

**THE ILLNESS EXPERIENCE OF INDIVIDUALS WITH CHRONIC
OBSTRUCTIVE PULMONARY DISEASE AND THEIR PERCEIVED
CARE NEEDS**

BY

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Submitted to the Faculty of Graduate Studies
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The Illness Experience of Individuals with Chronic Obstructive Pulmonary Disease and their Perceived Care Needs

ABSTRACT

Chronic Obstructive Pulmonary Disease has a serious impact on the health and quality of life of Canadians. Health Canada Statistics report that from 1991 - 1995, chronic obstructive pulmonary disease was responsible for some 100,000 hospital admissions and more than one million days in hospital.

Individuals with chronic obstructive pulmonary disease were asked about their illness experience and asked to document their perceptions of needs for formal and informal care and services in relation to their illness. The emphasis of this study is on the qualitative ethnographically-oriented interview using a purposive sample of eight individuals. The individuals in the sample were identified by the Health Sciences Centre Respiratory Outpatient Clinic. Interviews were arranged with individuals who consented to participate. The interviews used a semi-structured interview guide and were audio-taped, transcribed verbatim and coded for common themes.

It is anticipated that an understanding of the individual's chronic obstructive pulmonary disease illness experience and an understanding of the perceived care needs will provide information to care providers within health care and community services. This knowledge should enable care providers and family members to more fully anticipate and meet the needs of the growing population of individuals with chronic obstructive pulmonary disease.

ACKNOWLEDGEMENTS

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I. Introduction

Current conceptions and views of human life propound the importance of achieving an optimal health state. Despite the emphasis on achieving wellness, historical epidemiology shows a change in the total burden of illness from one dominated by infectious diseases to a burden of illness in the late 20th century dominated by chronic illness. Chronic illnesses are long term, incurable, uncertain, and disproportionately intrusive. Chronic illness affects the concept of self and challenges the relationship between the self and the body by forcing an awareness of the body and its limitations.

Chronic Obstructive Pulmonary Disease (COPD) is a chronic illness. The condition includes a medical diagnosis of emphysema, chronic bronchitis or asthma with persistent obstruction of airways or any combination of these diagnoses. COPD is a leading cause of mortality in North America (Tames, 1991). The impacts of COPD in terms of mortality, disability and economic cost to the health care system are significant. Most individuals are initially seen by health care professionals, after they become symptomatic and significant lung damage has already occurred.

There is no cure for COPD, but lifestyle changes such as smoking cessation and medical treatment can significantly impact quality of life. Individuals with chronic obstructive pulmonary disease (COPD) live with daily challenges and limitations. The illness shapes their lives everyday through its impact on functional performance. Individuals who are chronically ill make lifestyle changes, deal with disruptions, learn to preserve dignity and self-esteem and live in a health care system that is facing increasing resource constraints (Burckhardt, 1987). The individual may manage their condition

through a variety of functional adaptations. The availability of medical treatments, community services, support programs and personal support networks also influence the life course of persons living with COPD. The extent to which individuals utilize the different treatment modalities, service delivery options and supports can vary widely. Health care services, such as respite programs, adult day care, home support (e.g. for light housekeeping or grocery, etc.) and home nursing have been developed and delivered in the community since the 1950's in an effort to prevent or delay institutionalization of elderly persons (Logan & Spitz, 1994; Henry & Capitman, 1995; Neysmith 1993; Stoller & Cutler, 1993). The adaptation of these programs specifically to meet the needs of the individuals with respiratory difficulties is sparsely documented in the literature.

There are a multitude of biological, psychological and social factors that influence the coping and functional adaptation of individuals living with COPD (Dudley, 1981; Sandhu, 1986; Shekleton, 1987). Coping becomes a necessary component in both living with the disease process (Ben-Sira, 1984; Keller, 1988, Mattlin, Wethington & Kessler, 1990) and the maintenance of functional integrity (Shekelton, 1987). These adaptations are threatened when the individual experiencing the stress appraises a stressor as an immediate or future threat to him or herself (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). At present, the majority of the literature examines COPD-associated stressors from a medically defined or clinician perspective. In studies of COPD patients, specific concerns are discussed or described peripherally and the relationships among concerns, disease trajectory and care needs are not well understood (Barstow, 1974; Chalmers, 1984; Post and Collins, 1981-82; Sexton and Munroe, 1988, Price, 1996).

An exploration of the COPD illness experience from the client perspective in relation to client perceptions of care needs will provide insights relevant to providing or planning for more appropriate care.

This research project was guided by the following research questions:

1. How do individuals with COPD describe their illness experience?
 - a) How do they describe their functional performance?
 - b) How do they perceive their quality of life?
 - c) How do they describe their existing resources?
2. What are the perceived care needs identified by individuals with COPD who are patients at the Health Sciences Centre Respiratory Outpatient Department?
 - a) What resources do they identify as necessary, but unavailable to facilitate community living?

To answer these questions the researcher chose to utilize a semi-structured ethnographically orientated interview to encourage informants to describe their illness experience and identify their perceived care needs. Chapter I of this study provides an introduction to the issues related to Chronic Obstructive Pulmonary Disease. It also presents a composite case study that highlights some of the experiences and care needs described by the informants interviewed. The research design and methodology as well as a description of the researcher's expectation of results before the data collection began, are included in Chapter II RESEARCH DESIGN AND METHODS. Chapter III presents the literature review describing

Chronic Obstructive Pulmonary Disease from an epidemiological and clinical experience. It also summarizes the social sciences literature on COPD as a psychosocial illness experience. Chapter IV entitled WHO ARE THE INFORMANTS, outlines the demographic characteristics of the informants, reviews their illness states and describes the experience of the interviews in the section titled; dynamics of the Interviews. Chapter V titled LIFE WITH COPD includes the analysis and discussion detailing the themes that emerged in the interview narratives. Chapter IV provides a summary and applied recommendations.

The next section titled COPD Case study provides an introduction to a life narrative exploring the impact of COPD. In order to introduce some of the themes and issues brought forth by the informants in this research project, a compilation of narrative passages taken from the different interviews is presented below as a composite case study of a person's experience. This composite has been given the pseudonym "Peter". Peter's narrative is offered as an introduction to give a sense of the informant's life narrative.

COPD Case Study

"Peter's" narrative describes frustration, dependency, life changes and anxiety and in this way it is representative of the themes brought forward by many of the informants. Peter feels that medical personnel do not understand what it is like to be so short of breath that every little task that you might have before performed effortlessly and without thought, now requires thought, planning and in some cases modification. He reports

great frustration with this situation and describes some of the circumstances that cause him frustration. Peter also describes how sometimes being short of breath scares him and how it sometimes leads him to panic.

"...few medical people know first hand the frustration of being so short of breath you can barely make it to the bathroom and back or how difficult it can be to towel off after bath or even how it feels to be dependent on a little plastic tube that you wear in your nose and drag behind you everywhere you go...."

"..... they can't imagine how tears come to your eyes when you remember the way you used to get your work done -- in an orderly way and in reasonable time or the last time you danced across the floor with your wife or grandchild in your arms."

".... what it is like when you cannot breathe when you lie down, you know, so you spend your nights in a chair or not sleeping at all and and what it is like to now need from others the help you were always the first to offer them before. (long pause) And then, all the times when you are so scared, panicked and you don't think that you will be able to catch your next breath. And then there is when you get so down and depressed."

Peter discussed his experience with fatigue and dependency and how this changes the way he lives his life. He notes that he does not believe that he should feel fatigued, and how sometimes it seemed to occur for no reason at all.

"It makes you feel so tired. You shouldn't feel so tired, you think, then you try to do something and you can't. Your breathing, its, its just so much work that's all you can do. Sometimes you go ahead and do more anyway and then you really suffer later."

"...the one thing that I found absolutely stupid was this feeling of being tired. I became so tired for no reason at all when I was working....I would of course slow down, not because I had a choice though. I put it off for a long time I guess. You know dealing with the tiredness."

"It makes you realize that you are limited and you think it is just this time, but it is not.....You know that I had to retire early. Well, it was not my choice, but the it would take me longer and longer to do my route and

then I couldn't make it to the end of the day.....needed a rest and more rest after that, I don't know. Anyways, my wife and I talked and we decided we could make a go of it if I quit early..... well it was not that early really. Anyways, it made a big difference being at home, I hated it, didn't know what to do. But I guess I changed.

" Started doing different things and you know what is hard too? It is admitting to yourself that you can't do something and me you know I am stubborn, and having to ask for help – especially with everyday things. You know I can cut the grass, but well it takes me sometimes a whole morning or more now. I just can't catch my breath. So sometimes I get help, but I really feel I can look after myself unless..."

Peter states that sometimes his shortness of breath leads him to feel very anxious, because it feels like he cannot breath at all. He goes on to describe how this severe anxiety leaves him feeling "paralyzed".

"Well, because you can't catch your breath, you start to think that you can't breath at all and you know what that means. You are gonna die. At least that is what it is like then. You think that it is never gonna end. But then, it usually does ease up and you hope that it never happens again, but you know it does."

"Well sometimes I get really worked up, I am not sure what happens. It is really awful, to be so paralyzed."

"..... by fear really, but also by not being able to catch a breath. You just stop doing everything and hope that it will pass. No one should bother you then. You feel that you will not make it out the other end."

" Sometimes, it just passes, sometimes my wife will rub my back or bring me my medicine. I don't always know, but you just are so scared it is impossible to do anything -- even breathe.

Peter notes how these episodes of anxiety and panic seem to occur more when he is 'sick', that is to say when he has a respiratory infection complicating his chronic obstructive lung disease.

" I guess they seem to happen when I am sick."

“Well, you know when I uh have like an infection or need to be in hospital. That’s when. Sometimes I take some ativan and my puffers. Sometimes, I don’t know, you think it is all going to end. People don’t understand, I can’t explain.”

Peter believes that his lung condition will get progressively worse as time goes on. He recognizes that he will require different and probably more supports and services and has put some thought into how he would like to see this occur. Peter believes the future may hold medical advances, but is not optimistic that he will be able to benefit from them.

“Well, I think it is probably going to get progressively worse (clears throat) and there is moments when I realize that I have very much limited options, um I don’t know if I really dwell on that very much. I um. I think I am very aware of infection and getting a bad cold and you know I’m aware that could end up in the hospital in quite bad condition, it takes a long time to recover from that. We almost got out of our house, we got into an apartment which would have been less to deal with you know, like summer is going to come and have the garden, as much as I enjoyed the garden because it does take a lot of energy you know. On the one hand I think you know, I think it’s good for me and on the other hand I wonder where my head is sometimes for getting into it all. But, I uh, there is times when I can’t do it so it doesn’t get done and um, I couldn’t be by myself and say to people well I’ll probably end up in Deer Lodge, you know, which is, from my understanding, a facility that would be good. I probably won’t be able to travel on a plane, you know, without oxygen and able to do those kinds of things, and um, you know, it’s um, I don’t know I’ll probably be too old to get into a , be eligible for a lung transplant later on, I don’t know, and I don’t know much more medications or whatever. I guess I’ll deal with it as it comes you know, I don’t know. I think there is care out there, there are facilities out there that will help you and all these kinds of things and I will probably have to take advantage of it all you know. I don’t want to be a burden to my children, I think that is very difficult and hopefully I will get into some kind of accommodation what would be easier for everybody. Whether I know it’s time, you know, maybe I won’t feel right maybe it won’t be too long.”

“The future is more negative than anything isn’t it? I mean the sickness is going to get worse and it’s probably too late to change that, even if they do come up with some miracle of sorts. I am going to need more support in the future and I do not want to burden my wife or family and friends, so if possible I would look to some sort of institution....”

The composite case study of "Peter" using narratives of several informants conveys a sense of how the informants shared their illness experiences during the interviews.

II. Research Design and Methods

Methodology

The methodology section includes the operational definitions, the research design, sample selection, as well as data collection and data analysis.

Operational Definitions

Definitions of 'perceived', 'care needs' and 'resources' in accordance to their intended use through the study are as follows:

Perceived: refers to that awareness of, or observed through the senses or the mind

Care needs: refers to a useful or desired service or thing

Resources: refers to any actual or potential supply that will meet a need.

Research Design

To accurately describe the experience of living with COPD, to identify the perceived care needs of the individual with COPD and to understand the resources that they recognize as important and effective, a qualitative ethnographic approach will be used. In this study, data was collected through narrative interviews, focusing on life historical experience with illness, care-seeking behaviour and perceived needs for service.

This study is a descriptive examination, from the informant's perspective. Therefore it only deals with self-perceived service needs and a self-perceived sense of the illness. It

is recognized that there is an established service delivery system in the Winnipeg City area that focuses its services to individuals with COPD. This study design does not deal with the existing service system. It was however recognized that informants would reference specific services in their narratives. Therefore to assist in understanding the variety of specialty services that have individuals with COPD in Winnipeg may have access to, a service listing was developed and is located in APPENDIX D.

Qualitative methods were chosen because they are best suited for the study of process and meaning (Rubenstein, 1994). The advantages of this approach as stated by Gareth Williams (1987, 98),

“...significant contribution to understanding that can be derived from qualitative studies which examine patients’ experiences on their own terms and in their own contexts.”

Ethnography develops “concepts to understand human behaviors from an emic point of view” (Field and Morse, 1985). The use of this approach will facilitate knowledge development and understanding by generating rich, description of the meaning and values individuals attribute to persons, things or events (Fetterman, 1989, Morse, 1991). It is important to note that this research design is not an ethnography, but rather uses ethnographically-oriented interviews to gather qualitative data from individuals. It does not provide an ethnographic description of either clinicians nor the overall system of care provision.

Recruitment

Individuals with COPD who attend the Health Sciences Centre Respiratory Outpatients Department participated in the study. The physicians and the clinic nurses were asked to identify individuals that fit the project's inclusion criteria and then give these individuals the typewritten "Information Letter" (Appendix 1) that describes the research project. If after reading the information letter, the individual was willing to participate, they would indicate this to the physician or the clinic nurse and the individual's name and telephone number were recorded and provided to the researcher.

Each individual was informed about the project and a consent form, requiring signature was completed prior to the interview (Appendix 2). A semi-structured interview using a series of questions, allowing subjects to expand responses and explore related themes was used to encourage the individual to describe their illness experience. Other questions on care experiences were asked to identify current care needs and use of resources as well as the impact or usefulness of these resources from their own experience. Their interpretation of what constitutes a support, their description of it and their evaluation of its ability to meet their needs was documented. Suggestions for the improvement of services or development of new services were also recorded. The complete interview guide is included in Appendix 3. Pre-testing of the interview guide was conducted and revisions were made as necessary before the research project started.

Sample Selection

In qualitative research, the researcher attempts to select a sample of informants who have extensive knowledge of the phenomena under study (Marshall & Rossman, 1989; Field & Morse, 1985; Morse, 1991; Polit & Hungler, 1991). Many qualitative research projects utilize a small number of informants, chosen to provide detail about personal meaning and experience. Adequate sample size depends upon the unfolding of ideational consistency in the data and on thematic pattern saturation (Rubenstein, 1994).

Purposive sampling was used to select informants included in the final sample. This methodology enables the selection of informants who are capable of increasing understanding and developing knowledge (Field & Morse, 1985). Purposive sampling is suitable when the intention is to study a small subset of a larger population in which many members of the subset are readily identified, but the enumeration of all would be nearly impossible (Babbie, 1973). Purposive sampling is a form of non-probability, convenience sampling and as such, its greatest weakness is also its greatest strength. The concentrated detail derived from in-depth interviews of a selected few, is not generalizable to the population from which the sample was chosen. Characteristics of individuals to be represented, such as age, gender and severity of disease may initially be defined, and these may be adjusted as required during the study (Bernard, 1994).

The sample of individuals with COPD was recruited from the Health Sciences Centre Respiratory Outpatient Clinic. Inclusion criteria was as follows: the individual must have been medically diagnosed as having chronic obstructive pulmonary disease in the form of

emphysema, chronic bronchitis or asthma in combination with chronic bronchitis and emphysema. (Although asthma is named as a chronic obstructive pulmonary disease, individuals who have a diagnosis of asthma alone, will not be included in the sample population. The effects of and perception of symptoms in asthma and those of chronic bronchitis and emphysema differ in the characteristic quality of symptom experience such that they warrant separate study from each other (Gift, 1991; Janson-Bjerklie, Carrieri, Hudes, 1986; Janson-Bjerklie, Ruma, Stulbarg, Carrieri, 1987; Kinsman, Fernandez, Schocket, Dirks, Covino, 1983)). The individual must have been able to speak and understand English, live in or within commuting distance of Winnipeg, provide a written, informed consent, and be eighteen years of age or older.

At the outset, the design was to include 10-12 individuals that would form the sample, with the possibility of adding individuals as required to achieve repetition and thematic saturation. Two to three individuals from each gender for the moderate and severe stages in the disease trajectory were selected. Thematic saturation was achieved with eight interviews and the study design was adjusted accordingly. The variables included in the sample selection criteria included 1) stage of illness and 2) gender. The sample selection broken down by stage of illness and gender are included in Table 1.

Table 1**Sample Selection**

Stage of Illness	Gender		Total in each Stage of Illness
	Male	Female	
Moderate	2	2	4
Severe	2	2	4
Total Number of participants	4	4	8

Stage of illness was used as an element in the sample selection, because it was anticipated that there might be some variations in illness experiences and in perceived care needs in these two groupings. The determination of the informant's stage of illness was made by the clinic nurse and reported to the researcher when the individual's name was given as a potential project participant. In discussion with the clinic nurse regarding how this determination was made, it was a combination of documented physical assessment data and the individual's observed and reported functional performance. Generally, informants who were determined to be at the severe stage of illness were those who were dependent on supplemental oxygen and used a wheelchair for mobility, either part or all the time. More details about the sample are reported in Chapter IV WHO ARE THE INFORMANTS.

