

THE FAMILY EXPERIENCE
WITH
CHRONIC OBSTRUCTIVE PULMONARY DISEASE

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING

in
THE FACULTY OF GRADUATE STUDIES
(School of Nursing)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA
August 1985

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The Family Experience with COPD

This study was designed to gain an understanding of the family experience when an adult member has chronic obstructive pulmonary disease (COPD). It is recognized that illness within the family affects the well-being of the family unit and the health of all members. To understand the impact of COPD upon the family, however, the literature provides only knowledge of the experience of the individual who has COPD and the spouse, not that of the family unit. Thus, the purpose of this study was to describe and explain the COPD experience from the perspective of the family unit.

A qualitative method, phenomenology, was chosen for this investigation. Data were collected through semi-structured interviews with eight families who shared their experiences. From the content analysis of these data, three themes that were common throughout the families' accounts were identified and developed to describe and explain family life with COPD.

The first theme, disease-dictated family life, describes four aspects of a common lifestyle that is imposed on the family by the characteristics of COPD. The second theme, isolation, describes the isolation that accompanies the illness experience, for the family group and the individual members within the group. The final theme, family work, describes the four primary challenges the families face and the coping strategies they use to deal with them.

These findings revealed that COPD acts as an intense stressor within the family, requiring extensive family work to cope with COPD in a way that maintains the well-being of the family unit. Furthermore, it was found that living with COPD in many ways inhibits the resources within the family and those external sources of support that foster the family's ability to manage the stress associated with living with COPD. The implications for nursing practice and nursing research were delineated in light of the research findings.

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ACKNOWLEDGEMENTS

I would like to thank the professors who were the members of my thesis committee, Virginia Hayes (Chairperson) and Clarissa Green for the positive atmosphere that supported me through the process of my research: their expertise, their guidance, and their humour. For sharing an intimate part of their lives with me, I would like to express my thanks to the eight families who participated in my study. I would also like to gratefully acknowledge the Canadian Nurses' Respiratory Society and the Canadian Lung Association for the generous fellowship that helped to support my master's education and my research. Finally, I wish to thank my partner, Pat, for his support, insight, and ongoing belief in my work.

CHAPTER ONE

Introduction

With improved control of communicable diseases, chronic illnesses now represent the primary challenge to health care in Canada (Lalonde, 1974). For those afflicted with a chronic illness, life becomes "irrevocably different" (Feldman, 1974, p. 289). However, it is not solely the life of the individual that changes; because the family is the primary social unit, it is here that the chronic illness occurs, is managed, and the accompanying changes are felt (Litman, 1974). When faced with the reality of chronic illness, some families not only adapt to the inevitable changes, but grow and unify in the process. Others do not, unable to effectively manage the demands of the illness while maintaining the well-being of the family unit (Lenihan, 1981; McCubbin, 1979).

Throughout all areas of practice, nurses have opportunities to help families find more satisfying ways to live with chronic illness. An understanding of the impact of the illness upon the family, however, is needed to provide a theoretical base from which to plan appropriate and effective nursing care. Toward this end, this study explored the family experience of living with one of the most prevalent of the chronic illnesses, chronic obstructive pulmonary disease (COPD).

This chapter introduces the research by: describing the nursing context of the problem, explaining the framework

guiding the research, outlining the specific research questions addressed, and describing the methodological perspective chosen to explore these questions.

Background

Chronic obstructive pulmonary disease, the fourth most prevalent chronic disease of adults in Canada, represents the fifth leading cause of death for men and the eleventh for women (Health and Welfare Canada, 1982, p. 9, 20). Although mortality related to all diseases of the respiratory system has declined in the previous decade, mortality related to the chronic respiratory diseases has risen, increasing by 34.2% for women and 9.2% for men (Health and Welfare Canada, 1982, p. 2).

The label "COPD" is used to describe those diseases characterized by increased resistance to airflow. In adults, this includes chronic asthma, chronic bronchitis, and emphysema (Hodgkin, 1979). Typically such diseases occur together in varying degrees of severity, and result in shortness of breath, limited energy, and progressive disability (Hodgkin, 1979; West, 1977). The onset of the disease is gradual. As a result, significant lung damage has already occurred by the time symptoms prompt the individual to seek treatment (Petty, 1978). Because the lung damage is irreversible, medical treatment is aimed at symptomatic relief, prevention of further impairment, and rehabilitation to derive maximum potential from the person's remaining lung function (Haas, Pineda, Haas &

Axen, 1979). For the sufferers, living with COPD means constantly balancing breathing and energy reserves, to avoid the threatening sensation of breathlessness (Sexton, 1981; Traver, 1982).

As it is primarily people in their mid-years, forties to sixties, who develop the limiting symptoms of COPD, many are forced to leave their jobs before the time planned for retirement (Dudley, Glaser, Jorgenson & Logan, 1980). In fact, in 1977, obstructive lung diseases accounted for the second leading reason people received disability benefits in the United States (Kass, 1978, p. 7). Recognizing that women working in the home are excluded from receiving these benefits, the disability from COPD is actually greater than these statistics indicate. The symptoms of COPD not only affect the ability to be employed; abilities to carry out many other aspects of everyday life are also affected, such as the ability to socialize, travel, participate in family activities, fulfill household tasks, and if severe, even engage in conversation (Chalmers, 1984).

The impact of COPD, therefore, is not confined to the victim alone. The effects are felt by the entire family. The illness affects the health of all family members and the functioning of the family unit itself. To view COPD within this broader family context is then to view the family as a focus for health care and therapeutic intervention, whether the "client" is one family member or the entire group (Green, 1982).

The long-term progressive nature and the recurrent exacerbations typical of COPD bring the ill member into frequent contact with the health care system, in hospitals, clinics, and in their homes. Nurses practice in all these areas, so are provided with many opportunities to assist these individuals and their families in meeting the challenges that accompany life with COPD. Yet from the author's experience of caring for individuals with COPD in the hospital and community, it appears that the family seldom becomes a focus of nursing intervention; rather, the family unit is considered primarily as an environment that influences the treatment regime and health status of the ill member. It seems that nurses rarely attend to the fact that the illness reciprocally influences the family. Thus, the needs of the family unit are even less frequently addressed.

To promote and deliver family-focused care to families with COPD, nurses require an understanding of how the disease affects family life. Yet, an indepth understanding of this experience cannot be gained from the current literature, for the family experience with COPD has been virtually unexplored. Further, from the author's perspective, what literature does exist is primarily impressionistic rather than research based. It is provided from the perspective of health care professionals who have worked with individuals and families with COPD, rather than based upon research from the perspective of the families who live with COPD themselves.

To begin to address the need for knowledge of the family experience with COPD, this study was designed to explore the family experience when an adult member has COPD, as described and explained by the family unit. Furthermore, such insight is seen to contribute to the understanding of the experiences common to all families with a chronically ill member.

The following section explains the conceptual framework used to guide this investigation.

Conceptual Framework

Symbolic interaction theory provides the foundation for the conceptual framework. The following description explains this perspective of the family illness experience as created through the interaction of the family members with each other and with those in their environment.

From the perspective of symbolic interactionism, social life is seen to be constructed through a process of interaction between individuals (Lindesmith, Strauss & Denzin, 1975; Stryker, 1980). Through this interactive process, people give meaning to objects and situations they encounter. These objects or situations are seen as holding no inherent meaning for an individual; the meaning arises out of the way the object is defined by those with whom that individual interacts (Blumer, 1969). Thus, people transform meaning in light of the actions of others and their own previous experience. This interpreted meaning then acts as the basis for action (Blumer,

1969). As interaction involves reciprocally influenced behaviour, social interaction is more appropriately considered the creator of behaviour, not simply a form of its expression (Blumer, 1969; Lauer & Handel, 1977).

Blumer summarized symbolic interaction in three basic premises: humans act toward things on the basis of the meanings those things have for them; meanings emerge through social interaction; and, meanings are modified and dealt with through an interpretative process used by persons in dealing with those things they encounter (Blumer, 1969).

In relation to the family with COPD, the meaning of the illness for the family is created through the social interaction of the family members. As the individual members indicate their interpretations of the situation to each other, a collective definition of the situation forms. The family's definition of the situation is seen to be qualitatively different than the definition of an individual member. Each member contributes to this integrated view. The shared construct is a product of the group (Blumer, 1969).

Through a process of interpretation and interaction, the individual members' actions are influenced by the collective view. That is to say, the members of the family fit their actions in line with each other; their joint action is family behaviour (Blumer, 1969). From this perspective, the shared family construct serves to shape the family's particular pattern or behaviour (Reiss, 1981).

Given this framework, an indepth understanding of the

family experience must incorporate the subjective as well as the objective dimensions (Stryker, 1980). The situation confronting the family is the objective aspect; and, the meaning of the situation for the family is the subjective aspect. To achieve an understanding of the family experience with COPD, the subjective dimension, how the family members describe their situation and how they act in light of this interpretation, must be sought. Thus, the family group's description and explanation became the focus of this study of the family experience with COPD.

Problem Statement

Chronic obstructive pulmonary disease represents a health problem to the family as well as to the ill individual. The way the disease affects the family unit, however, has not been previously studied. To deepen the understanding of this experience, the research addresses the following questions: What is daily life like for families in which an adult member has COPD? How do families respond to the demands of the illness?

The description and explanation of the experience from the perspective of the family group provides an understanding practitioners can use to: anticipate potential family problems, identify resources that enhance the coping abilities of these families, and provide care that promotes the well-being of the family unit and the health of all members.

Definition of Terms

For the purpose of this study the following definitions apply:

Chronic obstructive pulmonary disease (COPD): Persistent airflow obstruction which cannot be completely reversed with bronchodilators or other treatment (Traver, 1975, p. 1778).

Adult with COPD: An adult with a medical diagnosis of chronic obstructive pulmonary disease.

Family: Those persons the adult with COPD identifies as his/her family.

Guided by the symbolic interactionist framework, an appropriate research methodology for this study is one that explores the diverse nature of the experience from the subjective perspective of those involved. The following section explains the theoretical basis of phenomenology, an interpretive research approach, which was chosen to accomplish this goal.

Methodological Perspective

Two distinct paradigms of scientific inquiry contribute to the knowledge of human behaviour, the quantitative method and the qualitative method. The quantitative method attempts to verify preconceived hypotheses. The purpose is to discover the objective determinants of particular phenomena, as a basis for prediction (Schwartz & Jacobs, 1979). Conversely, qualitative research is a descriptive method applied to study and describe

human experience as it is lived. The purpose is to deepen the understanding of the phenomena under investigation (Giorgi, 1975). It is from two different world perspectives that these methods approach the development of knowledge.

Different philosophical assumptions also underly each approach. In contrast to the assumption of the quantitative method that "there exists definable and quantifiable 'social facts' . . . outside and independent of the experience of any particular individual" (Rist, 1979, p. 17), the qualitative paradigm assumes that the only reality is the reality of the person who has the experience (Oiler, 1982; Schwartz & Jacobs, 1979). The subjective perspective is essential to understand the behaviour that can be observed objectively.

The perspective of qualitative methodology is conceptually compatible with the theoretical framework of symbolic interactionism that guides this investigation. Therefore phenomenology, a qualitative research method, was chosen to explore the research questions. A description of the method of phenomenology follows.

Phenomenological Method

The phenomenological method, developed by Edmund Husserl, allows the researcher to explore phenomena as they are lived and experienced (Knaack, 1984). The task of the investigator is to achieve an understanding of an experience from the subjective perspective of those involved, and from this basis

develop a rich, full description that projects the sense of this experience to others (Omery, 1983). The researcher is therefore the main instrument of the phenomenological investigation, entering into the research process itself and interpreting the experience as it appears to the people engaged in it (Davis, 1978).

The researcher's direct involvement reflects the epistemology of qualitative research, that is, "the researcher must participate in the mind of the other in order to acquire social knowledge, and that face to face interaction promotes the fullest participation" (Lofland, 1984, p. 12). Qualitative research is recognized as a social act, an interaction between the researcher and the participants. As such, the intent is not to eliminate the bias of the researcher, but to recognize it and incorporate it into the process (Davis, 1978).

The researcher employs descriptive methods to investigate the experience and communicate it (Colaizzi, 1978). To do so in a way that remains loyal to the participants' perspective, the researcher must acknowledge preconceived expectations and strive to set these aside. In this way, predetermined categories or frameworks are not applied to the experience; rather, the meanings identified are those that emerge from the participants' descriptions (Omery, 1983). This goal is pursued through a process of continual clarification and validation of the researcher's interpretations with the describers. A description true to the experience can then be developed (Omery, 1983). Greater insight into the process of analyzing

the data will be provided in the methodology chapter (see Chapter Three).

Phenomenology is seen to be an appropriate research method given not only the research questions of this investigation, but also the inherent nature of nursing practice. Nursing involves social action, therefore, knowledge integral to nursing practice is that which enables the practitioner to better understand the client's experience (Davis, 1978). This is the knowledge generated by the phenomenological approach. Thus, phenomenology is seen to be a valuable method for the investigation of this nursing problem.

Assumptions

Throughout the process of the research study, the researcher acted upon some fundamental assumptions. It is assumed that:

The family is the primary social unit (Goode, 1964), and as such serves two central functions: 1) to meet the needs of its individual members, and 2) to meet the needs of the society of which it is a part (Friedman, 1981). The illness of an adult member with COPD affects the daily life of the family, and the functioning of the family unit (Litman, 1974).

The illness experience constructed by the family members as a group represents the family experience. The perspective provided by the family unit is unique, and is not available from any one member or group of members of the family

(Blumer, 1969; Reiss, 1981). The description resulting from the research represents the views of the participant families and their culture (Giorgi, 1975).

Limitations

Because the research findings reflect the views of the participant families, the study is limited by the characteristics of the families who participated in the study (see Chapter Three, pp. 35-36). The description of the family experience of living with COPD may be limited, for example, by the following characteristics of the research group: primarily Anglo-Saxon ethnic background; access to specific health care, such as a medical specialist and a respiratory rehabilitation program, and the position of the ill adults within the families, being a member of the marital couple rather than an adult child or an elder parent.

In addition, data collection was constrained by the limitation of completing the research investigation within a restricted time period. Further interviews with the families may have achieved a greater depth of understanding and achieved saturation of the themes developed from the data, thereby enriching the description and explanation of the family experience with COPD.

Summary

This introductory chapter began by describing the nursing context of the research problem, thereby explaining the rationale and purpose of the study. To complete the introduction, the conceptual framework, the research questions, the methodological perspective, the assumptions, and limitations of the study were addressed. The next chapter provides a review of literature pertinent to the investigation.

CHAPTER TWO

Review of Selected Literature

This chapter examines pertinent theoretical perspectives and research studies in order to place this investigation within the context of current literature. The literature reviewed was selected on the basis of an interactional view of illness, that is, a perspective that views the disease, the ill person, and the family as reciprocally influencing elements of the illness experience (Lewis, 1976; Verwoerdt, 1972). From this perspective, the review of selected literature is organized in two main parts: 1) the influence of the family on the individual with COPD, and 2) the impact of COPD upon the family.

Family Influence on the Individual with COPD

In seeking to understand the influence of the family upon a member with COPD, it is useful to first examine the theoretical perspectives of a family's influence on a member with any illness, and then more specifically review the research concerning the family in which a member has COPD.

Theoretical Perspectives

It is widely acknowledged that the family acts as a primary influence upon an individual's adaptation to illness (Litman, 1974; Mauskch, 1974; Schontz, 1975; Wright & Leahey, 1984). This influence is expressed in two main ways: as a

factor influencing the perception of illness, and as a potentially supportive or disruptive factor in the adaptation to illness. Both these aspects are addressed in the following presentation.

People attach meanings to their experiences (Black, 1983). When ill, people actively define the meaning their illness holds for them. This meaning then acts as a major determinant in their response (Nerentz & Leventhal, 1983). Many factors contribute to the creation of the meaning of illness, primarily, the person's background and personal characteristics, the timing of the illness in the life cycle, the illness related factors, and the physical, cultural, and human environment (Moos & Tsu, 1977). However, the family is viewed by many as the single most important influence in the formulation of this definition of illness (Blacher, 1970; Feldman, 1974; Shontz, 1975). Because the family is the primary social unit, it is in this environment that the meaning of illness is created. For the chronically ill who confront not a temporary adjustment but a permanent lifestyle change, it is where "the meaning of chronicity comes to be born" (Quint, 1969, p. 61).

The family environment is also recognized as among those primary resources that can enhance a member's adaptation to illness. Caplan (1974, p. 8) explains that "the best known and most ubiquitous support system in all societies is the marital and family group," and goes on to describe its supportive functions as: sharing among members, providing feedback and

guidance, contributing to emotional mastery, acting as a source of aid, a haven to rest and recuperate, a reference group, and a source of identity. Although it is recognized that the family can buffer disruptive stressors, the family is also known to be a source of these stressors. In other words, the family has the potential to enhance or inhibit its members' abilities to cope with illness (Murawski, Penman & Schmitt, 1978).

Given the significant role of the family in the illness experience of its members, it is logical that the influence of the family would be reflected in studies of adults coping with COPD. Studies of individuals with COPD are reviewed to explore this assumption.

Research Studies of Individuals with COPD

A limited number of studies were found that explored the experience of individuals coping with COPD. Four pertinent studies are reviewed, focusing on the influence of the family on the individual's illness experience.

Substantial insight into how individuals cope with COPD is offered in an exploratory descriptive study by Chalmers (1980). She investigated the coping strategies of 30 people with varying degrees of airflow obstruction. Both qualitative and quantitative data were collected in relation to: the participants' perceptions of their health and how they coped, gathered by semi-structured interviews; their perceptions of

locus of control, measured by the Multidimensional Health Locus of Control Scales; and a numerical measure of health, provided by the Grogono Health Index. Quantitative findings supported the qualitative finding that coping ability was related to the individuals' perceptions of their disease, its effect on their daily lives, and their health status.

Chalmers indicated that her findings support the thesis that the meaning attributed to illness is a significant determinant in an individual's ability to cope. Because the family is known to be a primary factor in the formulation of the meaning of illness, the writer suggests that these findings also reflect the family's influence upon the individual's ability to cope with COPD. Consistent with the writer's premise, Chalmers further reported that the primary concern described by most participants was their ability to maintain a desired role in the family. This is clearly an aspect of the individual's experience that is integrally related to the family's response to his/her illness.

The significance of the family for the individual's experience with COPD is reflected in another study by Hansen (1982) that explored adults' perceptions of the effect of chronic lung disease on life in general and on sexuality. Survey questionnaires were completed by a convenience sample of 128 adults who were receiving outpatient care for diagnosed lung disease. The questionnaire addressed the effect of lung disease on the following areas: life in general; employment and income; self care, business and home responsibilities;

marriage; sexual aspects of marriage; emotional aspects of marriage; care of children/grandchildren; emotions; and, dependency on others. As well, the questionnaire addressed the effect of symptoms and treatments on life in general and on sexuality. On a seven point Likert scale, the participants overwhelmingly chose the highest numerical indicator of the effect of lung disease in each of the 11 areas. Although the participants perceived that the impact of lung disease was marked in all areas, their perceptions of how the disease had affected their lives varied between participants. For example, the effect of the disease on their dependency on others was perceived by 40% to be positive, 22% to be neutral, and 38% to be negative. The effect on marriage was seen by 37% to be positive, 2% to be neutral, and 61% to be negative. To the writer it appears clear that the way each family responded to the illness would have substantially influenced the individual's perception of the effect of COPD on these aspects of his/her life.

Because the Hansen study reported no reliability or validity for the questionnaire that was used, and did not use a random sample, the generalizability of the results are questionable. It is noteworthy, however, that the participants perceived that all aspects of life were greatly affected by COPD, and the majority of the aspects surveyed related to family life. The variability in the way the disease was perceived by the participants to affect aspects of their

lives could reflect, in part, the influence of the family in the formulation of their perceptions.

A study by Barstow (1974) also reflects the family influence on the adult with COPD. Barstow interviewed 11 adults with emphysema to explore their coping strategies. It was found that one of the most important factors promoting the individual's ability to cope was the presence of another significant person. To the writer, this finding indicates the importance of the family unit to individuals with COPD. After all, the family is the primary social unit, and as such provides the primary source for those relationships found by Barstow to enhance the ill person's ability to cope.

