easy enough. You gotta work at it all the time, to keep busy so you don't sit around and feel sorry for yourself."*

Betty<sub>4</sub>: *"You've got to keep active. We've always felt that and do so as much as you can and you feel better and you keep that breathing going and just don't become a rocking chair person. It's important to get out and do things, see people, keep mentally active, then you feel better."*

**Overdoing.** Although activity was important, informants also described their concerns about being over-active. Informants frequently discussed the possibility of overdoing activities or overextending themselves in activities. Overdoing an activity could prove difficult and problematic for the COPD informant. While doing activities helped control symptoms and manage the lung condition, overdoing an activity caused symptoms and the lung condition to worsen.

The prevention of overdoing involved adjustments in lifepace. These adjustments appeared to be more difficult for those informants who had lived fast-paced lifestyle. These informants frequently overextended themselves. This involved taking on too many activities, high levels of emotional stress and becoming run down. These informants often felt that they were 'pushing it', 'couldn't keep up' or couldn't do what they wanted to do and as a result felt angry, frustrated or depressed.

Dora<sub>14</sub>: *"Well it bothers him but he knows how far he can go now. And he still thinks he can do ... he still works himself up like he thinks he can still do it like he did before but he can't and I keep telling him to slow down, slow down. But he's always been a hard fast worker and now that he has to slow down he doesn't know how and I still have to get after him to slow down, slow down!"*

Over-extension by some informants sometimes could be an expression or symptom of denial of the illness, an indication of a lack of awareness of a problem, or an effort to gain permission to be ill. For these informants, keeping active was a sign of health and non-activity a sign of illness. These informants therefore, maintained active lives and overextended themselves to the point that activity become harmful. An



acceptance of the illness or modification of activity for these informants may mean submission to the illness and a fear of a loss of control over the illness and their lives, thus they attempted to remain active. These informants were also more likely to have less supportive and more critical marital relationships.

GAIL<sub>1</sub>: *"I think its psychological as it is other things that I get involved in things and I end up spending my time doing a lot of things I really would rather not be doing. And sort of when you get run down you get sick and you have to stay at home for like a month or six weeks and take it easy and stop doing things. Its almost like permission. I can see a pattern of that in my life."*

#### Psychological Responses and Management of the Effects of COPD

The informants' psychological responses to the effects of COPD were intense and extensive and included affective, cognitive and behavioral responses. Informants described their affective responses most frequently. However, not all informants were able to discuss their emotions and feelings with ease or comfort. This appeared to depend on their level of awareness of emotional responses, their ability to express their emotional feelings and their desire to disclose how they really felt. Pre-illness personalities and the present emotional environment of their marriage played a role in informants' psychological responses to the lung condition and to each other.

Affective responses to the effects of the lung condition. Informants described a variety of emotional responses that they had to the COPD, the symptoms and therapies, their losses, as well as toward their spouses and marital relationship. These included feelings of fear,

frustration, anger, guilt, embarrassment, depression, anxiety and resentment.

COPD partners expressed fear and panic in response to experiencing a lack of air or shortness of breath. They also expressed fear about their therapies such as their medications having damaging effects on their health. They were concerned and afraid of long term disability and dysfunction associated with the disease and ultimately a fear of death.

Informants were also afraid of psychosocial effects, such as becoming a burden on their spouse or fear of abandonment and marital breakdown.

SARA<sub>8</sub>: *"I have a fear of being on oxygen. I don't know if I could handle that. I guess you would but it would curtail my activities to a great extent. I have a dreaded fear of that. A fear of being a burden. I don't want to be a burden."*

GRANT<sub>12</sub>: *"I could run into that, where you are going to be in a nursing home. There's no getting away from it. I think I will have to if it gets any worse. But its that feeling of being by yourself. That feeling of lonesomeness, abandonment."*

Well partners also expressed similar fears. To watch a COPD partner suffer or struggle for air was frightening and they experienced apprehension, anxiety and helplessness about the lung condition. They also feared death of their partner and being alone.

Both well and COPD partners experienced feelings of frustration, anger and resentment. The anger arose from fears. For example, for some informants the fear that their life may be shortened by the disease caused them to feel cheated of life. This was both a painful and threatening thought to which they responded in anger as illustrated by Paula and Jean's responses.

Anger could in turn could develop into resentment toward the marital partner. The well partner could resent the changes occurring in his or her partner and the increased work load of caring for his or her ill partner. The COPD spouse may in turn resent his or her well partner's healthiness and ability to function normally. Frustration was associated with a feeling of being cheated of life, of being restricted and losing control.

PAULA<sub>5</sub>: *"I'm frustrated, angry and I feel cheated and I'm also starting to think about how fragile life is which bothers me. I'm very resentful of the fact that I can't control the asthma any more. I've always been able to control it. I'm mad but I don't want to think like this but I have to be realistic too. Its difficult and you know why? Because I'm afraid."*

JEAN<sub>10</sub>: *"I find that some days I just can't function and I just cry because I just get so frustrated and so angry and so depressed."*

EVAN<sub>13</sub>: *"When you feel sick you get depressed and that can make you cranky."*

Informants also described feelings of guilt and blame. Well partners might blame themselves and feel guilty for encouraging the ill spouse to take part in activities in which they became ill. The COPD partners might blame themselves for their disease and feel guiltily for affecting the lives of their spouse.

