EXPLORING THE SOCIAL CONSTRUCTION OF
CHRONIC OBSTRUCTIVE PULMONARY DISEASE

by

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A thesis submitted in conformity with the requirements
for the degree of Master of Science
Graduate Department of Rehabilitation Science
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Abstract
Exploring the Social Construction of Chronic Obstructive Pulmonary Disease

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A social constructionist perspective was used to investigate the experience and meaning of illness for the individual living with Chronic Obstructive Pulmonary Disease (COPD). Twenty-three persons with COPD were interviewed, and data were analyzed using a modified Grounded theory method. The major findings suggest that COPD has acute and chronic aspects to its illness course. There exist two pre-trajectories. Common to both COPD pretrajectories is the absence of the notion of chronic illness. These pretrajectory phases correspond to the early stage of the disease course. However, individuals with COPD do not acknowledge a chronic illness process. This shapes their response to illness, expectations and coping abilities. It also makes this group, among chronic illnesses, uniquely suited to sick role adoption. The findings of this study served to extend the literature on the illness experience of COPD, and chronic illness. In the thesis recommendations are made for practice and future research.
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CHAPERT ONE

INTRODUCTION

INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) refers to a group of disorders that produce irreversible impairment of lung function (Small & Graydon, 1993). In Canada, COPD ranks as the sixth leading cause of death among men, and the eighth leading cause of death among women (Small & Graydon, 1992). Additionally, in 1992, COPD was cited as the fifth leading cause of death in North America, and the only cause of death that was increasing in prevalence (Canadian Thoracic Society Workshop Group, 1992). The individual with COPD is faced with the challenges of a condition producing potentially debilitating physical, psychological and social consequences (Calverley & Pride, 1995; Small & Graydon, 1992; Snider, 1995). Thus, it is acknowledged as a common cause of morbidity and mortality in Canada (Enarson, Newman, Fan & MacArthur, 1991). Accordingly, this is an area of significance to health care and society. Given the prevalence and projected increase in the number of individuals with COPD, it is important to understand the meaning of the COPD illness experience and its implications.

PURPOSE OF THE STUDY AND RESEARCH OBJECTIVES

An understanding of the illness experience of people with COPD is required to enable health care practitioners to better understand the implications and subjective outcomes of their interactions with individuals with COPD. The purpose of this study was to investigate the illness experience of the individual
living with Chronic Obstructive Pulmonary Disease (COPD), and with the theoretical framework of the social construction of illness, identify those socio-medical factors which have significantly shaped the illness experience.

The principle objective was to gain an increased understanding of the lived experience of individuals with COPD in an attempt to gain insight into how health care practitioners interactions with individuals with COPD may be interpreted or impact on their illness experience. For some pathologies the illness and/or disease courses have been well documented in the literature. For COPD, research has focused on the pathophysiology and disease course. There is a paucity of illness experience research in COPD.

A further aim of this study was to identify any potential influences, such as institutional forces, shaping the illness course. Socio-medical influences that have been theorized or cited in the literature as impacting on illness response include diagnosis (Locker, 1983), medical management or knowledge (Brown, 1995; Friedson, 1970; McCormick, Min & Conley, 1995; Segall, 1976), societal acceptance or response (Miller, 1992), and stigma (Brown, 1995). Recognition and identification of the socio-medical influences of a person's illness, and the impacts of those influences on their understanding and meaning of the COPD illness experience is of great importance.

Specific topics of exploration included illness onset and course; physical, psychological and social consequences of this illness; and experiences with the health care sector and its impacts. Related questions in this inquiry were: how does the illness experience of COPD start?; how is the illness experience
described?; when do individuals seek medical attention?; how do individuals with COPD define their health state?; and what are the subjective outcomes important to the lives of individuals with COPD?