Results of a study from a different perspective support the view that the family is an important influence on a member's experience with COPD. In a quantitative study, Pattison (1974) examined physiological, psychological, and sociological factors as possible predictors of death in 12 men with emphysema whose mortality risks were high. Neither physiological status measured by blood gases and pulmonary function studies, nor psychological status measured by the Inpatient Multidimensional Psychiatric Scale, correlated with death or clinical improvement. The only variable related to clinical improvement was the presence of an intact, positive network of social relationships and the ability to use social resources. In contrast, disrupted and poor family relationships were correlated to earlier death. Although specific relationships are difficult to establish in a

situation with many contributing factors and the sample size of the study is small, the powerful influence of social relationships, especially family relationships, indicated by the findings is striking. Pattison postulated that the source of the influential strength of social relationships relates to the life force of "having someone or something to live for" (p. 145). Again, the family unit provides the primary source of these relationships. Thus, the family influence on the illness experience of a member with COPD can be inferred from Pattison's findings.

The implication of the integral role played by the family as a person copes with COPD is provided by the findings of the four studies reviewed. These studies also indicate, however, that the family can act as either a resource or a liability to its member's adaptation, which is consistent with the perspectives of other theorists (Kaplan, Smith, Grobstein & Fischman, 1973). Caplan (1974) indicates that to be an effective source of support to an ill member a significant degree of intactness, integration, and stability within the family is necessary. Relating this to the family with COPD, how the family copes with its member's illness is important to the well-being of the member with COPD, as well as to the well-being of the family unit. The following section reviews the literature to assess the theoretical base available to understand how COPD affects the family.

Influence of COPD on the Family

A review of literature to identify research concerning families coping with COPD revealed a dearth of research investigations specific to this important area. Only one study, the effect on the lifestyle of spouses of men with COPD, was found that focused on the experience of family members. Consequently, literature was reviewed that dealt more generally with families with chronically ill members, in order to provide a basis from which to view the family experience with COPD. Thus, theoretical perspectives are discussed in the first part of this section of the literature review, and in the second part, the current empirical base is reviewed for its adequacy in providing a more specific understanding of the family experience with COPD.

Theoretical Perspectives of the Impact of Chronic Illness on the Family

"Individuals have chronic diseases; families cope with chronic illness" (Mitchell, 1983, p. 2). It has long been recognized and supported by research findings that illness acts as a disruptive influence within the family (Anthony, 1970; Cooper, 1984; Klein, Dean, and Bogdonoff, 1967; Koos, 1946; Maurin & Schenkel, 1975). The well known writings of Hansen and Hill (1964) of families under stress cite illness as a stressful event that causes possible crises within the family. A stressful event for the family is defined as one that

produces changes in the family social system, its boundaries, structure, goals and processes, roles and values (Burr, 1973). The view of illness as stressful and potentially crisis-producing is now prevalent throughout the literature (Benoliel & McCorkle, 1978; MacVicar & Archbold, 1976; Mitchell, 1983). Benoliel indicates that "some health care problems can lead to social crises of serious dimensions that interfere with a family's capacity to function or with the human needs of some of the family members" (1982, p. 109).

The changes ensuing from the stress of a chronic illness, however, are seen to differ from those that accompany an acute illness; for chronic illnesses are permanent rather than temporary. They are uncertain in their prognosis and in the occurrence of acute exacerbations that usually accompany the illness. They intrude on lifestyle, commitments, and activities at home and socially. Furthermore, the accompanying symptoms demand that efforts constantly be aimed at relief (Strauss et al. 1984). Obviously, these characteristics of chronic illness pose challenges that do not accompany a temporary illness.

Based upon studies of people who have chronic illnesses, in their book, Strauss et al. (1984) identify multiple problems these individuals commonly face: preventing medical crises and managing those that occur, controlling symptoms, carrying out treatment regimens, confronting potential social isolation, adjusting to the changing course of the disease, attempting to normalize interactions with others, managing financial

implications of the illness, and confronting the accompanying psychological, marital, and family problems. These authors emphasize that the strategies to handle these problems involve the family; assistance of family members, reorganization of family life, and new activities within the family are necessary.

Although Strauss and his colleagues add great insight into the problems that face the chronically ill generally, further knowledge of the way particular chronic illnesses create these problems would provide greater direction to enable nurses to plan care to meet the needs common to families coping with a specific chronic illness, such as COPD. Furthermore, their work provides the perspective of the individual coping with chronic illness, not the perspective of the family unit.

In contrast, McCubbin et al. (1980) attempt to place chronic illness within the context of the entirety of family life. From this perspective, the stressor of illness is only one stressor within the family's life. These authors propose that the family concurrently manages various aspects of family life: maintaining internal communication and family organization, promoting member independence and self-esteem, maintaining family bonds, maintaining and developing social supports, and continuing efforts to control the impact of the stressor and the amount of change in the family unit. Family coping behaviour is seen as "a process of achieving a balance in the family system which facilitates organization and unity

and promotes individual growth and development" (p. 865). The illness is only one force acting upon this process.

Mitchell (1983) contends that although the family manages these broader tasks of family life, the focus of the family changes during times of crisis, such as in crises accompanying chronic illness. Energy within the family at these times centers on crisis-oriented tasks of supporting one another and marshalling resources to restore the family equilibrium. She maintains that if the crisis is not resolved and symptoms of tension continue to exist, family growth may be permanently retarded. Consistently with Mitchell's assumption, Feldman (1974) indicates that the incidence of breakdown in families with a chronically ill member has been found to be higher than average. He goes on to describe that this has been attributed to the continuing force of poor health within the family and the disrupted family functioning accumulating over time.

The theoretical base presented here clearly indicates that the family with a chronically ill member confronts a stressful situation and is susceptible to disrupted functioning of the family. Given this knowledge, nursing attention to the needs of the family as well as the ill member is integral to the promotion of the health of all members and the family unit itself. As was indicated earlier, in order to provide effective family-focused care to families in which an adult member has COPD, nurses require an understanding of what these families experience. Thus, the current empirical base is reviewed by the author to determine the adequacy of this

knowledge base to provide an understanding of the family experience with COPD.

Review of Current Research Base to Understand the Family Experience with COPD

Studies of the family with COPD are conspicuously absent from the literature. The research studies published about families coping with illness predominantly concentrate upon families with an ill child, a mentally ill member, a member with a stable disability, an acute illness, or cancer. In the author's opinion, the empirical base developed by these studies is inadequate to gain an understanding of the family with COPD.

The family with an ill child appears to have been the major focus of research in this area (Burton, 1975; Hayes & Knox, 1984). But an adult's illness represents a different experience for the family than when a child, who is in a dependency role, is ill (Davis, 1980). For this reason, studies of families dealing with a child's illness are seen as an inappropriate base from which to develop an understanding of the family with a chronically ill adult.

Studies of families with an acutely ill member or a member with a stable disability are also seen as inadequate for understanding the family with COPD. Significant differences exist between coping with a temporary illness or with a stable disability, and facing the permanent but progressive changes of a chronic illness (Beland & Passos, 1975).

In relation to an acute illness, Dimond and Jones (1983a)

describe the limitations of using the classic sick role framework by Parsons to interpret the social impact of chronic illness. According to Parsons (1951), individuals who are sick are not held responsible for causing their conditions, are exempt from usual social role responsibilities, and are only responsible to find competent medical help and cooperate to restore their health. Whereas the sick role framework may apply to acute illness:

In chronic illness, usual role performance may be only partially resumed after the acute stage of the illness; motivation to get well is an inappropriate expectation in the presence of irreversible pathology; considerations of quality of life may outweigh the obligation to seek treatment; and compliance with medical advice can be only a partial expectation when the client and the family are the major managers of the illness (Dimond & Jones, 1983a, p. 42).

Similarly, the expectations upon an individual with a stable disability can also differ from the expectations others hold for those with a progressive chronic illness (Melvin & Nagi, 1970).

In light of the difference between the social context of acute, chronic, and stable disabilities, the findings from studies of acute illness or stable disability within the family are seen by the writer as inadequate or possibly inappropriate as a base for nurses' understanding of families with COPD.

Even studies of families with adult members with chronic illnesses other than COPD are seen by the writer as insufficient to understand the COPD experience. Benoliel (1983) proposes that disease characteristics such as the

awareness of prognosis, effectiveness of available medical treatment, social visibility of the disease, and the anticipated disease course, influence interactional patterns in families. Different diseases then create different forces upon the family experience. This is not to say that families with members who have different types of chronic illnesses or with ill members of different ages do not share many similar challenges and experiences that are common to the family with COPD, but disease-specific demands also exist. Transferring knowledge gained from investigations of the family experience with another chronic illness to the family with COPD could lead to distorted interpretations of family behaviour. Perhaps the significant aspect of living with COPD may be overlooked or underrated without understanding the specific demands related to the characteristics of COPD.

However, few studies were found of the family with COPD, from either the perspective of individual family members or the family unit, that would enable a reader to gain an indepth understanding of what the family with COPD experiences. A recent study by Sexton (1984) is a beginning to address this need.

In an exploratory study, Sexton investigated how the lifestyles of women were affected when their husbands had COPD. Questionnaires were completed by 46 wives of men with COPD and 30 wives of men who had no chronic illnesses. The questionnaires comprised four sections: biographical data, an Illness Impact Form, a Subjective Stress Scale, and a Life

Satisfaction Index. The results indicated that of the men with COPD, half were dependent upon their spouses some of the time for activities of daily living. The wives of men with COPD reported additional responsibilities and the assumption of new roles as these became vacated by their husbands. The women identified psychological problems in relation to: their husbands' attitudes, irritability and complaints; their own loss of freedom; and the worry about their husbands' health and whether they would recover from acute exacerbations. Most wives kept disturbing information from their husbands in order to avoid distress-caused breathlessness. Most of these women had given up recreational and social activities because of the problems in planning, the day-to-day fluctuations in their husbands' health, and their intolerance to second hand smoke. Awakening during the night due to the husband's shortness of breath, coughing, or restlessness was reported by nearly all wives. Some had stopped sleeping in the same bed or same room with their spouses. The frequency of sexual relations was lower in the couples with COPD than those without. With the loss of the husband's income, many wives worked longer and nearly all assumed responsibility for financial management in the family. Finally, these women reported significantly higher stress scores and lower life satisfaction than wives of husbands without chronic illnesses. Visibly, the lives of the spouses of men with COPD are drastically altered, and certainly their well-being threatened.

Both Sexton's study of wives of men with COPD and studies of individuals with COPD, such as that by Chalmers, contribute considerable insight into the demands of COPD itself and the complex interaction between the disease, the ill person, and the family. This seems inadequate, however, without the perspective of the family unit, that is, how the family members as a group describe and explain their experience. After all, the members of the family together create a perspective distinct from that of the family members individually (Blumer, 1969; Reiss, 1981; Thorne, 1983). The experience of the individual family members, therefore, may not reflect the experience of the entire family unit. To understand the family experience, the family must be the focus of investigation.

It is not surprising that the perspective of the family with COPD has not been previously studied, as few studies of family phenomena have investigated the experience from this focus. From the literature, it appears that there are two main reasons for this. These are reflected in questions that are posed throughout the family stress literature, which are: is there a collective family perspective, and, if so, what is it? And, what is the best method to elicit it? (McCubbin, et al. 1980, p. 862).

The complexity of the task posed by studying the family members together can be formidable. Family life is complex, as is the method of capturing the abstract phenomena of family descriptions in concrete terms. The deterrent this presents is aptly reflected in the writing of Gourevitch (1973, p. 22):

"The family's reaction can be only examined within the context of the ongoing transactional observations that take into account the large numbers of variables involved, and this probably accounts for the dearth of studies of this type."

Regardless of the difficulties inherent in family research, investigating illness from the perspective of the family is necessary, for nurses and other health care professionals deliver care to families as well as their individual members. Furthermore, individual concepts alone are inadequate to provide these groups with an understanding of illness within the complexities of the total family system (Bishop, Epstein & Baldwin, 1981).

In conclusion, this literature review indicates the following: the family members' interactions affect a member's response to his/her illness; chronic illness represents a stressful situation to the family as well as the ill member, altering the family's way of life; and, the experience of the illness may threaten family functioning, affecting the health of each member and the ability of the family to support the ill member. This writer argues that the current research base does not provide adequate insight to understand the experience of the family with COPD, which is necessary if nurses are to be responsive to the needs of these families. As well, the author submits that the family experience can best be ascertained from the family group. This investigation of the experience from the perspective of the family group is seen to contribute to a

knowledge base presently inadequate in the literature, one that can enhance the nursing care provided to families with an adult member with COPD.

Summary

This chapter reviewed literature in relation to the influence of the family on the illness experience of a member who has COPD and the impact of COPD on the family in order to place this investigation within the context of the current knowledge base. Because there were limited research studies found concerning families with COPD, literature was also reviewed from the more general perspective of families with chronic illness. The author then critiqued the adequacy of the present research base for nurses to gain an indepth understanding of the family experience when an adult member has COPD, and found it lacking. The next chapter describes the process of this investigation undertaken to address the identified need.

CHAPTER THREE

Methodology

The methodological perspective of phenomenology, as described in Chapter One, provided the structure for this research investigation. This chapter will delineate the process of applying the method in this study of the family experience with COPD by addressing the following areas: the selection of participants, data collection, data analysis, and ethical considerations.

Selection of Participants

The purpose of the study was to describe and explain the experience of the family with COPD. From a phenomenological perspective, participants act as co-researchers, and therefore, are selected on the criteria that they have experience with the topic studied and can communicate it (Colaizzi, 1978). Consistently with this approach, the intent of the selection process in this study was to access families in which a member has COPD. A description of the selection criteria, the selection procedure, and the characteristics of the families who acted as participants in the research follow.

Criteria for Selection

The specific criteria established to select the participant families were:

1. The family has an adult member with COPD presently

living at home.

2. The adult is diagnosed with COPD, and as determined by his/her physician, is not in a terminal stage of illness.

3. A voluntary interest in being interviewed and sharing their family's experience is expressed by the members.

4. The family members have the ability to communicate fluently in the English language.

5. The family resides in the Greater Vancouver area.
The rationale for establishing each of these criteria follows.

It was specified that the ill member be living at home, as the focus of study was the impact of the illness upon the family's daily life, not solely the experience of having a member in the family with COPD. Those people who were determined to be at a terminal point in their illness were excluded in an attempt to avoid requesting families to participate in another emotional experience at a time the family is preparing for a member's death, as well as to avoid requesting individuals with extremely limited energy to participate in an energy consuming activity. Family involvement was sought on a strictly voluntary basis to respect the family's right to chose participation, as well as to enlist families interested in contributing to the study. This is consistent with the methodology chosen (Colaizzi, 1978). The language requirement was designed to ensure the families were not restricted in their ability to clearly relate their experiences to the researcher who is fluent in English only.

The geographic restriction ensured that the researcher, limited by time and costs, could travel to interview the families in the comfortable surroundings of their own homes. This criteria was also selected because it was anticipated that travelling to interview sites may be difficult for the ill adults.

Selection Procedure

A specific procedure was followed to acquire families who met the established criteria. Upon request, three respiratory physicians consented to identify people in their practice who met the selection criteria (see Appendix A). The names and addresses of the clients were provided to the researcher who then sent information letters to inform them of the study and request their participation (see Appendix B).

Allowing time for receipt of the information letter, the individual with COPD was contacted by telephone to discuss the research and request the family's decision about participation. The intent to interview all the family members together and to tape the interviews, as stated in the letter, was reiterated in the telephone conversation to ensure the data gathering process was understood. If a verbal consent was given by the client on behalf of his/her family, a mutually convenient time for a family interview was arranged. At the outset of the first interview, the entire family's consent was formalized in the signing of the Family Consent Form (see Appendix C).

The selection of some participant families was directed by

the results of early data collection and analysis. The ill adults in four of the six initial families interviewed were involved in a respiratory rehabilitation program. Because it was thought that participation in this program may affect a family's experience, it was decided to include families where the ill adults were not involved in such a program. Consequently, a respiratory physician was contacted who did not refer his clients to a rehabilitation program. Using the same procedure and following the selection criteria, additional families whose ill members were not involved with a rehabilitation program were solicited for participation in the study. This decision about participant selection made during the course of the investigation was consistent with the qualitative method, wherein additional participants are sought to obtain data that will more fully address questions arising in the process of investigation (Lofland, 1984).

Description of Participant Families

Eight family groups ultimately acted as co-researchers in the investigation of the family experience with COPD. A description of the families is provided to share their demographic characteristics with the reader.

Composition of the family groups. In five of the eight families, the marital couple represented the family group. Each of these couples has adult children living away from home, but in the Vancouver area. In the other three families, the groups comprised: a marital couple and their daughter; a

marital couple and their three children; and a marital couple, maternal grandmother and brother, son, daughter and her young child. In all families, only the marital couple is presently living at the family home.

Characteristics of the ill adults. In all families the adult with COPD is a member of the marital couple. Four of the ill adults are women and four are men. The ages of the ill members vary: one is 49, five are in their sixties, and two are in their early seventies. All the ill people perceive their airflow obstruction to limit their activities. Four of the ill adults participate in a respiratory rehabilitation program. None are able to work, or else they are retired. Three of these individuals have additional chronic illnesses, namely arthritis, systemic lupus, and coronary artery disease.

Characteristics of the family members. The age range of the spouses corresponds closely to their partners, except in the case of one wife who is approximately 10 years older than her ill husband. The children who participated are 35 years old or younger, and live away from home. In all families the spouses and other family members have no disabling illnesses. Only one of the spouses, the husband of the youngest ill woman, is employed.

Cultural characteristics. In six families, all the members are Canadian born. In the other two families, both members of the marital couple were born in England, coming to Canada in their early adult years.

Data Collection

"From a phenomenological perspective, description or language is access to the world of the describer" (Giorgi, 1975, p. 74). Indepth interviewing was, therefore, the method of data collection chosen. The adult with COPD and the family members together were interviewed in their homes, the environment selected to promote the members' expression of their feelings and ease in describing their experiences (Omery, 1983).

Arranging the interviews, the researcher experienced some of the limitations demanded by COPD. For example, an appointment was cancelled because a daughter had a cold and was consequently unable to go to her parents home. The interviews were usually planned on a tentative basis, because of the daily uncertainty of the ill member's symptoms. Phone calls on the day of the interview confirmed the appointments. The interviews usually took place in the afternoon, as for many with COPD this was the time of day when their breathing was easiest and their energy the greatest.

Originally, two interviews were planned with each family. An interview guide of open-ended questions (see Appendix D) served in the initial interview to help elicit the families' descriptions of their experiences. The researcher then asked questions that arose from the analysis of the family's description and from interviews with other families (Lofland, 1984). Six of the families were interviewed twice. It was the

researcher's experience that as she became more familiar with the experience described by the families and more skilled at facilitating the members' construction of their accounts, indepth data could be achieved with some families in one interview. Consequently, only one interview was held with two of the families.

All interviews were audio-tape recorded. In addition, written field notes were kept of the interviews and telephone conversations. Often after the tape recorder had been turned off, further data was revealed in the pursuant conversation. These were subsequently recorded as field notes. During one interview the recording tape broke, which necessitated that the interview be recorded from the researcher's memory, immediately after leaving the family's home. The interviews varied in length from 45 minutes to two hours.

As the essence of data collection is the family's description, the reseacher's ability to help the members provide a clear, rich description of their experience was an integral part of the interview process. Taking time initially with the families to promote a sense of mutual trust and respect, fundamental to any effective relationship (Egan, 1982), was important to enhance the family's ease in telling the researcher its "story" (Olesen and Whittaker, 1967). Therefore, prior to the interview, the researcher shared some personal information about herself, such as the area of Canada she was from, her nursing background, and her interest in the experience of families like their own. In addition, the

researcher explained her intent of disseminating the research results in order to influence the care available to families who had an adult member with COPD, and briefly outlined the process of the research in which the families were involved.