MIKE<sub>7</sub>: *"She always felt guilty about going away and leaving me for a few days but now I've got that machine I don't have any problems."*

Int: *"How did that make you feel knowing she felt guilty?"*

MIKE<sub>7</sub>: *"Well, you don't feel good about it but you hate to have anybody trapped."*

Mary<sub>7</sub>: "There is a certain level of frustration. You get frustrated because you can't do things. You go out and he has to stand and cough and your ready to go and he can't go right away. You get frustrated and wish it wasn't there but it is and ;you have to live with it. Sometimes its hard having someone that's sick around all the time. You wish it wasn't there. Not that I want to get rid of him! I don't mean that! It just never really goes away. Trying to do things and he has a tough time breathing, like sometimes it wasn't that I was trying to force him into doing things, going out or going somewhere or ding something and he had a bad time and coughed and one thing or another and we had to come home. Well then I felt guilty for encouraging him to go and that kind of thing. I thought I shouldn't have encouraged him yet I didn't think sitting at home was good for him either. There is a certain amount of guilt, guilt that you created the problem."

Feelings of guilt, blame, anger and fear often resulted in depression. Depression was considered to be a major problem in itself because it was felt to magnify the effects of the lung condition. Consequently, several couples stated that it was important to work on avoiding depression by maintaining a positive attitude and atmosphere in their relationship. For instance, well spouses encouraged and accepted their ill partner and worked on building their self-esteem. This was reciprocated by the COPD spouse who encouraged their well partner to carry on with life and remain active.

GARTH<sub>6</sub>: "It's just like any illness. You just automatically deal with it. Its either that or die or become depressed. Well at times you do get down, 'Oh God here I go again', and of course it's medications again which is very debilitating. So you've gotta stay positive. Boy it's much easier to deal with. If you get down and I've been there, you get down and its hard to get back up again and I think it has an effect. Definitely can't help but have an effect on your recovery."

The management of affective responses involved the use of cognitive skills, such as problem-solving, decision-making, learning and restructuring . An example is the attempt to rationalize their illness and to identify the role illness played in their lives. This might involve restructuring their value system and developing areas of their lives that were previously less important.

EVAN<sub>13</sub>: *"The one thing it does, it makes you aware of the needs of all other types of people. I find myself giving to charities more generously than I ever did. You think about your relationships with each other and they become more important. Try to establish some different values than what you have had all your life. Well that happens with age too with concern for your kids and grandkids as they grow."*

Informants achieved this type of management by seeking information and learning about those things that were now important to them. They then used that knowledge to make modifications, after which they would practice what was learnt. For example, knowledge about symptom control through the use of correct breathing techniques was not helpful for the management of the dyspnea until informants put this knowledge into action and practised these techniques to receive the benefits of their knowledge. Informants learned various behaviours to manage their affective responses, such as going for a walk, having a sleep or relaxing.

Rena<sub>11</sub>: *"Emotionally if I get too upset over the situation I just go for a walk and forget about it. Come home and have a nap and get over it. There is no use worrying or getting upset or uptight about something you have absolutely no control over. I don't have control over his disability."*

MIKE<sub>7</sub>: *"You find ways to try and relax yourself, try to talk yourself out of a panic. Panic makes it twice as bad if you allow*

*yourself to get tense. I find I can take my weight off and lean on something that seems to be the best thing to stop and simmer down. I think to a point you can control your emotions. You have to try and control your emotions. Some people do it better than others. If you can find something to relax you can take your mind off, but it can't be anything that your using your energy up, so you've got to find something to do like read."*

### The Issues of Loss

Many of the psychological responses were associated with informants' experience of loss, the number and types of which increased with increasing illness severity. These losses included the loss of health, physical bodily changes, the ability to perform functional activities such as those described in Chapter 4, social losses such as the loss of roles associated with those activities and the loss of relationships, and psychological losses such as the freedom to express emotion and changes in mental functioning.

JEAN<sub>10</sub>: *"It's almost like a grieving process. I was reading a book and it talked about grieving and all the things you go through, denial, anger, depression and acceptance. Just like the things I went through when my mother died. But it's the same sort of things. Yes all those changes. My husband well he's a meticulous sort of person and well he doesn't like fat and here I've gained 90 pounds. I wasn't like that when we got married and here I've become what he doesn't like."*

PAULA<sub>5</sub>: *"I feel like I'm right in the middle of a process. 'Cause I don't feel any acceptance right now. I accepted the asthma the way it was, but now I have to accept it in a different mode. I have it. I know I have it and that's why I feel in turmoil about it. I feel everyday in turmoil about it. 'Cause its there all the time and I think about the effects."*

The continual change represented a continual threat of loss for informants and confronted them with a need to develop loss management

strategies to cope with the losses and their reactions to the loss. Informants responded to the loss with normal grief responses such as fear, anger, depression, guilt and blame and acceptance. The processes of denial and acceptance were clearly expressed by informants. The movement from the phase of denial to acceptance was associated with coming to terms with the illness. This involved the accepting various aspects of the illness, such as the diagnosis of the disease, the restrictions and the progressiveness, irreversibility and symptoms of the disease. Those informants who displayed the most successful and effective management of their illness had reached an acceptance of the illness.

The denial process. The interviewer did not encounter an informant who denied the existence of their disease. Although all informants described their disease and expressed concerns about it, approximately half of them appeared to be in some stage of denial. This, is illustrated by Lee's continual focus on her ear problem and Wendy's focus on her arthritis, a less threatening illness, and her preference "not to think about" her lung condition.

The interview process itself drew the lung condition to informants' attention. Because they were willing to talk about their lung condition they may not have been in a true denial stage but in a covered-up acceptance, as in the case of Lee and Will. They discussed her lung condition and their concerns about it in concrete terms (e.g., air, dust, humidifiers). These terms were vehicles through which they expressed their concerns. Will also noted a change in Lee's behaviour, such as it taking her longer to get dressed. Lee tried to normalize this change by

focusing away from the problem. This was for her own benefit as well as her husband's, as they were both worried about the lung condition but had difficulty saying so and generally avoided the subject.