**BACKGROUND TO THE STUDY**

As a physiotherapist, I had worked for several years with individuals living with COPD, and observed that individuals’ presentation of disease signs and symptoms were invariably inconsistent with my expectations based on my understanding of the disease course and medical management principles. I found that an individual could be categorized or diagnosed with severe lung disease and be functionally more active and independent than another individual diagnosed with mild or early staged lung disease. It was also my experience that there was great variability among my patients with respect to how “successful” their rehabilitation programs were to them, and how much they participated in their care. An individual diagnosed with early stage lung disease with few complaints of symptoms could be highly active and participatory with the rehabilitation program, and another individual with advanced lung disease and many complaints of symptoms could also be highly participatory. Or individuals with the same clinical presentation could equally be not participatory. Certainly the clinical categorization of mild or severe lung impairment was not predictive of which individuals would be more involved and apparently interested in participating in a rehabilitation program. Nor did it appear to be indicative of how individuals would perceive their rehabilitation programs in terms of usefulness.
These observations in my clinical practice suggested to me that other factors may be influencing the disease course, and that an investigation into the lived experiences of individuals with COPD may produce some insight into these paradoxical observations. I believed that a research study with the focus on the experiences and meanings of illness for individuals with COPD, and the interpretations and meanings of their clinical interactions would be the most appropriate methodology to address these clinical observations. A study with the focus on the subjective experience, divergent from the majority of literature that focuses on the disease course, would contribute to the body of research on COPD.

COPD DISEASE COURSE AND HEALTH CARE MANAGEMENT

COPD is defined as a disease state characterized by the presence of chronic bronchitis and/or emphysema associated with airflow obstruction (Snider, 1995). The disease begins at a relatively early stage in life and is characterized by a slowly progressive insidious deterioration of lung function (American Association of Cardiovascular & Pulmonary Rehabilitation, (AACPR), 1993; Pride & Burrows, 1995; Williams, 1989). Individuals with COPD experience a progressive loss of elastic recoil, beginning between 20 and 30 years of age, which changes the balance of forces acting on the lungs so that the resting end-expiratory position tends to enlarge with age, and the alveolar dimensions increase (Cugell, 1988). These irreversible changes result in obstruction to the normal flow of air (Pride & Burrows, 1995). As a progressive disease affecting
the vital supply of oxygen to muscle, brain, and other body cells, COPD affects all aspects of life quality (Petty, 1988).

In the early stages of the disease, individuals are generally asymptomatic (Clark, 1995), with shortness of breath occurring as a response to strenuous activity or intense emotions (Petty, 1988). As the disease progresses, less and less activity is required to produce shortness of breath, such that eventually individuals may be short of breath at rest (Snider, 1995).

Since the lung damage takes time to develop, most individuals are in their sixth decade or older when they first acknowledge symptoms as possibly arising from serious disease (Pearson & Calverley, 1995). Elderly persons often regard loss of function and independence with aging as 'normal' (Charmaz, 1991). There are biological, psychological and social changes involved in the usual aging process that may impact on an older person's ability to function, but usually such changes are adapted to and do not result in disability (Wilkins & Cott, 1993). However, because aging is often regarded as a process of unavoidable deterioration (Wilkins & Cott, 1993), this expectation of decreased abilities can have disability created by illness go unrecognized.

Other symptoms may or may not include: persistent cough; excessive mucous production; impaired mobility; fatigue; anxiety; and ineffective breathing patterns (AACPR, 1993; Snider, 1995; Williams, 1989). It is recognized that individuals with COPD function at levels independent and largely unpredictable from lung function (Pride & Burrows, 1995).
COPD is a frustrating illness, not only for patients, who may suffer considerable psychopathology, but also for their physicians whose medical treatment has only partial success in alleviating symptoms and improving functional capacity (Clark, 1995). The limitations of conventional medical intervention in ameliorating symptoms are well-documented (AACPR, 1993; Clark, 1995; Small & Graydon, 1992; Snider, 1995). Medical management of COPD is largely aimed at symptom control and improving oxygenation during an acute exacerbation (Petty, 1988; Mador & Tobin, 1995). Individuals in acute respiratory distress are likely to be treated with a combination of respiratory stimulants, sympathomimetic agents administered in parenteral, oral or inhalation forms, and short term oxygen therapy (Mador & Tobin, 1995). The four most common medical complications of acute respiratory failure are barotrauma, cardiac arrhythmias, gastrointestinal bleeding, and nosocomial pneumonia (Mador & Tobin, 1995). The majority of patients with COPD and acute respiratory failure will survive the acute episode. However, their long-term prognosis is variable and depends primarily on the severity of the underlying disease (Mador & Tobin, 1995).