The investigator found it beneficial to clarify at the beginning of the first interview the restrictions on her participation in the discussion, that is, she was enacting the role of a researcher rather than a clinician. The need for this role clarification was evident during the second and third family interviews when families asked questions to draw upon the researcher's clinical expertise. These questions were dealt with by either reiterating the constraints of the researcher role, using the question as an area for further discussion, or providing concrete answers to the information requested, as appropriate.

Data Analysis

The families' accounts were analyzed using constant comparative analysis (Giorgi, 1975). Following the transcription of an interview tape, the content was analyzed to identify "units of meaning" within the account. Initially each description was read from a fresh perspective, holding the other family accounts apart, to allow the important aspects of that family's experience to emerge. Often times the themes would not be found in the actual words of the description but "between the lines" (Barritt, Beckman, Bleeker & Mulderij,

1984).

Once the transcript was analyzed, the identified meaning units were then compared with those from the accounts of other families, to identify common themes and variations. This analysis involved continual movement back and forth from the transcripts to the themes, from major themes to small meaning units. Although not all families described each of the shared themes, those identified reflected common patterns of meaning across several accounts. Variations in the accounts were also identified, which added further insight into the meaning of the experience.

In keeping with the constant comparative method, data analysis occurred simultaneously with data collection. The emerging themes identified from the analysis became content for subsequent interviews, to deepen the families' descriptions and to clarify and validate the researcher's analysis. Once all interviews were complete, analysis of the data continued until the themes were synthesized into a broad framework that described the family experience of living with COPD.

Ethical Considerations

Participant families disclosed their experiences, thoughts, and feelings, and gave their time and energy to the research study. To ensure that the rights of the families were protected, a protocol was followed (Canada Council, 1977; Canadian Nurses Association, 1972):

Confidentiality was ensured. The families' participation in the study was not revealed to any persons, including the referring physician. The tapes and transcripts were coded, any identifying marks removed, and stored in a locked filing cabinet. Access to the data was restricted to the investigator and the two members of her thesis committee, and the latter only in a limited manner. Arrangement was made to erase the tapes and shred the transcripts within three to five years of the study.

Measures were taken to respect the families' right to refuse participation, to refuse answering any questions, and to withdraw from the study at anytime. This was achieved through the method of consent described earlier in the chapter. The information letter and the consent form (see Appendices B and C) informed the families of their rights. Furthermore, at the beginning of the interviews, the researcher reiterated the rights of the families in the process of the research.

The families' right to receive health care was respected. Referral to appropriate contacts for assistance were made in two incidents, assessed through discussion with family members who indicated they were experiencing disrupting family problems due to coping with the illness. Information requested by the families that was judged as inappropriate for the interview process was provided to the families once the interviews were completed. These related to areas such as medication regime, exercise, energy-saving techniques, handicapped parking,

respiratory rehabilitation programs available in the community, and of most significance, the experiences of other families with COPD.

An agreement was made to share the findings of the study with the participant families by sending them a written summary of the research findings once the thesis was completed.

Conflict arose for the researcher due to the temptation to step into a therapeutic role during the interview process, that is, to fulfill the role of a clinician rather than that of a researcher. Although it was not the goal of the family interviews, the therapeutic value of the experience was communicated by the families. Families indicated that through the interviews the members had achieved a greater understanding of other members' thoughts and feelings. Most families reported that it was the first time the members had discussed their experience together as a family unit.

Summary

This chapter outlined the process undertaken to apply the phenomenological method in this study of the family experience with COPD. The outcome findings, the families' accounts of their experiences, their discussion and significance, follow in the subsequent chapters.

CHAPTER FOUR

Families' Accounts

This chapter addresses the findings of the research study. Family life with chronic obstructive pulmonary disease is described and explained through an integration of the participant families' accounts and the researcher's analysis and interpretation.

As stated in Chapter Three, the data were analyzed through a process of constant comparative analysis. Although each family's story was unique, this process enabled the researcher to identify the commonalities among the family accounts. These data were then developed into interpretive themes that describe the meaning of the experience from the perspective of the participants. For this thesis, the researcher selected and developed three of the central themes to describe and explain family life with COPD.

The first theme, "disease-dictated family life," provides the foundation from which the description builds. Here, the pervasive control exerted by COPD is addressed by describing four aspects of family life dictated by the disease. The second theme, "isolation," builds upon this content by describing the isolation that accompanies the illness experience, for the family group and for the individual members within the group. The final theme, "family work," enriches the description by explaining four challenges the families living with COPD face and the coping strategies they employ to deal

with them. These three themes and the subthemes of each are developed throughout the following description of family life with COPD.¹

Disease-Dictated Family Life

When the families related their experiences of living with COPD, they projected the sense of living with a disease that insidiously enters their lives, closing in more and more on family life as it progresses: H: "It all happened so gradually that we were just trapped before we -- IW: realized it." The family gradually comes to feel surrounded, owned by the demands of the ill member's lung disease. That the disease dominates the ill member's life and in turn dominates family life is illustrated by this ill woman's comment: "Everything seems to be according to your every whim. You don't want it that way, but that is just the way it is."

The powerful grasp of COPD upon the family originates from the nature of the disease itself. COPD attacks the essence of life -- breath. The profound threat this poses was clearly and succinctly captured by one man's comment: "You can't stop breathing or you die." The life-threatening nature and the suffocating symptoms of the disease highlight the COPD member's ability to breathe so that it takes priority within

1. The following abbreviations are used in the body of this chapter to identify the speakers being quoted: IW: Ill woman; IM: Ill man; W: Wife; H: Husband; D: Daughter; S: Son; R: Researcher.

the family. The whole family group must conform to a lifestyle aimed at avoiding breathlessness. It is not a choice that is deliberated within the family, but one that emerges from necessity. The necessity of adopting this lifestyle is evident in this passage:

IM: I was panting at first, wasn't I? (W: Yeah) Short of breath and panting. You know, as though you'd run around 100 yards in ten seconds.

R: So trying to get your breath. (W: Yeah)

IM: But now, you -- you don't pant now. Panting, you don't do any of that now, because you don't do anything that gets you to that stage. (R: Ahh) 'Cause you know you can't do that. You know that if you got to that stage, that'd be it. . . .

R: So you know your limit, and so you avoid pushing yourself?

IM: Oh, you bet. (W: No doubt about it.) You have to. You're reminded of it right away.

Thus, to avoid breathlessness and accommodate for the changed COPD member, the entire family assumes a disease-dictated lifestyle. What this entails was clearly articulated by the families: A) a breather-protected environment, B) an energy-economy, C) a present-time orientation, and D) altered roles within the family. In order to describe the lifestyle that is dictated by COPD, each of these four aspects is addressed in the following passages.

A. Family Life within a Breather-Protected Environment

The families explained that the sufferers of COPD need an environment that is "breather-protected," that is, an environment controlled for anything that provokes shortness of

breath or could extend the lung damage:

IM: I'm not even supposed to go near anybody else who does smoke, you see. . . . The doctor has given me strict orders to stay well away from anything or anybody that causes any odors, or smoke or gases or impurities in the air or anything.

As a result, the environment of all family life must be breather-protected.

Maintaining an atmosphere that is as irritant free as possible becomes of foremost import in the family. This was obvious by the emphasis the families placed on describing the behaviours they used to achieve this goal. For example, because respiratory infections compromise the COPD member's already limited lung function, the family members avoid introducing infections into the family environment:

D: And I think, you know, if you even suspect that you're getting a scratchy throat or anything like that, you can't come, you know, within a hundred miles. . . .

D2: You take colds for granted until you, you know you're carrying lethal weapons.

The intensity of the threat this evokes is obvious. An infection not only robs the ill member of air, it may mean his/her death.

Furthermore, family members stop irritant producing habits, such as wearing perfume and frying foods. Because smoke is one of the most potent of these irritants, this habit must either be stopped or isolated:

H: I smoke, stupidly, but I smoke out on the balcony.

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IM: But my wife spends half her life in the kitchen now. We have a kitchen you can smoke in because there's no cold air register there. So we close this door and the other door, and open the back door. Then if the furnace comes on it can't suck the smoke down and puff it up around the house. It just goes out the back door.

As illustrated by these quotations, there is no question as to what takes precedence. The smokers in the family must devise ways to protect the COPD member if they are to continue their habit, for an irritant free environment takes priority.

In addition to controlling irritants and infection, the family members restrain the expression of emotion. For they know that intense emotions are also breather-hostile:

H: As long as my wife's nerves are reasonably calm, and she's not upset or worried about something, the breathing is a lot better. But when she gets upset, for whatever reason, I mean I could name a thousand things. It could, might be nothing related to the illness, I mean, it could be something happening outside, or something that I've done or something the family has done or hasn't done type of thing, and you're --

IW: All of a sudden -- just can't breathe.

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W: That's another thing, no upset -- you know. He tries to avoid any upset in any way, shape or form. Because (IM: Whether it's good or bad) . . . Right out of breath he goes -- in any excitement.

Indeed, the COPD member's need for an irritant free environment imposes pervasive restrictions on the family. Much of family life becomes confined to a breather-protected environment.

B. Family Life within an Energy Economy

The families indicated that COPD diminishes the ill member's capacity for activity. Extra energy is expended to breathe, at the same time that the capacity for oxygenation is restricted; so only limited energy is available for other activities. Consequently, the families find their life as a group dictated by the limited energy capacity of the ill family member. In other words, family activities are confined within an "energy economy," the capacity of which is determined by that of the COPD member:

IW: Even a dinner party is almost, well it's impossible. It is impossible really, I can't do it.

H: Can't plan it or anything.

IW: I'm in bed usually by 8:00 at the very latest, and usually by 7:00. And you just can't go for dinner and expect people to have you for dinner. When they're starting, as I say, when you're ready to go to bed. So our dinner parties are more like late lunches. (D: Yea, usually in the late afternoon.) So that stops that right there. As for any other kind of activity, I can't think of anything else we do, except go out and shop once in a while.

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H: There's no point in us getting a trailer or a motorhome, because they are fine and dandy when you are hauling them along the highway. But when you stop at night, you've gotta do something. And that something requires walking. (R: energy) Energy. It's all very well to drive a motorhome to the Grand Canyon, you can't drive the thing right up to the edge and have a look at it. You've got to park it back there and walk to the edge.

Any activity of the family group consumes a portion of a limited resource -- energy. That the family must be constantly aware of energy was illustrated by their emphasis on the

necessity to plan and organize family activities. Activities are planned for the maximum use of minimum energy. These limitations on the family's activities and the planning efforts necessary are reflected in this passage:

W: Well, you can't go any place. Like if you go shopping, you can't walk very far. He has to stop and take a breath all the time. That's not too bad, we have all day to do that. When we do go we have a parking ticket on our car, so you can park and you walk slowly.

Energy has become a limited commodity that must be rationed for use in the most valued activities -- if those are to be activities of all the members of the family group. The extent of the COPD member's lung disease establishes an energy economy that dictates the activities now possible for the family.

C. Family Life within a Present-Time Orientation

Another aspect of family life dictated by COPD is an orientation to life in the present. This present time orientation is linked to a sense of uncertainty that pervades family life.

Firstly, the family cannot predict how the COPD member will be feeling, or what s/he will have the ability to do, from day to day or hour to hour, as these following passages indicate:

W: It's a funny thing this emphysema, you know. It really is. It's up and down.

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D: You have days when you can do more than you can do other days.

IW: Oh yeah. Some are better than others.

D: Some days you can't do anything but sit in a chair.

One man captured the unpredictability of the symptoms and the uncertainty with which the family lives:

H: I think you can sum it up in that, is that everyday, for us, is a new day. We don't know what to expect.

No matter what is done to control the environment or activity, the family cannot be sure what might affect the ill member's breathing:

IM: Even the weather change was a big factor. Even though I wasn't doing anything, just a change in the weather would make a difference.

The influence of something as uncertain as the weather emphasizes the unpredictability of the disease to which the entire family group must attempt to coordinate its life. Because the family activities are contingent on the ill member's capabilities, the unpredictability of the symptoms force the family to focus on the present.

Secondly, the very life of the COPD member is fragile. Even a small change can upset this unstable balance. The family recognizes that each acute illness could be the last. That the family lives with a constant awareness of the possibility of intense illness and death is evident:

D: Well, and everytime, everytime someone starts to feel lousy in a situation like this, you say to yourself, too, well, you know. How bad is it going to get? (IW: Yeah) You know, no one just gets a cold, you know. It's always a major catastrophe. So you just -- You're always waiting for the other shoe to drop. (R: Not knowing what the future holds. Like,

what's going to happen with this one?) That's right. You know, is this going to be a scratchy throat or is it going -- you just don't know.

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S: I think the major effect is mental, in uh -- hoping that you -- the realization, I guess, that the next attack may be the last one. You never know with each one if she's going to pull through.

Because the risks of investing in the future have risen too high, the family learns to focus on the present. After all, the future may not include the ill member.

Thus, with little predictability or stability to the ill member's health, the family has no choice but to live in the present. The "here and now" becomes the only psychologically comfortable reality to them. This limitation to the present was illustrated by the families' descriptions of their inability to emotionally invest in future plans. Most families make few plans, others continue to plan, but for all, plans are tentative, as the following quotations indicate:

IM: But it is hard to make plans just day to day. If I do make plans to do anything, it's all qualified by how I feel when the time comes.

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IM: I can't make any plans ahead either because it depends on how you feel. It seems funny, you can do so good and then, bingo! Ten minutes later, you're down.

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D: So you tend to keep everything really flexible, and do things more at the last minute, I would say.
(H: Yeah, that's right.) Have to be spontaneous.

This persistent sense of tentativeness that creates an orientation to the present, allows the family members little

opportunity for indepth involvement in activities. As described by one man, they live "a superficial life."

Thus, not only did the families describe a disease that prescribes the family's environment and controls its activities -- it even dictates an orientation to time. In addition to these extensive impositions on family life are demands on family roles.

D. Altered Roles within the Family

Because abilities of the COPD member have changed, s/he can no longer fulfill roles previously established within the family. As a result, pressure builds for other family members to accommodate and compensate for the curtailed abilities of the ill member. The extent to which role shifts are required depends in part on the degree of limitation. The greater the limitation, the less able is the COPD member to carry out tasks. The following passages indicate the role alterations that are necessitated by COPD:

W: He couldn't look after our boat anymore. We have to have a gardener. . . .

IM: Oh yeah, I can't do anything now.

W: He had been known to even paint the house, but that's out now. I think he must get very frustrated because he sees things that should be done, and he's got the tools to do it -- (H: Oh, I do.) But he can't do it.

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W: He used to be able to run around and do this, that, and the other, and it affects him that he can't. And that I'm having to do most of the shopping, and that sort of thing. . . . There's lots of things that he

can do. He washes the dishes, for instance, and things like that. But vacuuming he couldn't do. . .

IM: Well, you've got to do things that you weren't used to doing before. . . . I never thought about doing dishes years ago, when you were doing something more manly.

These role alterations within the family are complicated by the variability in the ill member's capabilities. At one time the COPD ill member can carry out a certain task, while days or weeks later it is impossible:

IM: Simple little thing like going for the paper, newspaper (W: Just at the corner) at the corner. Sometimes I can go up there, and have no trouble and come back. . . . Other times I can only get half way, and I've got to stand for a few moments and come back.

The reverse may also happen, gradually the COPD member may regain the ability to do tasks that were previously beyond possibility.

For most families these adjustments in roles evolve almost without conscious effort:

IW: Well especially, you know, your Daddy's chief cook and bottle washer. Now he does the cooking and the cleaning and the dusting and the laundry, and you mention it, he does it.

R: And what was it like before?

H: Oh, well I -- I always helped (W: because we were both working) with the housework, yeah. But she did all the cooking. But then when I saw she was getting, oh, you could see she was going downhill. (R: Mhmm) Then I started to hang around the kitchen more, 'cause I knew that I -- (D: you were going to have to --) Sure. And that's another thing, it, it wasn't a decision consciously made.

D: It's a growing thing.

S: You gradually get into, that -- (W: It just happens.)

As the passage illustrates, the subtle role alterations relate to the scarcely noticeable deterioration in the COPD member's health. The other family members gradually move in to compensate as the ill member's capabilities decline.

For other families, however, these role shifts create much more tension and stress. Although the need for the alterations are clear, the compensation required within the family is resisted. The ill member may not readily give up tasks and the well members may resist assuming the vacated roles, as is indicated in the following passage:

IW: I have a hard time. I don't wash the floors as often as I used to. And I don't clean my oven as often as I used to. I find those two things hard. Umm, I don't wash windows as often. What else? (H: Me neither.) No, he doesn't help one darn bit. (laughter) He's not filling in the spaces that I'm leaving. He's not doing anything around here. He's going fishing!

The tension in the family is masked by the use of humour that is used to enable the woman to relate her feelings to the researcher. Nonetheless, the stress related to role alterations within the family is obvious.

Regardless of the ease of transition, role shifts must be made, not out of choice, but out of necessity. These are enforced by the very nature of the changes that accompany COPD.

These four subthemes presented: a breather-protected environment, an energy economy, a present-time orientation, and altered roles, evidence the pervasive impositions of COPD on family life. Although the intensity of the experiences described varied from family to family, these four aspects of

life, dictated by COPD, were found to be common across all family accounts.

The families were able to clearly articulate both the changes that COPD brings and the consequences of these changes. From the descriptions of their illness experience, a powerful sense of isolation emerged. Building upon the content from the first theme, the following theme describes and explains the isolation that accompanies family life with COPD.

Isolation

The families communicated their experience that a sense of isolation is intimately associated with living with COPD. To present this complex aspect of the family experience, this section is organized in relation to two dimensions of the family experience: A) the isolation for the family group, and B) the isolation of the individual members within the family.

A. Isolation for the Family Group

The families' descriptions indicated that isolation for the family group emerges from three primary sources: the restrictions in family life that result from accommodating the COPD member's needs, the family's attempts to maintain normalcy in social interactions, and the lack of outsiders' understanding of what living with COPD means for the family. The meaning of each of these forces is explored in the following passages.

A major isolating force develops as the family assumes a lifestyle compatible with COPD. The very behaviours that support the needs and accommodate for the changes in the ill member foster isolation for the family group.

First, avoiding situations that threaten the ill member's ability to breathe forces the family to insulate itself from many aspects of its previous environment, particularly those that are breather-hostile. Although irritants can be controlled within the family home, they cannot be as easily controlled outside the home. For example, the potent irritants of second-hand smoke and automobile exhaust, intolerable to the COPD member, are widespread environmental pollutants. In order to protect against these, the family withdraws into its breather-protected world. However, this action also isolates the family.

The unpredictability of the ill member's ability to breathe compounds the isolation that results from the attempts to avoid breathlessness. In new circumstances, the COPD member becomes even more vulnerable to breathlessness. One way the family can therefore avoid threatening situations is to withdraw into safe controlled environments, where the greatest degree of control can be maintained. But this again is an isolating behaviour.

The more fragile the ill member's ability to breathe, the greater is the need to confine family life to protected environments, and as a result, the greater the isolation experienced by the family. One family had become so wary of

the ill member's response to different situations that all family life took place, literally, inside the home:

D: I remember one of the first times we realized that, we went to visit friends and we had to park about a block away. And then coming out, we got about halfway around the block and then Dad couldn't get his breath. And so we had to run and get the car. It's really scary.

IM: Rather than face that you kind of stay at home. . . .

W: You know, because you are scared of getting caught out. You know, maybe the car breaks down, and it's very dark, and he couldn't get his breath, you know.

D: And I think after awhile you just stop thinking about it. (IM: . . . You just forget about it.)

The passage not only depicts the isolation that results, but the resignation of the family to its isolation. It is as if there is no choice -- it is just a fact.

Heightened risk is seen to be involved with venturing away from safe environments, and is reflected in one family's decision not to go on a three hour trip because there are seen to be too many uncontrollable factors:

IM: We used to go over to Victoria. (W: He's got a sister over there.) But it's three years since we went, and it's a simple matter that we don't want to put anybody out unnecessarily. And on the other hand, we don't want to get stuck, having to get an ambulance on the way there. So we pack the idea in. Not because we don't want to go -- but because we would be unable to complete it, probably. Or too sick to travel, they used to say years ago.

W: We've got an offer to go at Christmas with his nephew. He'd come right to the door with a car and take us right on the boat. But, that's all right, that sounds fine. But if it started to snow, he couldn't go . . . (IM: -- could stop the ambulance coming down) -- waiting around in traffic, you know, in the car and the fumes.