Both male and female participants were selected for each stage in the disease trajectory in order to explore the relationship between perceived care needs and gender. Past research with individuals with COPD disproportionately represented the experience of the male gender (Barstow, 1974; McSweeney, et.al., 1982, Sexton, Munro, 1985). With the increasing numbers of female smokers (Gelsky, Macdonald, Young, 1991; Lamarch, 1990; Greaves, 1990) and the subsequent rise in the incidence of COPD among women (Semenciw, Hill, Yang, Wigle, 1989) point to the need for gender-balanced research of individuals with this disease. There have been gender differences identified peripherally in COPD research (Kline-Leidy, 1990; Sexton, Munro, 1988, Barstow, 1974). In addition, studies report that women experience specific COPD concerns with greater intensity than their male counterparts. For example, gender-associated differences in the experience of dyspnea and anxiety were reported by Janson-Bjerklie, Carrieri, Hudes, 1986; Emery, Leatherman, Burker, MacIntyer, 1991.

Data Collection

Life historical and illness narratives were collected through semi-structured verbal ethnographically-orientated interviews. These interviews focussed on individual experience and treatment/service perceptions and did not involve a description of the system of treatment. In addition, field notes were kept to facilitate interpretation of observed non-verbal behaviours (Sexton, 1983, Swanson, 1986) and to define the context of the interview (Schatzman & Strauss, 1973). All interviews were audio-taped and transcribed verbatim. Polit and Hungler (1991), indicate that the interview is the most useful methodology because of the quality and depth of data it generates. Interviewing in

ethnography serves as a means to understand the participant within the parameters of group beliefs and experiences (Fetterman 1989). The data collection, coding and analysis, were concurrent to allow for the investigator to develop grounded theoretical interpretations (Becker 1993).

Data Analysis

The data analysis centered on the identification of common themes and codes that emerged from the data on the illness experience and perceived care needs. The interview transcripts were coded and organized by category. The categories were modified and refined as awareness and understanding of the themes grew and the research process continued. Comparison of illness experience and of perceived care needs for similarities and differences involved looking for coexistent or contrasting issues between participant interviews (Fetterman 1989, Spradley, 1979, Yin, 1989). It was anticipated that in response to the data collected and the status of the project, additional or altered interview questions need to be instituted. There were no additional interview questions required. There were, however, some questions where the manner in which the questions were introduced to the informants was refined so that it would be sensitive to potentially difficult subject matter.

A microcomputer and a word processing program were utilized, however the actual coding and development of categories was done manually by the researcher. This process assisted this researcher to remain sensitive to the data and allow for the

continuous process of inductive and deductive reasoning that are important in unfolding and developing conceptual depth in substantive or formal theory (Becker, 1993).

Ethical Considerations

Ethical issues present in this research project included negotiation of informed consent, maintenance of confidentiality, risk of exposing the informant to fatigue or shortness of breath during the interview process and bringing up potentially difficult subject matter like the future to individuals with a chronic illness. When the individuals/potential informants were asked to participate in the research project, they were informed about the objectives, methods and any risks or benefits of the research. Potential participants were also informed that they may withdraw from the research project at any time. Explanation and consent forms emphasized that any health or health related service that they were receiving or will receive in the future would not be affected by their withdrawal. The maintenance of anonymity is important in relation to those individuals who choose to participate and those who choose not to participate. To ensure the both anonymity and informed consent, the individuals were given an information letter (Appendix 1) by the Health Sciences Centre Respiratory Outpatient Clinic nurse that described the research project and provided them with the opportunity to consider whether they wish to participate. The name and telephone number of the individuals who agree to participate were provided to the researcher at this point. In this manner, the researcher was not aware of the names of the individuals who declined to participate.

The participants read and signed the consent form (Appendix 2) at the time of the interview. After the potential participant read the consent, the interviewer reviewed the form by reading it aloud together with the informant and asked for any questions or concerns at this point. Once informed consent was obtained, the researcher made every effort to maintain subject confidentiality. The participant's name was not used in relation to any aspect of the research and was not released to any individuals other than the researcher and the primary research advisor, as required. There were no participant refusals or withdrawals from the sample.

If in the course of the interview, the participant requested that an issue be brought forth for further discussion or follow-up, the participant was referred directly to the care provider involved. It was explained to each informant that the researcher had previous employment as a nurse manager at the Health Sciences Centre, but that she was on a leave of absence from that position and that she would not be returning to that position after the leave of absence was complete. To reinforce this reality and assist in the identification of roles, the researcher ensured that no form of Health Sciences Centre work identification was worn during the interview. The researcher also dressed in a manner that is more readily identified with the student role (e. g. casual dress, no lab coat or business suit).

The researcher had an awareness of the potential for observer bias in the course of the interview, related to her nursing and care provision background. Being cognizant of this potential bias did assist in minimizing the potential effect and additionally, the

interviewer found it advantageous that the individual informants had control over the selection of location for the data collection interview. Given this control by the individual at the outset and given that the majority of individuals interviewed chose their home to be the site of the interview, supported the identification of the researcher in the student role.

The researcher, a nurse experienced in the care of individuals with COPD, monitored the participant for signs of respiratory discomfort such as laboured breathing and cyanosis. If the participant developed shortness of breath or stated that he/she is short of breath during the interview, the researcher took a pause in the interview questions. It was then suggested that the participant rest for a while or discontinue the interview to complete it at another time that would be suitable for the participant. These measures to deal with the risk of fatigue are significant, in that dyspnea is a physiologic stressor in COPD (Kniesel & Ames, 1987) and dyspnea may invalidate the data or prevent the collection of complete data (Sexton, 1983). There were two occasions that occurred in two different interviews where the interviewer assessed the need for the informant to rest and take time to recover related to their shortness of breath.

There were several informants who in discussing the future became emotional and needed to take a pause in the interview to recover composure. There were two informants who broke down and cried during the course of the interview. Although these informants were reassured (as they had been prior to the start of the interview) that they did not have to answer any question that they did not feel comfortable with, they did

continue with the remainder of the interview. The question that prompted this emotional response was asked in the early part of the interview and it dealt with the issue of the future. The timing of this question was fortuitous in that it allowed occasion for further support or discussion with the individual, before the interview was completed.

Researcher expectations

In initiating this project, this researcher had certain expectations of the themes that she anticipated would be discussed by the informants. It was anticipated that informants would describe the onset of their symptoms as a slow, insidious process that accumulated over time to physically debilitate them. It was expected that informants would recognize cigarette smoking as a major risk factor for COPD and be unanimously against smoking. It was also anticipated that informants would be frustrated by the physical limitations of COPD and that a fair amount of time might be spent describing what they could no longer do as part of their daily life. The researcher expected that informants would be able to clearly describe and list the services that they thought would be of value to them. Finally, it was hypothesized that informants would be fairly negative in their viewpoint when they described their circumstance.

Some of the researcher expectations and hypotheses were realized in the interviews and some were not. Informants' description of cigarette smoking as a major risk factor for COPD, frustration by physical limitations and impact on daily life activities occurred as anticipated. The description of onset of symptoms, attitude towards smoking, description of perceived needs, and attitude as they described their circumstance were not

as expected by the researcher. The themes identified will be described in detail in

Chapter V, LIFE WITH COPD.

III. LITERATURE REVIEW

The literature on chronic obstructive pulmonary disease brings forward information related to the diseases that comprise COPD. It focuses on disease trajectory, the etiology of COPD, diagnosis and assessment of COPD, and the impacts of smoking on COPD. Psychosocial research has focused on stress and coping with chronic illness, impacts on the family and the effect on support persons. This literature review encompasses the diseases that comprise COPD, the diagnosis and assessment of COPD, the disease trajectory of COPD, stress and coping, coping with chronic illness, coping in COPD, the effect of COPD on the family. The literature review is organized into the following sections: medical definition and population impacts of COPD, clinical diagnosis and assessment of COPD, etiology and risk factors, medical management, disease trajectory, stress and coping, coping and chronic illness, coping and COPD, COPD and the family, and COPD and psychosocial factors.

Chronic Obstructive Pulmonary Disease

COPD is identified as the most common form of respiratory disease involving ventilation (Skelton, 1987). COPD is a progressive and irreversible chronic illness involving a symptomatic presentation of dyspnea, cough and gradually increasing levels of disability (American Thoracic Society, 1995). The assessment of the condition includes a medical diagnosis of any single or combinations of emphysema, chronic bronchitis or asthma with persistent obstruction of airways (Webster and Kadah, 1991). In Canada, over 750,000 individuals are reported to have a diagnosis of COPD (Statistics Canada 1995). In 1992, COPD was the seventh leading cause of death in Canada and is

accountable for the loss of 120 years of life for every 100,000 individuals (Wilkins & Mark, 1992). In 1996, approximately 9,000 Canadians died of COPD. In the United States, COPD is the fourth most common cause of death (Lacasse, Goldstein Lancet article, USA, 1993). Each year 8.5 billion patient visits are made to Canadian hospitals for treatment of COPD (Health and Welfare Canada, 1991) and are responsible for 5.2 billion dollars in direct and indirect health care costs (Wigle, Mao, Wong and Lane, 1991, Manfreda et. al. 1989).

Diagnosis and Assessment of COPD

The development of COPD is progressive, gradual and insidious. Individuals with mild airflow limitation resulting from cigarette smoking generally have few symptoms (Chapman 1996). Symptoms may be nonspecific in nature, such as a bronchitis or a chest cold that lasts longer than expected or that reoccurs on a frequent basis (Tames, 1991). Similarly, physical examination findings may be minimal, as auscultation for wheezes is difficult in detecting mild airflow obstruction. At this point the individual is able to maintain an active, normal lifestyle in the presence of impaired lung function (Kanner, 1987). As a result, COPD is often recognized only when the disease is severe and advanced stage (Ferguson, 1993, Chapman, 1996).

The individual's physical assessment in combination with pulmonary function tests, chest x-rays, arterial blood gases and computed tomography scans (C.T. scans) provide the basis for a diagnosis of COPD (Tames, 1991, Chapman 1996, Kniesl and Ames, 1987). A basic and routine test, the pulmonary function test is the most frequently used

means of diagnosing airflow obstruction (McCarthy, 1990). The spirometry test (part of pulmonary function testing) is a measure of forced expiratory lung volume in one second (FEV_1) (Chapman, 1996). The FEV_1 and the FEV_1 / Forced Vital Capacity ratio are compared to the predicted "normal" pulmonary function values based on age, sex and height and in this way determine the presence of airflow obstruction (Burrows, 1990). With COPD the respiratory muscles work at a mechanical disadvantage in that they are faced with the increased load of obstructed airways and the respiratory muscles may become fatigued. (Chapman, 1992, Ferguson, 1993, Chapman, 1996).

Etiology – Risk Factors

The lung function changes that individuals with COPD experience is generally a slow decline with episodic periods of rapid deterioration and although, there are periods of stable lung function, deterioration is certain (Dudley, et al 1980). Various factors contribute to the development of COPD. Risk factors cited in the literature as contributing to the disease development include: hereditary abnormalities (a homozygous deficiency in alpha-antitrypsin in the lungs), occupational exposures, gender, cigarette smoking and air pollution (Tames, 1991, Petty, 1990, Holland, 1988). Cigarette smoking has been identified as a primary factor in the development of COPD (Thurlbeck, 1990, Petty, 1990, Sherman, 1992). The smoke from cigarettes damages and destroys lung tissue by stimulating inflammatory processes within the respiratory system that often progress to the development of COPD (Gross, 1990, Tames, 1991, Canadian Thoracic Society Workshop Group, 1992). Smoking has been identified as the single most

important risk factor in the development of COPD, contributing to 81.5 % of all COPD deaths (Sherman, 1992).

Once COPD has been identified in an individual, health care practitioners begin secondary prevention by working with the person to ensure that they realize the importance of maintaining a non-smoker status or becoming a non-smoker (Fletcher, 1977). Smoking continues to be a lifestyle choice for many Canadians. The numbers of individuals who smoke has decreased among the older adult population, and 72 percent of all Canadian smokers are between the ages of 20 - 54 years of age (Eliany and Cartemanche, 1992). The trends indicate a growing number of female smokers and a growing number of heavy smokers among both male and female smokers (Eliany and Caremanche, 1992, Greaves, 1990). The statistics indicate that the use of tobacco is gradually decreasing and that the percentage of Canadian smokers has decreased from 50 to 32 percent in the period between 1965 and 1989 (Eliany and Caremanche, 1992). Prevalence of smoking is still high among sub-populations including aboriginals and women. Given the recent statistics that reflect a decrease in smoking as a lifestyle choice, it may be that the incidence of COPD may gradually decline. Notable decreases in the number of individuals with COPD will not occur until the cohort of present and past smokers has been replaced by those who are presently the younger non-smokers. Many of the current and past smokers are still at risk for developing COPD, as the latency period between exposure and disease onset is 20 -30 years (Tames, 1991, Kanner, 1987).

Medical Management

The medication treatment strategy is structured on a foundation of regular inhaled anticholinergic bronchodilator therapy that can be supplemented by beta agonist or sustained release theophylline preparations (Gross, 1988, Braun 1989, Tashkin 1986). The health care practitioner may prescribe a graded exercise rehabilitation program if exercise tolerance is limited. In the chronically hypoxemic individual with COPD, supplemental oxygen therapy may be prescribed and is shown to reduce mortality (Fletcher, 1987, Medical Research Council Working Party, 1981, Nocturnal Oxygen Therapy Trial Group, 1980).

Disease Trajectory of COPD

The term trajectory is used here to describe the overall pattern of disease and the social illness response over the life of individuals. The development of COPD occurs over a period of years, twenty to thirty years according to Tames, 1991. The individual may not have an awareness of the disease in the early or mild stages as it displays slow progression. COPD manifests itself by slowly decreasing the exercise tolerance of the individual and increasing the amount of dyspnea with activity. At this stage a chronic cough, and possible sputum production, not unlike a persistent or recurrent chest cold (Tames, 1991) are likely to be present. The individual at this stage with COPD is probably able to live an active and productive life despite the presence of impaired lung function (Kanner 1987).

COPD is often diagnosed in the moderate to severe disease stages (Tames, 1991), since the mild stages often present with fluctuating symptoms and pulmonary function tests (Kanner 1987). As the age of the individual advances, often in the middle to late 50's, disease related disability gradually becomes more prominent. Respiratory tract infections occur and often the symptoms worsen (Kneisel and Ames, 1987).

In the moderate to severe stages of COPD, the individual experiences dyspnea and wheezing while performing activities such as walking: an activity that could previously be performed without the occurrence of such symptoms (Tames, 1991). Ultimately, the disease will progress to the extent that the individual experiences dyspnea even at rest (Tames, 1991). The consequent hypoxemia leads to cor pulmonale and ventricular failure (Fishman 1971, Openbrier, Hoffman & Wesmiller, 1988). The administration of supplemental oxygen and periodic mechanical ventilation may be necessary at the moderate to severe stages of COPD. For the majority of individuals as the COPD progresses, eventual death by respiratory failure in the presence of respiratory infection and cardiac failure occurs (Tames, 1991). Medical treatment and rehabilitation therapies may slow the disease process, but again, for the majority of individuals, the physical decline that occurs related to COPD is unavoidable (Shekelton, 1987; Kniesl & Ames, 1987).

Stress and Coping

COPD impacts the individual in terms of lifestyle adjustment and quality of life. When individuals are compromised by the physiologic, psychologic stressors of disease,

there is a potential negative impact on health (Lazarus and Folkman, 1984) or the disease process may be exacerbated (Antonovsky, 1972). Stress has many meanings (Monat and Lazarus, 1985). Kneisel and Ames (1987) characterize stress as a natural element of daily life that is responsible for initiating coping. Stress can be “any event in which environmental demands, internal demands or both, tax or exceed the adaptive resources of an individual, social system or tissue system” (Monat and Lazarus, 1985). Stress can arise from events that involve change, an enduring negative environmental condition and particular types of situations where no change occurs (Monat and Lazarus, 1985). Stress can be acute or chronic (Elliot and Eisdorfer, 1982). Chronic stress is associated to chronic illness (Bombardier, D’Amico, Jordan, 1990, Felton, Revenson and Hinrichsen, 1984). Chronic stress, if uncontrolled, has the potential for exacerbation of disease (Antonovsky, 1972).

Coping in relation to chronic illness maintains the physical, psychological and social integrity of individuals facilitating adaptation to disease (Burckhardt, 1987). Coping is established as a defensive and protective behaviour in response to stress (Pearlin and Schooler, 1978). Coping reconciles and soothes the stress by changing or removing the conditions that are the cause of the stress, or by regulating the emotions associated with the stress (Pearlin and Schooler, 1978, Monat and Lazarus, 1985).

Coping with Chronic Illness

Life with a chronic illness requires the use of coping resources that exceed those needed to deal with daily stresses, short term or acute illnesses (Mattlin, Wethington,

Kessler, 1990, Burckhardt, 1987). Stressors associated with chronic illness regularly challenge and threaten the individual (Burckhardt, 1987). Correspondingly, chronic illness stressors may lead to self-destructive behaviour, anxiety, depression, anger and decline of physical health (Burckhardt, 1987, Bombardier, D'Amico, Jordan, 1990).

Coping is used as a resource to ease the stress confronting the individual with a chronic illness. Individuals often find that previous coping strategies are no longer effective as they adjust to the physical, social and psychological changes that come with living with a chronic illness and so new coping strategies are developed (Burckhardt, 1987, Ben Sira, 1984). Lipowski (1970) states that coping behaviour in illness is a result of the individual characteristics, situational context and the stage of illness. Other researchers have endeavored to identify the relationship between the use of coping strategies, adjustment to chronic illness and the function of the individual (Bombardier, D'Amico, Jordan, 1990, Ben Sira, 1984, Felton & Revenson & Hinrichsen, 1984, Keller, 1988, Mattlin, Wethington & Kessler, 1990, Lipowski, 1970, Viney & Westbrook, 1984).

The term 'resources' includes any actual or potential supply that will meet a need. Shapiro (1993) identifies resource needs of elders as involving responsive physicians, a community care program, a geriatric assessment/rehabilitation unit, adult day care and respite care. Logan and Spitz (1994) classify spouses, children, relatives, neighbours and friends as informal supports and seniors centres, meals services, and transportation services are seen as more formal supports. In this study, any relationship, program, service, business or organization that is identified by the individual as having a supportive, helpful in relation to their life with COPD will be considered a resource.