For individuals with mild to moderate impairment of lung function, pulmonary rehabilitation programs exist, however, utilization and benefits vary greatly in the literature (Clark, 1995). These multidisciplinary programs generally include pharmacological therapy, patient education, physical therapy, nutrition therapy, occupational therapy and oxygen therapy, as necessary (Clark, 1995).
For the individual with COPD who has persistent symptoms of moderate or severe lung impairment, the active treatment options are limited. In the end stages of the natural history of COPD, individuals tend not to seek medical intervention (Miller, 1992).

The focus of past research on COPD has been on medical management, pathophysiological presentation of the disease, and the disease course. Despite the abundance of literature on COPD, the biomedical research emphasis has neglected to consider the COPD illness experience and, thus how the meaning of that experience may account for some of what is observed, but not understood about this illness and its varied presentations and responses to medical management.

Additionally, within the chronic illness literature, COPD is infrequently referred to, or often absent, from comparative commentary. There is little research that has examined the sociological dimensions of the COPD illness experience in reference to what we know of chronic illness in general. Therefore, this thesis will situate the findings within the Illness Trajectory Framework and the larger chronic illness literature.

In the next chapter I will discuss the psychosocial and sociological literature relating to COPD, respiratory illness in general, and chronic illness. I also discuss the two theoretical orientations used to frame this research study – the Illness Trajectory Framework, and the Social Construction of Illness. Chapter 3 describes the research methodology. In chapters 4 and 5 the findings are
presented. The COPD illness experience is described using phases within the
Illness Trajectory Framework.
CHAPTER TWO
LITERATURE REVIEW

In this literature review I will examine the psychosocial literature on COPD and the relevant sociological literature related to the lived experience of people with COPD. Additionally, I will discuss the theoretical orientation to this study, the social construction of illness, and the research objectives of the study.

PSYCHOSOCIAL LITERATURE

Most investigations concerning the psychosocial characteristics of individuals with COPD have identified depression, sadness, ego weakness, authority conflict, dependency behaviour, irritability, anger and anxiety, and social isolation (Leidy, 1995). These individuals often express feelings of uncertainty (Small & Graydon, 1993), diminished mastery and locus of control over their disease process (Williams, 1989), anxiety and irritability (Sandhu, 1986). One of the most common psychological states among individuals with COPD is depression (Lewis & Bell, 1995; McSweeny, 1988; Williams, 1989).

Keele-Card, Foxall and Barron (1993) interviewed thirty individuals with COPD and their spouses to examine differences in the relationships among loneliness, depression and social support. The data were collected using two standardized scales and a questionnaire. They found that the individuals with COPD and their spouses did not differ significantly on measures of loneliness and depression. They also found that social support satisfaction was linked to loneliness and depression for the individual with COPD, but not for spouses.
They concluded that psychological reactions to COPD, by individuals and spouses, may be expressed in feelings of loneliness and depression.

Other authors have conducted psychosocial research related to quality of life. Ketelaars and his colleagues (1996) conducted research with 126 individuals with diagnoses of severe COPD. Using lung function tests to assess lung impairment, and the 12-minute walk test to assess physical disability, they attempted to assess health related quality of life by means of the St. George’s Respiratory Questionnaire, a medical psychological questionnaire for lung diseases, and a COPD coping questionnaire. The primary findings of this research were that the activity, well being, and impact components of the questionnaires correlated with coping. Thus, the authors concluded that individuals with COPD require teaching around adequate coping in order to improve quality of life.

Okubadejo, Jones and Wedzicha (1996) attempted to examine the relationship between impairment of the partial pressure of oxygen in arterial blood, and quality of life as reported by individuals with COPD. Their findings were that, in patients with severe COPD, quality of life is related to the severity of hypoxemia. Ironically, they also concluded that this relationship is only detectable when using a disease-specific health measure.

The relationships between psychosocial status of individuals with COPD, relative to their functional status and/or social costs, with respect to use of health care services, have also been explored. Browne, Arpin, Corey, Fitch and Grafni (1990) demonstrated the significance of the relationship between the
psychosocial adjustment of individuals with chronic illnesses and the use of health care services. They used a convenience sample of 215 chronically ill, individuals (including individuals diagnosed with COPD) and rated these individuals using a tool that divides patients into three groups according to their adjustment to illness: good, fair and poor. No correlation was made between prognosis or disease severity and health care use. The findings revealed that the well-adjusted group used health care services totalling $9,291, and the poorly adjusted group used services totalling $23,883.