Int: *"Do you have to change your routines or do anything different because of the breathing?"*

Will<sub>3</sub>: *"I have to wait for her. It takes her longer to get ready in the mornings."*

LEE<sub>3</sub>: *"Ya but most men expect their wives to take a little longer to powder their noses and then throw forty fits."*

Informants attempted to cure or heal themselves, which was another management strategy that reflected a denial process. This type of response may result from a lack of knowledge about the lung condition, unrealistic expectations, fear or the need to control the lung condition.

Int: *"When you talk about healing yourself what do you mean?"*

GAIL<sub>1</sub>: *"By changing patterns, by changing the purpose for which a disease functions in your life. You know those books that have been written recently about healing yourself of cancer and those things. I went through a whole stage of thinking that was true for me. But the physical reality for me, a healthier approach for me is to accept it rather than still trying to think that their's going to be a miracle, disillusionment. The damage is in the lung, the damage is there and will never be, its not curable."*

The fact that the lung condition was hidden made it easier for informants and others to deny its presence. However, this coping strategy might become more difficult and ineffective as the lung condition progressed and became visible. A crisis associated with the lung condition may eventually force an individual to confront his or her



illness and move out of a denial process and adopt different coping strategies.

Denial was not always a negative defense mechanism or coping strategy. Denial allowed a person to cope with as much of their illness as they were able. It is a normal initial response in the early stages of grief and could act like a filter to allow information through as it was processed. Time was required to come to terms with observed changes and to take action with regard to those changes.

SARA<sub>g</sub>: *"When I came back from abroad, I noticed that my breathing was not what it had been. And I guess I somewhat buried my head in the sand thinking Oh well its just one of those things that will improve, I just found I couldn't even, even in doubles keep up. That's what made me realize I'm pushing it..... When we got back to Calgary I had noticed it (breathing) was quite a bit worse and once again I had not quite faced the fact that I had to go and see a doctor. .... Finally I went to the doctor who did a battery of tests and came up with the suspicion of a lung problem."*

Denial could become an ineffective management strategy if an individual remained in that phase. This could occur if the individual was unable to cope with the reality of changes or losses because of a lack of inner personal resources or coping skills. Remaining in denial might allow such individuals to continue to function in their daily life whereas they might otherwise become incapacitated with anger or depression. This may be so in the case of Wendy.

Denial of the lung condition by the well spouse could create difficulties for the COPD spouse. Non-acceptance of the illness by the well spouse could leave an ill partner feeling unaccepted and insecure in

their marriage and this could threaten their marital relationship. Denial may be used by well partners to protect themselves from perceived threats and losses in their relationship, but this could lead to blame and anger and create a non-supportive and conflictive relationship. The COPD spouse may in turn respond by attempting to hide their illness from their well spouse so as to restore a balance in the relationship.

The process of acceptance. The movement from denial to acceptance of the lung condition is part of the loss process. Those informants who were in more advanced stages of their illness were more likely to talk about the need to accept the lung condition. Approximately half the informants were in the stage of acceptance. The ability to accept the lung condition appeared to be grounded in an acceptance of the reality of the lung condition, for example, that the condition was not going to get better but worse. Work was required to achieve acceptance and to incorporate the lung condition into their lives.

JACK<sub>14</sub>: "I know I have it. I know it's there. I just have to learn to live with it."

Greg<sub>5</sub>: "I'd rather live with it but work with it as well. I think that the initial reaction for everybody when something like this happens is that you feel that you've been dealt a raw deal. You feel why is it me and not someone else. That's the initial reaction. That's understandable but overtime you just come to say well maybe its not such a bad deal after all, because I could be a whole lot worse off. When you come to that point you begin to work with the solution. Not a solution to the problem but the tolerance to it."

JEAN<sub>10</sub>: "My denial changed through education. Through understanding and talking to other people, through realizing I'm not so bad off. I just have to realize if I can't do it, I can't do it. I don't want to accept it but I'm trying. This is my problem. I'm still fighting it, but I feel I've come along way. I'm having more good days than bad. I'm accepting it more than I did before."

A positive attitude emerged with an achievement of acceptance and a movement from feeling like a victim to taking action and working on the problem. The achievement of acceptance resulted in greater feelings of fulfilment in life, a reduction in problems for informants, a sense of hope about life and a serenity. Informants maintained that a satisfying life could still be lived though limited by the boundaries of the illness.

The acceptance of the illness by marital partners was achieved through understanding and learning about the illness and by addressing fears and concerns about the illness. Acceptance by one's partner was considered an important part of the marital relationship as these feelings of acceptance created a secure supportive environment for the COPD partner which facilitated the verbalization and expression of their fears and concerns.

Informants previous experiences with loss assisted in their ability to achieve an acceptance. Through previous experience informants may have already developed effective loss management strategies which they used to integrate COPD into their lives.

#### **A Social Dimension of the Management of the Effects of COPD**

Informants used various support systems such as the spouse, family members, friends, medical services and other organized groups such as the asthma association to manage the lung condition. Support from the marital partner was considered especially important.

Both partners in the relationship could provide support for each other. The well spouse helped the COPD spouse cope with various changes,

such as changes in the roles of friend, parent and spouse. These changes occurred as the spouse's ability to perform various functions decreased.

The provision of support by the well partner involved providing for the ill partner, sustaining them and encouraging them. There were various ways in which support could be provided, such as running errands, taking care of medications, helping with therapies, and providing housekeeping assistance and emotional support. The latter included encouragement and affirmation of the ill partner's identity and value's. Role reversal and assisting with social responsibilities such as financial matters were other means to support a partner. Finally, spiritual support was expressed by some informants as they shared and practised their beliefs and philosophies with their partner.