Examples include the daughter-in-law who does their grocery shopping, the home care nurse, the respiratory physician, the taxi service, the neighbor who makes friendly visits, and the church social club.

Coping and COPD

Early research of coping and COPD attempted to describe coping. Barstow (1974), described the individual coping with COPD in terms of pacing and the simplification of activities of daily living. The activities of daily living (ADL's) identified as influenced by COPD included: eating, bathing, dressing, grooming and sleeping. Barstow (1974), noted that individuals with COPD changed, modified or obtained assistance in the performance of ADL because of fatigue, dyspnea, weakness and coughing when attempting ADL. Barstow (1974) also noted that elements such as economic situation, access to health care services, transportation, treatment regimes and the support of significant others were influential in facilitating adjustment in the performance of ADL's.

Chalmers (1984), in a qualitative study of 30 individuals with airflow obstruction identified three categories of coping strategies: cognitive, behavioral and expressive. The cognitive coping strategies were those that required thought, for example, individuals who consciously thought of pacing activities. The behavioral coping strategies were those that involved actions, for example, avoiding contact with individuals with respiratory infections. And the expressive coping strategies were found to be those that involved expressing of emotions such as crying.

Fagerhaugh (1986) studied coping in relation to physical mobility and social issues. The primary resources used were noted to be energy, time and money. Coping strategies were noted to include lifestyle changes to prevent the occurrence of dyspnea. These included planning activities, moving to areas where public transportation was plentiful, asking for assistance and the avoidance of emotional and excitable situations.

The level of severity of COPD does not necessary correlate to the level of coping. Instead, research has identified that coping is associated with a variety of factors. McSweeny et. al. (1982) identified depression, anxiety and fatigue as factors influencing quality of life and coping. The researchers used a large convenience sample (n=203) and observed that some individuals are better able to cope with disease than others. They noted that the severity of the disease is probably not the most influential factor in determining coping and suggested that factors such as age, neuropsychological functioning or socioeconomic status may be important in facilitating coping. A limitation of this study is the use of predominantly male subjects. The male or female role (Sexton and Munro, 1985), and their methods of coping (Janelli, 1991) have been identified as being different and therefore influencing study results.

The literature regarding coping and COPD creates an awareness of the relevance and essential nature of coping. And it is noted that coping as a process does not exist alone, but rather is a response to an event perceived stressful by an individual. Stressors have been identified by both clinicians and individuals, but since stress only emerges when the individual perceives a stress to be present (Folkman & Lazarus, 1980, Folkman &

Lazarus, 1984), it is important to consider the clinician's perception of stressors or concerns may differ from that of the individual with COPD. Clinically defined risk factors and symptoms of COPD may not be recognized as concerns by the individual and as a result coping processes will not be initiated or required. Since stress can negatively affect health (Lazarus & Folkman, 1984) or exacerbate disease (Antonovsky, 1972), studying concerns as perceived by the individual can facilitate coping (Fleishman, 1984; Sexton, 1981). It is therefore necessary to identify the concerns as perceived by the individual with COPD.

COPD and the Family

Studies of social and support networks have noted the link between social networks and the well-being of individuals (Lubben, 1988; Orit et.al. 1985). Social support networks such as family and friends have been shown to diminish concerns as well as facilitate coping (McHaffie, 1992; Orit et al. 1985). Family and friends may provide a number of forms of social support, emotional support, support social participation, provide material assistance, information, advice and physical assistance (Procidano and Heller, 1985, Orit and Paul, 1985). Sexton and Munro (1985 and 1988), report on the relationship between the social support of both family and friends and how such support facilitates the well-being of the individual even in the presence of alarming circumstances (Ross, 1991). The presence of supports alters the environment of the individual and thus the perception of the concern (Orit and Paul, 1985; Procidano and Heller, 1983).

COPD impacts the individual through the physiologic and psychologic stressors of chronic disease and the negative impact on health (Lazarus and Folkman, 1984). The goal of this project is to describe the illness experience of individuals with COPD and to explore their care needs as they perceive them.

COPD and Psychosocial factors

Harthill (1998) examined the psychosocial factors in pulmonary function and disease. This study examined the longitudinal associations between psychosocial factors such as stress and neuroticism and indices of pulmonary function (percent FEV1, FVC values) and disease over time. The study was performed by analyzing biomedical, psychosocial and behavioral data from a sample of 1,500 men who were followed over a twenty-five year period of time. It examined the effects of psychosocial variables on repeated measures of pulmonary function. The study findings supported a significant role for psychosocial factors in influencing pulmonary function values over time and incidence of disease. These findings are consistent with the literature that suggests components of negative affectivity and stress play an important role in outcomes related to physical health and disease.

Scharloo et al. (2000) studied the physical and psychological correlates of functioning in patients with chronic obstructive pulmonary disease. Their longitudinal study of 64 patients used a Medical Outcomes Study Instrument (A. L. Stewart et al, 1988) and the Illness Perception Questionnaire (J. Weinman et al 1988). They also collected data on coping and severity of illness, which they measured with spirometry. Their regression

analysis results indicated that first-time illness perceptions and coping significantly contributed to the prediction of social functioning, mental health, health perceptions and total functioning score and the prediction of visits to outpatient clinics and prescribed medication one year later.

Leidy and Haase (1999) studied the functional status of twelve men and women with moderate to severe COPD from the patient's perspective. The participants in this qualitative study participated in unstructured tape-recorded interviews. The results suggested that people who are ill with COPD face an ongoing challenge of preserving their personal integrity, defined as a satisfying sense of wholeness, as they encounter a variety of changes that can interfere with day-to-day activity. The study reported that the qualities most important to integrity are a sense of effectiveness, or "being able" and of connectedness, or 'being with'.

The next chapter presents a description of the informants and their illness states. It also provides a depiction of the interview dynamics that may assist in setting the stage for the descriptions and analyses of the themes that emerged from the interviews.

IV. Who are the Informants?

Demographic characteristics

Eight individuals who were patients at the Health Sciences Centre Respiratory Outpatient Clinic were interviewed for this study. Seven were permanent residents of Winnipeg and one was a rural resident who was residing with family in Winnipeg. Four informants were male and four were female. All informants were adults between the ages of 57 and 79. Marital status included six who were married and two who were widowed. Seven of the informants identified themselves as having "retired" and one was still actively working full-time.

Illness States

In terms of illness, the informants can be divided into two major groups, those with moderate chronic obstructive pulmonary disease (N=4) and those with severe chronic obstructive pulmonary disease (N=4). This determination of illness was based on the assessment of the Health Sciences Centre Respiratory Outpatient Clinic at the time that they identified the individual as a potential research participant. It was then confirmed by the researcher's own assessment at the time of the interview. Severity of illness is also reflected in the individual's level of dependence on oxygen and whether continuous or occasional oxygen was required. Three of the informants indicated that they used supplemental oxygen the majority of the time, one indicated that he used it when he felt it

Illness experience of Individuals with Chronic Obstructive Pulmonary Disease and Their Perceived
Care Needs

Table 2
“Who are the Informants?”

Informant	Gender	Age	State of Illness	Marital Status	Oxygen Use	Smoked cigarettes in past	Smoke cigarettes now	Working	Use of wheel chair
#1	Female	60	Severe	married	yes	yes	no	no	Yes
#2	Male	68	Moderate	married	no	yes	yes	yes	No
#3	Female	57	Severe	married	no	yes	no	no	Yes
#4	Male	63	Moderate	widowed	no	yes	yes	no	No
#5	Male	66	Severe	married	yes	yes	no	no	Yes
#6	Female	79	Moderate	widowed	yes	no	no	no	Yes
#7	Female	69	Moderate	married	no	yes	no	no	No
#8	Male	72	Severe	married	yes	yes	no	no	Yes

was needed and four informants indicated they did not use it unless they were “sick” in the hospital. The use of a mobility aid such as a wheelchair can reflect diminished physical capacity. Therefore individuals were asked about wheelchair use. Five of the individuals reported that they used a wheelchair at times to assist in mobilization and three indicated that they did not utilize a wheelchair. Seven of the eight individuals indicated that they had smoked cigarettes in the past. One individual reported that she had never smoked cigarettes. Five of the seven individuals who had smoked indicated that they had quit.

Dynamics of the Interview

All interviews were conducted face-to face by the principal investigator using open-ended, semi-structured questions (see Appendix 3 for Interview Guide). The audiotape recorder was 'on' for the whole of the interview. Informants were told at the beginning of the interview that they could at anytime request that the audio recording be stopped. None of the informants indicated the need to stop the tape.

As noted in the Ethical Considerations section, the background of this researcher is that of a nurse with work experience in Respiratory Medicine at the Health Sciences Centre and this was explained to the informants at the time of the interview. As well, it was explained that this researcher was present in the interview only in the researcher role and not that of care provider. The researcher was on a leave of absence from the workplace at the time of the interviews and therefore had no role in care provision or clinical management. This was also explained to the informants.

Initially, the interviews were to be conducted in the Health Sciences Centre Respiratory Outpatient Clinic, where the patients normally come to see their Respirologist. The interviews took place in the wintertime. In attempting to set up the first couple of interviews, it became apparent that the preference was to have the researcher come out to the home of the informant. Six of the eight informants requested that the researcher come to their home to conduct the interview. The reasons given for the request related to transportation (i.e. actually getting to the clinic was too great an effort or challenge) and physical mobility (e.g. wheelchairs and navigating on icy

walkways) was difficult for the individuals as well the cold weather was a concern to them. Two of the informants requested that the interviews take place at the Respiratory Clinic. One of these two informants resided fairly close to the Respiratory Clinic and he indicated that he preferred to meet there for the interview. And the other informant felt that he was feeling very well that week and he wanted to travel to the Respiratory Clinic to participate in the interview.

The interviews lasted generally about one hour to one and one half-hours. In two of the interviews informants broke down and cried at different points in the session. When this occurred the researcher stopped the questions and supported the individual. The informants then were asked whether they were able to continue with the interview. Both of these informants indicated that they wished to complete the interview and that they felt composed enough to continue. One of the informants both laughed and cried during the session. Two of the informants spoke very very softly. Both of these informants explained how the COPD caused them to lose strength in their voice. This did pose some challenges for transcription of those two interviews. Four of the informants indicated that they used supplemental oxygen. Three of these four individuals wore nasal prongs to deliver oxygen during the whole interview. One informant wore the oxygen nasal prongs intermittently during the interview. All of the interviews were punctuated by the informant's coughing. Some of the interviews had to be stopped to allow the informant to recover from a coughing episode, or to allow for a rest break as they grew tired from talking or at a time when their voice faded away to be inaudible.

The next chapter entitled Life with COPD details the themes that emerged from the narratives. Building the themes centered on describing the life adaptations to COPD.

V. Life with COPD

Rather than present only case studies, the findings presented in this chapter will be organized thematically. The themes presented are the dominant themes and sub-themes e.g. “panic and coping with panic”. They are not exclusive of one another and there are areas of overlap and dependence between themes. Pseudonyms are used in place of the informants’ names to protect the anonymity of the sources.

All informants were asked questions based on the interview guide (see Appendix 3). The interview questions centered on the individual’s description of their illness experience and daily functioning. As well, the informants were questioned directly regarding their self-described care needs. The analysis of these accounts revealed a number of themes that were referenced by a majority of the informants. These themes revealed the individual’s illness experience and personal interpretations of their care needs. The major-shared themes include:

- 1) Onset-first signs
- 2) Smoking
- 3) Attitude
- 4) Frustration
- 5) Life Impact of COPD
 - a) Limitations on activities in daily life
 - b) Fatigue/shortness of breath

- c) Dependency
- d) Anxiety/Panic
- 6) Coping Strategies
- 7) Self-described care needs
- 8) Access to services
- 9) The Future

Themes have been organized to reflect both the logic of how the interview questions were posed and the order of illness progression as described by the informants.

Onset/first Signs

Illness narratives often begin by asking the individual to describe or reconstruct the initial phases of the onset of their illness. As per the interview guide, informants were asked to describe when they first became aware of their illness and to describe the situations that made them aware that their respiratory function was changing. All of the informants discussed the onset of chronic obstructive pulmonary disease and described their first signs of illness. Seven of the eight individuals described the onset as a single event, a sudden awareness of illness and one of the individuals described the onset as a slower, more gradual process. An element to consider is whether the narrative descriptions reflect the actual progression or are they a factor of reconstruction of life events. Those who described onset as 'a sudden awareness' where a particular event in time was identified as the start of the illness as opposed to a more 'gradual' illness

progression as one might medically anticipate might form an element of an explanatory framework regarding COPD etiology.

The following quotes are from informants who described onset more as a sudden awareness of their illness and changes in their respiratory function. Deb, Steve, and Bob, described memories of onset as being marked by changes in their walking related to shortness of breath.

Deb: "I just realized I had it, I couldn't walk like I used to – 'oh come on', I was just totally out of breath. It didn't make sense."

Steve: "I'm thinking this can't be a problem. I can't all of a sudden walk as far as I could. I was all puffed out and it seemed that all of a sudden I realized it, this isn't working. Really scary, really scary."

Bob: "I was taking a bus to work, walking from here to – I found very difficult. Trying to get across Avenue to catch a bus, you could never hurry and all of those kinds of things."

Beverly described that she first became aware that her respiratory function was changing when she had shortness of breath walking a set of stairs that she could walk without difficulty in the past.

Beverly: "At one time, I use to go to Weight Watchers, and going down the stairs was no problem, but coming up, I started noticing I was having a lot of trouble breathing. That was the first time I noticed that I was really struggling.....you know, something was wrong....."

Harriet and Diane shared that they first became aware of their illness when they had coughing episodes.

Harriet: "I had a very bad cough and this friend, said 'you know, you should see about that, it doesn't sound very good'.....But I was, I was really, when I really, really knew there was something different, I was out playing bridge and I walked home a block, you know, it was really cold and I had to lie on the floor to breathe. I thought 'that's unusual' because"

Diane: "Well, I was...I first became aware of it one summer, on holidays, I really started just to cough and cough and cough really didn't go away properly and I was smoking and ah. It just progressed from there, like I coughed during the night, it would wake me up and I eventually reached the point where I um, really found it hard to get dressed, I was out of breath and um, I knew something was wrong."

Kevin was the one informant who described the onset of chronic obstructive pulmonary disease as a slower, more gradual process. He shared the following:

Kevin: "I guess I first became aware of it in '78, I had shortness of breath. At that time I didn't realize what it was and uh, I didn't think anything of it, just getting older, out of shape. Um, I guess when it really started to affect me was late 1980, um when, you know, when I walked to the store, doing the lawn, chores around the house....."

Smoking

All informants were asked 'what do you think brought this on (COPD)?'. The dominant theme that emerged was cigarette smoking. Seven of the eight informants had smoked cigarettes and believed that this was a major factor that caused them to have COPD. One informant had never smoked cigarettes and commented that she did not 'understand how this (COPD) could happen to her', because she never smoked. Two of

the informants were cigarette smokers at the time of the interview; the other five had quit smoking.

Some informants independently brought forth the issue of smoking before the above noted interview question was asked. Many informants discussed smoking not only in relation to themselves, but also as a potential risk factor to others.

The issue of smoking and the impact on others brought forward discussions of: 1) smoking as a risk factor affecting some people more than others, 2) smoking as a visible risk factor which should cause others to quit, 3) the role of smoking in the explanatory frameworks with individuals who continued to smoke after being diagnosed with COPD, and 4) how past/present smoking might have impacted families of the informants in relation to the effects of second-hand smoke.

The following narratives referring to smoking were in response to a generic question:

Interviewer: "What do you think brought this on? What do you think brought on your COPD, chronic obstructive lung disease?"

Beverly: "Well heavy smoker and then I went into the hospital....and got pneumonia so something tells me that that is where it all started. I was so sick, I almost died, so I figure that's where it started with the emphysema..."

Claude: "...I'm quite honest with my family and I told them 'look, I've sinned, and I have been smoking all my life and I have to pay for it now'..... "It's probably the smoking, I am quite sure it is, it cannot do you any good. Cause when I was in college we didn't smoke, only at recess, four or five cigarettes day. For the last 10, 15 years I have been smoking half a pack a day. The most I ever smoked, was a pack a day."

Kevin: "Smoking."

Interviewer: “That’s what you firmly believe?”

Kevin: No question in my mind. When I see somebody smoking I just....(shaking head)....I hope you don’t smoke?”

Deb: “ I never heard the doctor say, but I do believe it’s partially hereditary and I smoked for years which I never should have. Worked with chemicals. A combination of a whole lot of things. But I really honestly believe that hereditary has a lot to do with it.”

Diane and Steve discuss smoking as the cause of their COPD and how smoking as a risk factor seems to affect some people more than others. Both seemed to have issue with ‘why me?’ when others smoke more or still smoke.

Diane: “Smoking. There is no question and I don’t know why I got it. My sister still smokes. I have a couple of kids who smoke—go figure, but I think there is a relationship to when I worked at, I really do. I don’t know, they would never admit it, but I think that someday all that will become obvious. I do think that when you are around those kind of things there will be an effect. I am aware of cleaning products and stuff that I don’t use anymore because of the very strong smell. So smoking, plain and simple.”

Steve: “You, I guess it would be smoking. That is what they tell me and I guess that is the case. Um yeah, I know a lot of people who smoke, smoke a lot and they are not like me, so I don’t know, but it is what they tell me.”

Beverly shares her perceptions of smoking as a visible risk factor and how her sons can see the effects of smoking in her and therefore they should quit smoking.

Beverly: “ but I have three boys, and two smoke, so I thought they would have quit, but yeah, they, they were upset and ah, I just seem to get worse every year and they see it and they don’t quit. You know, so I don’t know.”

The two individuals that had not quit smoking at the time of the interview related how they really enjoyed smoking cigarettes and of how others talked to them about quitting smoking. Claude and Steve describe how notwithstanding the recognition of the risk, that they continue to smoke cigarettes. They also discuss how their continuation of smoking may seem irrational and shared their thoughts and attempts on 'quitting smoking'.