Similarly, a 1985 study by Judd and colleagues, specific to patients with COPD, used the same adjustment tool and a comparison to COPD symptom severity self-reports of shortness of breath. The results indicated that 21.5% of the 135 individuals were poorly adjusted, and that functional status, rather than severity of disease, was most significant in predicting poor adjustment.

Limits of the Psychosocial Literature

In Williams' (1989) critical review of the psychosocial literature addressing chronic respiratory illness and disability he cited two major failings. His primary criticism is in the failure of researchers to determine the areas of physical and emotional dysfunction that patients themselves subjectively experience and feel are important. Secondly, he questioned the meaning of standardized questionnaires and rating scales which have not been validated to be relevant instruments on the basis of illness experience investigation. In response to these primary criticisms, he identified a real need for "rich qualitative data in its own right, in which patients and their families are allowed to discuss, from their own
perspective, the difficult business of living and coping with their illness on a daily basis". These qualitative biographical data will facilitate the building of the [illness] picture which cannot be gained from quantitative assessments alone (Williams, 1989).

**Sociological Literature**

**Disease and Illness**

The distinction between illness and disease is readily acknowledged in the literature (Nettleton, 1995). Disease is generally referred to as the biophysical condition, or the problem as seen from a biomedical perspective (Kleinman, 1988). Thus, the concept of disease is specific to the medical profession, and is shared by other health professions. Disease is usually defined in biological terms (Conrad, 1987). An individual will state that she/he is ill, and doctors decide whether or not they have a disease. The physician translates expressions of illness into terms that fit theoretical models of disease (Kleinman, 1988).

Illness is viewed as the social and psychological phenomena that surrounds or accompanies the disease (Brown, 1995). Thus, illness is the subjective phenomenon. Illness refers to "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (Kleinman, 1988).

Illness is inherently a social phenomenon that may or may not have disease as a foundation (Conrad, 1990). Thus, illness and disease may coexist, or one may be present without the other. Following from that, it is recognized
that disease and illness courses are likely to differ. This distinction is central to my thesis research.

**Insider Orientation to Chronic Illness**

An investigation into the experience of chronic illness must focus on the subjective experience of people with illness (Conrad, 1990). It is now common in sociological studies to distinguish between disease and illness, and between "outsider" and "insider" perspectives on illness (Conrad, 1990). Outsider perspectives minimize or ignore the subjective experience by viewing illness from outside of the experience itself. The patient, illness or disease is viewed as an "object" to be affected and studied (Conrad, 1990). An insider's perspective typically explicitly focuses on illness experience, treating the individual as subject (Conrad, 1990).

Outsider perspectives like Parson’s sick role have made significant contributions to medical sociology. Sick Role theory became the classic outsider framework for examining illness in its conceptualization of illness as deviance and the physician as social control agent. Sick role theory emphasized the doctor-patient experience and, as the dominant paradigm throughout the 1970’s, severely limited the perspective of chronic illness (Conrad, 1990). The sick role does not consider the social and psychological aspects of illness relating to the individuals' perceptions and expectations of their illness.

The study of illness behaviour began in the 1950’s and was intended to identify the various socio-cultural, environmental and psychological factors that affected variability in reactions to symptoms and illness (Mechanic, 1995;
A major finding of the illness behaviour literature is that patients conceive of illness very differently than physicians, and that findings and concepts derived from studies of patients with acute illness may not apply to the experiences of individuals with chronic illness (Steward & Sullivan, 1982).

By the late 1970's an "insider" line of research was emerging (Conrad, 1990). Central to understanding an insider perspective, illness experience, is the meaning individuals attribute to their experience, how they make sense of what is happening to them, the perceptions they hold of health and illness, and how these things impact on what they do (Conrad, 1990). The focus of this data collection is on the meaning of illness, the social organization of the individual's lived experience, and the strategies used in adaptation (Conrad, 1990). Relevant questions would include how people first notice that "something is wrong", what it means to them, how they make sense of events, what they do in response to the events, when and how they seek health care, concerns and expectations of health care, impact of diagnosis, coping with a medical label and treatment regimens, and the impacts on relationships (Conrad, 1990).