Another family illustrated the need for a safe environment by continuing to go to the same place for its twice yearly holiday. Although the wife indicated that she would rather go to a different place, the ill man preferred to stay with a known environment. His need to have a known safe environment took priority:

IM: There's a whole section of Maui, in the center part we stay in, that is flat. I don't think any part of it is more than three feet above sea level. You don't have hills to climb, the beach is flat. And that's partly why we -- why I like to go there. . . . (W: I'd like to go to Mexico.)

Thus, the coping behaviours used to protect the ill member from becoming breathless enforce a form of isolation on the family, for it is confined to breather-protected environments.

In addition to the isolating force of living within a breather-protected environment, the family's energy restriction exerts an isolating force. For within its energy economy, the family has limited capacity for activity generally, and specifically, limited energy to expend in various activities outside the home. When energy is extremely limited, the family can become essentially confined to the home:

R: You mentioned before the social aspect, trying to still carry on a social life that everybody enjoys.

IW: We don't.

D: We sit and watch T.V.

H: I think that's the simple answer.

IW: Anything that is done is generally done here. If we're going to visit, and that's all we do, we just --

D: -- sit and talk, or watch T.V.

As this passage explicitly conveys, the reduced energy capacity of the COPD member can isolate the entire family within confined energy-limited boundaries.

Furthermore, the behaviours used to accommodate for the needs of the COPD member can isolate the family from its social world. The lifestyle changes compatible with COPD are, after all, not compatible with a social world that is typically breather-hostile, activity-based, and future-oriented. The family requires a breather-protected environment, yet in most social situations there will be people smoking. The family has a limited capacity for energy-consuming activities, yet any social activity is an energy-consuming experience. The family is oriented to the present, yet socializing with others requires future planning. As the disease progresses, so do the barriers to socialization.

Because of the smoking restrictions and energy limitation, not only is it difficult for the family to go out to participate in social activities, it is also difficult to have visitors into the home:

W: We don't have people in. We used to play cards and we had people in.

IM: Two or three couples, sometimes all of them, sometimes just one other couple. We'd sit and play cards at night and have a couple of drinks, and we all smoked. That's been cut out completely. I don't have the energy in the evenings now, in the first place.

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D: Also too, when you've got people over, people smoke. (IW & H: That's right.) So, that's a problem again.

(D2: Yeah, you can't smoke in here.) So large dos are out too. (IW: It's just exhausting anyways.) And it makes it very difficult now to go to somebody's house.

The tentativeness associated with the disease also fosters isolation. Other people are not oriented to tentative or last minute planning, which makes it difficult to arrange social gatherings:

W: You can't ask people in for dinner, arrange it, 'cause I don't know how he's going to feel. He says wait and see. Well that's no good.

As well, it is difficult for the family to attend social gatherings:

W: I don't make any plans ahead. Like Christmas dinner, you just have to wait and see how he is. We are staying at home, and if he's well enough, we'll go.

As a result, the family's social life shrinks, while its isolation grows. The extent of the isolation felt by the family is captured by one woman's comment: "Social life becomes a telephone call." It is clear that assuming a lifestyle compatible with COPD brings isolation for the family group.

Further to this, attempts by the family to maintain a sense of normalacy in social interactions creates another significant isolating force. In trying to avoid situations that emphasize the family's difference from others, a barrier to socialization develops, as is illustrated in the following passage:

IM: And the same thing as going out to dinner in a restaurant, we don't do much of that anymore. Because I don't get enough oxygen apparently to eat a good sized meal. And it says in the literature

that they've given me to read that I might have to eat six or eight small meals a day. So what's the use of going to a restaurant with a bunch of other people, and I sit there and watch them eat? So its made quite a difference in our social life in that way too.

Rather than draw attention to the ill man's difference, this family group feels forced to withdraw from these social situations.

The isolation that results from controlling perceived threats to normalacy was also illustrated in some families by their rejection of the practice of asking others to respect their need for a cigarette smoke free environment, even though this would allow them to attend social functions. Rather, the families further separate themselves from others by avoiding these occasions, as the following passage illustrates:

W: Last year we were invited down for a nice Christmas dinner. I'll ask him, and he doesn't feel up to it. We don't go because other people are going to be there. He doesn't know who is going to be there.

IM: Well, I mean, I don't like this thing, we go to visit friends of ours, like one couple in particular, and if anybody else drops in they make it loud and clear to their friends that they can't smoke because I am there. And this is a little bit embarrassing.

R: So it bothers you more --

IM: Yeah, not only they are not smoking, our friends aren't, but they knew this when they invited us over. But if their friends drop in, they've got to tell them that they can't smoke either.

R: You feel like you are being an imposition, or whatever, on them?

IM: Well certainly you are.

The isolating force this exerts is compounded by the fact that the ill people have a shared history of smoking with those

they now need to ask to not smoke: "It's so hard for me to ask them, knowing they have smoked for over fifty years. I can't ask them to stop." In the age group of many of the adults who have COPD, smoking had been the "thing to do." So most family friends still smoke: "All the people that we know smoke, or at least one out of each couple does." Rather than place demands on those that smoke, the entire family withdraws from these situations, perpetuating its separation from others. The resulting isolation is especially prominent when smokers make up a large component of the family's social group. As the previous passages illustrate, the family's attempts to maintain a sense of normalcy can result in isolation from its usual social world.

The families' accounts also revealed that a lack of understanding by others of what it means to live with COPD fosters the sense of isolation for the family group. The families claim that most people have little awareness of chronic lung disease, of the disease itself, or of the limitations it poses:

D: I don't think there's much awareness with most people of respiratory diseases. So, they don't know what's happening, and they're not -- I mean if somebody goes in with, well, a walking stick it's obvious something's wrong. So they are not really, well I wouldn't say -- maybe they're not watched as much. But at least people know what is wrong, or they have an idea what might be wrong. But when someone's just standing there and starts doubling over and trying to breathe, you know, it's very alarming for everybody.

This passage illustrates the result of the invisible nature of COPD's handicap. Being largely unnoticable to most people, it

does not promote others' awareness of the disease. But when the silent disability suddenly emerges with the ill member's acute breathlessness, s/he just as suddenly becomes the centre of attention. However, with a lack of understanding of the symptoms, others do not interpret the ill member's behaviour with sensitivity. For example, the attention and alarm stimulated when the COPD member becomes breathless while in public only serves to intensify breathlessness. As a result, the family avoids these provoking circumstances, thus isolating itself.

Even close friends and relatives often do not appreciate what living with the disease means for the family:

W: Nobody, but nobody understands, including your relatives. They'll say, come on, let's go here, let's go there, and they'll take him here. They don't know that he can't do it.

IM: Don't really. They know that you're sick, but they don't. They don't know the obstacles, that everything is an obstacle. (W: They don't endure it.) . . . No, they are very well meaning, and they'll do anything for you, us, but they think that you are -- you've got something like a -- broken ankle.

That the ill member has to actually perform work to breathe, even when at rest, is usually not apparent to others:

IM: This is what is hard for other people to realize. For a long time, every breath I took was hard work. And you can't stop breathing or you die. So you are working, and you are lying flat on your back and you are still working hard, pulling every breath in and pushing it out again.

The lack of marked visible symptoms masks the intensity of the disability of COPD, contributing to the lack of understanding

and the seemingly inappropriate behaviours of others:

W: They see my husband sitting in the chair, and say, 'There he is. You are looking good.' They just -- it's hard to explain to them. It seems like you are always explaining that he is not well, his lungs are all shot.

Consequently, the family does not feel that its illness experience is fully understood. Rather, it feels as though it endures the illness alone.

This lack of understanding also results in misinterpretations. For instance, when the family does not accept invitations to join in social activities, rather than see that this is because of the second-hand smoke and energy expense, the refusals may be viewed as a lack of social interest:

H: Well, this fellow that I worked with for years and years, he phoned up when his wife was giving a retirement party . . . and he didn't realize that my wife is, uh, has been -- had this damned emphysema. And he just thought I didn't want to go, and I couldn't convince him.

IW: He said, 'Well, if you don't want to come.'

H: 'If that's the way you feel.' But emphysema to him, it could have been a place in (D: That doesn't mean anything) North York or somewhere.

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W: 'Cause he has a very good friend, and uh, he's 'phoned him up three or four times to go to a football match at that big stadium. Well, he couldn't go.

IM: I couldn't go, you know. I couldn't go the way I've (W: But he didn't understand.) He didn't understand. (W: -- didn't understand it at all.) So I have to, you know, 'Well, I'm sorry, but --.' 'Well, he didn't look sick yesterday.' Oh, this is the attitude, but they don't, they don't understand. (W: How you look doesn't matter you see. But they

can't -- they don't know.)

That others do not comprehend the meaning behind the family's explanations and behaviour is clear from these descriptions. Thus, it can be seen that the resulting communication breakdown potentiates the family's isolation.

While the families may recognize that this breakdown exists, their accounts revealed that they tire of trying to bridge this gap by explaining their situation repeatedly to others:

IM: It's a thing that you -- a thing you have to accept, and it's a thing that you, you can't explain to people in a split second, you know. And I'm to the point where I don't. You know, if they don't know, and they haven't met me before, I don't bother explaining anything. I just don't do it. (R: Mhmm) And if I -- if I'm offending them in any way, well, that's just too bad. You know. Don't have any words about it. You just don't bother about it.

The accounts also illustrated that even those families that do try to explain find that it is hard for others to realize the significance of the disability they face, as reflected in this husband's comment:

H: Well, and most of the time, people say, 'Hey, I thought you said she was sick.' (D: Well, we know she is, but this is someone coming in off the street or something.) Yeah, I've had those comments many, many times, especially, someone will phone and ask for me. My wife answered and they say, 'She sounded great. Is she feeling better?' I say, 'Oh, she is always feeling pretty good.' But, you know, to a certain extent it's very difficult to try and translate the severity of the impairment. They don't understand that somebody can be like that.

It is especially frustrating for the family when its explanations about the illness go unacknowledged or uncomprehended by others. For example:

IW: They keep asking how soon I'll be better.

H: Sure, and I've told the same people, 'It's just a condition that's not going to improve', you know. Boy, they -- two months later they say, 'Well, your wife should be better by now.'

R: That must be frustrating.

H: Drives me crazy to tell you the truth! I just smile and keep walking, 'cause I don't want to get into it, you know. It's not that I mind talking about it. (D: especially when they've got the information).

Furthermore, the families' comments intimated that by not appreciating the importance of their limitations, others fail to respect the family's special needs:

W: If they (the neighbours) come to visit, they don't know when to go home, that he is tired. They don't understand that, you know, and you tell them but they don't seem to realize. They don't come around anymore. I don't mind them coming around, but they have to realize that you are sick and you can't take too much.

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IW: They can't understand that if you don't smoke, it shouldn't bother you that they're smoking. But they're polluting the air and that's not good for you. I mean even the doctors say you should have a sign in your home that says: 'No Smoking'. . . . We've just had to stop having some of our friends over.

When this happens fatigue and shortness of breath become the tradeoff for socializing. Hence, if people in the family's social world do not accommodate for the changed needs demanded by COPD, and the costs of socializing are then seen to outweigh the benefits, the family withdraws from social gatherings.

Moreover, others withdraw from the COPD family:

R: Because people don't understand very well, does that affect what you do socially with other people?

IM: Well yes, because -- because what is normal to them isn't normal to you. And you've got to compensate yourself for that. Compensate and just -- you can't always go. And some will understand, and others don't put up with it, you know. (W: -- leave you alone, and say, 'Oh to heck with it.')

R: After while they just leave you alone?

IM: Well, yeah. They don't -- don't say that much, but it shows in their absence (R: Mhmm. Shows in their absence.) -- speaks a thousand words.

Invitations become less frequent or gradually stop:

W: When he first took sick, some of our friends would 'phone up and say they are going to drive to Whistler, and be going up for the weekend and would we come. He doesn't like riding in the car anymore. He wouldn't go. . . . They thought they were doing us a kindness. I was going to start and go with them, but they just got tired of asking us. They don't ask anymore.

The isolation the family experiences is obvious.

Not only do the families feel that their experience is not understood by friends, relatives, and the public generally, but also they perceive that health care workers do not understand. It was apparent from their comments that health care workers do not communicate that they recognize that the whole family is affected by COPD, and need information and support as a group:

H: With her medical doctor, they seem to think that the disease only involves her because it involves her physically. (R: Mhmm) OK? And that's where it ends. Who knows, the rest of us are just scrambling around.

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D: But I think anything that I have, any knowledge that I have is -- I've gained it myself, or from, you know (H: yeah) second hand information from you (the ill member).

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H: She's got all these specialists, whether they know what the hell they are doing, I have no idea. But you know, not one of them has ever approached me and said, 'Well, Mr.-- I realize that you are having these problems, okay, within your family. (D: It's, 'Oh hi. How do you do.')

The superficial contact and lack of addressing or even acknowledging the family's needs are obvious in these passages, as is the anger felt by the family. Isolation of the family group is thus potentiated by these interactions with health care workers. For when the needs of the family are ignored, the family copes with the effects of COPD alone.

As described, numerous forces promote the isolation of the family group: the restrictions necessary to live with COPD, the attempts to maintain a sense of normalacy in social interactions, and the pervasive lack of understanding by others of what it means to live with COPD. Not only does the family as a group experience isolation, isolating forces also act upon the individual family members.

B. Isolation of Individual Members within the Family

The families' accounts indicated that three primary isolating forces act upon the individuals within the COPD family: the gap between the needs of the COPD member and those of the well members, the restricted expression of emotion within the family, and the lack of mutual understanding between family members. The following explores the meaning of each of these forces.

As the COPD members become more ill, they are less able to tolerate irritants to breathing, their energy reserves decline, their abilities to fulfill family roles diminish, and their lives become more fragile. The gap that emerges between the ill member's needs and capabilities and those characteristic of family life can separate the members from one another. This was emphasized in descriptions of traditionally family-focused occasions that could no longer be celebrated as a group:

W: Our daughter got married last September and he couldn't go to the reception. . . .

R: That must have been hard for both of you.

IH: I didn't have the energy anyway. I made it to the church and got down the aisle. And then standing outside the church, where the thing sort of breaks up, it was all I could do just to stand for that length of time.

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IW: Last Christmas, I couldn't go because of the dry cold. I couldn't even breathe in that dry, cold weather. (R: Mhmm). I've got to have moisture. So anyway, we're trying to figure out how I'm going to get from here to there and we figured you couldn't do it. So, I just stayed home. I phoned up (my daughter) and said, 'Sorry, we just can't come down.'

The greater the limitation of the COPD member, the more difficult it becomes to be included in activities desired by the well members:

H: Under normal conditions of living, it's very, very difficult to involve her in things we do. And so we have to stop and redesign our own plans, and at the same time --

IW: You never did, you just leave me at home.

The divisive force this creates within the family is obvious. The family is faced with the choice of the well members

engaging in activities on their own or withdrawing from these activities completely, thus narrowing the focus of their activities within the parameters of the ill member's capabilities. It is apparent that frustration can emerge from the sacrifices made to accommodate the ill member:

W: You can't go to any gatherings. We went to a wedding reception a while ago. My husband got embarrassed because the hostess was shooing everybody from every room that smoked, and what not. He wanted to come home. As far as I was concerned, it wasn't worth the effort to get dressed to go out.

Either option selected by the families carries with it a dimension of isolation. If the desired activities are abandoned, the family group becomes more isolated, and feelings of frustration and of being deprived are fostered in the well members. On the other hand, if each member pursues those activities that are within his/her capabilities, it fosters guilt feelings in the well members and feelings of being abandoned in the ill member, and thus isolates the members from each other.

Furthermore, family members can be wedged apart as the family tries to comply with the ill member's disease-related needs as well as meet the needs and desires of the other members. This can create a gap between members, as was graphically demonstrated in this family where the wife continues to smoke:

IM: And the biggest problem from day to day is that my wife spends alot of her time in the kitchen, and I spend my time in here. I think of something I want to say to her and by the time she comes back 20 minutes later, I've forgotten what it is. So there

is quite a difference in home life that way.

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W: When we were going to Hawaii I go in the smoking section and he goes in the non-smoking. . . .

R: So it's almost meant a separation, you know, a real physical separation?

IM: Yeah, when you've both been accustomed to smoking for that long, then all of a sudden you've got a -- the cigarette thing comes up, and one of you quits and the other doesn't, it's bound to make a tremendous difference, a separation between you.

Trying to accommodate conflicting member's desires and needs fuels the separation of changing long established habits and patterns of time together.

Control of the expression of emotion within the family exerts another separating force between members. Although this control is used to protect the ill member from emotion-induced breathlessness, it can impede communication between family members, and isolate one from the other. The separation that results between members was reflected, for example, as the families described that the ill members may be excluded from family discussions:

D: She's not included in our little discussions and things, because we don't want her to know that we are all upset and worried. Because then she'll get all upset and worried.

And members may not share their feelings or thoughts as openly within the family:

D: Well, you just don't get excited about the same things.

H: We don't argue or fight.

S: Overlook things, that's all. And that's the truth.

You have to -- no choice.

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D: But I vowed I'd never, I mean I used to babble in front of her, but now I don't anymore. I go home and as soon as I hit the car, I can't see when I'm driving, all sorts of things, but I won't do it in front of her. She can probably still tell if I'm upset, but at least it's not obvious that I'm just about devastated or something.

It is clear that in keeping emotions to themselves and not sharing their thoughts and feelings, individual members cope alone with the painful aspects of life with COPD. Although an effective strategy for avoiding breathlessness, the monitoring of emotion-laden communication wedges apart the members and may not allow them to draw upon the strength of their collective abilities to cope.

The avoidance of emotional issues within the group was further illustrated by the fact that almost all family units had before the research interview never discussed the impact of the illness on their lives. Moreover, the benefit of less restricted communication within the COPD family was indicated as the participant families commented that they had enjoyed and learned from the sharing that occurred during the interview process.

The families' descriptions also indicated that the separating forces between members grow when a shared understanding of the ill member's needs and limitations is not achieved within the family, for mutually satisfying expectations are then not developed. The following passage illustrates the strain on relationships this creates:

H: Okay, now I'll accept it. Now I'll accept you as whatever you are or whatever you are, so that, I -- I could have some kind of relationship with her without, always -- not being too sure what ground you're standing on. If you say something which she may not like it -- like she often says, 'Well, maybe I'm not able to do that.' But then I don't know whether, she's not able to do it, or because she doesn't want to do it.

The already difficult process of redefining family relationships becomes even more strained when the members do not have a mutual basis of understanding of the limitations imposed on the ill member by COPD.

By not appreciating the ill member's reduced capabilities due to the changes from COPD, the same misunderstanding of behaviour exhibited by those outside the family can occur within the family, thus further isolating the members from each other. In such situations, the ill members essentially must justify to their own kin the validity of their symptoms, as is conveyed in the following passage:

H: I think a lot of it is again, psychological. She thinks she is going to run into problems, so she does. We start walking and all of a sudden she gets this -- all hyped up, you know. We have to sit down.

IW: Yet I don't think -- When he says, 'psychologically she's going to run into trouble,' it isn't that I think I'm going to -- it's that I know I'm going to.

As these quotations convey, the family members were able to openly express two different viewpoints within the family interview, viewpoints that reflect the gap between the members.

When a mutual understanding is not achieved within the family, members cannot fully appreciate what the illness means for the other. This was reflected by the incongruent

perspectives expressed by members in some families. For example, the effect of COPD was seen from one husband's viewpoint as, "actually, outside of physical things, it hasn't really changed a great deal," yet from the ill woman's perspective, "all of a sudden my whole life had changed. I found it frustrating, very frustrating. Still do." For one, the illness is a minor inconvenience, for the other, a drastic life change.

By contrast, in families where a shared understanding has been achieved, an acceptance of the ill member's changes and clear expectations of one another are projected:

IM: She understands it better than me. She'll tell me that you better not go with that, whereas I might have gone and done it. You know, she's got better judgement for it than I have.

Rather than a gap that isolates individual members, the shared understanding creates a unifying force. Clearly, the degree of understanding the family achieves significantly affects the intensity of the isolation experienced for individuals within the family.