Dora<sub>14</sub>: *"You've both got to work at it. You can't just be one person working at it even if I'm not the sick one. You've got to help him. It's just like any disease you've got to work at it and get the right diagnosis. Take the right medicine."*

Int: *"Do you help him with the medicines?"*

Dora<sub>14</sub>: *"Oh I don't have to help I just keep asking him did you take your medicines? I keep reminding him all the time. 'Cause lots of times I've caught him. I'll say did you take your medicine? 'Oh I forgot my pill.' So there I make sure he got his medicines and its the same with exercise. I say, 'did you do your breathing?' It's an encouragement. And outside I help and inside whatever I can do."*

Peter<sub>10</sub>: *"How do I manage it? I guess by trying to be understanding and compassionate and careful not to raise the level of stress so that I can keep her calm and not to get myself excited because that makes matters ten times worse. And hopefully she feels that she is loved and needed and wanted. Those things are important to her."*

The support between partners was generally unequal. The well partner provided more support to the ill partner as they became more dependent and required more assistance. Some informants with COPD emphasized the importance of supporting their well spouse because of this imbalance in support. These COPD partners provided support for their well partner to the best of their ability even though they were limited by restrictions of their illness. They supported their well spouse emotionally with empathy, understanding, and by encouraging their partner and including them in their illness experience.

KEN<sub>4</sub>: *"I think we've got the house pretty well beaten down. I do most of the construction. Betty does all the painting. It's not so bad when you're using water soluble paints but the oil base really used to get me. I think we try. I try. If I don't watch her she will do more than she should have to."*

Int: *"In what ways?"*

KEN<sub>4</sub>: *"Well doing more for me than I am capable for her."*

Int: *"Could you give me some examples?"*

KEN<sub>4</sub>: *"Well I have trouble at night. She wants to get up at night and get downstairs and get a pill for me and bring me up some, you've gotta eat something with it. Its rather nauseous. Anything like that. She'll do more of it."*

Int: *"How do you feel about that?"*

KEN<sub>4</sub>: *"Well intensely grateful for it. And I don't feel, I feel its an imposition that's all. I think on a sharing basis its about 90% on her side and 10% on my side at least I feel that way."*

The support provided by well male spouses and well female spouses differed. The support provided by well females tended to be all encompassing and focused on the development and maintenance of the

relationship. Well male partners tended to provide support through practical means, and by ensuring that the physical and functional needs of their partner were taken care of.

The most valued component of support appeared to be of an emotional nature, that of being understood, accepted and not alone. This was demonstrated by the fact that approximately half of the couples in this study had problems of emotional support in their relationship. Either the COPD partner felt a lack of emotional support or the well partner felt that their support was not being received by the ill partner. The dissatisfaction was more likely to be present in couples where there was an ill female spouse. These marriages were also more likely to be of a traditional style.

The support by a partner appeared to be comforting and effective if it met the emotional needs of partners. Women appeared to provide this satisfying support for their partner because they were more likely to encompass emotional and relational issues in their method of support. A few ill and well male informants also provided this emotional support for their wives, as illustrated above by Peter's comments. Although male partners tended to provide less emotional support for their spouse, the practical nature of their support was still important.

The qualities possessed by a spouse that contributed to successful, satisfying support included: an understanding and acceptance of the lung condition; a balance of physical, emotional, social and spiritual dimensions of their support; a presence to the relationship this included; an ability to integrate, share and work together in the relationship; an involvement of a partner in the changes occurring in one's life; and the

ability to communicate effectively. The absence of these characteristics created difficulties in the ability of one partner to provide support for the other.

### **Spirituality and Coping with the Effects of COPD**

Another approach to the management of the lung condition was provided by a spiritual dimension of informants' lives. Approximately half of the informants expressed the importance of their spiritual growth, search, belief or development in their struggle to deal with the lung condition and the changes it brought to their lives.

Informants' description of their spirituality referred to elements beneath the obvious outward aspects of religion. They referred to the deeper requirements of themselves, the need for love, meaning and identity. Informants appeared to meet these requirements through various spiritual means, such as the practice of meditation, spending time with nature or seeking God through organized religion. These informants felt confronted by their mortality and sought to find meaning in their lives. Their search for meaning involved a growth and a development of a belief system, a desire to find meaning for their illness and a need for hope. Informants' spiritual practices often provided them with a sense of serenity that appeared vital and important to the management of COPD and living successfully with the illness. Thus, the development of one's spirituality was considered to be important. It was part of a holistic approach in the development and care for one's self and for the management of the illness that involved integration of care of the body, mind and spirit.

KEN<sub>4</sub>: "I go up into the mountains. I go up there and just feel happy. The mountains to me are something I can never get enough of. I can drive up there and feel like my soul has been laundered."

JEAN<sub>10</sub>: "We go to church so we have a real good spiritual relationship and a good church relationship. We have friends that are Christians and we have a lot of contact which is good. I think that has really helped me in terms of myself and my inner peace sort of thing. Its the only time I really do have that serene, calm inner peace that there's gotta be something better. There are times when I feel that there is nothing anybody can do."