An experience-of-illness perspective should successfully conceptualize the chronic illness experience in such a way that it brings greater understanding to the specific illness and contributes to the general understanding of illness experience.

**Chronic Illness Experience**

Disease is characterized as chronic due to its permanent and continuing nature. The body of research on the experience of illness identifies a number of
recurring themes. The most prevalent of these have become part of the sociological basis of knowledge of chronic illness and have assisted in the development of frameworks with which to analyze other data. Prevalent concepts in the illness experience literature are: biographical work and reconstitution of self; careers; managing regimens; family relations; stigma; and uncertainty (Conrad, 1987). Only a few of these concepts, related to respiratory illness experience, have been identified in the literature.

Conceptualizations of chronic illness have recognized it as a process undergoing changes over time (Bury, 1982; Charmaz, 1983; Corbin & Strauss, 1987; Gerhardt, 1990). The term biography is used to suggest that meaning and context in chronic illness cannot be easily separated (Bury, 1991, Charmaz 1995). The meaning of chronic illness and disability is to be found in the problems it creates for the individual and his/her family/significant others (Locker, 1983). The chronic illness experience begins with the initial disruption of chronic illness and disability, followed by learning to manage the chronic illness, and finally adaptation to living with chronic illness (Corbin & Strauss, 1987). Throughout the chronic illness experience the individual must deal with uncertainty, stigmatization, management of their illness and recomposing their sense of identity (Charmaz, 1995).

The concepts of biographical disruption (Bury, 1982), biographical work (Corbin &Strauss, 1987) and identity reconstruction (Charmaz, 1987) have been used to conceptualize the changes over time that an individual with chronic illness faces.
Biographical disruption (Bury, 1991) relates to the initial phase of chronic illness, after the onset of symptoms, when the illness first causes a disruption in the life of the individual. The term relates not only to changes of the physical self, but also to the person's sense of identity (Charmaz, 1995). The experience of biographical disruption has been identified in a number of chronic conditions such as multiple sclerosis (Stewart & Sullivan, 1982) and cardiac disease (Cowie, 1976).

Biographical work refers to the process individuals go through to come to terms with their chronic illness and the resultant disruptions to their lives and self-images (Corbin & Strauss, 1987). Wiener (1975) describes the problems of living with rheumatoid arthritis, and the biographic work involved with that illness. She presents this work as a constant "balancing of options" related to all aspects of life, including activity levels to finances. Similarly, Peyrot and colleagues (1987) describe the biographical work involved for individuals with diabetes. Their account reflects on the influences of personal and professional perspectives, and the often conflicting or competing "work" that must be negotiated and decided upon to manage the illness.

Identity reconstruction is defined by Charmaz (1987) as an individuals' implicit or explicit objectives for personal and/or social identity. It is a process that seeks to override or negate identifications derived from illness. Being able to regain, attain, maintain or recreate a valued identity after an episode of chronic illness is a centrally crucial and significant work to people who are chronically ill (Charmaz, 1987; Corbin & Strauss, 1987).
Orona (1990) describes the loss of identity attributes that occurs in the case of Alzheimer's Disease. She describes how individuals with this disease, and their caregivers, employ different strategies to maintain identities, and the work involved in this process. Similarly, Yoshida (1993) describes the reconstruction of self and identity following traumatic spinal cord injury. In her study she found that, following traumatic spinal cord injury, individuals experienced a pendular shift back and forth between disabled and non-disabled aspects of self until they eventually incorporate their disabled identity as an aspect of their total self.

The chronic illness literature provided a good framework for understanding the experience of chronic illness, in general, and the foundation upon which to examine the illness experience of COPD.

**Respiratory Illness Experience**

My own literature search and review produced fewer than 15 publications on illness experience related to chronic respiratory disease. Of these, only a handful (Leidy & Haase, 1996; Locker & Kaufert, 1988; McBride, 1993; McBride, 1994; Small & Graydon, 1993) were purely qualitative approaches.