In short, the family with COPD experiences divisive forces that isolate members from each other, namely, the difference between the abilities and desires of the ill and well family members, the control of emotional expression, and the lack of a shared understanding achieved within the family.

Although the families' accounts projected varying degrees of isolation, for the group and/or the individual members, none escaped the experience. A sense of isolation was common across

all accounts: isolation is synonymous with COPD.

The disease-dictated lifestyle assumed by the family with COPD has been described, followed by a description of the isolation that accompanies the illness experience. The third section of this chapter enriches the account by describing the family work necessary to live with COPD.

Family Work

The families' descriptions revealed the nature and meaning of the "family work" required to live with COPD, that is, the challenges that the illness poses for the family and the coping strategies they use to deal with these. The researcher identified four of these primary challenges: A) accepting the chronic nature of COPD, B) facing an uncertain future, C) maintaining a satisfying shared family life, and D) managing the illness. The following section outlines the descriptions of each of these, and the types of coping strategies the families used to deal with the challenges.

A. Accepting the Chronic Nature of COPD

From the families' accounts, it is clear that living with COPD involves coming to terms with the realities of life with a chronic illness. Working through the losses the illness brings, accepting these, and finding a way to continue on with this new reality were all found to be parts of this challenge for the COPD family.

That pervasive losses are experienced was apparent in the families' descriptions. The group has lost its previously healthy member and its former way of life, as these passages illustrate:

W: As far as our life is concerned, it has changed drastically. I wouldn't say for the better.

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H: I think essentially, definitely, the social and all other aspects of life have changed because of the illness. I mean, she's not the same person she used to be, definitely. For her a taxing day would be to get up in the morning and have a bath. (R: Mhmm) And that would be taxing. And that's definitely not the personality she used to be.

The descriptions of the loss of valued aspects of family life exemplify the grief the family experiences in the process of accepting the chronicity of COPD:

W: We used to love to go out and prospect. That was our big thing. It was great. . . . The past summer we didn't go any place. The summer before that, we were gone three months prospecting. But we can see the change from two years ago when prospecting. He was doing a little bit, not last summer but the summer before that. Then he didn't do nothing. He just barely sat on a stool, and barely made it to the car. But it was a change, and it was so nice up there, and the time went by so fast.

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H: We used to a lot of things together. . . . We did a lot of physical, nature type things, spent time at the cottage. (D: canoeing) And doing, you know, just even walking. (IW: hiking) We hiked, right. I mean literally hiked more than ten feet at the same time.

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W: We had our own boat. We'd tie it up down there (at the moor), people with their boats. But the ramp is too steep for him now. . . . He can't manage the

boat. . . . Anyway, we miss it.

Not only must the family accept the losses that COPD brings, they must also accept that the demands of the illness that enforce these changes are permanent. Life is changed:

IM: It's what you call a -- a scourge. (W: You've got to live with it you know.) And you know you can alleviate it a bit, but you know that it's never going to actually clear up.

It was clear that the acceptance of the chronic nature of COPD is a process that takes place over time, as is conveyed in the following passages:

H: I don't think we were even being honest with ourselves at that time. (IW: No, I don't think we were.) . . .

D: Thought you could do more than you could do. . . .

S: 'Cause I remember even when going down for Chinese food with you a couple of times, you didn't enjoy yourself at all, because you were so out of breath. You didn't enjoy your dinner, and you could see it.

R: But you were still going, and trying to do -- (IW & H: Oh, yes.) Thinking that, 'If I only tried harder'?

IW: Yeah, I would get more energy.

D: We thought that it would eventually go away.

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H: It took me months and months to even get wise. She would be playing games with me, and I -- The first thing I knew I was doing most of the housework. But I didn't know why. (D: Yeah) Yeah (laughing) But, you know -- (D2: Well, it's a really hard thing to face.) You just put a little bit more effort forth.

It takes time to face the fact that the ill member is different, and as a result, so is the life of the entire family. Each family develops ways to cope with this reality.

One prevalent strategy described by the families is to assume a positive outlook or attitude toward the illness. The families illustrated various ways that they maintain a positive outlook. For example, positive health-related information is emphasized: "They told him he was no worse. No better, but no worse. Well, that's something." Sometimes locating something positive is accomplished by comparing their situation to something seen to be worse: "I'm still thankful to the extent that she's ambulatory as much as she is. It could be a lot worse." "He went on the bus and came back on the bus. See, some people can't do that. So I think to myself, 'Well, it's -- there are a lot of other people worse.'"

Recognizing that relationships have grown closer through the illness experience provides some families a positive focus:

H: I think maybe it's made me take a long look at what I've got and be a little more appreciative. Should have been more in the past. And I think now, yeah, you do consider more than you did in the past.

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IM: Oh, I don't know how she puts up with it. You know, sometimes I think to myself, reverse the position, like, and I wouldn't be able to -- to do the same. I wouldn't be able, not because, I say, not because I wouldn't want to, but I wouldn't be able to do the way she's been able to.

R: So through this you've really come to appreciate -- ?

IM: Oh yes. (W: Oh, yeah) Yeah, more so than you know.

Despite extreme limitations something positive can be found:

IM: Actually, I think it's taught me -- They say it's an ill wind that blows nobody any good. You learn things that you weren't interested in before. You

know, things that you, you never knew were existing.

Another strategy is to perceive the illness as outside the family's control, as illustrated in the following passage:

W: I used to go the the doctor a lot, and I know what is coming and I know how to handle it more now. I had to talk to somebody. But now I just say, 'Put it out of your head. Take deep breathes.' I talk to myself. I go to bed if I have to. You take deep breaths. That is the only way -- push it out of your head. You can't be worrying about something that you're not in control of.

Viewing aspects of the illness as beyond influence enables the family to avoid focusing and dwelling on the illness. But, regardless of the strategies each family develops, all face the challenge of accepting the reality that COPD is now an ever present part of a different way of family life.

Although the families described the difficulty of accepting the chronic nature of COPD, the same degree of difficulty was not apparent in accepting the occurrence of the lung disease itself. This happens readily, and appears to be linked to the fact that in most families the development of the disease is not a surprise. To them the cause is obvious: a life-time of smoking:

IW: Now I say, I've said it many, many times, I know why I'm an invalid, because I smoked too much. But, I feel sorry for the people who have emphysema that never smoked. (D: That's right) I always feel -- Well, how do they feel about this? I would be so angry, I really would.

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IM: I mean I've known all my life that smoking was bad for me. Unfortunately, I worked at a job which I think encouraged my smoking . . . a very boring tedious job. So you smoke, one cigarette after the other.

W: But you know to think we used to have our boat and go down there and play cards and everybody in the place smoked. No wonder you'd get up in the morning and be short of breath.

IM: Oh yes, it's been an atmosphere of smoke for 40 or 50 years.

Rather than focus on 'why,' the significant component of family work involves 'how,' that is, accepting what the nature of the chronic illness means for the family and finding a way to live with this reality.

B. Facing an Uncertain Future

The family must not only find ways to face the reality of present life with COPD, it must also find ways to cope with an uncertain future. One factor that makes this difficult is the knowledge that the ill member may become increasingly limited as the disease progresses:

IW: I dread the day when I'm going to be in bed and not getting out. See I'm not planning on dying, that might be easier, right? . . . But you know, I -- that's a part that really worries me.

D: She doesn't want to be totally dependent on anybody on anything. She's always been far too overly independent.

R: That must be strange for everybody in the family to think about. Like, what about tomorrow, what about -- ?

H: I was looking at this program and it was talking about this husband looking after his wife and, for four years day and night, and everything else. Well, that's nice, but where do you get the money to do these things? I mean, we couldn't afford it, if -- if it came down to that. . . . If I didn't have a job I couldn't even support you at home, nor could I support you anywhere else. . . . So therefore, you're in a real dilemma. . . . I don't think about it. I would sooner think, 'No, she won't get into

that invalid stage.' I suppose in many ways I'm denying it. (D: she's sick) The fact that she is sick, right. In saying to myself, it's not going to happen.

Because much of family life is dictated by the health status of the ill member, envisioning an even more limited lifestyle is an immensely difficult future to face. In families where the ill member had previously been extremely sick, they had seen what the future could hold. One family's comments illustrate the tension created within the family by the fear of the illness progressing and the anticipation of the impact upon the family:

W: I just tell him that I will not go through what I went through before (when he was very sick at home). I am not going to stay home and look after him. He can go to the hospital. (IM: Yes you are, Honey, you are.) No, I won't. You can't go anywhere.

R: From what you said last time we talked, I know how hard it was for both of you and knowing that that had happened before, and never wanting to go through that again.

W: You don't see anybody. You can't have anybody see you. No assurance there's going to be an end to it. (IM: Well, it never will go away completely.) I know, but at least if you're better you can have friends in.

It is recognized that the ill member's limitations will become limitations of the entire family. Knowing this fate, these limitations seem unbearable.

Another factor that makes facing the future a challenge is that the future could conceivably be one without the ill member. It is evident that the family must constantly prepare itself for its COPD member's death, as illustrated in these passages:

D2: Well see, I lived overseas for years, and would come home every summer and I would see more of a change than possibly people who were here all the time. And there were times I got on that plane not knowing -- (H: when you were leaving -- IW: if I'd be here when you came back.) Many times. . . . (H: Our partings were always emotional.)

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S: Personally, I guess, I mean -- I know Mom never needed me for anything. She always seemed to cope and get along quite well. But I know that I needed her a lot, and she's always been there when I've been in trouble or wherever I've been. She's always given me advice and helped me out. And I think that's probably where I'm going to miss her the most is -- I'm not going to know where to turn to.

The preparation for inevitable deterioration and death is at once unavoidable and painful.

Coping with the uncertainty of the future is impeded, however, when the family's knowledge of how the illness experience will proceed is limited:

H: I suppose if we had any brains we would plan, but then what do you plan, 'cause, you know, like I say, we don't even know what it is we're up against. (sigh) What to look forward to.

The families explained that little information to help them prepare for their future is shared by health care workers. In fact, the subject of the future with COPD is often not even broached. The following comments reflect the desire of the family to address this need, and the contrasting lack of attention felt by the families to be given to this by health care workers:

H: I mean this is not, as far as we understand, it's just not going to get a hell of a lot better. But if you mind your p's and q's, it won't get a heck of a lot worse, you know. And there's an awful lot to

minding your p's and q's. I don't know what makes it better or what makes it worse, smoking of course. But what's the record on patients with (IW: Survival rate, you mean?) lung disease? I mean, I don't know anything. The doctor doesn't seem to want to tell us anything. Maybe, probably, they don't know.

Not only is the family unsure of future possibilities, it does not express confidence in its knowledge of what behaviours to use to try and shape this future.

Some families used resourceful information-seeking strategies, such as talking to other patients in the doctor's waiting room. But most families do not personally know other people with COPD, so their opportunities to learn from the experiences of others are minimal. However, families did indicate that talking with others going through similar experiences would help them prepare for the future as well as to cope with today:

H: That'd be excellent, I think, if you all got, you know, people with any experience with it. If they would be willing to sit down and say, as a group or whatever even over a beer, who cares. Sit down. Okay, these are the things that happened to my wife. (D: as time goes on) And I found her doing these things, and so --

IW: Yeah, but how about if you talked to the person that it's going to happen to.

D: You don't know either. (H: You can be there.) . . .

In addition to seeking information, each family develops other strategies to cope with the uncertainty of its future. Families, realizing that the next acute illness could be the last, adopt the approach of living for today: "Especially after a couple of crises, you tend to -- you just say to yourself, 'Well, you just take the time you have left and, you

know, make it as good as you can.'" Others view that they are not in control of their destiny. In this way they try to function to the maximum that their present abilities allow, rather than be constrained by the fear of possible disaster, as the following comments illustrate:

IM: I wanted to go back of Edmonton this year so bad and look around. I've got to go back. . . .

W: If you want to go back so bad, we will go. You might die halfway up there. That is the chance you have to take. Like if you want to go to (another town). In fact, the last time we went up there I said to the people up there, 'If he dies here, he dies here. But if he wants to come we're coming!'

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W: If he's going to have one of those attacks on the bus, he'll have it. And if he's going to have one he'll have it here too. So we go.

Maintaining hope was one strategy common to all families.

Some hope for improvement:

IW: Of course we lost all of this spring and summer with me being so sick, but by next spring and summer I hope to get out more, and a lot more.

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W: Well, I don't know, if he keeps improving I might get him to church one of these days.

Others hope that the illness will not progress:

H: We -- we live with it from day to day, and miraculously, I suppose, we think that if it doesn't get any better, it shouldn't get any worse, you know. What else can you say? . . . Like I say, just hope it doesn't get any worse.

But in each family, hope is an important coping strategy toward meeting the challenge of facing an uncertain future. Another challenge the COPD family faces is to find a way to maintain a

satisfying shared family life within the restrictions imposed by the illness.

C. Maintaining a Satisfying Shared Family Life

Accepting that COPD has changed family life, the members must find a way to make these changes so that a satisfying shared family life continues. As described in the previous section, life with COPD creates forces that isolate members from one another. If the family unit is to stay intact and have a life enjoyed by the members together, the family must ensure that changes in family life are not only compatible with the ill member's needs, but continue to meet the needs of the other family members and the family unit itself.

Because only those individuals with COPD who were currently living with others and part of a self-defined family unit met the criteria for inclusion in this study, the research does not reflect the experience of those families that were unable to achieve the level of family work necessary to keep the family unit together. Some ill adults contacted during the process of entering families into the research indicated that a minimal degree of satisfying family life existed within their families. Two men expressed interest in participating in the study, but said their family members were not interested in their illness and would therefore not participate. Also a wife of a man with COPD indicated her interest, but said that her husband refused to be involved in the study. The researcher

decided to have interviews with one of the ill men and the wife by themselves and separately in an effort to gain insight into how COPD had affected those families where all members were not interested in participating, or the family situation did not allow participation in an open family discussion. In these interviews, both individuals described how they felt they were basically coping with their situations alone. Although they were living in the same homes as their spouses, sharing between members and activities of the family together were almost nonexistent. Their accounts reflected the divisive influence of COPD upon the shared life of the family unit.

From these two extra interviews as well as the participant family accounts, it appears as though a commitment of the family members is necessary in order for the family to live together in the confined world demanded by COPD. That the members of the participant families have allegiance to maintain the family unit was reflected in these statements: "After all, we're man and wife." "Anyways you gotta live with it, what else can you do"? The only other choice available is for the family unit to break down.

Even though all of the participant families have made the choice to stay together, there was an unspoken recognition that another choice exists. This was reflected by one man who described that he did not pressure his wife to quit smoking: "I don't know if our positions were reversed, I can't guarantee at all that I would quit. I might get rid of her first." It is implied that this demand may be too great a sacrifice for

the already stressed family union to bear. The awareness that there is a limit to the family adjustment that can be made was also indicated as another family discussed the possibility of the disease progressing. The comment was made: "He's telling me that he'll just ship me off to a home someplace." And in another family, the ill wife expressed the frustration and continual effort necessary to look at the positive side of life when faced with the ever present demands of COPD. At the end of the interview, her husband said, "Well, laugh and the world laughs with you. Weep and you weep alone." Although these comments were not pursued in the discussions, they demonstrate the recognition that there exists the choice to leave the COPD member or consider institutionalization if the sacrifices made within the family become too great. Thus, it is evident that family work is necessary if a mutually satisfying shared family life is to be maintained.

To achieve this, each family develops strategies that are compatible with its lifestyle and interpretation of its situation. For some families this means focusing on activities still within their capabilities:

H: You have to spend a little bit more time doing the things you enjoy doing, because, if nothing else, that will give you some form of pleasure. Whatever it may be, you have to spend a little more time doing that, because if you are going to spend -- You've got a limited number of hours in the day that you can actually expend physically doing something, sure as heck might as well be doing something that you like.

Others find new activities that the family can participate in together:

H: We have to change some of the patterns that we had and do things that we would like that we can do together.

Some families change their activities or the way they do them to energy saving patterns:

IM: Well, we go but we go at a low level sometimes. There's just a basic, going and sitting down.

R: Just a slow pace. (W: a slow pace) . . .

IM: We're spectators you know.

Sometimes staying together means recognizing the need for others to have activities outside the family:

IM: Or I'll make her go out and see people. You know for her own. She doesn't want to be stuck with me.

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IW: You have to do that. You have each have a bit of a life of your own, and then we can enjoy our time together in the evenings.

Finding a way to maintain a satisfying shared family life for a couple where the spouse continued to smoke meant biannual trips to Maui, to an environment suitable to their differing needs and their desire to be together:

IM: That's what's great about Maui. There you can be outside. You don't worry about air conditioning. We can be together outside. My wife can smoke and it doesn't bother me.

The ill member's energy capabilities greatly influences the kinds of strategies the family can develop. The greater the energy capacity the greater the ability to develop new patterns to meet the needs of the family group. When energy is extremely limited, so are the family's options. It is within these extremely energy limited families that the greatest

potential appears to exist for family disruption. Because limited energy is available to develop new patterns, old activities must simply be stopped and a restricted shared family life accepted.

Regardless of whether the family can develop new patterns, or adapt old ones, all described how they have to accept their limitations and live within these: "You can only do the best you can." "It's something you just have to learn to live with. You just have to get used to it, you know." "You just have to keep trying to help yourself and help each other. You do the best you can today."

Another strategy used to maintain family life is to redefine roles within the family in a way that retains a contributing place for the ill member. As described earlier, family roles are altered because of the reduced capabilities of the COPD member. Maintaining a valued place for the ill member during this process supports the family's ability to stay together and find a satisfying family life. However, the difficulty of achieving this goal because of the blurred lines of the ill member's abilities is illustrated in the following passage:

D: We are all wondering what on earth are we going to do when she's gone and we can't turn to her and all those things. And then even now when we do we think, 'Should we'? Because she's got all these other things to worry about. Should we be bothering her with our problems? But then on the other hand, when we don't come to her, she feels as if she's not contributing. So you're sort of stuck in the middle. How much can you really ask her to do without overtaxing her, but not making her feel as though

she's totally, I don't know -- not useless. But she likes to be kept in touch.

That the family members make a conscious effort to communicate that the COPD member still has an important place within the family was evident during the interviews, by such comments as:

D: It's frustrating for us too, in that we can see that she -- I think quite often she feels like she should be doing more. I mean, I think she does more than most people anyway, but she feels as though she should be doing more. And we can see that she doesn't like that herself, and it makes her feel kinda down. 'Oh, I didn't do anything today.' And then she tells you what she did, and you just about feel like collapsing yourself. But, so it makes me feel sad for her that she feels she's not contributing when I would say that she is.

In families where the well members did virtually all household tasks, the ill member's contribution could still be identified:

W: You were always good at adding up, bookkeeping. Good thing, 'cause I can't.

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W: They gave him this machine which is what they call a Ventolin machine. And he mixes it up himself, with so many millimeters of saline, you know. And he can do that himself, so he doesn't have to have anybody. I couldn't do it, to tell you the truth.

Although these tasks could have been easily assumed by others, they symbolize the importance of the COPD member to the group.

The comments illustrate the attempt to communicate acceptance of the ill member as changed while making a valued place for that changed member in the family. The work of redefining the ill member's place within the family in a meaningful way is an integral part of the challenge of maintaining a satisfying shared family life.

D. Managing the Illness

To monitor and manage the COPD member's illness presents another challenge to the family with COPD. Although the lifestyle changes maintained by the family are aimed at controlling the symptoms, strategies specific to coping with the threat of acute exacerbations are also employed.

The entire family, for example, learns to identify potential problems and initiate control, even though the ill member may take the primary responsibility:

R: You mean that you feel that you have to, or should know what's going on too with her, so that you can -- ?

D: Just so we know, well, today which thing is causing her problems. So that you can sort of figure out which, you know, thing to try and keep under control.

The family members become alert to subtle signs that signify a deterioration in the ill member's health:

D.: But you can always tell when she's on a bad day or not just by talking to her. The way she answers the phone, the way she's gasping or not talking. And yet, she tries to reassure you.

R: So you've got your own ears now for figuring out, listening to the words she is saying as well as how she is saying it.

D: Umhmm (Nodding).