#### SUMMARY

The continual downward progression of COPD created a continual process of change that impacted greatly upon informants' lives. The continual change meant a continual need to adapt to the effects of the lung condition. Informants' responses to change addressed this need as they tried to maintain a balance in their lives and achieve some level of normality in their lives and to compensate for the losses they experienced. This was achieved by a restructuring of their lifestyles and marriage. Informants developed various management strategies to accomplish this. Positive management involved a holistic approach integrating the body, mind and spirit through the use of strategies from functional, psychological, social and spiritual dimensions of couples lives. Effective and successful management was influenced by personality factors and by personal resources and coping skills. Informants with well-developed skills developed creative and useful management strategies. These individuals had high levels of self efficacy (a belief in one's



ability to produce desired results) and perceived a mastery over the effects of the lung condition. These individuals were also more likely to have positive marital relationships that were supportive in all dimensions of management. Positive marital relationships and individual coping skills facilitated the movement through the stages of denial and acceptance of the illness. The acceptance of the illness reinforced a positive attitude in relationships and facilitated a feeling of contentment and serenity which appeared to be vital to living successfully with the lung condition. The process of change and the effects of the lung condition could also facilitate the development of personal skills and coping strategies as individuals sought to learn about the lung condition and develop adaptive responses to threats and conflicts that COPD and its effects produced in their lives and marital relationships.

## CHAPTER 7

### DISCUSSION

This study was designed to contribute to the current state of knowledge about the impact of COPD on marriage. This was done in three ways. First descriptive data related to six research questions were presented in Chapters 3 through 6. The second way was to generate theoretical propositions about the relationship of COPD to marriage and to suggest propositions for future research. The third way to contribute to knowledge was to identify relevant issues of a theoretical and practical nature. This chapter presents a theoretical framework and propositions that emerged from the data and discusses salient theoretical and practical issues.

#### THE FRAMEWORK AND PROPOSITIONS

A theoretical framework was derived from the data to describe the dynamic of relationship between COPD and marriage (Figure 4). Marriage is conceptualized as a dynamic and open system that interacts with the biopsychosocial environment, which includes COPD; physical, psychological and social restrictions; management strategies; perceptions of COPD and restrictions, psychological resources and personality; and confounding

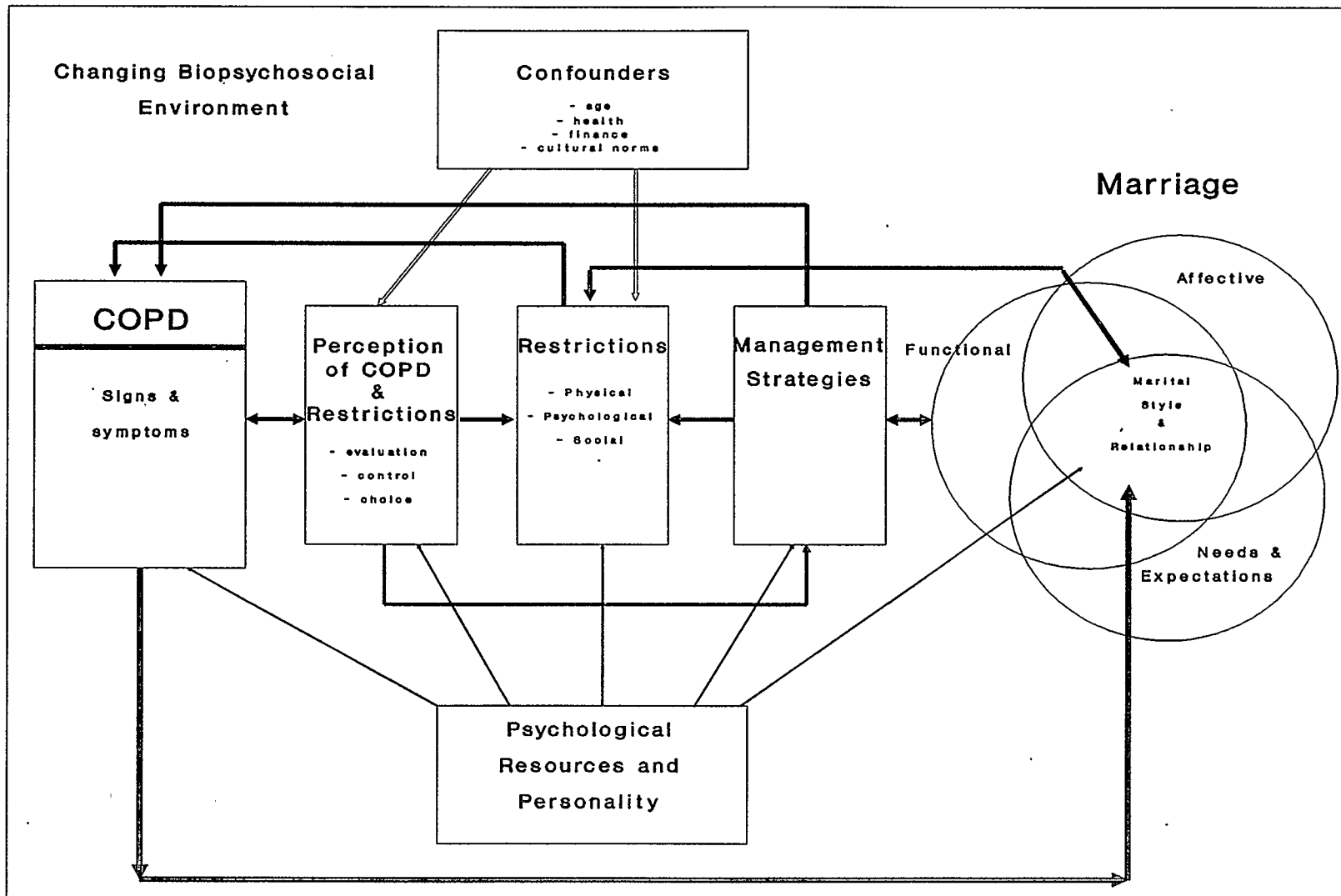


Figure 4. The Dynamic Relationship Between COPD and Marriage

factors.

Marriage is comprised of functional and affective components, and individual needs and marital expectations. These interact to form a particular marital style and relationship. The needs and expectations are influenced by an individual's personality and psychological resources.