A description of functional performance, from the perspective of 12 people with COPD, is presented by Leidy and Haase (1996). The intent of this research was to gain insight into functional performance in people with COPD by developing contextual descriptions of the major areas of functional activity and describe the factors that those individuals perceive as contributing or impeding to their performance. The study participants were a convenience sample of 6 men.
and 6 women, community dwelling, diagnosed with moderate to severe lung impairment. The interview approach was naturalistic inquiry, where following an initial explanation of the intent and purpose of the study, and the research question, participants reportedly chose the direction and content of the interview. The findings were that decisions to perform activities were influenced by a sense of deriving satisfaction, weighed against the potential discomfort of the activity. The findings were presented as a framework for assessing functional performance and developing interventions sensitive to patient values and expectations.

The primary focus of the research by Locker and Kaufert (1988) was on the illness experience related to the use of technology. These authors used qualitative methods to build upon epidemiological research in order to gain an understanding of aging and adaptation among ventilator-dependant individuals living with the late effects of poliomyelitis. There were 10 study participants who were interviewed in-depth about their personal interpretations of the meaning of disability and the impacts of changing respiratory-support technology. Each of the 5 men and 5 women who were interviewed had major limb disability in addition to respiratory impairment. Each person was interviewed on 2 or more occasions using a semi-structured interview schedule. The interviews explored different dimensions of living with respiratory support including individual management strategies to maximize the benefits of technology and minimize social and psychological impacts. The findings indicated that participants perceived that technology not only created positive impacts on energy levels,
mobility and well-being, but it also produced significant and dramatic social impacts. Some of the social impacts included the imposition of new routines, new management strategies, and new dilemmas for individuals and their support networks.

The research of McBride (1993) was an exploratory study into the relative impact on attitudes and beliefs on intentions of adults with COPD to engage in conditioning exercises, energy conservation, controlled breathing, self-pACING and relaxation techniques. The author argued that the performance of these acts would increase activity tolerance. Thus, she reasoned that an understanding of how individuals attempt to control their opportunities to perform these acts would be meaningful information which may guide health care initiatives. The findings indicated that recurrent themes of: acceptance and resignation; determination and perseverance; and impatience and tolerance were linked to individuals decision making around engaging in the above mentioned activities. The results were then discussed in relation to a theory of planned behaviour and the notion of perceived control.

In McBride (1994) a secondary analysis of the data produced in the previous McBride (1993) study is presented. The data obtained through the semi-structured interviews of the 32 individuals with COPD were re-analyzed from the conceptual framework of belief systems, versus the framework of control previously reported. The focus of this paper is an examination of the utility and applicability of the belief system and planned behaviour models to individuals with COPD. The discussion then goes on to relate the findings, within the
framework of belief and control systems, to impacts on future health care initiatives.

Small and Graydon (1993) investigated the perceptions of uncertainty of hospitalized patients with chronic bronchitis and/or emphysema. Twenty-five interviews were conducted. Each interviewee was asked to describe any feelings of uncertainty that they were experiencing as a result of their illness and hospitalization. Additional questions were reportedly used to prompt and/or guide the interviewees as necessary. The interviews were audiotaped and later transcribed and analyzed for themes. The five major themes that emerged from the data were managing home and self-care, planning for the future, unpredictable course of illness, positive thinking, and social support and material resources. The first three reflect themes of uncertainty, and the latter two related to coping resources.

**SUMMARY AND GAPS IN THE LITERATURE**

There is a scarcity of literature addressing the needs of individuals with advanced COPD. The majority of the published research on COPD is focused on the medical management of individuals with mild or moderate lung impairment. The disease course and defining characteristics are also well defined, from a pathophysiological perspective. Although COPD is recognized to have significant psychosocial consequences (AACPR, 1993; Lewis & Bell, 1995; Miller, 1992; Sandhu, 1986; Small & Graydon, 1993; Williams & Bury, 1989), there is comparatively less literature addressing the social and psychological aspects to this disease. For example, issues not addressed in the literature
include how individuals with COPD perceive their diagnosis, and their illness trajectories. Thus, the literature review indicates a gap in understanding of many critical aspects of the lived experience of individuals with COPD. For example, we do not know how health care management may or may not have been perceived to have an impact upon that experience. The literature largely ignores the socio-medical structural influences which may be impacting on illness experience.