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W: He is on antibiotics so much, and he will be on one and all of a sudden he is sick again, and it doesn't work, and then he has to go on another one. It's just horrible. But he coughs. I can always see when it is coming, you know. His chest is all gurgly.

As the passages illustrate, even though the COPD member may not express how s/he is honestly feeling, the other members come to

learn how to interpret cues in the ill member's behaviour themselves.

One significant factor, however, that influences the family's ability to meet this challenge is its knowledge of the disease and its treatment. The families stressed that an important part of gaining this knowledge is to be given adequate information by health care workers:

D: I really feel very strongly about that though, that it's important to have things explained. . . . It's not so important for me because I'm not here all the time, but I can understand how my Mom would want to know as much as she can.

W: You really need to understand. I mean, I didn't. No, I really didn't understand. When I was saying that, well, he can't get his breath, and what about giving him oxygen? But then I didn't realize until it was explained to me that it's -- it's really the air that isn't coming out. That's way he can't breathe. Because he's already got air in. But I should have known that because I, you know, I'd read all about that before and had it explained to me, but just --

D: Sometimes you have to read it and hear it several times before it penetrates.

From this family's comments, it is also clear that the information must be communicated repeatedly and in a manner that ensures the family members have understood and can apply it.

One source of information that was identified by the families was the respiratory rehabilitation program. The nurse in the program, specifically, was viewed as a valuable source of pertinent and accessible information:

W: Well, you feel you do have more support, definitely. I feel that you know with the nurses down there.

D: Well, there is somebody you can ask a question. . . .
I mean if we have a question, we can feel like we can
get an answer.

Without adequate information the families do not have a
sufficient basis for making decisions and trouble shooting
problems that arise, as is plainly illustrated in the following
passage:

IW: But I think if somebody had once said to me that
these Aminophylline pills or whatever they're called,
I was taking Theodur, had a tendency to make you
nauseous -- (D: But Mom sometimes the power of
suggestion is so strong.) Yeah, but I don't work on
powers of suggestion. (D: But a lot of people
might.)

R: Are you saying if you knew the side effects to watch
out yourself?

H: Right. (D2: You might have diagnosed the problem
sooner. IW: Much sooner . . .) I honestly feel that
if you had been told of the side-effects you wouldn't
have gotten into that condition. (IW: That's what
I'm saying. I wouldn't have, no way.)

The ill woman had lost tremendous weight before the family
finally stumbled onto the information that Theodur can cause
nausea. This information came from a technician who monitored
the oxygen machine in the home. Clearly, adequate information
is a basic ingredient in the success of the family to manage
the illness.

Another strategy for managing the illness is to establish
a backup system for when the family can no longer cope alone.
The main backup mentioned by the families was for emergencies:
"If I get flustered then I call the paramedics." "I know the
firemen are just a block away."

A doctor in whom the family feels confident is described

as a major source of this support: "That's half the battle." This means someone seen to have the expertise to provide the complex medical care they feel is needed, and who knows the ill person's history:

IW: Oh, I felt much better being in the hospital there, because there's two doctors, both of them working out of the same hospital and both of them know my history right from the very beginning.

Finding a doctor that will make house calls is also a significant backup support for families. For when the COPD member becomes acutely ill, the effort of travelling out of the house to the doctor's office or Emergency Department can be too much of a demand on their limited energy supply.

Although good medical care is seen as essential, the families explained that they do not rely solely on their physicians, but assume for themselves the primary role in the management of the illness. They see themselves as the experts about their own members' illness. The families' comments indicated that they have learned that they are an essential part of ensuring the safe management of the illness. This was clearly demonstrated in a family who described its careful management of the illness after a nearly fatal experience that was viewed as resulting from inadequate medical monitoring:

IW: I started going down, down, down, and really nobody could figure out what was happening to me. . . . I wasn't eating, and I was taking high blood pressure pills. And my doctor had told me, and I had asked him and asked him, my own doctor (not the specialist), 'Did I need more potassium with these'? Because I understand high blood pressure. 'Oh no, no. These are new ones and they don't affect you that way.' So I'm not worrying about it, I drink a

glass of orange juice if I feel like it, and if I don't feel like it, I don't bother. . . . Anyway, so my electrolytes were all scrambled, I was just -- Well I went into a coma, that's what happened!

The family living with COPD learns that it plays a primary role in managing acute exacerbations as well as controlling symptoms:

IW: Oh, I think I do (have to know about managing my illness) Because you never know for sure which hospital you are going to end up in. And if you end up in one where there's no doctor that knows your case at all, they are just scared stiff when, you know. They ask you what kind of drugs you are on and you give this list that's this long.

D: And then when you usually end up in there it's pretty critical. She can't even talk, so then you are sitting there, and nobody knows what to do.

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H: The next time, (that the wife was very ill) I phoned the doctor and he said, he asked me, he says, 'Do you think she should be in the hospital?' I felt like saying, 'Well, jeez, you're the doctor.' But I said, 'Yes, I honestly believe she should be.' So he just took a look at her and made arrangements to transfer her into (the hospital).

R: So do you feel like you have to know about her illness and be able to watch and see her changes, as well?

H: Oh absolutely, absolutely. (D: You can't rely on the doctors. IW: No, you can't rely on the doctors.)

The family knows that the COPD member's illness is complex and that not all general medical practitioners will be able to effectively manage the care without the family's help.

Therefore, the family exercises its responsibility for managing the illness within its capabilities.

Yet the health care system can provide barriers to the

family's involvement in the management of the illness to the degree that its knowledge equips it to. For example, some of the families described how they are not even consulted about the ill member's condition when s/he is in the doctor's office or in hospital. The family acquires indepth knowledge about the ill member's illness and develops strategies to monitor and manage the illness. However, the family can only manage to the degree that it is provided the necessary tools from health care providers, and its ability to participate in the care of its member is respected.

To find a way to live with the demands of COPD means the family has to work to develop strategies for facing the challenges the illness brings. This family works involves: accepting the chronic nature of COPD, facing an uncertain future, maintaining a satisfying shared family life, and managing the illness.

When the work of the family is viewed in light of the two previous themes, it is clear that there is ultimately a central focus in the family with COPD -- the work to breathe. As one participant said, "But of course, through it all you have to breathe." It is work that enforces a disease-dictated lifestyle on the family and brings isolation for the family.

Summary

This chapter has presented the participant families' accounts of life with COPD. The description progressed from

the description of a disease-dictated family life, to the isolation that accompanies the illness, to the final theme of the family work necessary to live with COPD. The meaning of living with COPD for the family as described in this chapter is illustrated in Figure 1, below. In the following chapter, these findings and their significance will be discussed.

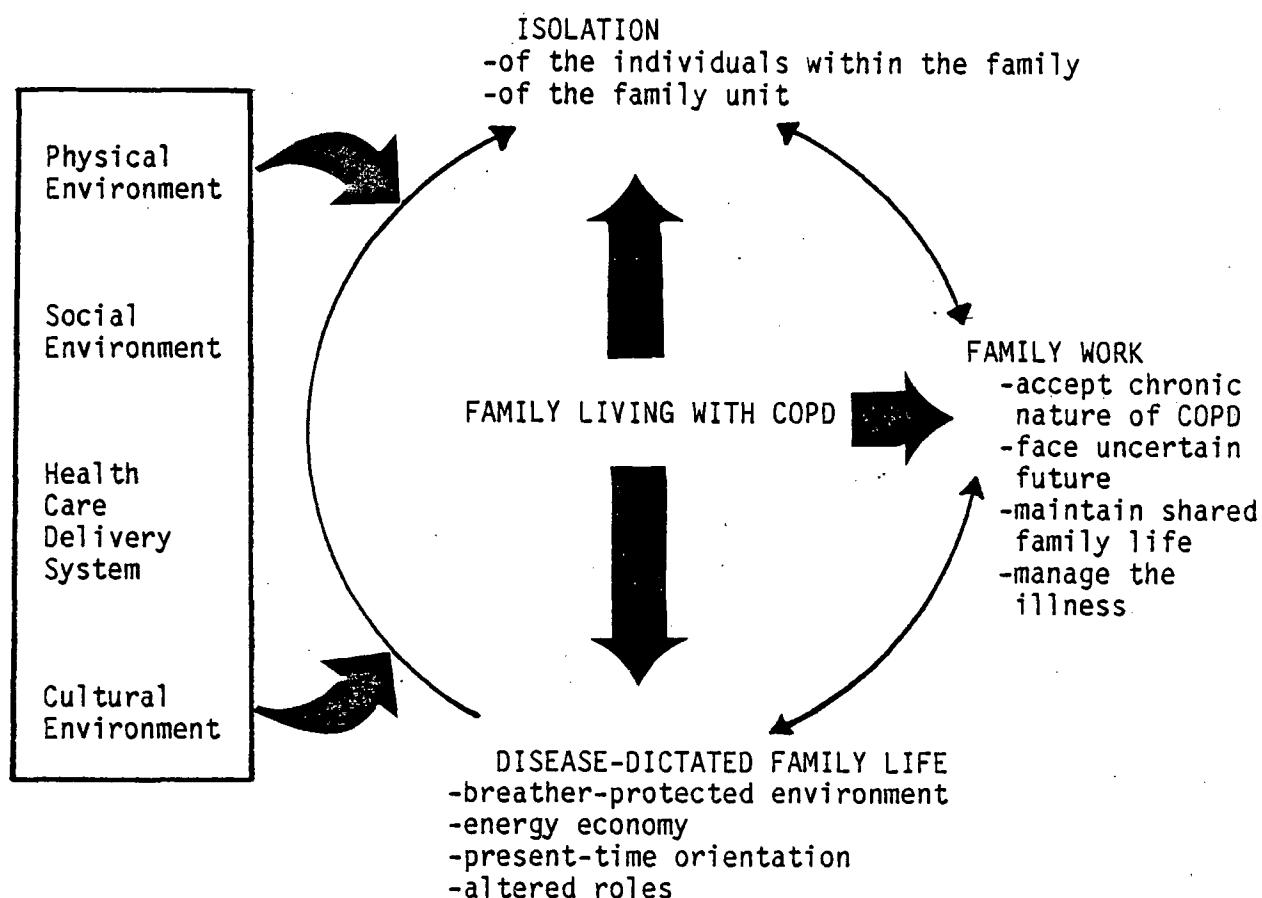


Figure 1. The Meaning of Living with COPD for the Family

CHAPTER FIVE

Discussion and Implications

This chapter provides a discussion of the research findings presented in the previous chapter and a presentation of the nursing implications. The discussion focuses upon the significance of the findings in terms of the well-being of the family who has an adult member with COPD, the place of the findings within the context of current theory, and the implications of these findings for nursing.

The discussion is organized into three sections. The first section, "stressor of COPD," examines the findings that indicate the quality of the stressor exerted by COPD upon the family. The second section, "impact of COPD on family resources," addresses the influence of COPD on the family's resources to deal with this stressor. The final section, "nursing implications," identifies specific implications these findings provide for nursing practice and further research. Throughout this discussion, reference is made to literature reviewed in Chapter Two and to additional literature required to provide the context for the research findings.

Stressor of COPD

The content of the three themes constructed from the families' accounts indicates that COPD exerts an intense stressor within the life of the family. To provide a context in which to consider these findings, the following discussion

begins with a brief overview of stress in relation to family functioning.

For the purpose of this discussion, stress is defined as a nonspecific response of the system to any demand upon it, and a stressor is defined as any demand that increases the need for readjustment (Seyle, 1977). According to Seyle's definition, a situation can produce eustress (agreeable stress) or distress (disagreeable stress). It is the intensity of the demand for readjustment or adaptation and the resources of the system to deal with this demand that determine the effect of the stressor (Scott, Oberst & Dropkin, 1980).

In relation to family functioning, the family is continually confronted by, and thus adapting to, stressors. If the family is to adapt in a way that maintains an effective level of family functioning and well-being, the stressors experienced by the family must be balanced by the family's resources to deal with these demands (Friedman, 1981). A key determinant in the strength of the demand for adaptation is the family's definition of the stressor. In other words, the family reacts not only to the presence of a stressor but to its perception of the challenge this poses (Hansen & Hill, 1964). Because the focus of this discussion is to consider the experience found to be common to families living with COPD, this distinctly individual component of the family's response to stress, although integral to gain an understanding of each family's experience, is not included in this discussion of the common family experience with COPD. The focus of this

discussion is to explore, first, the research findings that indicate the quality of the stress exerted by COPD within the family, and second, to address the findings that indicate the influence COPD exerts on the family's resources to deal with this stressor.

As was presented in the literature review, illness has long been recognized to act as a stressor within family life (Hansen & Hill; 1964; Koos, 1946; Mitchell, 1983). In congruence with this theoretical perspective, the research findings reveal that COPD acts as a stressor on the family unit. More important, the findings indicate the quality of this stressor for the family. The duration and strength of stressors are known to differ; thus each creates different demands on the system for adaptation (Friedman, 1981). Knowledge of the quality of the stressor of COPD for the family, then, contributes to the theoretical base nurses can use to provide care aimed toward decreasing the strength of this stressor acting upon the family unit.

The research findings that most clearly reveal the powerful nature of the stressor of COPD for the family are: the pervasive changes in family life required to adjust to COPD, the extensive losses experienced by the families, the priority given to the ill member's needs, and the type of challenges that resulted from living with COPD. Each of these findings is discussed in the following section.

It was found that the families adopted common lifestyle changes to adapt to their members' illness; indeed, that the

nature of the illness demanded these changes. Rather than being chosen ways of coping with the illness experience, it was as though the lifestyle changes were imposed on the family by the very nature of the disease. For no matter what the family's background, coping style, or philosophy, all families were found to have made the same lifestyle changes. The families lived within a breather-protected environment, an energy economy, and a present-time orientation, and made role alterations within the family. If the families were to live with the ill members and support their health, complying with a "COPD lifestyle" appeared to be required.

The lifestyle changes the families were found to adopt follow logically from the known symptoms of COPD: shortness of breath and energy depletion. Accordingly, the four aspects of the lifestyle found in this study are congruent with the types of restrictions noted in studies of the individual who has COPD by Chalmers (1984) and Dudley, Glaser, Jorgenson & Logan (1980). These researchers found that the individuals who have COPD are restricted in activities, roles, and relationships by shortness of breath and sensitivity to irritants, reduced energy reserves, and the variability of symptoms. Although the author found no other studies of the family with COPD with which to compare the lifestyle changes identified in this research, these changes also concur with the effects of husbands' COPD on the lives of their wives that were described

in a study by Sexton (1984). Sexton found that living with men who had COPD meant that the wives: limited their activities, had difficulty planning ahead, kept information and the expression of strong feelings from their husbands, assumed vacated roles, and took on new responsibilities. Building upon these previous findings, this research of the family with COPD indicates that in order to cope with the nature of the illness specific lifestyle changes must be adopted, and moreover that the limitations imposed by these changes, previously described for individuals with COPD and wives, are limitations of the entire family.

The need to redesign lifestyles to accommodate for the symptoms of an illness and to adjust to these lifestyle changes has been found to be a common task of living with a chronic illness (Craig & Edwards, 1983; Dimond & Jones, 1983a; Strauss et al., 1984). Thus, the lifestyle changes found to be commonly adopted by the families with COPD are representative of a well recognized phenomena of the chronic illness experience. However, the degree of the lifestyle changes made by these families signifies the powerful strength of the stressor produced by COPD. For having an adult member with COPD did not result in minor adjustments in family life, but in major lifestyle changes. The illness dictated what the families could do, where they could do it, when they could do it, and how it could be done.

Because of the constraints on family life as a result of

the dictated "COPD lifestyle," the families were also found to experience losses of many valued aspects of family life. This finding also supports the predominant theoretical perspective that chronic illness brings concomitant losses, and dealing with these losses is an integral part of the process of adjusting to chronic illness (Carlson, 1978; Crate, 1965; Feldman, 1974). What is striking about the losses experienced by the families with COPD is the extensive nature of the losses, for the families expressed the losses of previously well family members, family group activities, socialization patterns, and even aspects of family relationships. The pervasive changes demanded to adjust to a lifestyle compatible with COPD and the extensive losses this meant emphasises the strength of the demand for adjustment COPD exerts within family life.

The intensity of the stressor exerted by COPD is further highlighted when the research findings are considered in light of the multiple functions of the family. The family unit functions to meet the physical and psychological needs of all members (Friedman, 1981). McCubbin et al. (1980) explain that the family with an ill member must manage many facets of life simultaneously: maintaining satisfactory internal conditions for communications and family organization, promoting member independence and self-esteem, maintenance of family bonds of coherence and unity, maintenance and development of social supports in transactions with the community, and maintenance of some efforts to control the impact of the stressor and the

amount of change in the family unit. It was found that in the families with a member with COPD, priority was given to those behaviours that maintained ease of breathing. Thus, in most families, other needs became of secondary importance to the ill member's health needs. For example, the need to maintain open communication was supraceded by the need to restrict the expression of strong emotions that may induce breathlessness. To live within a breather-protected environments and energy economies, the families were isolated from many aspects of their social world. Furthermore, it was found that in order to modify family life in a way compatible with COPD, other family members often sacrificed the satisfaction of their desires, such as to smoke in the home, continue energy expensive activities, and attend specific social gatherings.

It is characteristic during periods of high degrees of stress that tremendous energy is expended to cope with the threat, and many other family functions are often temporarily set aside or minimally performed until the family has the resources to deal with these again (Friedman, 1981; Mitchell, 1983). Finding that the needs of other members or other family needs become of secondary import in these families implies that the intensity of the stress experienced requires significant family energy and resources to cope with it. As these families were also found to live within an energy economy, when the energy consumed in coping with the stressor of the illness is great, it may leave little energy to expend in meeting other

family needs. Strauss et al. (1984) indicate that the degree of stress imposed by a disease is reflected by the degree of the imposition on other family members. From this perspective, there is a high degree of stress exerted by COPD within the family.

MacVicar and Archbold (1976) indicate that there is a necessity in families with a chronically ill member to organize around the exigencies needed to maintain the balance between family and the ill member's needs. Given the finding that the needs of the members with COPD are given priority in these families, it appears that for the family with COPD this balance is almost impossible to achieve. Penn (1983) states: "A particular form of binding interaction exists in families with chronic illness, that winds itself around the family system, often holding it static under the threat of death" (p. 23). In the case of the families with COPD, the ever present fear of breathlessness appeared to intensify this underlying threat of death, to create an even more powerful hold on family life. Indeed, it was one that demanded that the families conform to a lifestyle aimed at avoiding breathless even though this lifestyle created pervasive change in family patterns, brought losses for the family, and meant the satisfaction of other family needs were sacrificed.

The intensity of the stressor exerted by COPD is also revealed by the nature of the major challenges that were found to be faced by families living with COPD. Significant energy was required to adjust to the chronic, long-term nature of the

disease, the losses the illness brought, and to accept that family life was permanently changed. The uncertainty of the future was emphasized for the families, a reality for which they had to develop ways of coping. The relationships within the family and patterns of everyday life were disrupted to the point that the families had to work to maintain the integrity of the unit. At the same time the families faced the ever present task of managing the illness. From the nature of these challenges, it is clear that COPD created continuous stressors within the families, demanding their continuing efforts to cope, if the families were to adjust and survive.

The powerful nature of the stressor of COPD for the family unit was revealed by the pervasive changes in the families' lives, the extensive losses they experienced, the priority given to the needs of the members with COPD, and the challenges faced by the families. From the stress theory presented at the beginning of the discussion, a balance between the stressors experienced and the family's use of the resources to deal with these stressors is needed to maintain the well-being of the family. Recognizing that the family with COPD is confronted with an intense stressor, the family will need sufficient resources to cope in a way that maintains the effective functioning of the family unit. The following section, therefore, addresses the insight the findings provide into the impact of COPD on the family's ability to use its resources effectively to manage the stress associated with COPD.

Impact of COPD on Family's Resources

The research findings not only indicate that COPD acts as an intense stressor for families, but also that COPD inhibits the families' resources to deal with the demands of this stressor. As explained earlier in the chapter, the resources of the family to deal with stressors are vital determinants in the effect the stressors have upon family functioning. Insight into how COPD influences family resources, therefore, provides important information to enable nurses to strengthen and develop the resources of families coping with COPD. As a social unit, the family's resources can be seen to be drawn from two sources: the interaction of the members within the family, and the interaction of the family with its external environment (Friedman, 1981). The following sections examine the findings that offer insight into how COPD affects each of these sources.