COPD is a force that acts upon the marriage causing a disequilibrium that potentially threatens the marital relationship by creating tension, strain and possible conflict within the system. The data suggest that COPD affects marriage by causing restrictions and various losses in a couple's life. The couple experience this change as a gradual, subtle yet continual process. The degree to which the restrictions are perceived to intrude upon their marriage, or to be problematic, depends upon the severity of the illness, the marriage style and relationship, management strategies, and perceptions of COPD and its restrictions, especially how COPD controls their life.

Marriage style includes the organization of functional aspects of a couples marriage, such as roles, tasks and responsibilities. The degree to which the COPD impacts the style depends upon a couple's ability to adapt to and integrate changes into their marriage. The marriage style may eventually require reorganization because of continual changes within the marriage. The degree of impact of change on the style, and the ability to restructure marriage is affected by the quality of the support in the marital relationship.

Data show that COPD effects the marital relationship indirectly through functional aspects and directly through changes in brain function during later stages of the disease process. The extent to which COPD

affects the marital relationship and is considered problematic at the relational level, is determined by an individual's psychological resources including self-esteem, self-efficacy, self-respect and cognitive abilities.

The data also show that effective management of COPD decreases the problematic nature of its effects on the marriage. Effective management is facilitated by a positive marital relationship and well developed inner psychological resources. These influence a couple's ability to effectively deal with the restrictions of COPD and integrate them into their lives. To achieve this, couples must be motivated to seek information, learn, make decisions and solve problems. The most effective coping of COPD involves a holistic approach to the management of the disease through the incorporation of functional, psychological, social and spiritual dimensions.

In responding to the restrictions of COPD a balance is restored in the marriage and some level of normality is achieved which compensates for losses and reduces conflict and stress. This may also slow or halt the downward movement of the COPD, which would further reduce the impact of COPD on the marriage.

Effective management is also influenced by the extent to which COPD is perceived to control an individual's life, which is again a reflection of an individual's psychological makeup. Individuals with high self-efficacy (i.e., the belief in one's ability to effect change or produce some results) are more likely to use various management strategies. These individuals also do not see the disease as controlling their lives to the same extent as those who have a low sense of self-efficacy.

Variables such as age, health, finances and cultural norms also influence the degree to which the restriction of COPD are problematic and impact a marriage. These factors either confound the problem of restrictions or make the reasons for change and restrictions difficult to discern. Health problems create additional stress on the system and tend to exacerbate existing problems resulting from COPD. Cultural norms influence how individuals perceive, experience and cope with disease. They influence expectations and perceptions of symptoms and how individuals label sickness (Kleinman, Eisenberg and Byron, 1978). This relates to issues of stigma associated with COPD. The data have shown issues of stigma and the invisibility of symptoms influence an individual's response to the disease and marital relationship. COPD partners may seek to over-extend themselves in an activity to gain permission to be ill. Some individuals may continue to keep active in an effort to hide their disease from their partner and other individuals. The decision to conceal information about COPD, or to disclose information about it, or whether pass oneself off as normal or conceal the problem, are issues that are also associated with other diseases and disabilities (Scrambler, 1984).

The various relationships between COPD and Marriage represented in Figure 4 require further study. In particular, the following propositions should be investigated:

- a) COPD impacts a marriage by creating changes through restrictions and losses in a couple's life which in turn creates a disequilibrium in the marriage that potentially threatens the marriages by causing stress and possible conflict within the marital relationship.

- b) The degree to which restrictions and losses are problematic and intrude upon the marriage depends on the severity of illness, a positive marital relationship, marriage style, effective management strategies, and perceived control of COPD on the lives of marital partners.
- c) Emotional support, an essential dimension of a positive marital relationship, is important for the psychological well-being of marital partners and this in turn is a precondition for effective management of COPD.
- d) A marital partner with a high sense of control over the effects of COPD will develop effective management strategies.
- e) A positive marital relationship helps partners to achieve an acceptance of COPD.
- f) An acceptance of COPD improves the management of COPD, especially by creating a sense of inner peace and serenity within the COPD patient.
- g) The variables of age, general health status and cultural norms are confounding factors in a) and b) above.

#### DISCUSSION OF RELATED ISSUES

There are some additional issues arising from the findings in this study that deserve special comment. These relate to management of COPD and perceptions of control, support and marital intimacy, spirituality, and age.

### Loss Management and Locus of Control

One of the important effects of COPD is a couple's experience of various losses as the COPD partner moves through changes in the disease. The data suggest that couples are continually moving through a grief process in response to this loss. Thus, emotions accompanying the changes and effects of COPD can be typical affective responses related to grief. These emotions are normal and effective psychological adaptations to the experience of living with COPD. Therefore, it would be expected and not unusual to find psychological responses such as anger, frustration and depression in both well and COPD partners. Problems moving through the grief process might be expected in those individuals who have less developed inner personal resources. Their grief process may become halted at a particular phase, such as denial. These individuals could become chronically depressed or anxious and in need of some form of intervention. Thus, some psychological disturbances associated with COPD are related to difficulties in coping with the effects of the disease. The findings associated with the psychological responses to COPD and its effects are supported by the literature (Agle and Baum 1977; Casselith et al. 1984; Dudley et al, 1980).

Movement through phases of grief from denial to acceptance of the disease has several benefits. Acceptance of the disease facilitates effective management of COPD, integration of COPD and its outcomes into couple's lifestyles, and development of a positive, satisfying and fulfilling life. Acceptance of the disease does not mean submission to the disease. On the contrary, creative management that accompanies an achievement of acceptance gives couples a sense of hope and encouragement



to continue working on and living with the disease. The purpose of working on the disease appears to be grounded in hope. This hope is more than just an affect or an individual's unrealistic expectation or desire. Hope has a quality of transcendence above the disease and situation and plays an important part in an individual's need to construct a meaningful future by working on and living with the disease in the present.