THEORETICAL ORIENTATION TO THE STUDY

The major theoretical orientation used in this thesis is the Social Construction of Illness. In addition, the concept of the Illness Trajectory Framework is discussed in this section. In this work, the Illness Trajectory Framework is used to organize and analyze the COPD illness experience data.

The Social Construction of Illness

A central organizing theme in medical sociology is the social construction of diagnosis and illness (Brown, 1995). The social constructionist proposes that reality is constructed through, and cannot exist independent of, human action (Mishler, 1981). Therefore, health, illness, and medical care are socially constructed categories that define and give meaning to certain classes of events (Mishler, 1981; Nettleton, 1995). Social constructionist perspectives are founded in the distinction between disease and illness. Disease is regarded as the biophysiological phenomenon that affects the body, while illness is the social phenomenon that surrounds or accompanies the disease (Conrad & Kern, 1994). Illness reflects a more subjective phenomenon (Brown, 1995). Consistent with this
distinction is the belief that social forces shape our understanding of, and actions toward health, illness, and healing. The social construction of illness deals mainly with the illness experience (Brown, 1995).

There exists a wide variety of definitions of social constructionism which, although related, lack a unitary social constructionist theory or perspective (Brown, 1995). There are three main versions of social constructionism that apply to medical sociology (Brown, 1995). Traditionalists focus on the social definition. The traditional constructionist refutes any notion that fundamental social structures in society play key roles in health and illness (Brown, 1995). Thus, they would not acknowledge any effects from factors such as class, race or gender (Brown, 1995).

The postmodern approach to constructionism is to deconstruct language and symbols in order to show the creation of knowledge (Brown, 1995). Postmodernist approaches would critique positivist emphasis on given sets of social actors, groups and institutions (Brown, 1995).

The third major school of constructionism in medical sociology is related to the sociology of science. This viewpoint argues that the production of scientific facts is the result of mutually conceived actions of scientists (Brown, 1995). It focuses on examining the work of professionals’ discovery of disease, and the development of medical technology (Brown, 1995).

It is clear from the literature on medical sociology that the term “social constructionism” can be subject to a wide range of interpretations and varying perspectives from the three main schools. The perspective of social
constructionism that I have adopted for my thesis research is concerned primarily with the social construction of illness as presented by Friedson (1970).

Friedson's social construction of illness perspective contains elements of symbolic interactionist and structuralist approaches (Gerhardt, 1990). This perspective acknowledges a link between medical knowledge and illness. It recognizes an interactionist approach of experience at personal, dyadic, and group levels, by acknowledging that individuals deal with illness largely in accordance with the dominant social elements of medical knowledge (Friedson, 1970).

Consistent with this perspective is the view of diagnosis as active interpretive work, rather than a technical procedure (Mishler, 1981; Turner, 1987). Social construction begins with an examination of the ways in which individuals, organizations, and institutions determine that there is a condition. The illness experience, decisions regarding treatment, and social understandings of what constitutes outcomes are other components of a social constructionist investigation.

Friedson's social constructionist perspective has been used by a number of social scientists (Brown, 1995; Waitzkin 1989; Zola, 1972). The commonality between these works is an acknowledgement of the multiplicity of social forces that create and modify the illness phenomenon, and a recognition of the importance of examining how conditions are identified and acted upon. This perspective is concerned with such questions as "Why did a condition get identified at a certain point in time?", "Why was action taken or not taken?", "Who benefits by identification?", "How do divergent perspectives on the phenomenon merge or
clash?", and "How does the person's experience of the illness affect the course of the illness, as well as the social outcome?" (Brown, 1995).

**Illness Trajectory Framework**

The Illness Trajectory Framework was first introduced by Corbin and Strauss in 1991. The authors have since provided updates and refinements to the framework in acknowledgment of the changes in health care, technology and the transition and growth of professional groups (Corbin, 1998). The framework remains true to the fundamental principles and concepts upon which it was built, but has been updated to extend the context of its application to our present day health care environment (Corbin, 1998).