Internal Family Resources

The inner strength of the family is seen to lie in its ability to pull together into a cohesive, integrated unit and draw upon its collective ability to deal with stress (Friedman, 1981). The findings indicate that COPD erodes this inner resource by fostering the isolation of members within the family from one another. This was indicated in relation to two major areas.

First, it was found that the expression of intense emotions were restricted in the families as a means of preventing emotion-induced breathlessness of the COPD member. This finding supports other studies that have identified that a narrow range of emotion is tolerated by the individual with COPD. Dudley, Glaser, Jorgenson & Logan (1980) described the individual with COPD as living within an emotional straightjacket in an attempt to control breathlessness. Also, Sexton (1984) reported that wives of men with COPD tend to control the expression of strong feelings to avoid precipitating episodes of shortness of breath for their husbands. Apparently this emotional straightjacket is not just limited to the ill individuals or the wives, but can apparently envelop the entire family.

It is the recognition of the divisive result of the emotional restriction that has ramifications for the family's ability to cope with the stress of COPD. For this behaviour can wedge members apart. Meaningful, clear communication is seen to be the key element in fulfilling family functions, and bonding the family together (Friedman, 1981). Restrictions on open communication between members insulates the members from one another which inhibits the potential resource of strong bonds within the family.

The finding that understanding between family members reduced the isolation experienced between members within the family lends support to the theoretical perspective that clear communication builds the strength of the family to deal with

stress. A participant family's experience with role alterations exemplified the heightened degree of stress on family bonds that occurs when mutual understanding is not achieved within the family. Here, tension was evident as the family members resisted needed role shifts. It seemed that there were unclear expectations on what were appropriate expectations of the ill member now that her abilities had changed, and in turn, unclear expectations of the roles of others. Rather than resistance to role changes per se, Bishop, Epstein and Baldwin (1981) propose that it is the ambiguity of the need for the role changes that creates stress for families with chronic illness. The findings of this study support this view. It appeared to be the unclear communications between members and lack of mutual understanding of the need for change within the family that promoted the tension in relation to role alterations, not the assumption of the role tasks themselves. As reflected by this finding, understanding between members, whether achieved through verbal communication or not, supports the family's ability to make changes in familiar patterns in a way that maintains strong bonds between members.

The second finding which revealed the inhibitory influence of COPD on the family's inner resources was that the family's abilities to participate in shared activities were diminished. The energy limitation of the family unit was found to delete many kinds of family activities, from family dinners to family holidays. Many situations had to be avoided as they became

viewed as breather-hostile or energy-consuming. The influence of the illness of the ill member set him/her apart from the lifestyle the well members were capable of continuing. Again, these constraints were found to create a wedge between the members. Thus, the unity within the family was eroded, and the strength of the inner resources to cope with the demands of living with COPD inhibited.

A finding that is thought provoking and demands further exploration, relates to characteristics of the participant families that agreed to the family interview. The majority of the families were found to be committed to the family group and did not experience problems in relation to role alterations. Theorists have described these to be two important characteristics that strengthen the inner resources of families to deal effectively with threats. That these were found to be characteristics of this group may indicate that these families are "survivors" or "successful copers." They have been able to deal effectively with the stressor of COPD and maintain the functioning of the family at a level that enabled them to participate in a forum where open sharing among the members was an expectation. Given the restriction on the expression of emotional issues, the agreement to participate in this group process is even more suggestive of their ability to cope effectively with the demands of COPD. Perhaps some of the families who chose not to be involved in the study had not maintained a level of adaptation to life with COPD that would enable them to cope with the additional stressor created by the

group interview.

External Family Resources

The importance of examining the findings that indicate the influence of COPD upon the family's external resources is based upon a view of the family as part of a larger societal system. As such, the family requires interaction with those outside the family to function. The family alone cannot serve all the member and group needs (Friedman, 1981). Thus, the following section examines the findings that indicate the influence of COPD upon the family's external resources.

The research found that the COPD experience means isolation for the family group from others. This finding is one that could have been anticipated from the current theory base. Other theorists and researchers have described a loss of social contact, that can extend to great social isolation, that is a likely consequence of chronic disease (MacVicar, 1980; Maurin & Schenkel, 1975; Strauss et al, 1984). These authors propose that isolation develops as families with chronic illness withdraw from others into a very family- if not patient- centered existence, and as those in their social world withdraw from the families. This study's findings support this proposition. However, the significance of finding that the family with COPD experiences isolation lies not in this congruence with the literature, but in understanding what the isolation then means for the family. That which is seen to

hold the greatest significance for the well-being of the family unit provides the focus of the remainder of the discussion: the COPD family's isolation from external resources. The findings indicate that the family is isolated from the support provided by friendship networks, community organizations, and even health care workers to cope with the demands of COPD on family life. Thus, as was evident in the families' accounts, the sense of coping alone with the illness develops.

Access to external resources has been recognized as a powerful supportive force in the management and resolution of the stress associated with illness (Cobb, 1976; Dimond & Jones, 1983b; Norbeck, 1981). Caplan (1974) identified three primary external resources of the family: informal networks, community organizational support, and organized health care support. The insight the findings provide about the impact of COPD on each of these areas of support is addressed.

Living with COPD was found to inhibit the family's access to the support of informal networks. As the disease progresses, the COPD family's contacts with friends and acquaintances decrease. Consequently, the family tends to become isolated from those outside the family group.

Statements by the families that no one understood what it meant to live with COPD and that they knew of few others coping with this same illness demonstrated that the COPD families were isolated from a network of common-concern relationships. Relationships that Weiss indicates permit "the development of pooled information and ideas, and a shared interpretation of

experience, . . . a source of companionship and opportunities for exchange of services" (1974, p.23).

Having few informal relationships impedes the access of the family to information that would help it develop effective coping strategies. All members of a family group have basically the same information. "Weak ties," informal relationships outside the family, are the "channels through which ideas, influences, or information" is acquired (Granovetter, 1973). Without the contacts with informal networks information sharing is limited, an important source of ideas for developing coping strategies to deal effectively with the demands of the chronic illness is lost (Strauss et al., 1984). Without this input from others, resources that facilitate the ability of the family to cope are inhibited.

Without these relationships, important sources of feedback are also lacking. For example, the families do not access knowledge that their experiences with COPD are not unique, but common to those in situations such as there own. Sharing with others fosters a sense of commonality of experience which reduces the sense of isolation (Bloom, 1982). Receiving this type of validating feedback from others is even more important because the family with COPD cannot acquire this input through other informal media, such as lay literature and television, as is possible with other diseases. There is not an acquired pool of general knowledge about the experience of life with COPD to provide a basis for interpreting their own experiences, which

compounds the sense of isolation.

The involvement of the families in organized community support groups was also found to be lacking. Certainly the positive effect of social support has been illustrated in the ever expanding numbers of self-help groups. It then seems peculiar that at a time of movement toward self-help groups and the emphasis on social support in the current literature, that families with COPD appear to have remained isolated. Some reasons for this occurrence are offered by the research findings.

The nature of the illness itself appears to contribute to the isolation from support groups as well as from informal sources of support. In the first place, the onset of the symptoms of COPD are insidious, as is the gradual control it takes of family life. Given this, there is no single event that signals to others that the family is experiencing a stressful time and thus requires support. Indeed, there does not even seem to be a signal to the family itself that this is the right time to seek out support. This seems to wait until the family experiences a crisis. An interesting finding that may reflect this lack of a signal was the minimal involvement of the adult children in the illness experience of five of the eight participant families. This occurred even though these children lived close to their parents. That some sort of signal is needed to indicate to these children that they should become more intimately involved in their parents lives seems illustrated by the fact that the three participant families

with involved children had experienced a life-threatening event, such as an intensive care admission. This event may have provided the signal to the children to become or stay closely involved.

Secondly, the diagnosis of COPD, itself, did not produce intense emotional responses within the families, as occurs with the diagnosis of other diseases, such as cancer or a heart attack. The families did not dwell on questioning the occurrence of the disease or even discuss the diagnosis. It seems that the ill members' decreasing capabilities and smoking habits had provided ongoing clues that enabled the families to conclude that their members had lung disease before it was formally diagnosed. Whereas in the case of other diseases, diagnosis precipitates support from others, this was not found to be the case for the individual with COPD and his/her family.

Furthermore, the disease itself does not stimulate empathic responses from others. The feelings expressed by the families that the illness has been self-induced can be assumed to also be a prevalent view of those outside the family. Thus, the impetus for others to provide support is inhibited. Similarly, the view that "it is my own fault" inhibits the family from seeking support. The families' minimal support-seeking behaviours also reflect an attitude that was subtly projected in the interviews: "it is something we have brought on ourselves, we should deal with it ourselves."

Another reason that self-help groups have not been popular

for individuals with COPD and their families relates to finding that the entire family functions within an energy-economy. Getting out to attend support groups that may exist is energy consuming. The families who have the greatest energy restriction, and therefore probably experience the greatest isolation, appear to be the groups that would need this type of support the most, but they also would be the least likely to be able to attend. The energy consumed in getting out to attend the group may be seen to counter the benefit that would be gained. Similarly, the energy involved in establishing a peer support group may be considered too great an expense.

A finding that demands serious attention is that the isolation experience was also found to be potentiated by the families' interactions with the health care delivery system. One source of isolation was found to be their individually-focused interactions with health care workers. Although the findings indicate that COPD is a family experience, the family rarely was viewed as a focus for care. On the contrary, the families indicated that their involvement in the illness experience was in many cases "politely ignored."

Ransom (1983) explains that there are three different views of the family that direct care. The family is viewed as: a collection of individuals where care is given to each individual in the family as needed; an environment where a change in the state of an individual's health is attempted by changing the environment in the family; and, a functioning unit where the focus of intervention is the family group. The

findings of this research indicate that the family with COPD has needs that cannot be met through care directed solely toward the ill family member. Similarly, there are needs left unattended when the family is viewed only as part of the environment. Interventions must focus on the family as a unit of care. Although most of the individual-oriented interactions cited by the families were in relation to physicians, there was also a noticable absence of reference to a more family-focused orientation by the nurses involved in their care. Although nursing theorists have been advocating a family-focused perspective for nursing (Friedman, 1981; Leavitt, 1982; Wright & Leahey, 1984), and the findings of this research support this need, it appears that the view of the family as client has not yet widely filtered into practice.

The findings indicate that one result of this lack of family-focused health care is that the families' needs for information and support go unaddressed. Although the literature acknowledges that managing chronic illness is a task of the family unit (Griffin, 1980), and the findings of this research support this reality, the ability of health care workers to assist the COPD family in this task may not be wide-spread. It seems there is a gap between the health care workers' perspective of the illness experience and the reality that COPD is a family experience. The majority of nursing interventions with families with COPD now appear to predominantly focus on teaching the family about the treatment

regime to ensure the environment is conducive to supporting the ill member. Although this focus is important, it cannot be at the expense of the needs of the families to cope with the tasks of everyday living.

The families expressed the need for information in relation to the trajectory of the illness and the management of the illness. But, it was indicated that the information the families received was minimal and inadequate, particularly the information that would enable them to prepare for the future. Miller (1980) describes anticipatory planning as an integral part of living with a chronic illness. She states that families need to be told of specific problems they may conceivably face and be helped to explore ways in which these may be handled. Finding that an uncertain future presents a primary challenge to these families even more clearly indicates that nursing interventions that aid the family in anticipatory coping are needed.

The emphasis the families placed on information may also be an expression of the need for support to cope with the daily stress of living with COPD. Cohen and Lazarus (1979) indicated that the nature of the process of the family's interaction with those in the health care field may be more important to the families than the receipt of the information. Given that the families with COPD perceived that others did not understand their experience, it follows that the emphasis the families placed on the lack of information received from health care workers may in fact reflect their sense of a lack

of support. A major reason for offering information to the family, therefore, may be to communicate that support is available to help them deal with the challenges of living with COPD.

The findings also suggest that because the health care delivery system is so acute care oriented, the families feel limited support for their chronic, long-term needs. Assistance from health care workers was found to be primarily related to acute exacerbations of the illness, such as during emergency services. The families may have in turn come to see these as the only legitimate concerns for which they could seek help. The view of the health care system as only appropriate for crisis, "disease" problems, is not surprising, for this has been the traditional orientation of the Canadian health care system (Torrance, 1981). That the families described their needs primarily in relation to coping with the problems of chronicity emphasizes the importance of ensuring the health care delivery system provides services oriented toward clients living with long-term illness. There must be tangible support for nurses to act in this capacity so families do not continue to "drop through the cracks" of the health care system.

From this discussion of the findings, it is argued that COPD creates a powerful stressor within family life, while at the same time it acts to inhibit the family's resources to deal with these demands. The following section identifies the implications these findings hold for nursing practice.

Nursing Implications

What is daily life like for the family in which an adult member has COPD? How do families respond to the demands of the illness? The findings in relation to these research questions have implications for nursing. Implications are presented in relation to two areas: nursing practice, and nursing research. Implications for nursing education are seen to stem from the implications for practice and therefore are not specified in this presentation.

Implications for Nursing Practice

The phenomenological description of the family experience when an adult member has COPD provides an indepth understanding of this experience. Knowledge of the type of stress COPD creates for the family and the potential family problems that arise contributes to the theoretical base nurses can use to provide appropriate and effective care for families living with COPD. The findings provide specific implications for nursing practice toward decreasing the strength of the stressor exerted by COPD and increasing the family's resources to deal with this stressor in a way that maintains the well-being of the family unit. The implications for nursing practice are identified in relation to these two foci.

Decreasing the strength of the stressor exerted by COPD.

Finding that the families experience pervasive changes and

losses as a result of accommodating the demands of COPD and supporting the ill member indicates that nurses should promote family behaviours that will enhance the resolution of the losses. The expression of the feelings evoked by a loss are known to be necessary for its resolution (Bowlby & Parkes, 1970). Thus, nurses should provide opportunities for the family or members within the family to share their feelings about the experience, listen and accept the family members' expressions of grief, and validate that the members' feelings in relation to the loss are normal responses. If a family retains few relationships outside of the family, and also becomes used to controlling the expression of emotion within the family, the expression of grief is likely to be hampered; thus, outside assistance may be even more strongly needed.

Finding that managing the illness presents a primary challenge to the family indicates that nursing care should be directed toward strengthening the family's ability to meet this demand. As the limitations of the ill member were found to become limitations of the entire family, nursing interventions toward minimizing the limitations of the ill member can be seen to meet both the needs of the individual and the family. Thus, the importance of nursing care toward the individual's rehabilitation is emphasized.

Finding that the uncertainty of the future created stress within the family, nursing care should include fostering the process of anticipatory coping within the family. The findings indicate that this should involve providing information about

specific problems the family may conceivably face and an opportunity to explore possible ways that these problems may be handled.

As living with COPD was found to exert a powerful stressor within the family, helping the families to learn how to recognize the level of the stress within the family and to develop positive strategies to release this stress is also indicated.

Strengthening the family's resources to deal with COPD.

Recognition of the divisive influence COPD can exert within the family, indicates that nursing action should be directed toward fostering the cohesion within the family. The families' comments that they benefited from the interview process, even though most had never before discussed the impact of the illness on their family life, and finding that the members were able to share their thoughts and feelings within the group setting suggests that families may benefit from nurses promoting and facilitating family group discussions. These would provide an opportunity to enhance the sharing among members.

The findings indicate that the use of emotional restriction within a family should be assessed to see how this coping strategy is affecting the family. Interventions to decrease separation between members could then be initiated, if appropriate. Understanding that the expression of emotion is

often restricted in these families, and that relationships outside the family may be limited, indicates that the families may also need assistance to develop healthy avenues for the release of these feelings.

As mutual understanding of the limitations of the illness and realistic expectations of members for each other were found to enhance family cohesion, nursing interventions should be oriented toward facilitating mutual understanding within the family. This could involve such nursing interventions as the provision of information about the limitations common to individuals with COPD and the needs of the ill member, to ensure all members have a basic understanding of the disease. The ill member would then not need to continually justify his/her limitations to the family. Initiating opportunities for several families to interact would also provide a forum for family members to learn about the needs of the ill member. This also would provide an opportunity for sharing ways each family has handled problems that have emerged when living with COPD. Joint information sessions between families could also be arranged, where the nurse basically acts as a mediator to facilitate the sharing in the group.

Finding that families with COPD receive little support from friends, other kin, and community organizations indicates that nurses should become more involved in fostering common-concern networks. Because of the energy limitations of these families, energy conscious types of supportive strategies are indicated. For example, as telephone contact is energy

efficient, networking between COPD families could be facilitated by nurses who link the families by telephone.

The findings demonstrate the need for nurses to view the family with COPD as a focus for health care. Not only is this indicated because the families were found to have needs that are not addressed through care oriented solely toward the ill members, but because these individual-focused interactions were found to isolate the families from what should be an accessible source of support. Furthermore, rather than wait for families to enlist assistance when near crisis or in crisis, the findings suggest that nurses should reach out to these families. If only physical problems are seen as appropriate reasons to seek assistance, the families may not know who to ask for help, or they may be unsure of what type of help it is that they need. It also appeared from the findings that the families did not understand what services they could access. Therefore, early contacts with families should be used to communicate the various health care services available, from respiratory rehabilitation clinics, to home care, to family counselling. Families should also be educated as to the need to request services they wish to receive, such as to be included in health care decisions in relation to the care of the ill member and for attention to the health care needs of the family unit and/or individual members. The skills nurses have to offer in helping the families cope with COPD should also be communicated, for example, nurses' abilities to assist

families in their preparation for the future, in learning how to manage the illness, and in minimizing the limitation the ill member's COPD exerts on their family life.

Implications for Nursing Research

Further investigation of the family experience with COPD would be useful to develop the knowledge base that was generated from this investigation. Greater depth of understanding may be gained by interviews with individual family members to complement the family group interview. This would enable the investigator to explore the relationship of the individual members' experiences to the development of the experience of the family group.

A study of nurses' perceptions of the needs of families with COPD is also indicated by the research findings. Such a study would indicate whether nurses lack an understanding of the COPD family's needs, or if these are recognized but not acted upon, and if so the barriers to this action. The knowledge provided by a study of this nature would direct interventions aimed toward nursing education and administration to promote appropriate nursing care of the family with COPD.

The following questions have been raised as a result of this investigation that with further study would contribute to knowledge of the family experience with COPD. What factors influence the support-seeking behaviours of the family with COPD? How do families perceive the role of the health care system in meeting their needs? Is there a consistent

relationship between the perception of the limitation of the ill member, the lifestyle changes adopted, and the isolation experienced by the family unit? What factors influence family members who live separately from a COPD member to become involved with the illness experience? Do family discussions affect the family's perception of the stress it experiences in living with COPD? Do joint family discussion sessions or telephone networking affect the family's perception of isolation and support?

Summary

Consolidating the findings of the study, this chapter addressed a picture of family life greatly structured around the disease of the member with COPD. The discussion focused upon the significance of the findings for the well-being of the family unit. First, the insight provided by the research results into the powerful quality of the stressor COPD exerts within family life was addressed. Second, the inhibitory influence of COPD on both the internal and external resources of the family was examined. Current literature that related to the findings provided further explanations of the significance of the effects of COPD on family life. Finally, the value of the phenomenological description for nursing was evident as the findings were found to provide extensive implications for nursing practice. In addition, the findings were found to

generate several research questions for further investigation of the family experience with COPD. The next chapter will provide a summary of the research study.

CHAPTER SIX

Summary and Conclusions

Summary

This study was designed to gain an understanding of family life when an adult member has chronic obstructive pulmonary disease. From the current theoretical base, it is clear that the effect of COPD on the family unit greatly influences the illness experience of the COPD member, the health of the other family members, and the well-being of the family itself. And yet, the literature offers little knowledge of how COPD affects family life, knowledge that would enhance the appropriate and effective provision of nursing care for these families. The available literature addresses the perspective of the individual who has COPD or the spouse, but not that of the family unit. This group perspective is seen essential if the family's experience is to be understood.