The ability to develop and carry out effective management strategies and a sense of hope can be related to the concept of internal and external locus of control. Internal control is the belief that outcomes are primarily contingent upon personal skills and efforts while external control is the belief that outcomes are primarily determined by forces greater than oneself, chance or fate (Leiberman and Tobin, 1983). The findings of this study suggest that individuals with an external locus of control are more likely to see the COPD as controlling and thus they submit to the disease feeling a sense of hopelessness that is associated with helplessness and giving up. Individuals with an internal locus of control are more likely to take responsibility and action with regard to the effects of COPD. These individuals have a higher sense of mastery over the effects generates confidence in being able to affect outcomes and this in turn leads to the development of management strategies to cope with the COPD. Although the concept of hope is separate from the concept of locus of control, the individuals in this study who showed a higher level of internal locus of control also demonstrated a greater sense of hope about living with their illness and the future.

### Support and Marital Intimacy

This study suggests that the quality of the marital relationship in terms of marital intimacy is important for successful spousal support and contributes to a couple's successful management and adaptation to COPD. Role theory has been used to understand issues of support and the nature and dynamics of family and marital relationships. Much of the psychosocial literature on COPD has focused on psychological disturbances in relation to family issues, social losses, role change and the need for social support. There is a dearth of literature which focuses on emotional support for a COPD patient and their spouse in terms of marital intimacy. The concept of marital intimacy includes feelings of love, acceptance, belonging, emotional stability, commitment and sharing, all of which are factors related to basic human need to be loved. Therefore, while social support is important for the COPD patient, emotional support may be critical because the emotional component of COPD is a distinctive feature of the disease.

A range of emotions associated with loss and marital interactions is experienced by couples. As shown in the literature in Chapter 1, intense emotions are problematic for the COPD sufferer, and as shown by the data in this study, COPD has a wide ranging impact on the marriage. The emotions experienced by couples, in turn, can affect the COPD. This sets up a cycle of events similar to the dyspnea spiral because the expression of emotions cannot be prevented.

The significance of the emotional impact on COPD can explain why the quality of the marital relationship is important for coping with COPD. A supportive, close, loving relationship creates an emotionally secure

environment that is protective for the COPD partner. This type of relationship fulfils the basic needs for love and provides a safe environment for both partners, but particularly the COPD partner, to restructure their values and views of life and self-concept which are changed or threatened by the losses they experience.

Because of the importance of an emotionally secure environment the value and need for couples to develop management strategies to restore and protect the equilibrium of the marriage becomes apparent. There is a need to compensate for losses, reduce stress and conflict within the marriage. However, of most value for the management of emotions is the development of an individual's inner personal resources such as self-esteem and self-acceptance. This development involves a growth and maturity that would allow individuals to better understand, accept and handle their emotions and give them inner peace and serenity which seems vital to successful living with COPD.

### **Spirituality**

An additional observation that emerged from the data is the significance of spirituality in couples' lives. The development of spirituality is seen as a means to achieve a sense of inner peace and serenity and to fulfil such deep needs as the need for love, identity, meaning of life and hope. This spiritual approach is integrated into various aspects of an individual's life to manage body, mind, and spirit. The development of an individual's spirituality is part of a holistic approach to the management of COPD and may be an interesting concept to

include in future research on the management of COPD or other chronic illnesses.

Spirituality is frequently ignored by researchers partly because it is difficult to define and not readily studied by conventional scientific procedures (Moberg, 1973). Spirituality is often based on non-objective parameters such as intuition, insight and introspection that are difficult to measure. Because it is difficult to study, spirituality is often ignored and assumed to be unimportant or insignificant. The importance of spirituality emerges in this study, however, and appears to be receiving more attention as a holistic approach to the management of disease and illness is explored in health care.

#### Age

Age is also an interesting variable that emerged from the data and warrants further mention. Age is a confounding variable in respect to the effect of COPD on marriage. It is sometimes difficult for individuals to make the distinction between normal aging and changes resulting from COPD. The concept of aging is used by partners to manage and accept the COPD. The effects of COPD are normalized by seeing them as part of the aging process. This may reflect a cultural stereotyped attitude or expectation of old age, that is it is normal to be sick when old or to experience fatigue, loss of energy or a slowing down in life.

Age also appears to play a role in an individual's ability to accept COPD. Younger couples have more difficulty accepting COPD in their lives, often feeling more cheated of life. Older couples, on the other hand have moved through other changes in the life cycle (e.g., retirement)

and adjustment to such changes may make the restrictions of COPD or its intrusiveness less significant. Because older couples were more likely to have experienced other losses or changes they may have already developed coping skills to deal with loss.

A concept of spiritual aging may help to explain why some older couple's have greater acceptance of COPD. Gress and Bahr (1984) describe spiritual aging as "the process of developing a philosophy of life and coming to terms with oneself, one's place in the world and ones relationship with others". These changes would appear to reflect a differentiation occurring in an individual's inner resources over time and represent growth and maturity. These changes become apparent in an individual's response to life experiences such as COPD and in the verbal and non-verbal expression of emotion associated with COPD.

#### PRACTICAL CONSIDERATIONS FOR REHABILITATION

There are several issues that emerge from the theoretical framework of this study that may have practical application for the rehabilitation of COPD. Firstly, support and grief counselling may be beneficial for some people by helping them understand their experiences of loss and their feelings associated with it and to help them cope with continual change.

Secondly, education and rehabilitation should not just focus on medical issues, such as symptom control through medication and exercise. There should also be a focus on the development of coping skills and personal resources. This would facilitate coping with change and the development of management strategies. This could be part of a holistic approach to rehabilitation that could incorporate medical, physical,

psychological, social and spiritual issues that are associated with learning to live with COPD.