Claude: "I'm smoking now. Now I smoke, maybe 7 or 8 a day, which is still. I enjoy smoking tremendously, or I tell myself and then I think 'well do I spend 20 years not doing what I like to do to save 6 months of my life', which I am trying to justify to keep on smoking, there is no sense to it, that I realize."

Claude: "Um, mostly, 'well it's been your decision dad'. In the past, when I was young, we did not know about the bad effects of smoking and I explained that to them and of course they understand that. They also understand that 10 years ago I could have done something about it and I haven't been doing anything about it. There is maybe a little bit of resentment there, but there is also a lot of help. I know if I need help doing something, I'll phone my son... 'sure dad, I'll be right down' and all that you know. There is always little reminders, you know, 'you should quit smoking' and so on. On the other hand they are accepting and so... it my family makes it in a sense very easy for me to carry on. Now, I must stress at this point that I don't feel it is interfering with my life very much you know and they also realize that."

Steve: "It may be stupid, but I still like my smokes. Oh, there are those friends and the kids who tell me I should quit, but it is just in me to smoke. I have tried to quit, but never for very long and it was hell. Sometimes I think people don't understand that it is really hard to quit when they talk to you."

Claude: ".....when I wanted to quit smoking and I brought the literature home and so on and they could explain how a nicotine cigarette dependency was like a drug addiction-it was very strong one and I know my wife, I couldn't convince her. She has a brother who used to smoke a cigar a day and he quit smoking like that, and I think she thinks that anybody can just quit. She says 'its just a matter of not having a cigarette', 'no it's not a matter of not having a cigarette, please read it and ...I don't think she ever did and a (coughing) and she always gives me the impression that if you want to quit smoking - you smoke all the time? And this

is one part where, sometimes I think if she would have been a little more pushy, or helpful or showed more interest, realize how tough it was and then I think back au, this is just an excuse, you know. My daughter has always been 'Dad, you should quit smoking' –very polite. My son, the same.—'You haven't quit yet maybe you can, maybe you will, you haven't yet'.

Steve and Bob share some of their thoughts related to the potential impacts of their second hand smoke.

Steve: "Sometimes I think, what smoking did, maybe to my wife when she was alive. She didn't smoke. She never nagged me to quit or anything, but she would tell me that she wished that I didn't smoke. I can't think of that too much....."

Bob: ".....I think of my wife and kids and sometimes wonder if they think that I have hurt them with the smoking. I really hope not. You know, both that they don't believe it and that I didn't hurt them."

Attitude

In describing their responses to their awareness of the fact that they had chronic obstructive pulmonary disease the informants also conveyed their attitudes and thoughts on their life at this point. Remarks like: "I was shocked ...", "I came home and cried and cried and cried...", and "I didn't want to believe it" were contrasted with reactions like: "I didn't pay too much attention" and "I didn't think too much about it." Although, there was consistency in the message that you "just needed to get on with it", there were variations in the connotations and associations that informants attached to this message. The attitudes seemed to fall into two categories; those who were positive and

those who were negative. The current stage of illness does not seem to have an impact on whether a positive or negative attitude was described. As well the positive or negative attitudes did not seem to be impacted by gender. Those informants who seemed to have a positive attitude would share comments like:

Claude: ".....as soon as I can't do this, I go to something else and uh, I don't go back and think about it, and feel sorry for it, I always look to the future and I'm kind of happy-go-lucky you know.....and so you just go forward."

Diane: "I think I am growing in many ways like I've always wanted to and um, I don't know, tried to make the most of every situation."

Harriet: "I am a positive soul really, um I wish I could cross country ski and the like, but you know there are limits and you find that there are other things that you come to like as well. So, you take things as they come and carry on the best that you can."

Deb: "I just get mad that you can't do this and then, you know, you push yourself and uh, it's stupid. I mean, I know I can't do it, but I still push myself to try and of course the more upset I get, the puffier I get, you know, so it's it's very hard to sort of relax and go with the flow. I'm getting there (laughing), I think I am (laughing), but it's hard."

Interviewer: "What do you think about that?"

Deb: "It's not good, I know that, but I think I just sort of, I've got to the point now where I'll live today to the fullest and not worry about tomorrow. Because I can't do anything else, you know. Live one day at a time and maybe down the road somebody will come up with something. That's the best I can do, so that's what we try."

The 'positive' theme, 'just carrying on', and going forward were consistent attitudes that Claude, Diane, Harriet and Deb expressed at various points in the interview.

Although Beverly conveyed a negative attitude, she also expressed thoughts that were not overwhelmingly negative, but seemed to reflect some humour and reconciliation related to their situations. Beverly both laughed and cried during the interview as she described difficult subjects. Bob, and Steve, were more consistent in terms conveying a negative attitude theme, they brought out issues of hopeless, helplessness and feeling sorry and getting mad.

Beverly: "Well, I'm sixty, I'm wrinkled (laugh), I'm old and I've got this, ah, there is not much more, you know and I sit here and think about things. I'm taking prednisone, so I'm puffy, that's about it. There is not much I can do about anything and it is really hard to take especially when you think about it, it just makes it all the worse."

Steve: "It's not fair. This disease. I don't know why it would happen to me like this. Life is hard enough and now ... I wish things were different, it makes me mad when I think about all the things I've lost. What a shame to live this way you know."

Bob: "Um it leaves you feeling helpless. You just can't seem to do anything right anymore. You do this and it leaves you in the ditch for I don't know how long. Things are not so good and well I guess they will never change now that I have this lung sickness. It is useless really and what can you do?"

Frustration

Seven of the eight informants brought forth the issue of frustration. Frustration was discussed in relation to limitations of their bodies and tasks that they could not perform, but felt it was either their role or responsibility to perform as part of their 'normal' daily life. Informants noted feelings of frustration associated with limitations that they experienced in their social and family life. Frustration was also noted in relation to activities that they enjoyed doing, and could physically no longer do. Two individuals talked about frustration together with 'getting mad' and one individual talked about frustration in relation to depression. One informant discussed frustration in relation to wanting to escape to another place. Another individual shared his sense of frustration regarding the tasks that he could not perform and that he could not expect his wife to take over.

Four of the seven individuals that discussed frustration also mentioned it in association with a spouse member having to assist or take over some tasks that they could not perform. One informant shared feelings of frustration and how she did not like to admit not being able to do certain things that she felt were expected of her.

Kevin relates his frustration at feeling his body is functioning at the level that he might expect of a much older person than himself.

Kevin: "I feel like a 25 year old trapped in an 85 year old body. I don't feel any different now than I did at 25, but my body feels, in other words it's ah, frustrating. I suppose if I had a lot more pain discomfort, I might feel different, but I don't. I can sit here right now and feel like I'm 25, but when I try to do something, ah, then I know my body's not working."

Kevin also discusses his frustration in relation to limitations in his performance of certain activities and then being limited to doing other 'substitute' activities, like reading and watching television. He shares how his feels of frustration are linked to his feelings of depression.

Kevin: ".....Uh, I can't cut the lawn anymore. I do a little bit of the housework, when I feel better. Um, it leaves you with a feeling of frustration more than anything else, because you can't do it. You tend to read a lot and watch television, those are the only things you can do without putting too much effort into it. Even with your thinking... but it is frustrating, to really uh, you get down, you become um, you really become depressed. And then of course your thoughts are taking you down physically too and then this is not helping you in your depression, but still in your mind its not uh....your still depressed. So, that's the way it's affected me anyways.....But you can't throw everything at yourself, you have to try to work around it and I, I try not to feel sorry for myself because it's something that I've got and uh a card played and you've got to do the best you can. So, other than being depressed at times, I'm not unhappy, I'm just frustrated. I'd like to do a lot more. I'd like to do a lot more with my wife as far as travel and golf and everything else, but I mean those aren't the most important things in the world. Like I have two children, grandchildren, I mean you got to weigh it all."

Beverly shared her frustration regarding limitations in her performance that are related to having COPD. She also related her frustration regarding the need to adapt to doing simple tasks differently or having to limit household activities.

Beverly: "My house bothers me more than anything, you know. Yeah, the dust collecting and, I sit here, I mean I try to do a little bit, you know dust, if I can I'll try and dust but, I don't know. Wash clothes and fold it, and do that at least. Actually, I'd like to fly the coop and take a trip and fly down to Hawaii."

Role transfer appears to be a part of the frustration for some of the informants. Deb and Diane describe their frustration at having tasks transferred to her partner.

Deb: "No, well I suppose, but it slows everything down, we just don't do what we used to. I get mad because he's cleaning cupboards, my husband and it needs to be done and you know now I can't that kind of thing and uh, I get mad at myself and frustrated, but it doesn't help you know."

Diane: "Frustrated, um tried to do it, in spite of it all because you don't like to admit that you can't do them (household tasks). Um, I don't know how else- eventually I think it just became obvious that I, you know, I remember telling my husband that 'you'll have to do this' because I really couldn't do it. Um, he's been very good at ah, I don't really know."

Bev shares frustration related to role transfer and also to the competence of her partner in performing the transferred tasks.

Beverly: ".....if I ask my husband to do something and he doesn't get it done, I get frustrated cause otherwise I'd just go and do it myself, you know. So that... little things, stupid... and I miss going in the garden, I like to garden. He puts the seeds in for me and then I can't pull the weeds out, its hard for me to, you know, I tried my hardest to see if I could water the garden, but anyway he's not very good at pulling out the weeds. And uh, my garden is probably the second thing that frustrates me. I can do the dishes and make my husband's lunch and supper, it takes me all afternoon, but I do that. So that helps a little bit, eh."

Diane, Steve and Bob express frustration at being restricted in what were previously routine activities.

Diane: ".....Its frustrating and I am aware of, you know, like I said before, stairs, when we are going someplace. No air, a place where there is a large crowd, like at Christmas time at my brother's place, I am very aware of that, all of a sudden there is no air in the basement and I got to get out. Uh, steam in a bathroom, you know, leaving the door open. If you get sick you are just going to get limited quickly and you do uh recognize that you need help or back up. That part is frustrating to admit and you know own up to."

Steve: ".....there are lots of things that I enjoy that I just can't do anymore. I love fishing. Do you think I can do that anymore? No! I tried, and I had to give

it up. It's frustrating, you can't fish if you can't cast out your line or pull in your fish properly. And well, you just give it up."

Bob: "Sometimes you just get mad, but then you think, you shouldn't be mad. I don't know, but there is a lot of frustration to this. You really do not live life the way others do, those who don't have a lung problem do and you can't expect your wife to take over everything, she has got her own problems."

Although there were no interview questions that directly asked about or that mentioned frustration it arose as a consistent theme for seven of the eight informants. There was one informant who did not bring up frustration. This informant could be considered the least effected by the chronic effects of COPD and accordingly the individual with the least amount of limitations at this point. Performance of the routine tasks that were part of the individual's life role holds a source of meaning in the lives of the informants. Limitations in performance of previously routine tasks, the transfer of roles to partners, the competency of partners to perform transferred tasks and the restriction to simple tasks or to pragmatic adaptations in performing tasks were all sources of frustration that were brought forward by informants.

Life Impact of COPD

Throughout the interviews, concerns regarding the informant's life with COPD came forward. The main concerns of life with COPD articulated by the informants included a) limitations in daily life, b) fatigue and shortness of breath, c) dependency and d) anxiety and panic. These concerns appeared in both the moderate and severe stages of disease and for both male and female informants. Those interviewed shared how it felt to be

tired or short of breath and the impact of that feeling on their activities. Many of the informants either stated directly or inferred that the tiredness and shortness of breath made them feel helpless. It was something that was often beyond their control and that made them feel helpless. Sometimes feeling short of breath could be prevented, but the informant in that instance chose to continue with the activity they were doing and therefore became short of breath.

Limitations on activities in daily life

All of the informants spoke extensively about the limitations they believed were present in their daily life as result of living with chronic obstructive pulmonary disease. They described the activities that they could do before and could no longer do in the same way and in some cases could no longer do at all. Although some of the informants were considered to have a moderate state of illness and some were considered to have a severe state of illness, all of the informants described these changes. Changes in functional performance included decreases in capacity to perform activities of daily living, such as bathing, dressing, ambulating and eating. They also included more complex instrumental activities such as food preparation and housework. All of the informants also described examples of how living with chronic obstructive pulmonary disease changed their family and their social life. Several informants recalled changes that they experienced in their work lives, during the period of time before they retired. The one informant who was employed at the time of the interview also described examples of work life changes that he experienced. Most individuals attributed the

limitations in their performance of daily activities to feelings of shortness of breath, fatigue, and/or decreased strength.

Beverly and Diane described changes in how they were able to modify their performance of activities of daily living and maintain some symbolic activities such as holding grandchildren.

Beverly: "Ah...getting up in the morning, It's hard to, you know, it's hard to breathe and uh, slow in the mornings and um....."

Beverly: ".....you know, like I like to garden and I can barely get out there, to the garden and um, I can't pick up my grandchildren you know. The youngest one is, you know, she'll be two in March, and, even before that, my other grandchildren, it's hard for me to pick them up. Things like that I notice I can't do and um, when I do go out, I need a shopping cart, I can't walk by myself, it's too hard for me, but if I'm not able to go shopping and ...unless I have a cart."

Beverly: "...Well, I remember going to Safeway a couple of times and I was having so much trouble breathing I started crying"

Diane: "you know, you can't get your coat on as quickly, your can't put your shoes on as quickly, your can't um answer the door sometimes as quickly; having a bath. All of those things. I started to realize that you know, those things were difficult and um looking after the grandchildren was difficult. Um, just doing every day things, I mean, as far as housework around the house, vacuuming was you know, I had reached the point that I just don't vacuum, haven't for ages...for years. Making beds. All those things just progressively became harder..."

Diane: "...sleeping is difficult; I have to sleep elevated."

Claude, Diane, Kevin and Deb described situations where they experienced changes in performance related to the impact of COPD. They compared their present performance to descriptions of performance in the past when they were able to cut the grass, shovel the snow, turn the wheel of the car, walk the dogs, enjoy sex, and look after the house.

These descriptions of past functioning were contrasted with description of change resulting from the impacts of COPD.

Claude: ".....A couple of years ago, I know I could cut the grass, I had no problem, I would run do the back, I was all sweaty and last year, this year, I do the front and phew, not so fast. I would be half way and I would have to slow down, you know and that kind of stuff."

Diane: ".....I used to not have to think about it at all, I just drove the car, but now it is too much. Having to turn (the car), having to turn the wheel hard, you know."

Diane: ".....like we have two dogs and I can't walk the dogs, not very well, I have to take them in the car and let them run somewhere. Could I manage this house by myself – no! Even though I can do a lot of things, I can't do a whole lot of necessities."

Kevin: ".....it puts a lot of the bull work on Donna (my wife) for the simple reason I can't carry the load. I can't do any of the heavy lifting. I have, I pay somebody to come in and shovel the snow in the wintertime and Donna looks after the lawn in the summer. Ah, it affects your sex life. You can't breathe. It might be enjoyable, but it's not good when you're dead. It affects her (wife's) life along with mine, ah, in every way."

Deb: "Yeah, directly because of this and you know, some days I get up and I can do whatever I want but then another day, I get up and if I clean the table off and manage to get the floor mopped, it's a good day."

Diane, Kevin, Deb and Steve touched on how COPD impacted them in their work life.

Diane: "I found I was very aware that walking into work, from the parking lot, it was...a couple of my kids who worked at ___too, and we would go one was living at home and we would go in together and I couldn't keep up with him, you know, even walking in..."

Kevin: "I had to be careful of what I did (at work), you know how many stairs I climbed, how much I'd carry, um I was using Ventolin a the time, that's all I had was a puffer, I got by, but it was uncomfortable."

Deb: "I had to quit work, yeah I couldn't, because I was walking lots, lots and I couldn't keep up."

Steve: "At work, it really was a problem, I would have to stop and sit down every so often and it would happen more and more until I really was not getting much work done. They were really good to me about it, but I know my boss was just waiting for me to retire."

Kevin and Deb described how COPD impacted their social lives. How they have lost friendships, slowed things down in terms of visiting with family and friends and had to adapt to not going into crowds, avoiding elevators and strong scents.

Kevin: "You know, I've lost an awful lot of friends too over it, not lost my friends, but I can't do what they do. Like they are down South right now playing golf and that's exactly where I'd be if I didn't have the problem I have."

Deb: "Yeah, or perfume, hair spray, after shave, although...I get on the elevator and somebody gets in, I have to get off. I can't breathe. I just can't breathe. You know, and um, and I don't think crowds ever used to bother me, but no, of I'm in the store and it's packed, I can't breathe."

Deb: "Oh, it affects, I think all aspects of your family life. Uh huh, uh huh. From having the kids there all the time to our private lives, our sex life, going out, everything. Totally everything, you know. Yeah, but it hasn't been content around the house.slows everything down, we just don't do what we used to."

Fatigue/Shortness of breath

In the moderate to severe stages of COPD, individuals will likely experience dyspnea (shortness of breath) and wheezing while performing basic activities such as walking will

occur. As the disease progresses, so does the dyspnea. The following passages reflect some of the issues related to fatigue and shortness of breath experienced by the informants.

Harriet: "If only there was something that could give me more energy. So tired a lot of the time. More energy to do the things I enjoy. It takes so much effort. If I had more energy, I could breathe easier and that would be great. It is really awful to feel that no matter what you can't catch your breath. Your helpless."

Diane: "I lose strength in my voice, you know and I just really, everything I do I'll break out in a sweat, you know, I just have overdone it and I'll need to do nothing until my body recovers from it."

Kevin: ".....If I get to a point where it's -if I'm doing something and I get to the point where I get short of breath, I stop; and if I go back to it and I try again and I can't get it done - I can't get it done. I don't know what else to say, except that you get tired and that's the end of whatever."

Steve: "It makes you feel so tired. You shouldn't feel so tired, you think, then you try to do something and you can't. Your breathing, its, its just so much work, that's all you can do. Sometimes you go ahead and do more anyway and then you really suffer later."

Interviewer: "What do you mean suffer?"

Steve: "Well, then you are off your feet for an even longer time. It takes longer to get going again."