This viewpoint is based upon a symbolic interactionist perspective, the conceptual framework which guided this investigation. From this perspective, the illness experience of the family is seen to be created through the interaction of the family members. Together, the members form a collective definition of their situation which serves to shape the family's behaviour. Thus, to understand the family experience with COPD, the family unit's description of its situation and actions became the focus of this investigation.

To gain an understanding of the meaning of COPD from the

perspective of the family unit, an interpretative research approach, phenomenology, was employed. Guided by the conceptual framework, this approach allowed the investigator to fulfill the purpose of the study, that is, to describe and explain the family experience with COPD, from the perspective of the family group.

Eight families acted as co-researchers in the investigation by participating in semi-structured interviews. Through the interview process, the researcher helped the family construct an account of its experience: What the family's daily life is like, and how the family responds to the demands of the illness. Through the data collection and content analysis process, the investigator gained an intimate understanding of the meaning of COPD for the family, and translated this data into a narrative description of family life with COPD.

Three interrelated themes embody the research findings: disease-dictated family life, isolation, and family work. The first theme addresses the disease-dictated changes in family life that were the foundation of the families' accounts. The families revealed that pervasive changes in family life are necessary in order to meet the COPD member's needs and accommodate for his/her diminished capabilities. This involves four primary aspects of family life. First, in order to avoid breathlessness, family life is confined to breather-protected environments. Conforming to this irritant-free environment imposes emotional as well as physical restrictions on the

family. Second, group life is constrained by the limited energy capacity of the ill member. It is as though the ill member's energy-economy prescribes the amount and kind of activities now possible for the family group. Third, a present-time, "here and now," orientation is imposed by the unpredictable and variable disease symptoms and the instability of the ill member's health status. Finally, role alterations are an integral part of family life. Other family members must accommodate and compensate for the diminished abilities of the COPD member.

Further to these lifestyle changes, the second theme addresses the isolation these families experience. Living with COPD means isolating forces act upon the family group. The very lifestyle changes the family adopts to support the ill member's needs end up isolating the family. Attempts to minimize the family's differences from others also means isolation from those situations where this is impossible. As well, a sense that others do not understand what it means for the family to live with COPD contributes to the family's sense of coping alone with a new way of life.

Also part of this isolation are forces that insulate members of the family unit. The gap between the needs and abilities of the COPD member and those of the other family members isolates members from one another. The control of the expression of intense emotion within the family in order to avoid emotion-induced shortness of breath potentiates this separation. As well, the limited degree to which the

limitations of the ill member are understood and accepted by other family members often extends the isolation members feel from each other.

The families' descriptions of the family work necessary to find a way of life with COPD was developed into the third interpretive theme. The families focused upon four primary challenges. First, work is required to accept the chronic nature of COPD, that is, accept the losses it means and adjust to the extensive changes required within the family. Second, the family must learn to live with an uncertain future. It was described as a future that could hold further restrictions for the family unit as the illness progresses and eventually the ill member's death. Third, because of the disruptive and divisive forces within the family fostered by the illness, family work is required to maintain a satisfying shared family life. The families demonstrated that commitment to the family unit and to maintaining a valued place for the ill member within the family contribute to meeting this challenge. Finally, managing the illness poses an ever present challenge.

Conclusions

A number of conclusions can be drawn from the findings of the research. The most distinct of these findings is that COPD is indeed a family experience. The accounts of family life with COPD reflect Mitchell's statement: "Individuals have chronic diseases, families cope with chronic illness" (1983, p.

2). The limitations of the ill member were found to be limitations of the family; the isolation that accompanies COPD, isolation experienced by the entire family unit; and the work required to live with COPD, family work.

A second conclusion is that a "COPD lifestyle" is commonly adopted by families who have an adult member with COPD. Although the degree to which the lifestyle was evident in each family varied, it was part of each family's life. The components of the lifestyle are imposed on the family by the characteristics of the disease.

An important conclusion is that living with COPD is a stressful and potentially disruptive experience for the family unit. It is an experience which inhibits the strength of cohesion of the family group, isolates the family unit from the support of others, and evokes minimal support-seeking behaviours by the family itself.

A fourth conclusion is that COPD creates common challenges to which the families must respond. The challenges are common, but each family develops its own coping strategies compatible with its unique style to adjust to life with COPD.

Finally, and perhaps most important, families with COPD have needs which are not presently being addressed by health care workers. Families need accurate information from health care workers, and need support in order to adjust to a new way of life, face an uncertain future, manage the illness, and develop effective coping strategies to accommodate the demands of COPD.

This research investigation into the family experience with chronic obstructive pulmonary disease contributes to the knowledge base nurses can use to improve care provided to the family with COPD. It also emphasizes the need for further investigation into intervention strategies that will promote the well-being of the COPD family in light of its special needs.

BIBLIOGRAPHY

- Anthony, E. (1970). The impact of mental and physical illness on family life. American Journal of Psychiatry, 127, 138-146.
- Barritt, L., Beckman, T., Bleeker, H. & Mulderij, L. (1984). Analyzing phenomenological descriptions. Phenomenology and Pedagogy, 2, 1-17.
- Barstow, R. (1974). Coping with emphysema. Nursing Clinics of North America, 9, 137-145.
- Beland, I. & Passos, J. (1975). Clinical nursing pathophysiological and psychosocial approaches. New York: MacMillan.
- Benoliel, J. (1982). The nurse-family relationship. In L. Curtin & M.J. Flaherty (Eds.), Nursing ethics: Theories and pragmatics (pp. 103-123). Bowie, Maryland: Robert J. Brady.
- Benoliel, J. (1983). Grounded theory and qualitative data: The socializing influence of life-threatening disease on identity development. In P. Wooldridge, M. Schmidt, J. Skipper & R. Leonard (Eds.), Behavioral science and nursing theory (pp. 141-187). St. Louis: C.V. Mosby.
- Benoliel, J. & McCorkle, R. (1978). A holistic approach to terminal illness. Cancer Nursing, 1, 143-149.
- Bishop, D., Epstein, N. & Baldwin, L. (1981). Disability: A family affair. In D. Freeman & B. Trute (Eds.), Treating families with special needs (pp. 3-14). Ottawa: Alberta & Canadian Association of Social Workers.
- Blacher, R. (1970). Reaction to chronic illness. In B. Schoenberg, A. Carr, D. Peretz & A. Kutscher (Eds.), Loss and grief (pp. 189-198). New York: Columbia University Press.
- Black, K. (1983). Short-term counseling. Menlo Park, California: Addison-Wesley.
- Bloom, J. (1982). Social support systems and cancer: A conceptual view. In J. Cohen, J. Cullen & L. Martin (Eds.), Psychosocial aspects of cancer (pp. 129-149). New York: Raven Press.
- Blumer, H. (1969). Symbolic interactionism: Perspective and method. New Jersey: Prentice-Hall.
- Bowlby, J. & Parkes, C. (1970). Separation and loss within the family. In E. Anthony & C. Korpernik (Eds.), The child in his family (pp. 197-216). New York: John Wiley & Sons.

- Burr, W. (1973). Theory construction and the sociology of the family. John Wiley & Sons.
- Burton, L. (1975). The family life of sick children: A study of family coping with chronic childhood illness. London: Routledge & Kegan Paul.
- Canadian Council. (1977). Report of the consultative group on ethics. Ottawa: The Canada Council.
- Canadian Nurses' Association. (1972). Ethics of nursing research. The Canadian Nurse, 68(8), 23-25.
- Caplan, G. (1974). Support systems and community mental health. New York: Behavioral Publications.
- Carlson, C. (1978). Loss. In C. Carlson & B. Blackwell (Eds.). Behavioral concepts in nursing intervention (pp. 72-86). Philadelphia: J.B. Lippincott.
- Chalmers, K. (1980). Coping with chronic airflow obstruction: A study of non-hospitalized adults. Unpublished master's thesis, McGill University, Montreal.
- Chalmers, K. (1984). A closer look at how people cope with chronic airflow obstruction. Canadian Nurse, 80(2), 35-38.
- Cobb, S. (1976). Social support as a moderator of stress. Psychosomatic Medicine, 3, 300-314.
- Cohen, F. & Lazarus, R. (1979). Coping with the stresses of illness. In G. Stone, F. Cohen, N. Adler & Associates (Eds.), Health psychology: A handbook (pp. 217-254). San Francisco: Jossey-Bass.
- Colaizzi, P. (1978). Psychological research as the phenomenologists view it. In R. Valle & M. King (Eds.), Existential phenomenological alternatives for psychology (pp. 48-71). New York: Oxford University Press.
- Cooper, E. (1984). A pilot study on the effects of the diagnosis of lung cancer on family relationships. Cancer Nursing, 7, 301-308.
- Craig, H. & Edwards J. (1983). Adaptation in chronic illness: An eclectic model for nurses. Journal of Advanced Nursing, 8, 397-404.
- Crate, M. (1965). Nursing functions in adaptation to chronic illness. American Journal of Nursing, 65(10), 72-76.

- Davis, A. (1978). The phenomenological approach in nursing research. In N. Chaska (Ed.), The nursing profession: Views through the mist (pp. 186-197). New York: McGraw-Hill.
- Davis, A. (1980). Disability, home care and the care-taking role in family life. Journal of Advanced Nursing, 5, 475-484.
- Dimond, M. & Jones, S. (1983a). Chronic illness across the lifespan. Norwalk Connecticut: Appleton-Century-Crofts.
- Dimond, M. & Jones, S. (1983b). Social support: A review and theoretical integration. In P. Chinn (Ed.), Advances in Nursing Theory Development (pp. 235-249). Rockyville, Maryland: Aspen.
- Dudley, D., Glaser, E., Jorgenson, B., & Logan, D. (1980). Psychosocial concomitants to rehabilitation in chronic obstructive pulmonary disease: Part I. Psychosocial and psychological considerations. Chest, 3, 413-420.
- Egan, G. (1982). The skilled helper. Monterey, California: Brooks/Cole.
- Feldman, D. (1974). Chronic disabling illness: A holistic view. Journal of Chronic Diseases, 27, 287-291.
- Friedman, M. (1981). Family nursing: Theory and assessment. New York: Appleton-Century-Crofts.
- Giorgi, A. (1975). Convergence and divergence of qualitative and quantitative methods in psychology. In A. Giorgi, G. Fischer & E. Murray (Eds.), Duquesne studies in phenomenological psychology (pp. 72-79). Pittsburgh: Duquesne University Press.
- Goode, W. (1964). The family. Englewood Cliffs, N.J.: Prentice-Hall.
- Gourevitch, M. (1973). A survey of family reactions to disease and death in a family member. In E. Anthony & C. Korpernik (Eds.), The child in his family: Vol. 2 (pp. 21-28). New York: John Wiley & Sons.
- Granovetter, M. (1973). The strength of weak ties. American Journal of Sociology, 78, 1360-1380.
- Green, C. (1982). Assessment of family stress. Journal of Advanced Nursing, 7, 11-17.
- Griffin, J. (1980). Physical illness in the family. In J. Miller & E. Janosik (Eds.), Family-focused care (pp. 245-268). New York: McGraw-Hill.

- Haas, A., Pineda, H., Haas, F. & Axen, K. (1979). Pulmonary therapy and rehabilitation: Principles and practice. London: Williams & Wilkins.
- Hansen, D. & Hill, R. (1964). Families under stress. In H. Christensen (Ed.), Handbook of marriage and the family (pp. 782-821). Chicago: Rand-McNally.
- Hansen, E. (1982). Effects of chronic lung disease on life in general and on sexuality: Perceptions of adult patients. Heart and Lung, 11, 435-441.
- Hayes, V. & Knox, J. (1984). The experience of stress in parents of children hospitalized with long-term disabilities. Journal of Advanced Nursing, 9, 333-341.
- Health and Welfare Canada. (1982). Chronic diseases in Canada, 3(1), 1-35.
- Hodgkin, J. (1979). Chronic obstructive pulmonary disease: Current concepts in diagnosis and comprehensive care. Park Ridge: American College of Chest Physicians.
- Kaplan, D., Smith, A., Grobstein, R. & Fischman, S. (1973). Family mediation of stress. Social Work, 18, 60-67.
- Kass, I. (1978). Disability benefits for chronic lung disease patients. American Lung Association Bulletin, 64(1), 7-10.
- Klein, R., Dean, A. & Bogdonoff, M. (1967). The impact of illness upon the spouse. Journal of Chronic Disease, 20, 241-248.
- Knaack, P. (1984). Phenomenological research. Western Journal of Nursing Research, 6, 107-114.
- Koos, E. (1946). Families in trouble. New York: King's Crown Press.
- Lalonde, M. (1974). A new perspective on the health of Canadians. Ottawa: Department of National Health & Welfare.
- Lauer, R. & Handel, W. (1977). Social psychology: The theory and application of symbolic interaction. Boston: Houghton Mifflin.
- Leavitt, M. (1982). Families at risk: Primary prevention in nursing practice. Boston: Little, Brown & Company.
- Lenihan, S. (1981). Quest for meaning in the face of chronic illness. In B. Perdue, N. Mahan, S. Hawes & S. Friik (Eds.), Chronic Care Nursing (pp. 33-38). New York: Springer.

- Lewis, J. (1976). The family and physical illness. Texas Medicine, 72, 43-49.
- Lindesmith, A., Strauss, A. & Denzin, N. (Eds.). (1975). Readings in social psychology. Hinsdale, Illinois: Dryden Press.
- Litman, T. (1974). The family as a basic unit in health and medical care: A social-behavioral overview. Social Science and Medicine, 8, 495-519.
- Lofland, J. (1984). Analyzing social settings: A guide to qualitative observation and analysis. Belmont, California: Wadsworth.
- MacVicar, M. (1980). A conceptual framework for family-centered cancer care. In B. Glynn & M. Miller (Eds.), Current perspectives in nursing (pp. 35-43). St. Louis: Mosby.
- MacVicar, M. & Archbold, P. (1976). A framework for family assessment in chronic illness. Nursing Forum, 15, 180-194.
- Maurin, J. & Schenkel, J. (1975). A study of the family unit's response to hemodialysis. Journal of Psychosomatic Research, 20, 163-168.
- Mauskch, J. (1974). A social science basis for conceptualizing family health. Social Science and Medicine, 8, 521-528.
- McCubbin, H. (1979). Integrating coping behavior in family stress theory. Journal of Marriage and the Family, 41, 237-244.
- McCubbin, H., Joy, C., Cauble, A., Comeau, J., Patterson, J. & Needle, R. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42, 855-869.
- Melvin, J. & Nagi, S. (1970). Factors in behavioral responses to impairments. Archives of Physical Medicine and Rehabilitation, 51, 552-557.
- Miller, J. (1980). Anticipatory family guidance. In J. Miller & E. Janosik (Eds.), Family-focused care (pp. 395-403). New York: McGraw-Hill.
- Mitchell, P. (1983). Crisis management for families living with chronic illness. Washington State Journal of Nursing, 54, 2-8.
- Moos, R. & Tsu, V. (1977). The crisis of physical illness: An overview. In R. Moos (Ed.), Coping with physical illness (pp. 5-21). New York: Plenum Medical.

- Murawski, B., Penman, D. & Schmitt, M. (1978). Social support in health and illness: The concept and its measurement. Cancer Nursing, 1, 365-371.
- Nerenz, D. & Leventhal, H. (1983). Self-regulation theory in chronic illness. In T. Burish & L. Bradley (Eds.), Coping with chronic disease (pp. 13-37). New York: Academic Press.
- Norbeck, J. (1981). Social support: A model for clinical research and application. Advances in Nursing Science, 3, 43-59.
- Oiler, C. (1982). The phenomenological approach in nursing research. Nursing Research, 31, 178-181.
- Olesen, V. & Whittaker, E. (1967). Role-making in participant observation: Process in the researcher-actor relationship. Human Organization, 26(4), 273-281.
- Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 5, 49-63.
- Parsons, T. (1951). The social system. New York: The Free Press.
- Pattison, M. (1974). Psychosocial predictors of death prognosis. Omega, 5, 145-159.
- Penn, P. (1983). Coalitions and binding interactions in families with chronic illnesses. Family Systems Medicine, 1, 16-25.
- Petty, T. (Ed.). (1978). Chronic obstructive pulmonary disease. New York: Marcel Dekker.
- Quint, J. (1969). Some theories on chronicity. In Proceedings of the first national Nursing theorists conference (pp. 58-67). Kansas City University of Kansas Medical Center, Department of Nursing Education.
- Ransom, D. (1983). On why it is useful to say that "the family is a unit of care." in Family Medicine: Comment on Carmichael's essay. Family Systems Medicine, 1, 17-22.
- Reiss, D. (1981). The family's construction of reality. Cambridge, Mass: Harvard University Press.
- Rist, R. (1979). On the means of knowing: Qualitative research in education. New York University Education Quarterly, Summer, 17-21.

- Schontz, F. (1975). The psychological aspects of physical illness on disability. New York: MacMillan.
- Schwartz, H. & Jacobs, J. (1979). Qualitative sociology: A method to the madness. New York: The Free Press.
- Scott, D., Oberst, M. & Dropkin, M. (1980). A stress-coping model. Advances in Nursing Science, 3, 9-23.
- Selye, H. (1977). A cope for coping with stress. AORN Journal, 25, 35-42.
- Sexton, D. (1981). Chronic obstructive pulmonary disease. St. Louis: C.V. Mosby.
- Sexton, D. (1984). The supporting cast: Wives of COPD patients. Journal of Gerontological Nursing, 10, 82-85.
- Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., Maines, D., Suczek, B. & Wiener, C. (Eds.). (1984). Chronic illness and the quality of life. St. Louis: C.V. Mosby.
- Stryker, S. (1980). Symbolic interactionism: A social structural version. London: Benjamin/Cummings.
- Thorne, S. (1983). The family cancer experience. Unpublished master's thesis, University of British Columbia, Vancouver.
- Torrence, G. (1981). Hospitals as health factories. In D. Coburn (Ed.), Health and Canadian society: Sociological perspectives (pp. 254-273). Don Mills: Fitzhenry & Whiteside.
- Traver, G. (1975). Living with chronic respiratory disease. American Journal of Nursing, 75, 1777-1781.
- Traver, G. (Ed.). (1982). Respiratory nursing: The science and the art. New York: John Wiley & Sons.
- Verwoerd, A. (1972). Psychopathological response to stress of physical illness. Advances in Psychosomatic Medicine, 8, 119-141.
- Weiss, R. (1974). The provisions of social relationships. In Z. Rubin (Ed.), Doing unto others (pp. 17-26). New Jersey: Prentice-Hall.
- West, J. (1977). Pulmonary pathophysiology. Baltimore: The Williams Company.
- Wright, L & Leahey, M. (1984). Nurses and families: A guide to family assessment and intervention. Philadelphia: F.A. Davis.

APPENDIX A

Physician Consent Form

Date: _____

I give Della Roberts permission to recruit participants for the study "Family Experience with Chronic Obstructive Pulmonary Disease" from the patients in my medical practice.

I understand the study will be approved by the University of British Columbia Behavioural Screening Committee for Research prior to any contact with potential participants.

Signature _____

APPENDIX C

Family Consent Form

The Family Experience with COPD
Investigator: Della Roberts

I understand the purpose of this study is to understand how COPD affects our daily family life.

I understand this study involves:

1. One or two visits by D. Roberts for an interview with our family, lasting from one to two hours.

2. Discussion of what it is like for our family now that one member has COPD that limits his/her ability to carry out previous activities.

3. Tape recordings of the interviews.

I understand the information obtained will be confidential, and all information will be destroyed once the study is completed.

I understand I am under no obligation to participate in the study; my refusal would not influence any further care I receive; I may refuse to answer any questions asked; and may withdraw from the study at any time.

I consent to participate in the project as explained, and acknowledge the receipt of an explanatory letter.

Date: _____

Signatures: _____

APPENDIX D

Interview Guide

I understand that an illness like COPD not only affects (the name of the adult with COPD), but must affect your whole family.

What is it like for your family now that _____'s COPD limits his/her usual activities?

What aspects of your daily life would you say are affected?

How does your family deal with these influences?

What aspects of your family life are most important to your family now?

Have these changed?

What are those things which now are of most concern to your family?