Thirdly, it is useful for caregivers involved in rehabilitation to determine patients' perceptions of COPD. This information provides some insight into problem areas that may emerge in the rehabilitation process. Whether or not an individual perceives the lung condition as controlling their life may affect their ability or motivation to learn or use skills presented in the rehabilitation process. The severity scale used in this study may be helpful in providing insight into an individual's perceptions of COPD. A comparison of physician and patient ratings of severity may indicate problems in coping or accepting the disease. Patients who rate themselves higher than the physician may either be effectively coping with the illness or denying it. Lower patient ratings may indicate ineffective coping.

Fourthly, the inclusion of a marital partner in the rehabilitation process may increase caregivers' awareness of marital dynamics that may lead to problems in managing the COPD. If marital problems are observed, appropriate counselling may be provided or recommended. The inclusion of both partners in the process could help couples to work together on the problem and increases their knowledge of the disease and the concerns faced by the ill partner. This may increase well spouse compliance with their ill partner's treatment and management strategies recommended by caregivers.

Finally, while there is a value in developing an individual's inner resources and coping skills, only those individuals who are motivated or willing to make changes can be helped. The purpose of rehabilitation

should not be to force change or rescue difficult or problem patients, but rather to provide an informative and supportive environment that would facilitate growth and development if an individual so desires and to be sensitive to patients' psychosocial problems.

#### LIMITATIONS

The findings in this study are based on a population of COPD patients and their spouses who are living in the community. Thus, findings may be generalized to that group. The issue for COPD patients in long term care settings and their spouse may differ and consequently so may the issues for rehabilitation. A major difference between a COPD patient in the community and in long term care is the degree of severity. Individuals living in a long term care setting would more likely have a higher severity of illness. This may mean increased complications from medical problems associated with COPD. Increased impairment may also mean increased problems in brain function and cognition due to oxygen shortage. This in turn would impact issues for rehabilitation.

In this study sample there was an under-representation of severely ill COPD patients. This bias can be explained by the following reasons. The first is that the sampling criteria included only those couples residing together. More severely ill partners may have already moved into a long term care setting. In addition, patients who perceived themselves to be severely ill may have been unwilling or too ill to participate.

This study sample may also have been biased toward couples who were in healthier marital relationships and may represent a group of marriages

that have generally worked well or have survived the impact of COPD. Couples who were in negative or problematic relationships may have been less likely to participate in the study. Interviews with separated or divorced couples would be interesting to compare for the purpose of challenging the study findings.

#### A FINAL NOTE

As a final note to this study the researcher would like to emphasize that the impact of COPD on marriage is wide ranging and produces tremendous stress on many areas of couples' lives as the disease progresses. The losses experienced by couples can be extensive and some individuals experience a difficult struggle coping with the COPD. Despite this, the researcher noted the positive attitudes, enthusiasm and hope that many of the couples expressed. Although most couples lived lifestyles that were necessarily limited by the disease, some were still able to live satisfying and fulfilling lives. An attitude of acceptance and a general sense of inner peace and serenity appeared to be important to successful living with COPD.



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## APPENDIX A

## FIVE LEVELS OF ILLNESS SEVERITY FOR COPD

- 1) Patient with recognized disease, with no restrictions, is able to do what peers can do, and continues with usual life patterns.
- 2) Patient with minimal or moderately restricted activity, is able to produce work, has some difficulty keeping up with peers and has begun to modify life patterns.
- 3) Patient with markedly restricted activity, is not homebound, may not be able to do productive work, but is able to take care of him/herself.
- 4) Patient with severely restricted activity, is not able to do productive work, is essentially homebound, but is able to take care of him/herself.
- 5) Patient with very severely restricted activity, is homebound or in an institution and is not able to take care of him/herself.

## APPENDIX B

## QUESTION GUIDE FOR INTERVIEWS

- |          |  |
|----------|--|
| COPD     | 1) Could you describe and explain your lung condition (LC) to me?<br>2) Do you see it as a problem?<br>3) Do you see it affecting yourself? Ways? How do you feel about this? How do you think your spouse feels?<br>4) Has this changes over time? How? Feelings?<br>5) Do you see the LC affecting your spouse? In what ways? How do you feel about that? How do you think they see it affecting them? How do you think they feel?   |
| MARRIAGE | 6) How would you describe marriage in general? How would you describe your marriage?<br>7) Has the LC affected your marriage? Your relationship with your spouse?<br>8) Could you describe your feeling toward your spouse? How do you think your spouse feels about you?<br>9) Does your spouse help you with problems or the LC? In what ways? How do you/they feel about that? Are there ways in which you help your spouse? Has this changed?<br>10) Are you able to talk/confide with your spouse about the LC? How do you feel about this? Does your spouse listen to you? Has this changed?<br>11) Do you get along with your spouse sexually? Does the LC affect this? How do you feel? How do they feel? Has this changed?<br>12) Has the LC put a strain on you or your spouse? Your relationship? Have you ever considered ending your marriage?<br>13) Have you and your spouse become closer or more distant? How do you/they feel about this? Has this changed?<br>14) Has the LC changed your view of marriage? |

- 15) Are there things about your marriage that help you deal with the LC?
- 16) Have there been other problems or difficulties in you lives? How did you deal with them? Is that similar or different to the way you deal with the lung condition now?
- 17) What advice about marriage would you give to a couple in a marriage with a LC?
- 18) Has your marriage changed? Are there any other ways the lung condition affects your marriage?
- MANAGE 19) How have you dealt with or managed the LC/changes?
- GENERAL 20) Is there anything else you would like to mention or talk about or that is important to you?