Bob: "...the one thing that I found absolutely stupid was this feeling of being tired. I became so tired for no reason at all when I was working....I would of course slow down, not because I had a choice though. I put it off for a long time I guess. You know dealing with the tiredness."

Interviewer: "What do you mean by that?"

Bob: "It makes you realize that you are limited and you think it is just this time, but it is not.....You are tired because you can't breath. You know that I had to retire early. Well, it was not my choice, but the it would take me longer and longer to do my route and then I couldn't make it to the end of the day.....needed a rest and more rest after that, I don't know. Anyways, my wife and I talked and we decided we could make a go of it if I quit early..... well it was not that early really. Anyways, it made a big difference being at home, I hated it, didn't know what to do. But I guess I changed."

Bob: "...few medical people know first hand the frustration of being so short of breath you can barely make it to the bathroom and back or how difficult it can be to towel off after bath or how it feels to be dependent on a little plastic tube that you must wear in your nose and drag behind you everywhere you go."

Dependency

Many informants brought up their concerns about dependency on others as they discussed the decreasing functional performance of activities of daily living with COPD. Some informants also linked their discussion of dependency with themes involving frustration. Among all but one informant, concern with being 'dependent' was talked about as something they wished to avoid and that they did not like.

Beverly: ".....he(husband) usually does the washing, cause I can't get downstairs, and that depends on how good a day it is. Sometimes I can get up the stairs, sometimes I can't."

Interviewer: "It's unpredictable?"

Beverly: "Yeah, so he usually does the washing. He brings it up and I slowly fold it, you know, and um, actually everything is frustrating you know. I hate that he has to do this and I try to do it myself if I could."

The theme of dependency also involved concerns of sharing of functions and overlapped with the theme of frustration.

Deb: ".....just all the things I can't do, that I used to do. It just drives me crazy. Like, for instance, to wash the floor, like, you know, I just could not get through it. Things like that, I think those types of things are really, really hard for me. Where you have to have somebody else take over. It is really hard."

Harriet: "Yes, really take things differently, but I'm not an independent anymore. You know since my husband died, well I wasn't so bad then, but I thought it was my plan to take an apartment on my own...(longer pause with coughing). Well, that wasn't going to work. My daughter here has been really good to me and the family helps a lot. I try to stay out of their hair and the house is big enough with me here on this side."

Steve: "You really don't want to ask people to do things for you all the time – even family. Maybe it's even harder to ask family, I don't know? Like getting things done around the place. I used to be able to fix and do everything, but now if it means lifting, or you know, for a longer time, I can't do it and well someone else has to eh?"

Diane describes her dislike of people trying to “take over” activities for her when she is experiencing shortness of breath. She relates that she knows what is best for her and doesn't mind people helping, but not taking over.

Diane: "And the worst part of it is, I guess, you do get out of breath and people are aware that you are having a bad time and you know... the people that we associate with now are very aware of it, so it isn't such an issue, but when I first started to get it, they were always uncomfortable with all that and now I just tell people, 'leave me alone, don't tell me to sit down', cause I just have to stand still until I recover and I will recover in most situation and I put myself into many situation that I shouldn't have and that's the one that turns you know. Some people are pushy, they take your arm and they want to guide you to a seat, most people are very great they will go and get the car instead of making me walk a long way and all that kind of stuff. Well, I don't mind that, but not where people are pushy or taking over."

For Diane, the issue of control seems to be critical in terms of maintaining her independence even when she is experiencing periods of shortness of breath.

Bob reveals that he really can look after himself in most instances, but perhaps in a different way. He describes some tasks that he considers part of 'everyday' living that may be part of the functions that help him define his role.

Bob: "Started doing different things and you know what is hard too? It is admitting to yourself that you can't do something and me you know I am stubborn, and having to ask for help – especially with everyday things. You know I can cut the grass, but well it takes me sometimes a whole morning or more now. I just can't catch my breath. So sometimes I get help, but I really feel I can look after myself unless..."

Anxiety and Panic

There is evidence suggesting pathophysiologic relationships between panic anxiety, dyspnea and hyperventilation (Smoller et. al. 1996). There appears to be a feedback loop in which panic feedback accelerates the symptoms of dyspnea. The literature reports that individuals with obstructive lung disease, have a high rate of panic symptoms. The pathogenesis of the panic may be related to respiratory physiology through several mechanisms, including the anxiogenic effects of hyperventilation, the neurobiologic sensitivity to CO₂, lactate or other signals of suffocation. The relationship between perception of control, dyspnea, fear and anxiety has also been described in individuals with COPD.

Four of the eight informants spoke of anxiety and panic. Anxiety and panic were feelings that they noted when they discussed episodes of shortness of breath. They described how awful these episodes were for them, and how they dreaded the sensation and felt helpless and 'doomed' when they occurred. One of the

informants, Kevin, discussed his feelings of anxiety and panic at several different points in the interview and also linked them to his feelings of depression.

Steve: "Sometimes when you are in a hurry, or whatever, you kinda get spooked or really anxious I guess."

Interviewer: "What do you mean?"

Steve: "Well, because you can't catch your breath, you start to think that you can't breath at all and you know what that means. You are gonna die. At least that is what it is like then. You think that it is never gonna end. But then, it usually does ease up and you hope that it never happens again, but you know it does."

Beverly: "It never used to be like that before. But now when sometimes I can't catch my breath, I feel doomed."

Interviewer: "What do you mean doomed?"

Beverly: "It's like you are fighting your own body to breathe. And you think that it is the last of you. It seems to take so long. It's usually not really so long, but it feels like it will never end. Ah, I suck back that oxygen and really just pray that it passes. It makes you very nervous to think that this keeps happening again."

Kevin describes how his anxiety is related to shortness of breath and how this leads him to experience increased anxiety and further increased shortness of breath.

Kevin: "Shortness of, (breath) yeah that's, then you get to a point where you get so short of breath you panic and once you panic, as a nurse you know that, you can't get your breath, I mean you're totally standing here.....but anyways, after the operation I was feeling not too bad for two years, but I started to um... anxiety took hold. I was just at the point it was paralyzing and that's what I'm going through now. I'm going through a lot of anxiety. Where I've, you know, I'm thinking, I'm taking pills for anxiety and uh, which don't work, I don't know what else I can do about it. But I am very anxious, I am very, I've got anxiety – it's hard to explain, I know anxiety – it just, shuts you right down. You just can't breathe and I know it's all to do, a lot of it is to do with I have the problem breathing but the anxiety gets so bad that it just closes everything down. Like,

I'm not getting any air that's why, uh, my blood gases are at the point where they decided I needed oxygen for it."

Kevin shares his belief that the COPD affects his mind and creates his panic. He then takes this thought further to suggest that treatment of the mind as well as the body is important for individuals with COPD.

Kevin: "Well I think the body and you know the brain. I think this disease does affect the mind in the sense that ah, a man under water or somebody is underwater it creates panic I think that's what this disease does.I never had panic attacks until after my operation. After that I started having panic attacks, you know to a point where it was unbearable. And even today ah, I mean, I thought about myself going back and talking to somebody that could help me mentally, not just physically. But they treat the body, but very little done for the mind. I think that's important."

Bob describes his experience with fear and panic when he is not able to catch his breath and at the end he also comments on depression.

Bob: "well sometimes I get really worked up, I am not sure what happens. It is really awful, to be so paralyzed."

Interviewer: "What do you mean paralyzed?"

Bob: "by fear really, but also by not being able to catch a breath. You just stop doing everything and hope that it will pass. No one should bother you then. You feel that you will not make it out the other end."

"Bob: ".....All the times when are so scared, panicked and you don't think that you will be able to catch your next breath. And then there is when you get so down and depressed."

Strong words like fear, panicked, scared, paralyzed and doomed convey the message that anxiety and panic appear to have a large impact on the lives of these

informants and how they are able to function. Notwithstanding immediate and long-term impacts of COPD on life, like all chronic illness processes, informants had learned to mediate the impact of their illness.

Coping Strategies

As the informants described how COPD affected their lives, they also provided examples of coping strategies that they employed. The coping strategies were, for the most part, techniques that were designed to normalize performance of activities of daily living for them as individuals. In some of the examples it was clear that the intent of the coping strategy was to make a change that would enable them to maintain as much independence as they could. Certain strategies involved personal changes that involved assisted living and sometimes, individuals gave examples of strategies where they were dependent on other people. All eight of the informants gave details 'of about taking more time' as a strategy. This meant that they could perform the task independently if they did it at a slower rate or took breaks to rest. The informants described details of how they used medication 'puffers' and assistive devices such as home or portable oxygen, wheelchairs, shopping carts and chairs as coping mechanisms. They described coping through talking to other individuals who they found to be supportive about their circumstance and how this assisted them to deal with some issues. They described techniques involving altered methods of performing activities of daily living. For example, one woman described washing her hair before getting into the shower so that she could sit down on a chair in front of the sink. Through modifying the task, she was

able to take rest breaks while washing her hair and then when she is ready get into the shower. Another informant described a technique that she termed “planning and avoiding”. She would anticipate an activity or event and assess if there would be an impact to her breathing either environmentally or related to activity. Then she would either plan to accommodate altered activity or plan to avoid the activity or event where it might occur.

Examples of coping strategies involving the use of assistive technology and medication include:

Harriet: “I had to go on that machine to give me my medication (pointing at an aerosolizer/compressor) when things got very tight and that helped a lot. Now that I have it here I still use it when I need to. It helps.”

Harriet: “Well, I use two puffers too. One I use two times a day, two puffs a day and one there is more crucial and I can use it anytime. Also I do this (sits upright in her lounge)...When I stand up or sit up straight and really think about using my ribs when I breath, that helps.”

Diane: “Well I try not to put myself in a position where I have to rush. Uh, that’s the biggest thing. Um, I have a bath, I don’t take a shower, I have a bath, that’s always strenuous. Um, going to bed. I usually have to sit for a bit, before I lie down, or else I’m in trouble. Taking medications, um I guess when I go out, I don’t always do it but I know I have to do it in certain situations to, you know take medications maybe 15 or 20 minutes you are going to do something (clears throat). Taking my medications, you know, not forgetting to take it. Um, I try to have everything. We usually, if we are having people over, it’s upstairs, you know, rather than, you know, I can’t go up and down stairs um give myself enough time; and not wearing tight clothing, um you know like going to a show, some of these shows are a long walk in and stairs and I can’t manage that, plus I’m more easy about using a wheelchair now. My sister really got me going to phone to get a wheelchair because it uh, it can be very difficult. You sit for a whole length of time and then you get up and start moving around and that doesn’t work (clears throat) it is best, you are better off to keep moving around.”

When getting up in the morning, if I just can't get up and get dressed, I can't, you know, you get up then recoup a bit and then get dressed slowly, I don't know what else."

Claude: ".....I'm taking a broncho dilator and plus taking Atrovent which dry up your mucous. When I know that I am going to do something like that, I take, I don't know what you call it, but what it does it opens up the passageways and makes the breathing a bit easier. That's all I take, and when if I feel I am running out of breath when I am shoveling, I'll go back in and sit down for ten minutes and then go back."

Kevin: "Oh sure. I uh, I drank, I'd have a couple of drinks if I had to do something stressful, which helped. You know, relaxed, going and do it, and if you were a little short of breath – so what! But ah, you can only do that for so long. Um, other than regulating what I was doing, I, I would, I would have stayed in when I should have gone to a function. I'd rather not go, because of smoke, so I'd stay home because of that."

Bob: "Using whatever things I can to get things done. What I mean is I try to use my oxygen or my wheelchair so that I don't hold the family up when we go out somewhere. And if there is the place to sit, take a rest when I can that way I can still do more."

Examples of coping strategies involving planning and anticipating trouble areas

include:

Harriet: "I also try to protect against cold air and getting infections and to be careful not to panic."

Harriet: "Yes, well if I can think and know how something should happen, then I can decide if I can do it or not or if I need help or whatever."

Beverly: ".....Washing my hair. I wash my hair up side the sink instead, you know, you usually wash when you shower, well I wash mine outside the sink, the bathroom sink, so I'm rest, so I can rest eh. Then I can sit or whatever, so that's

where I wash my hair now, the last five or six months I guess, I wash it outside the shower, get my hair all wet and soapy, then I get in the shower.”

Diane: “Um....walked more slowly. I remembered being aware if I went slower I wasn't out of breath. I remember trying to give myself more time, this was when I was going to work everyday. I went to work being aware of that. I was always looking for how many stairs there were into something and how many or how difficult it was going to be and I wouldn't be able to do that. You know, realizing the breaths I take take my breath away that type of thin. Um....planning and avoiding that's what I called what I do. Plan ahead and avoid it if you can't do it.”

Diane: “Going to somebody's house that has the bathroom upstairs, that can be hard. You are aware, I am always aware of that when I am going out, you know, what steps are involved. You have to give yourself enough time to go there, to get to the bathroom. Again planning ahead.”

Kevin: “Just knowing what I can and what I can't do. I guess that's how I cope.”

Steve did not mention planning ahead and anticipating what he could or could not do as a coping strategy, but he did describe how he used pacing and task simplification to assist him with his daily tasks.

Steve: “Coping? Well I guess that's what you could call it. Mostly, if there is something that is a problem and I can't do it myself with some rest breaks or something, then I just don't do that. That's coping I guess? Oh, there are a lot of things that I just don't do anymore. I do take my puffers and they help me. I don't use any wheelchair or anything like that though, just take it slower.....a lot slower, like a really really old guy. Oh, well.”

Beverly and Bob described coping with the assistance of others, including how talking to others about some of the issues they have experienced in their life with COPD has been useful to them.

Beverly: ".....So, um, my sister helps a lot, I'll talk to her about it a lot. She's my youngest sister. She's got ovarian cancer and um, I get some of my stuff out, my frustration out. So I feel better you know, after I've talked to her. We don't talk as much as we used to because she is awfully busy, but, yeah, she helps me a lot. A lot of things I don't like telling my kids, you know. So, she has been a real help, so."

Bob: "I do spend a fair amount of time talking to the physiotherapist when I go there. Well I can't talk when I'm on the treadmill, but I talk to him before and he's a good listener. He sometimes talks about other people similar to me and that is always interesting, and its really good just to talk sometimes, you know."

Beverly provided many examples of coping strategies that she used, yet, there came a point in the interview that she described how maybe she was not coping.

Beverly: " I don't know, I just, I don't know, I don't know how I cope. I just uh, maybe I'm not coping. I don't know, I don't know. Just take one day at a time I guess, and uh, I don't know. Whether I keep things to myself and maybe I'm not coping that well, I don't know."

The coping strategies theme and the subthemes that emerged including the use of assistive technology and medication, the planning and anticipating trouble, the pacing and task simplification and the assistance of others, including how talking to others about some of the issues had some overlaps with the topic of self-described care needs. As

individuals were describing the strategies they utilized, they would also indicate these as care needs.

Self-described Care Needs

This research project was designed to examine the informant's perspective on their care needs. The design was to be descriptive and non-evaluative of care received. One of the direct interview questions asked informants to describe any and all the care needs that they could think of. The majority of the informants described how their family, usually their spouse, were currently meeting their perceived care needs. Although themes centering on family care would generally be the answer to the direct question about perceived care needs, these same informants would then at some other point in the interview bring forth a service that would be useful to them. In order to describe the care needs, this section offers longer narrative sections from the individual informants. Although there is overlap and common repeated themes, these longer narrative segments are presented to set up the themes and to give more of a sense of the care needs.

Some of the needs that were described were being met through existing arrangements or services. Some of the needs were for services or programming that had been experienced in the past, and that the individual wanted more of and some were unmet care needs. The needs described included services like an exercise program, a support group, counseling services, more information about COPD, information about what to expect in the future related to their COPD and an improved access to oxygen services.

Two of the informants also commented that they could not name what their future care needs might be, but imagined that they would require 'something'. One of the informants identified the need for more flexibility in the cost coverage of drugs by the Pharmacare program.

Kevin: "Well, I've got the support that I need, my wife does whatever care I need. If I didn't have or I wanted some, um there are lots of services – somebody to drive, somebody to maybe get together with a group of people going through the same problems. I have seen a little of that on the internet, that kind of information. That would be good, as long as it wasn't just a gripe session. It would have to have more to it than that."

Kevin: "Well, I've taken an exercise program at Misericordia, which I enjoyed for six weeks."

Interviewer: "That was a group of people who had similar...."

Kevin: "Yeah, yeah, it was a whole group together and we exercised. There were presentation things too. But mostly for me it was the exercise and the socializing that I liked."

Kevin: "I am self-reliant and relying on my wife so I have no need for....They are probably in the community but I, right now don't use them, except for oxygen of course. That I had to really fight for and I really need to have it."

In describing self-perceived care needs, some informants included narratives that were critical of the care they received. Diane was considered to have a severe state of illness with COPD. She talked about getting information about her lung condition. Diane's narrative tells us about caregivers assuming she had knowledge of things that she did not. It also informs us that while she was in the hospital, she received some good information, but that she still feels the need for more information and education.

Diane: "All that because you had to consider, you know, you're sick and you had to see all the doctors and um just going and getting lung function tests, and other things, you know, so those people would speak to you and say 'well you know, your this or that' but they haven't told you anything and you don't know. I'm just reading, trying to think they haven't uh really gone over things with me."

Diane: ".....and when I was in the hospital, the nurses in the hospital, I know the Head Nurse, um she was good, she would explain these kind of things, so she was very very good there, but I haven't a lot of information. (Clearing throat)"

Diane: "Lots of education. Well, the doctors...I think the general practitioners, doctors, need to show people how to take their medication more than they do. Um, I don't think doctors have time or even, whatever, know how to tell you a about a lot of these things."

Diane: "You know, I think it's my fault. I think information is out there, but I don't really understand all the lung functions. I think I could find that out if I really wanted to but it would be nice if it was within reach. Um, I know that they say that your 'not moving air", I don't really understand what that means."

Diane also discusses her past use of support groups. She describes how getting to the support group is difficult and can stop her from attending.

Diane: "You know, it would be nice to um, sort of understand it in your body to (clears throat), but I don't suppose there isn't any clear cut sign, I think it's just going to be a gradual thing. I know that I lose my voice quickly (clearing throat), I seem to um, I get hoarse, um maybe say about the last six months or so. I don't know what the reason is for that. People tell me that, like when I'm not feeling well, they know right away because I have no volume in my voice. I don't talk the same, I don't know if I'm aware of that, but I know it now because people told me, but sure I would like lots of information if I could get it. I did go to a lung thing at Deer Lodge, they have a what do you call them....."

Interviewer: "A Seminar?"

Diane: "A seminar thing where they had quite a bit of stuff and my husband and I went. I go to the lung, um what do you call it (pause), through the Health Sciences Centre, the Lung, it's a group."

Interviewer: "Like a support group, you're thing? The Easy Breathers? (Manitoba Lung Association Pulmonary Support Group)"

Diane: "Easy Breathers, that's right. I went to that for a couple of years."

Interviewer: "Useful information?"

Diane: "Uh huh, it was very good (clears throat). We found out a lot about medications and um they seem to be right up there you know every time.....But I think those things are very beneficial, and I know it's out there. I could go to the one at Deer Lodge for a bit. Sometimes it's getting there; when my husband was working it was very difficult and I found it, you know, sometimes it was just too much trouble. I would have to park the car and walk and open all these doors and you know, you think 'why am I doing this?'."

Diane: ".....But the more information you have the better off you are."

Diane indicates that an exercise program tailored to individuals with COPD is something that would be beneficial.

Diane: "Yeah, and I've read things that are available at Misericordia. I think, personally they should have a program, an exercise program for people like me. Where you go two or three times a week, where they provide some kind of transportation and put you through this program for you, that's going to be a benefit to people who have the same kind of problems as you do."

Interviewer: "Are you thinking of a continuous program?"

Diane: "Yes.....Yeah, they keep going, you know, like where you can go. Like they have a Reh-Fit, which is great and that's geared to heart and a lot of other things I guess, but if they had some kind (clearing throat) of a something where, you know, they putbecause um, for people there for you.....so, if they had something out there for people to stay active."

Deb is an informant who was considered to have a moderate state of illness. She, like Diane, described her need for information and information in terms that she can understand. As well, she brings forth the need for continuity of relationship with the same doctor, the need for better coverage of medication costs through Pharmacare coverage and the need for a support group.

Deb: "What kind of things have doctors and nurses told me? Nothing! (laughing) I'll be honest with you but I have to tell you first off, I lost my sister about five years ago and she had emphysema. So, we had been living with this in the family for some time before I got it so I was pretty familiar. I think that's why I knew my symptoms I will ask him (doctor), you know, he'll tell me something, I don't know what he's talking about, talk English and then he comes down to my, you know level."

Deb underwent the assessment process for the lung volume reduction research project. She explained that even though the process was physically difficult at times and that she did not meet the criteria for the project, she was glad to have gone through it because of the explanations she received related to her physical condition.

Deb: "That lung reduction thing and I did okay and went through all them tests. None of them were invasive, but some of them were um, I was totally exhausted. Some of them took me a couple of days to recover. They were hard. But I got two of them on, but my lungs were, I wasn't able to get into the...but said to the doctor, 'okay, but at least I tried' plus I learned a whole lot more about everything. Because that Dr. T. he explained it and he was very, very good and he felt so bad. He said to me 'I'm sorry', but I said 'nobody tells me anything' and I was really glad after that I had done it. Even though I couldn't get in to it because he explained.....He explained like what's happening in my lungs, not why it's happening, but how it's happening and where I'm going and you know and how it affects my bones and all the rest of me; which I really didn't, hadn't pushed for explanations before. So, he did explain all that to me. Maybe just help me to accept a lot of things that I was sort of pushing away and yeah, I think it made it easier knowing. Yeah."

Deb discussed the issue of drug costs and the need for better coverage of medication costs through Pharmacare coverage

Deb: "It's running close now to between the two of us (husband and herself) a \$1000.00 a month. I know Pharmacare covers quite a bit, but there are things that they don't cove and then we use a lot of Ventolin, because Dr. W. directed us to use it as needed, not as directed, and now they (Pharmacare) cut us off – they say we use too much, we got to buy it from now on (laughing). That's something I really need."

Like other informants, Deb responded to the direct question regarding perceived care needs, indicating that most of her care needs are met by spouse, except...

Deb: "Most of my housework I can do but my husband does a lot. I cannot vacuum, that's one thing I can't do, but we have a lady coming we hired who vacuums....But we haven't tapped into what you call Home Care yet. We have been paying.....And maybe there is a fine line between stupidity and pride (laughing).

Although Deb is staying with her sister in Winnipeg, because she had an appointment with her Respiriologist, her permanent residence is in a rural Manitoba town. She identifies the need for access to a consistent physician who knows you.

Deb: ".....And we have, like my doctor is from Winnipeg um, it it, that's difficult because if I have to go to hospital, I go to the local hospital but it is isn't really fair to the local doctor because, you know, they are dealing with me and they don't really know my condition.....But then I would go to the local doctor, but because it is one of these communities, we get these doctors who stay five years and then they are gone, then you have to start all over again."

Deb: "To most people, it matters. Oh, yeah, because nobody wants to go to a different doctor every time you are sick. You know, and so, yeah, that's hard, that's really hard.....If I had a doctor that was going to be there consistently, I wouldn't have to just take whoever was you know, whatever day it was. I could stay there because I'd get better, it's the best...."

Deb also identified the need for a support group that would be convenient for her to attend. In this, she identifies the issue of her difficulties commuting and alternatively, having access to services outside of Winnipeg

Deb: ".....I think a lot of times a support group would make me think that I'm not in this by myself type of thing. But, um, maybe they figured out how to do something easier than I can, but you know, that kind of thing would be good. Cause I know, again, back to my sister(with emphysema), when I was at her place one time, she said 'you know, I want to have a bath so bad, but I'm simply

exhausted when I'm through and I said 'well , have a shower' and she said, 'why?' and I said 'you don't have to get yourself in and out of the tub and it takes less energy'. 'I'll try it' she said, ' why didn't you tell me that years ago?' I didn't have my lung problem yet or I would have seen her problem earlier. But little things like that, you just don't think what other people just automatically do, or think of – that kind of support group would help. And I know that I could come again (into Winnipeg), but then again, it's driving 75 to 80 miles."

Beverly identified her care needs to include, housecleaning services, 'group therapy' – where she could share feelings and ideas with others, better access and coverage of oxygen services and information related to respiratory rehabilitation.

Beverly: "Yeah, yeah, my sister was cleaning the house at one time, but she's working and my Mom is sick, so she is doing everything for my Mom, where I could be helping, but I can't. So she you know, she used to come over and clean my house, now she can't do that. So someone I need someone to do the housecleaning. I wish the house was cleaner."

Beverly: "Um, well, I don't know whether you know, seeing other people in the situation I'm in you know maybe that would help me cope a little bit.A group with emphysema, you know and how they are handling it and what they do, you know. I don't know. I see people at the doctors, at the hospital and I seem, to be the worst of them all, you know and uh yeah, maybe something like, you know, how other people feel about things like that."

Beverly: '.....I mean maybe just, you know, group therapy or something. But you just aren't going to get any better with this, you just get worse, you know, so uh, I don't know. Maybe, you know take group therapy, find out how other people are feeling about it. Sharing feelings and ideas or....."

Beverly describes how she obtained home oxygen service. Her narrative identifies that there are provider differences in entitlement criteria.

Beverly: "No, it's not covered for me (oxygen)."

Interviewer: "So you pay on your own?"

Beverly: "No, I've got insurance through Great West and they're paying for it, but before that I was paying for it because Dr. K. said I didn't need it. But my other doctor got it for me, Dr. W., my family doctor. He figured I needed it and K. didn't think I needed it. It has been a real hassle. I got rechecked again and Dr. K. still says that I don't need it. But I can't be without it. He doesn't seem to get it. Dr. W. listened though and wrote me a prescription so at least I didn't have to pay for it myself and I got Great West to cover it. So, oxygen that's what I need, got to have it."

Beverly: "A couple of years ago, I went to the Misericordia and they gave me this (*Patient Manual for Respiratory Rehabilitation*). It is really good. I still look at it. It's got information that I can use like exercises and foods to not eat and good reminders."

Interviewer: "So, this was a Respiratory Rehabilitation Program?"

Beverly: "Yeah, I guess so, first of all we had to listen to someone talk for an hour. And every time she talked, I fell asleep. I felt so bad, but I couldn't help myself. Then we would go on treadmills, then we would do exercises, you know. Then she would tell us how to use these (puffers).....and what food to eat. What food was not good for you and which is that pretty well it. But they seemed more concerned about the exercising you know and what medications you were on. For me I really liked this book and seeing other people. It was kind of hard to get downtown to go to the sessions, but I went.....The book tells you how to breathe. How to exercise. How to get prepared for exercising. How your emotions are very important. That's true and how to control your breathing. Those are the things you really need."

In talking about his care needs, Bob brings up thoughts that some sort of preparation for managing the anxiety, fear and panic of breathlessness, that a support group for sharing and that education/explanations would be useful to him.

Bob: "What services would I find useful? You know that is hard to say, because you just kind of live life as it comes, but if I think about it, I would say that something to help prepare you for the fear and panic of not catching your breath and how best to get through that. That would be very helpful I think. Maybe some sort of sharing with others in the same boat you know with lung problems.....And explanations of what is going on would be appreciated. After

all it is your body and if you are going to help yourself, you need to know what is going on."

Bob: "Just going back to what are my needs, the handicapped parking pass is really useful and helps me get around, I don't know what I would do if I did not have it."

Steve described two care needs, one for the use of a 'test' walker and one for a relationship with a doctor who "knows what they are doing".

Steve: "I don't know really. I guess everything is okay.....I did want to see if I could get a walker though. When I asked the doctor, he said if I thought I needed it I should use it. But I didn't know if I needed it and it's a lot of money. I didn't want to use a wheelchair and that is what they were going to give me to use. I can still walk pretty good I think, just sometimes....."

Steve: "Well you really need a doctor who knows what they are doing so that you don't get worse."

Claude was the individual who really presented himself as the informant who was the "least sick" and his comments regarding care needs may reflect that:

Claude: "I don't have to rely to anybody right now. For my care needs in the future, I don't know."

Claude: "As far as resources in my present condition, I can't think of anything right now."

The informants identified many care needs. Some of the needs identified were being met in some way and some of the needs were unmet but considered necessary and desirable by the informant. The care needs noted included: spousal and family assistance, comprehensible information and education, oxygen service, group information sessions, support groups, specialized exercise programs, handicap parking passes, access

to consistent doctor, improved coverage of drug costs, housecleaning services, accessible services, and psychosocial assistance to prepare and manage the effects of COPD. These care needs will be explored more fully Chapter VI CONCLUSIONS AND RECOMMENDATIONS.

Although the next section deals with the role of caregiver reassurance as a discrete theme, it could logically have been included in the discussion of perceived care needs. It is, however being discussed separately because informants were asked directly in the interview, what part caregiver reassurance played in how they felt. The majority of the discussion pertaining to caregiver reassurance came out in response to the direct question.

Role of Caregiver Reassurance

One of the interview questions asked in each session was: what part does caregiver reassurances play in how you feel? All of the respondents answered the question. No definition of caregiver was provided. If the informant asked for clarification, they were informed that a caregiver could be anyone who in their perception, provided care to them. Six out of eight informants assumed the caregiver to be the physician. One informant spoke of her daughter and physician as care providers; another informant spoke of his wife and the physician and one informant spoke of his family and the physician as care providers. Six of the eight informants believed that their physician -caregiver's reassurance was important to them. The informants who referred to their family, wife and daughter as caregivers all felt that their reassurance played a big part in how they

felt. There were two individuals who stated that physician-caregiver reassurance was not important to them. These two informants related that they were 'independent', one even described himself as 'fiercely independent' and in this context, did not feel that reassurance was important to them.

Those informants who identified caregiver reassurance as being important noted feeling like it gave them a sense of trust, that they were heard, that they felt better, that they were on track and reassured that they were doing the right things.

Beverly: "Yeah, well, I guess Dr. K. ...before I go to see Dr. K., I'm thinking 'oh, I feel lousy', so I get there and find out my blood gases are good and even better, I'm improving, yet sometimes I don't feel like it. But it feels good when he tells me, you know, he's surprised I'm doing as well as I am, is what he says."

Deb: "I think it's important I really do. Dr. L. is very comfy and perky and he's busy, lots. You know when he finally, uh if I go there and I'm really puffy, he just sort of sits and visits and gives me a chance to relax before he starts, yeah, yeah, I think I have a good relationship with him and it does help make me feel better.....yeah it is important, a good relationship with at the hospital too, with nurses, a good relationship, it goes so far in helping you feel you know."

Diane: "It's um important. You know it makes you feel that you are on track and maybe that someone has heard or understands what you are going through. And then, you also develop a relationship of sorts and trust I've always said that those kinds of things are, they're good and important. And really like you know, you don't feel like a burden necessarily, although I'm sure there are moments when it would be easier if I was a healthy person."

Kevin: "Well, I think that's important, not just to me but to anybody who has a problem. I know there is something about hearing that reassurance. Something about that they are receiving care after. That they are doing the right things and everything that is possible. I think it is important."

Harriet: "My daughter. They are good, they are very, very good. I feel that I really put all my trust in her. I can call her anytime, but I don't do it, because I don't think, she has a family too. She is very very good. Dr. K, I really like him, a nice man. You wouldn't be afraid to go to him with whatever. He seems to listen and that is reassuring."

Bob: "It is important to me that my wife believes that I am doing okay. She really is my rock and it makes a difference what she says. My doctor too, I guess it makes a difference, but not as much."

As these informants described what meaning caregiver reassurance had for them, they brought forward subthemes of empathy, reassurance and open feedback as important functions of caregivers.

Sometimes, the informant's responses reflected on a timeframe in the future. Claude was an informant who did not think that caregiver reassurance was important to him at this time but that in the future it might be and at that time, he would rely on his family.

Claude: "I don't know, I don't feel at this point where I have need of reassurance. I like to get reassurance to myself. I wasn't always maybe fiercely independent? If I want to quit smoking, I'll do it, I don't need drugs or whatever and if I want reassurance, I will get it from myself. I don't know. I feel when the time comes, my family will be there to support me. Right now I don't feel that I need that."

Steve was the one informant who indicated that caregiver reassurance did not impact on how he felt.

Steve: "I don't know that he does that. It really doesn't matter. It's not going to change things is it? It is, what it is."

All informants, with the exception of one, portrayed both professional and family caregiver reassurance as an important element of their perceived needs. Informants did

not seem to spontaneously bring up reassurance as a care need. The direct question regarding what part caregiver reassurance played in how they felt was asked as question #12 in the interview. In all but one interview, this care need was not mentioned until this direct question was asked.

The next section deals with access to services. Unlike caregiver reassurance, the need for accessibility of services came up spontaneously as a care need and also in response to the directly asked question.

Access to Services

The theme of access to services presented at different points in six of the eight interviews. In addition, there was a standard interview question in the guide that focussed on access to services. Informants were asked if there were some community resources in the area that they felt would be useful and that they are not receiving? Further, were there community resources that they were told they were ineligible for? All of the informants answered the question. There is some necessary overlap with this theme, 'access to service' and the theme of 'self-described care needs'. When asking these questions, the researcher had awareness that consumers involved with services may be reluctant to negatively evaluate a service they need. Yet given this, two of the informants explained that there were differences between their self-perception of needs, caregiver evaluation and evaluation criteria, particularly in relation to the Manitoba

Home Oxygen Program. They described how they circumvented the system to get the service they felt they needed.

Individuals in Manitoba can receive home oxygen services with a physician's prescription. There is a formal program entitled the Manitoba Home Oxygen Program that provides and funds home oxygen to individuals as an insured health service. In order to receive home oxygen through this program, individuals must meet the eligibility criteria that includes a physician assessment, recent arterial blood gases, and 6 minute walk exercise tolerance testing. Individuals can also privately purchase home oxygen services with a physician prescription or they can use private insurance policies to fund it if they have this type of coverage.

Beverly shared her frustrations at her difficulties in getting oxygen for herself and how she did not meet the eligibility criteria for the Manitoba Home Oxygen Program and had to find another way of obtaining the oxygen that she felt she needed. Yet, when asked the interview question that focussed on access to services, she answered that there were no services that she had difficulty in accessing. Perhaps, because she had already shared her story regarding her difficulties in obtaining oxygen service, when it came to the question, she perceived it as referring to 'additional' service access issues?

Beverly: "No, I've got insurance through Great West and they're paying for it, but before that I was paying for it because Dr. K. said I didn't need it. But my other doctor got it for me, Dr. W., my family doctor. He figured I needed it and K. didn't think I needed it. It has been a real hassle. I got rechecked again and Dr. K. still says that I don't need it. But I can't be without it. He doesn't seem to get it. Dr. W. listened though and wrote me a prescription so at least I didn't

have to pay for it myself and I got Great West to cover it. So, oxygen that's what I need, got to have it."

Kevin discussed his concerns regarding access to oxygen services and shared how he "put himself on it" for about one year before his physician got him onto the Manitoba Oxygen Program.

Kevin: ".....That's right, I put myself on it. Which I think is, to me, is unfair because I think you are probably very low in your numbers (oxygen saturation). Somebody who is saturated, their saturation's are below 90, are having a problem and their numbers are 84 or 85, you get down to that you're tongue is pretty well hanging out. Quicker access to oxygen is really important. I think that you know the way that government's waste money ah, to help somebody be mobile at home – they should bring those numbers up, there would be a lot more people that would be able to do a lot more than what they are doing."

Kevin also identifies his need to access a personal oxygen saturation monitor and indicates that he finds it reassuring to have this self-monitoring technology at hand. At a different point in the interview, he described how access to service to treat "the mind" and not just the body would be of great value to him.

Kevin: "Having this little thing really helps me. (showing a small hand held oxygen saturation monitor) It tells me my oxygen number and my pulse. When I am feeling like something is going on and I put this thing on and I check my numbers and the number is okay, well then I don't panic as much maybe."

Kevin: "I think the body should be treated, but I think the mind should be treated as well. I think there should be a service – you should be able to sit down with a psychiatrist to talk about your feelings; look for ways that maybe they think could relieve some of panic or feelings of tension. Which they don't. They look after the body but they never give thought to a....."

Beverly and Harriet bring forward the issue of physical access to services related to transportation issues. Beverly described how access to the group exercise program that

she attended at the Misericordia Hospital was problematic because transportation downtown was a problem for her.

Beverly: "It was kind of hard to get downtown to go to the sessions, but I went....."

Harriet also comments on how it was difficult to get out to the lung program at the Misericordia Centre. Although it is not reflected in these narratives, the informants in general, related that transportation was difficult primarily because travel increased their fatigue and secondarily, because of inconvenience of the location.

Harriet: "When I was in hospital they told me that I would do better if I used this compressor instead of just puffers. It does seem to make a difference. Very noisy though. I have got that now and I don't know what other service.....Well, the time that I attended the sessions at the Misericordia on lungs. I really found that valuable, but hard to get out to though. I guess that's access?"

Deb brings forward the issue of access related to transportation from a different perspective. Deb was staying at her sister's home in Winnipeg at the time of the interview. She shared how it is difficult to commute and come into Winnipeg to see her doctor and how for her it would be much better if she had a doctor that could work out of her rural community hospital. Deb then brings forward another access need when she describes why she does not receive care from the local doctor who attends at her community hospital. She indicates her need for continuity of access to a specialist physician who can follow her chronic illness so that she does not have to "start all over again" with a new physician." Deb at a different point in the interview shares how she has friends who have sold their houses and moved to Winnipeg so that they could access

the physician service they required. These accounts reflect both rural and urban specialist access needs and the issues related to rural doctor turnover.

Deb: ".....And we have, like my doctor is from Winnipeg, um, it, it, that's difficult because if I have to go to hospital, I go to the local hospital, but it isn't fair to the local doctor because, you know, they are dealing with me and they don't really know my condition.....if you have to go to the hospital, it's the place to go. But I feel so bad when I go because I know I really am not being fair to the doctor. But then I would go to see the local doctor, but because it is one of these communities, we get these doctors who stay five years and then they are gone, then you have to start all over again. And that's too hard on me, I don't have the energy and how can you really know what they are going to do, it is different with everyone. That's too stressful."

Deb: "We have friends in (rural community about 100 km from Winnipeg) that have actually sold their houses and moved to Winnipeg because of no doctor that they could rely on."

Interviewer: "And you're not at that point right now?"

Deb: "It will come. I can see it coming."

Diane, who resides in Winnipeg, has a different perspective on transportation access issues.

Diane: "Well, I think there are resources. If I had to go to appointments I could go through Handi-transit. If I got whatever I need to do that

Diane felt that she had access to the services she needed right now and seemed assured that should she need other services that she would have access to them. She does bring up the issue of access to facilities with 'true' no smoking areas where one would not be exposed to smoke at all.

Diane: ".....Um, I know, um like I said there is the information, Easy Breathers, and all that, that's all available. They help with all your medications, you know, they will give you lots of help I'm sure. Um, I think getting in and out of facilities is getting easier and easier. I think 'No Smoking' areas is just a huge question, I mean, how can you not be exposed to smoke. When in a lot of places you are right across from a smoking area."

When asked the direct question regarding access to services, Bob stated that he thought service access was okay except for "somebody to listen".

Bob: "Like I was saying when we talked about the physiotherapist sessions, it is really good to have someone to talk to that will listen and that has some background in chest problems. It lessens the anxiety some of the time. It's good."

Steve and Claude were the two informants that indicated in the direct question that access to services was not an issue for them. The theme of access did not present itself in their interviews, except for Steve who thought that if he had access to a 'trial' walker for no dollar charge that he would find that useful. He would then know if it would be worthwhile to get a walker for himself. One should consider that perhaps the informants without access issues may reflect the difficulties of measuring perceived needs among persons without full awareness of the options or of their potential future needs.

The Future

The interview guide included a question that asked informants what they thought about the future. All of the informants answered this question. Six of the eight informants brought forward thoughts on the future at other points in the interview either before or after the question was asked. In the narratives, there were examples where

informants explored their understanding of the future by looking back on the past and by looking at others who are in similar circumstance to their own. With this framework individuals looked ahead to the future and shaped their perception of the changes that would occur in the COPD trajectory. Quite unanimously, the informants all stated that they would be “worse” in the future. Many discussions included common issues like death, suffering, and burden to others.

Claude was the one informant who stated that he was looking forward to the future, although like all the other informants he also stated that he believed that the impact of the lung disease would be worse in the future. In Claude’s interview, he describes himself as a realist when he talks about the future. He relates his experience with his dad’s death and his brother’s advanced emphysema and imagines what his future might hold. Claude stays positively focussed, as was his attitude throughout the interview. He considers himself lucky at this point and is looking forward positively for another ten good years. He is also optimistic that the future may hold other good things like advances in medicine that may assist him. Claude concludes with a message that in the future, children should be told and “forced” not to start smoking cigarettes.

Claude: “The future, I’m rather in a sense I always look forward to the future, in another sense I know I am going to get worse. I’ve seen my Dad pass away from the complications of emphysema and all that and I’ve been told that emphysema is developing. I do not relish the thought to see myself at the point where Dad was. There is a point where I can hope to say okay if something is bad, I’m a burden, I’d like something to happen. If there was something I could see maybe developments in science that would reverse this disease, something like that, that would be good. I do not see myself reaching that point for many years to come yet. And I think, when I reach that point, there is always a little something in a man’s body that says ‘look, this is still working, you don’t know what’s going to happen tomorrow’ so I acknowledge it’s almost impossible to say. I may sound cold when I talk about this but that’s reality, I’m a bit of a realist, I might be a bit

of a dreamer too, to think that in the future things will get better, but they won't, but it is not something that affects my life today. I don't dwell on those things."

Claude: ".....In two or three years from now when I'm worse, I don't know what it's going to be like. I hate to think of the burden which I might have caused my wife."

Claude: ".....My younger brother has it, but I know he has to carry an oxygen tank, because he has it really bad. He's younger than I am, but he is also worse off than I am because I see him more often take a few steps up the stairs and then he has to stop. I also know that he hasn't smoked for about 20 years and I've been smoking all my life, but he was a much bigger smoker than I. No, I've seen it all along. In a way I consider myself lucky, I'm 68 and I can still work all day long, I can move around and all that. I still enjoy life, so hopefully, I'm looking forward to another 10 years before I'm really sick."

Claude: "In a way they (family) are probably suffering emotionally more than I because they see, they know what the future is"

Claude: ".....Just tell kids, don't start smoking, force it on them, something like that."

Claude's projection of the future on the basis of his father's experience and comparison with his brother's situation gives him hope, concern and foretells the future.

Kevin starts talking about the future by describing his biggest fear. He worries about suffering. He anticipates that he will suffer and he is fearful of a slow death in a hospital bed. He anticipates that there might be some future hope to treat lung disease, but he ends by stating that he does not think he has a chance of benefiting from these advances.

Kevin: "Oh, ah, I guess my biggest fear is that I'm going to lay in a hospital bed and just eventually stop breathing. Ah, which is not the way I really want to pass on. That scares me. Um, I guess we'd all – just get up one day and die of a heart attack, when you die, that's the way to do it. There is no suffering with it. I wouldn't want to be in a long-term, wouldn't want to be laying in a hospital and watching me die and this disease is what I fear is going to eventually happen."

Uh, that's what I think is in the future unless they can do something. I look at the future as, you know, you always, there is always hope there, maybe somewhere down the road – Dr. K. will phone me up and say, 'come on in, we'll transplant, we've got a transplant'. I mean that's a pipe dream....it's a dream. But you know your chances of it happening are nil. Unless, I mean, I'm not at the point where I don't, I still enjoy, people stop me, I still enjoy chatting with them so things aren't all that black. It's just your looking at a, I'm looking at myself, I think I have a healthy mind and a worn-out body, which I blame myself; many years of abuse."

Like Bob, Harriet shares how she does not want to suffer in the future and expands this thought further to indicate that she does not wish to be kept alive "artificially".

Again, like Bob, Harriet hopes that her 'heart gives out before her breathing'.

Harriet: "I know, I haven't asked. I think it gets worse and not better. I hope the heart gives out before the breathing.....I don't want to die gasping and drowning. My daughter said, 'Mom I would take care of you, I want you to be here', but I don't want to, not like that."

Harriet: "I don't believe in keeping people alive artificially long and I don't want that. I would move to Holland where they have humane rules around dying."

In discussing her perceptions of the future, Diane begins indicating that she believes her condition will progressively get worse. She then goes on to share some things like avoiding infections and trying to move out of her house into accommodations like an apartment that may be less work for her as steps she is taking to maintain herself as well as she can be now and in the future. She describes living in a chronic care facility as a possible future need. Diane describes some of the limitations that she believes that she will have to live with in the future and she also indicates that she does not want to be burdened to her children. Diane hypothesizes that although lung transplantation and

advances in medications may be available that they will likely not be something that she will benefit from. She concludes by indicating that although she has recently observed other family members at the end of their life, she does not have a good sense of what lies ahead and what services are available.

Diane: "Well, I think it is probably going to get progressively worse (clears throat) and there is moments when I realize that I have very much limited options, um I don't know if I really dwell on that very much. I um. I think I am very aware of infection and getting a bad cold and you know I'm aware that could end up in the hospital in quite bad condition, it takes a long time to recover from that. We almost got out of our house, we got into an apartment which would have been less to deal with you know, like summer is going to come and have the garden, as much as I enjoyed the garden because it does take a lot of energy you know. On the one had I think you know, I think it's good for me and on the other hand I wonder where my head is sometimes for getting into it all. But, I uh, there is times when I can't do it so it doesn't get done and um, I could by myself and say to people well I'll probably end up in Deer Lodge, you know, which is, from my understanding, a facility that would be good. I probably won't be able to travel on a plane, you know, without oxygen and able to do those kinds of things, and um, you know, it's um, I don't know I'll probably be too old to get into a, be eligible for a lung transplant later on, I don't know, and I don't know much more medications or whatever. I guess I'll deal with it as it comes you know, I don't know. I think there is care out there, there are facilities out there that will help you and all these kinds of things and I will probably have to take advantage of it all you know. I don't want to be a burden to my children, I think that is very difficult and hopefully I will get into some kind of accommodation what would be easier for everybody. Whether I know it's time, you know, maybe I won't feel right maybe it won't be too long."

Diane: ".....But, um, uh, it's just general information about sort of what lies ahead and what are the, you know, services that are going to be available if this happens to you, all that kind of stuff. Although I have had a mother who was sick and a brother in-law, who just died of cancer, so you do get your eyes opened a little bit as to what is out there. But I don't know specifically to what."

Like Diane, Bob believed that things would be worse for him in the future, and that he would require sort of institutional support so as not to burden his family.

Bob: "The future is more negative than anything isn't it? I mean the sickness is going to get worse and it's probably too late to change that, even if they do come up with some miracle of sorts. I am going to need more support in the future and I do not want to burden my wife or family and friends, so if possible I would look to some sort of institution, like Deer Lodge?"

In his narrative, Bob anticipates not only that he will require additional support, but also gives some indication that he is aware of some end of life options for care.

In answering the interview question regarding their thoughts on the future, both Beverly and Steve stated that they tried not to or did not think about it. They were consistent in this and did not bring forward discussions of the future at any other point in the interview.

Beverly: "The future, oh God.....I don't know. I try not to think about it. It's just going to get worse. (sniffing) I don't think much about it."

Steve: "I don't think about it. Living today is hard enough. I guess when things get really bad I will end up in hospital and not come out."

In reflecting on the interview experience and bringing forth the issue of the future there were a number of elements that it would be beneficial to comment on. There were informants who seemed to have difficulty projecting into the future and in discussing the end of life. There were several informants who in discussing the future became emotional and needed to take a pause in the interview to recover and there were two informants who broke down and cried at this part of the discussion. Although these

informants were again reassured (as they had been prior to the start of the interview) that they did not have to answer any question that they did not feel comfortable with, they did persist in answering. In constructing the interview guide, this researcher was aware that inquiring about the future to individuals who have a chronic illness may a difficult subject for them to discuss or think about. Having this awareness assisted in introducing the question to the informants, but the emotional reactions were still difficult to contend with, as was the realization that perhaps one had opened an area of thought that the individual may not be prepared to deal with at this time. The question relating to the informant's future was posed in the first portion of the interview. This timing was fortuitous in that it allowed occasion for further support or discussion with the individual, before the interview was completed.

V. CONCLUSIONS AND RECOMMENDATIONS

What is it like to live with chronic obstructive pulmonary disease? What do individuals with chronic obstructive pulmonary disease identify as their care needs? This research project has considered these two questions and explored how individuals describe their illness experience and their functional performance, as well as what resources or services they currently perceive to be necessary or that may be necessary in the future.

A qualitative approach using a semi-structured interview was used to explore the illness experience of the individual with COPD and to document the perceived needs for formal and informal care. Eight illness narratives were analyzed and several common themes regarding life with COPD emerged.

All of the informants living with COPD identified the major life impacts of COPD, the limitations that this illness imposed on their daily lives, the concern over fatigue and shortness of breath, the issue of dependency and the concern of anxiety and panic. These concerns presented in the narratives of both the individuals with moderate and severe stages of disease and for both male and female informants. Those interviewed described how it felt to be tired or short of breath and the impact of that feeling on their activities. All informants offered vivid examples of how their lives had changed since the onset of their illness. They described how they were forced to change how they performed even

the very basic activities of daily living. The informants expressed concerns related to their dependency on others. The theme of dependency also involved concerns of sharing of functions and roles and had overlap with the theme of frustration. Individuals did not wish to be dependent on others to assist them with their day's activities. They also related a reluctance to give up or share the activities that helped define their role identity. Oliver (1999), reports that individuals with chronic obstructive pulmonary disease experience continual challenges in preserving 'a sense of wholeness' as they faced physical changes that impeded their daily activities.

Four of the eight informants brought forth the concern of anxiety and panic. They used strong words like fear, panicked, scared, paralyzed and doomed to convey the message that anxiety and panic have a large impact on their lives and how they are able to function. Smoller et al.(1996) reports that individuals with obstructive pulmonary disease have a high rate of panic symptoms. They indicate that there is reason to believe that pulmonary disease signifies a risk factor for the development of panic related to repeated experiences with dyspnea and life-threatening exacerbations of pulmonary dysfunction and the stress of coping with chronic disease.

Notwithstanding immediate and long-term impacts of COPD on life, like all chronic illness processes, informants had learned to mediate the impact of their illness. They described their coping strategies and identified techniques that were designed to maintain some of the aspects of their lives that they were accustomed to do. In some of the examples it was clear that the intent of the coping strategy was to make a change that

would enable them to maintain as much independence as they could. Certain strategies involved personal changes that involved assisted living and sometimes, individuals gave examples of strategies where they were dependent on other people. All eight of the informants gave details 'of about taking more time' as a strategy, that is they could perform the task independently if they did took more time or allowed for rest breaks. The use of medications such as 'puffers' and assistive devices such as oxygen, wheelchairs, shopping carts and chairs were described as coping strategies. Talking to supportive individuals about their circumstance or about issues related to living with COPD was also identified as a valuable coping strategy. Informants noted how planning ahead and anticipating trouble areas was a useful strategy for them. They described how they would plan ahead to avoid cold air and avoid infections. And how they would anticipate the activity ahead and the environment that it would take place in and then plan how they would safely accomplish it, e.g. by modifying the task or allowing more time to accomplish it. Related to this, was the strategy of pacing and task simplification and deletion of activities. Informants described the need for rest breaks during activities, taking it slower and eliminating some activities.

Predictably, the narrative descriptions of coping strategies had overlaps and connections to the theme of self-described care needs. As informants described the strategies they used to cope with the impacts of COPD in their daily lives, they would also indicate these as needs. In addition to this, the informants provided a listing of their perceived care needs when they were asked to do so as a direct interview question.

Some of the care needs that individuals described were being met through existing arrangements or services. Some of the needs were for services or programming that had been experienced by the individual in the past and that the individual wanted more of and some were unmet care needs. The self-described care needs included the following: an exercise program for individuals with COPD, a support group, counseling services, more information about COPD and information about what to expect in the future related to their COPD, housekeeping services, an improved access to oxygen services, continuity of relationship with the same physician and access to specialist physicians, more flexibility in the cost coverage of drugs by the Pharmacare Program, accessibility to services related to transportation and caregiver reassurance.

Exercise Program

Exercise programming that is tailored to individuals with COPD was identified as a perceived care need. Informants referred to having heard or experienced the Respiratory Rehabilitation program at the Misericordia Centre and believed the exercise component was a beneficial service to individuals such as themselves. The literature reports pulmonary rehabilitation as a preventive health-care program provided by a team of health professionals to assist individuals cope physically, psychologically and socially with COPD and this would seem to be a partial match with the descriptions of need by the informants. The informants did also seem to have ongoing needs for exercise tailored to individuals with COPD that might not be met by a pulmonary rehabilitation program.

Support Group

A COPD support group was noted as a perceived care need by informants. Informants expressed how they believed a support group could assist them in their coping. Talking with others and sharing thoughts, strategies, experiences and socializing were identified as valuable components of a support group. A more formal educational focus in a support group setting was also noted as a care need, particularly related to medications and COPD. Informants were clear that a support group had to be accessible service.

Counseling Services

Informants identified that individual preparation and assistance for management of the anxiety, fear and panic of breathlessness that they have experienced with COPD would be useful. Having the awareness that this may be an impact of COPD and having some professional guidance as to how to both psychologically and medically manage the episodes was identified as an important need.

Information

More information about COPD and information about what to expect in the future related to their COPD were consistently identified as a need by the informants. Information and education needs that were specifically noted include: what is COPD and what is the impact of the disease on their bodies, what are the respiratory diagnostic tests are measuring and what the results mean, how to take COPD medications, information related to techniques for breathing, and what exercises and diet that would be beneficial to individuals with COPD.

Housekeeping Services

Informants identified the need for housekeeping services. Housecleaning duties like vacuuming and cleaning laundry and reaching to dust furniture were too much effort for the informants who noted housekeeping services as a need. They described how they would 'pay' for their overexertion with subsequent days of fatigue if they attempted to perform these tasks. Some of the informants had organized housekeeping assistance from their family members, some were paying for assistance and some identified it as an unmet need.

Improved Access to Home Oxygen Services

Access to supplemental home and portable oxygen services was perceived to be a need by informants. Informants described experiences when their self-assessed need for supplemental oxygen did not match the assessment based on the Manitoba Home Oxygen Program. They believed that they required oxygen and were told that they were ineligible to receive it from the Manitoba Home Oxygen Program. This was a great source of frustration to these individuals. Some individuals worked with an alternate physician to gain a prescription for oxygen in order that they could get payment of the service covered by their private insurance plan. Other individuals paid for the supplemental coverage themselves. At the time of interview, the level of illness of the informants who used supplemental oxygen had worsened to the extent that they now met the admission criteria for and were receiving their service from the Manitoba Home Oxygen Program.

Consistent Physician relationships and access to Specialist Physicians

Informants reported the need have continuity of relationship with the same physician and access to specialist physicians as care needs. Informants described that it was important to have access to a doctor who knows you and your illness so that you do not have to 'start all over again' with each visit. They indicated this need for consistency related to family physicians. In terms of access to specialists, the informants reported poor access in the rural areas. They described how it was necessary to travel into Winnipeg to see a specialist and how they believed that as their condition worsened and they required more care by the specialist, that they would need to relocate to Winnipeg to receive necessary specialist services.

Flexibility in the Cost Coverage of Drugs

Informants identified the need for more comprehensive coverage of drug costs. They noted that the current Pharmacare coverage has a cap on the amount of Ventolin medication that it will pay for and that their respirologist has instructed them to take more Ventolin than is covered by the Pharmacare plan. This is providing them with financial hardship and therefore they have identified that coverage of this drug cost is an unmet need.

Accessibility to Services related to Transportation

Informants identified the need for accessible services. They noted how they tired easily and how factors such a long drive in a car, opening a lot of doors, stairs, and a long walk from parking the care or difficult to find car parking would prevent them from accessing some of the services that they would need.

Caregiver Reassurance

Informants noted that the reassurance of caregivers was important to them. The majority of the informants described the reassurance of the physician as the caregiver as important because it gave them a sense of trust, a sense that they were heard and that they were on track and doing the right things. The reassurance of family caregivers was also described as an important care need by some of the informants.

Some of the researcher expectations of the results of this research were realized in the interviews and some were not. Informants' description of cigarette smoking as a major risk factor for COPD, frustration by physical limitations and impact on daily life activities were generally presented as was anticipated. The description of onset of symptoms, attitude towards smoking, description of perceived needs, and viewpoint as they described their circumstance were not as was expected by the researcher. The identification of cigarette smoking as causative to the informant's illness, yet the attitude and continued enjoyment of smoking cigarettes was a notable unexpected result.

The illness narratives described the impacts of COPD on daily life activities of individuals. Shortness of breath and fatigue were described as increasing as their illness progressed and fifty percent of the informants had progressed to the point where they required supplemental home and portable oxygen services.

Lung transplantation and lung volume reduction were mentioned in some of the informant narratives. Three informants had been assessed for a lung volume reduction surgery. They described this as a procedure that would assist them to breathe better. All three of these informants indicated that they valued the assessment process because they learned so much about COPD as they were going through it. Two of these three informants actually went through a lung volume reduction surgical procedure. Three of the informants mentioned lung transplantation in the context of their discussions of the future. None of the informants felt that they would be eligible for a lung transplant, but they were hopeful that advances in medical science would continue and that something might be available to assist them or others. The literature indicates that lung volume reduction surgery and lung transplantation have been shown to improve lung function, exercise capacity and quality of life in individuals with advanced emphysema. Cordova and Criner (2001) indicate that lung volume reduction surgery may be used as an alternative treatment or as a "bridge" to lung transplantation. The National Emphysema Treatment Trial Research Group (2001) report that caution is necessary in the use of lung volume reduction surgery in individuals with emphysema who have a low FEV₁ and either homogeneous emphysema or a very low carbon monoxide diffusing capacity. The Group indicates that these patients are at high risk for death after surgery and also are

unlikely to benefit from the surgery. Other areas of research in COPD treatment are focusing on gene therapy and it is expected that clinical trials of this type of therapy will take place in the next decade.

Further examination is required in the areas that were reported as care needs by the informants and how these care needs match existing services in Manitoba is needed. The results of this research project offers a pragmatic understanding of the lives of individuals with COPD for information and targeted awareness to care providers. It also suggests information that would be useful to providers in areas of service to individuals with COPD as they undertake program reviews and program planning.

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APPENDIX A

Interview Guide

This guide is a proposed format, to be used with uniformity as appropriate. This study is using a qualitative approach that relies on the postulate of adjustment and flexibility in data collection based on the information gathered. Given this, some adaptation of the interview format is predicted and appropriate.

Thank you for taking the time in assisting me with my study. I will ask you to discuss your experience with COPD. The interview will be tape recorded. Your responses are completely voluntary and if you feel uncomfortable with any question, you can choose not to answer the question, or you can ask to have the tape recorder turned off. If you become short of breath, tired or you feel you cannot complete the interview today, please tell me and I will stop the interview and we can arrange another time and place to complete the interview.

Chronic Obstructive Pulmonary Disease can cause many changes in an individual's life...

- 1 Could you describe the situation when you first became aware of you illness?
 - (a) What was this like?
 - (b) At what point did other people and your family become aware of it?

- 2 Can you describe some situations that made you aware that your respiratory function was changing? Early examples? Present day examples?
 - (a) How did you respond to these incidents?
 - (b) Did you try to treat yourself? What did you do about it?
 - (c) When did you start to talk about it with your care providers?

- 3 Could you describe how COPD has impacted on your daily life?
 - (a) How does it affect family life?
 - (b) How does it affect work life?
 - (c) How have you adapted?
 - (d) How do you think of yourself and your body?
 - (e) What do you think about the future?

- 4 Could you describe how you manage your disease symptoms? What are your strategies for day to day management/coping?

- 5 What have the doctors and nurses told you about COPD?

- 6 What else would you like to know about your illness?

- 7 What do you think brought this on (COPD)?

- 8 Could you describe your main concerns of life with COPD?

- 9 Could you describe your care needs? Any and all that you can think of...

- 10 Do you feel your care needs are being met?

- 11 Thinking about the services that you now receive, are there other services or ways of providing you care that you can think of?

- 12 What part does caregiver's reassurance play in how you feel?

- 13 Access to services Are there some community resources in the area that you feel would be useful and are not receiving?

- (a) Are there community resources that you were told you were ineligible for?
- (b) If so, do you agree with the ineligibility assessment?

14 Can you think of other ways of providing care to someone like yourself?

- (a) more/different care in the home?
- (b) more/different types of services/programs?
- (c) more/different attendant services?

15 Have there ever been areas of conflict/disagreement with your care providers? Can you describe that?

16 Have there ever been areas of conflict/disagreement with members of your family who help with your care? Can you describe that?

17 Is there anything you would like to add to the previous discussion, that you may not have had a chance to say?

18 Is there anything else you would like to ask me?



APPENDIX B

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THE UNIVERSITY OF MANITOBA

BANNATYNE CAMPUS
Research Ethics Boards

A112 - 753 McDermot Avenue
Winnipeg, Manitoba
Canada R3E 0W3

APPROVAL FORM

Tel: (204) 789-3255
Fax: (204) 789-3942

Principal Investigator: Ms. C. DeKeyster Jaworsky

Protocol Reference Number: E99:91
Date: October 23, 2000

Protocol Title: The Illness Experience of Individuals with COPD and their Perceived Care Needs

The following are approved for use:

- Thesis Proposal
- Informed Consent Form, dated October 12, 2000
- Information Letter

The above was approved by Dr. A. Katz, Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated October 12, 2000. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba.

This approval is valid for one year only. A study status report must be submitted annually and must accompany your request for reapproval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

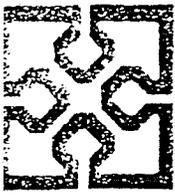
This approval is for the ethics of human use only. For the logistics of performing the study, approval should be sought from the relevant institution, if required.

Sincerely yours,

Alan Katz, MB., Ch B., MSc, CCFP, FCFP,
Chair,
~~Health Research Ethics Board~~
Bannatyne Campus

Please quote the above protocol reference number on all correspondence.
Inquiries should be directed to the REB Secretary
Telephone: (204) 789-3255 / Fax: (204)789-3942





Health Sciences Centre

OFFICE OF THE DIRECTOR OF RESEARCH

MS7 - 820 SHERBROOK STREET
WINNIPEG, MANITOBA R3A 1R9

DIAL DIRECT (204) 787-4587
FAX (204) 787-4547

115

October 11, 2000

Ms C. DeKeyster
Principal Investigator

Dear Ms DeKeyster:

**RE: THE ILLNESS EXPERIENCE OF INDIVIDUALS WITH COPD AND THEIR
PERCEIVED CARE NEEDS.**

ETHICS #: E99:09 RIC #: RI00:141

The above-named non-contract protocol, has been evaluated and approved by the H.S.C. Research Impact Committee. Would you please let Eliette Allec (3274) know when the study will be starting. Thank you.

My sincere best wishes for much success in your study.

Sincerely,

Luis Oppenheimer, MD, Ph.D., FRCS(C)
Director of Research
Health Sciences Centre

cc: Ms Gloria Dutchuk, Finance Division

LO/ks



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The Illness Experience of Individuals with COPD and their Perceived Care Needs

Information Letter

Date: *November 1, 2000*

Dear Sir or Madam:

Individuals with Chronic Obstructive Lung Disease (COPD) are a special group of people, who may have particular needs, and preferences for their care. The story of their life with COPD and what they feel are the care needs that are important to them are of particular interest.

Individuals with COPD are being studied in order to better understand the illness experience of the individual with COPD. In addition to this, the care needs of individuals with COPD are being studied in order to understand from the individual's point of view what they deem to be important.

Caroline Jaworsky is a University of Manitoba graduate student, in the Department of Community Health Sciences and her advisor is Dr. Joseph Kaufert. Caroline has many years of experience working with individuals with COPD and has a sincere interest in talking to individuals with this illness experience. She believes that by talking with individuals with COPD and hearing their experiences, that a better understanding of what resources they feel are important to their lives can be obtained.

She would like to explore questions about what it has been like to live with COPD, the resources, supports and services that have been available and used as well as the resources, supports and services that may have been useful if they had been available. This information would then be available to those health care providers or community agencies that would find it useful for planning purposes, in order to better meet the special needs of the individual with COPD.



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Information Letter

Page 2

Caroline would like to meet with you for about one hour, at a time that is convenient to you. Participation is completely voluntary and your participation will be kept confidential. If you decide not to participate, it will have no effect on your present or future use of health services. If you are interested and willing to participate, please give your name and phone number to the coordinator that has given you this letter, and Caroline will contact you by telephone to arrange an interview. Thank you very much for your interest and your time.

Should you have any questions, please do not hesitate to contact Caroline Jaworsky at () . Should you wish to speak to her advisor, Joseph Kaufert is available by telephone at the Department of Community Health Sciences, University of Manitoba at (204) 789-3798. Should you have questions regarding your rights in regards to this research project, you may contact the University of Manitoba Health Research Ethics Board at 789-3389.

Sincerely,

Caroline J.D. Jaworsky
Graduate Student, University of Manitoba
Department of Community Health SciencesDr. Joseph Kaufert
Professor
Department of Community Health Sciences



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Consent Form

The Illness Experience of Individuals with Chronic Obstructive Pulmonary Disease and their Perceived Care Needs

What is it like to live with Chronic Obstructive Pulmonary Disease? What does it mean?
What are the care needs, services, supports etc. that would be wanted by an individual
with Chronic Obstructive Pulmonary Disease?

The purpose of this research project is to explore what life is like for an individual
with Chronic Obstructive Pulmonary Disease and to find out what the perceived
care needs are from the individual's perspective. This will be achieved by talking to
people like yourself who live with Chronic Obstructive Pulmonary Disease.

You will be asked to participate in an interview regarding your illness experience with
Chronic Obstructive Pulmonary Disease and your perceived care needs. The interview
will be approximately one and a half hours in length. With your permission, the
interview will be tape-recorded. The interview tapes will be transcribed to prepare for
data analysis. The information revealed in the interview will be confidential and number



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The Illness Experience of Individuals with Chronic Obstructive Pulmonary Disease and their Perceived Care Needs

and letter coded, your name will be erased. Therefore no one will be able to identify your record except for the researcher. You will not be identified by name or any identifiable characteristic in any report. The transcript tapes will be destroyed at the end of the project. Caregivers will not have access to the tapes. Your participation in this research project will not affect the care you already receive.

Should you become short of breath or tired during the interview, you can tell the researcher to stop the interview for a rest or continue the interview at another date and time. In addition, if the researcher believes that you are short of breath or tired, she will stop the interview for a rest or continue the interview at another date and time.

Joining the research project is completely **voluntary**, if you feel uncomfortable answering any questions during the study, you are free to have the tape recorder turned off or refuse to answer any questions. If you do not wish to participate in this project it



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The Illness Experience of Individuals with Chronic Obstructive Pulmonary Disease and their Perceived Care Needs

will not affect the care that you receive and you may withdraw from the study at any time

The researcher is a Community Health Sciences Graduate Student at the University of Manitoba. The study is supervised by Dr. Joseph Kaufert (789- 3798). Dr. Kaufert is available as an objective individual should you have concerns about the project. In addition, if you have questions or concerns about your rights as a project participant, you can contact the University of Manitoba, Health Research Ethics Board at 789-3389. This research is not funded or initiated by the Health Sciences Centre.

There are no known risks to participating in this research project other than taking your time to answer questions and asking questions that may bring up personal problems or remind you of past difficulties. The benefits to participation may be that this will provide you with an opportunity to tell your story of what life is like with Chronic Obstructive Pulmonary Disease and what you see as necessary care. When completed, this research will assist both individuals with Chronic Obstructive Pulmonary Disease and health care



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The Illness Experience of Individuals with Chronic Obstructive Pulmonary Disease and their Perceived Care Needs

workers to understand more about how Chronic Obstructive Pulmonary Disease has affected individuals' lives and what services do or would make a difference in their life with Chronic Obstructive Pulmonary Disease.

If you have questions, please contact the interviewer Caroline Jaworsky at



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Fax: (204) 739-3905

**The Illness Experience of Individuals with Chronic Obstructive
Pulmonary Disease and their Perceived Care Needs**

I have been fully informed regarding the above research procedures and have had the purpose of this study explained to me. I have been provided with the opportunity to ask questions and these questions have been answered satisfactorily. I agree to participate in this research and understand that I may withdraw this consent and discontinue participation at any time without affecting my health care received.

Name: _____

Date: _____ Signature: _____

Informed consent form has been fully explained by:

Date: _____ Signature: _____

Caroline J.D. Jaworsky

I would like a summary report of the findings.

_____ Yes _____ No

Please mail the summary findings to:

Name: _____

Address: _____

APPENDIX E

Listing of Services related to individuals with COPD in Winnipeg

- a) Manitoba Lung Association (affiliation with the Lung Association of Canada)

- b) Respiratory Support Groups:
St. Jame's Senior Centre
"Easy Breathers" Group
Located at Deer Lodge Centre

- c) Pulmonary Programs:
Inpatient Pulmonary Rehabilitation
Riverview Centre

- d) Respiratory Day Hospital
Deer Lodge Centre

- e) Riverview Health Centre Day Hospital
Offers only partial program to the individual with pulmonary difficulties and although they will serve this type of client, it is not the focus of the program.

- f) Adult Day Program – "Huff'n Puff" group
Offers socialization and support to individuals who are oxygen dependent.
Offered one day per week. \$5/session cost to the client to cover lunch and transportation.

- g) Manitoba Lung sponsors the "Breath Easy" program - Pulmonary Management Program. 16 sessions are offered over 8 weeks. Sessions alternate between lecture and exercise and target anyone with a chronic breathing problem. Sessions are offered once annually in the spring. Sessions are free.

- h) Misericordia Health Centre offers the "MHC for Lungs" program - Pulmonary Management Programs. 10 sessions are offered over a 5-week period. Sessions are free. The program is designed for individuals with emphysema, chronic bronchitis, recent chest surgery, chronic asthma or other chronic lung condition.

APPENDIX E

Listing of Services related to individuals with COPD in Winnipeg (continued)

i) Manitoba Respiratory Home Care Program

Oversees the services provided to respiratory patients registered with home care in the community. These services include: 1) the Ventilatory Assistive Devices Program, 2) the Manitoba Home Oxygen Services and 3) Respiratory home care nurses, and 4) Cardio-respiratory Community therapy services.

j) Manitoba Home Oxygen Services

The program provides home oxygen therapy coverage for clients who have documented chronic hypoxemia. To be eligible clients must have an established diagnosis, be clinically stable and have documented a minimum of two arterial blood gases performed on room air no sooner than one week apart that show a $PAO_2 < 55$ mmHg at rest on room air. Or an arterial blood gas test confirming a PAO_2 of 56-59 mmhg at rest on room air in addition to other evidence of cor pulmonale or secondary polycythemia. The client would also qualify if there was documentation of an assessment demonstrating nocturnal or exercise desaturation with oximetry or a sleep lab study.

k) Notable Internet Websites:

COPD/Emphysema Online Support Mailing List
The Chronic Lung Disease Forum
The COPD Forum of the Colorado HealthNet
Emphysema/Bronchitis support Group
Secondwind Lung Health Magazine Online www.lung.ca
National Jewish Medical and Research Center www.nationaljewish.org
The Canadian Lung Association (with links to provincial associations) www.lung.ca
The American Lung Association www.lungusa.org