The Illness Trajectory Framework is a conceptual model that acknowledges the principle of anticipated change and variance over the course of chronic conditions (Corbin & Strauss, 1991). Disease course, or course of illness is a common health care term used to describe disease progression. Strauss and Glaser (1975) coined the term illness "trajectory" to refer, not only to the physiological unfolding of a sick person's disease, but also to the total organization of work done over that course by the individual, plus the impact on those involved with that work and its organization. The major unifying concept of the Illness Trajectory Framework is "trajectory", which denotes the illness course and the actions of various participants to shape or control that course (Corbin, 1998). The concept of trajectory is a useful one for illuminating the experiences and problems of people who are chronically ill, and of those who participate in their care (Strauss & Glaser, 1975).
Trajectories may be identified by phases. A related concept, trajectory phasing, represents changes in status that an illness will have over time (Straus & Corbin, 1991). The phases of the trajectory framework are pretrajectory, trajectory onset, crisis, acute, stable, unstable, downward and dying (Corbin & Strauss, 1991). The pretrajectory phase is defined as the period before the illness course begins, the preventive phase where no signs or symptoms are present. The trajectory onset phase marks the start of noticeable symptoms, and includes a period of diagnostic workup. Individuals in this phase are just beginning to discover and cope with the implications of diagnosis and illness. In the crisis phase the situation is critical or life threatening, and everyday life activities are suspended until crisis passes. In the acute phase, symptom severity or complications may necessitate hospitalization or bed rest to bring the illness course under control. Under these circumstances, everyday life activities are drastically cut back or temporarily placed on hold.

The stable phase marks the period in which the illness course and symptoms are under control. A period of inability to keep symptoms under control, or the reactivation of illness characterizes the unstable phase. In the downward phase, the illness course is characterized by a rapid or gradual decline of increasing disability or difficulty in controlling symptoms. This is followed by the final phase of the Illness Trajectory Framework, dying, marked by the final days or weeks before death. In this final phase there is a rapid or gradual shutting down of body processes and relinquishment of everyday life interests and activities.
Trajectory projection, another Illness Trajectory Framework concept, represents the vision of the illness course that each individual who is involved in the illness course has. Trajectory projections will differ among individuals related to the same illness course. These differences will be the result of differing levels of knowledge, experience, and belief systems (Thorne & Robinson, 1988).

Because trajectories, as defined here, are linked with peoples' definitions of what is expected of a disease, it follows that trajectories are defined differently for different conditions, potentially differently for individuals with the same condition, and differently for health care providers and family (Strauss & Glaser, 1975). Individuals faced with an illness integrate both their own personal internal influences of meaning with external influences (Dobratz, 1993). Examples of internal influences impacting on response to illness include individuals experiences with other illness sufferers (Jones & Wedzicha, 1996); perceptions of body image (Sexton & Munro, 1988); self-esteem (Lewis & Bell, 1995); and race, culture and gender (Brown, 1995). For example, it can be argued that an individual who has already lived through the experience of a family member suffering through an illness, will likely carry that illness experience with them into their own experience, and it will shape the meaning of their experience. Similarly, another internal influence that can shape response to illness is self-esteem. A self-confident individual, it may be reasoned, will have the internal strength to identify resource supports and draw on those supports. Another less confident individual may feel more isolated, and be unable to identify or draw on those supports. Therefore, for the former individual, illness may be identified with
resource gathering and the comfort of friends and support. For the less confident individual, the illness may mean loneliness and abandonment. Despite recognizable natural histories of disease progression, each individual involved with the trajectory work may have a different belief or perspective about the future recovery potential, life expectancy, potential for medical crises, potential to control symptomology, and future quality of life (Strauss & Glaser, 1975).

The Illness Trajectory Framework recognizes these potential influences on the illness course in the concept of 'conditions influencing management'. Trajectory management represents the process by which the illness course is shaped through all its phases (Corbin & Strauss, 1991). The natural course of a disease can be altered by the interplay of medical, social, political, economic, biographical, and psychological forces (Wiener & Dodd, 1993), examples of conditions influencing management (Corbin, 1991). The relationship among these variables affects both the management of that course of illness, as well as the fate of the person who is ill (Wiener & Dodd, 1993). The value of this theoretical framework is that it focuses on the social context and relationships affecting the work of illness (Wiener & Dodd, 1993).

The Illness Trajectory Framework provides a substantive theory about chronic illness, and was specifically developed to provide knowledge and insight into chronic illness. It has been a useful framework for this thesis research, and is used to organize the findings of the COPD illness course which follows. As initially presented by Corbin and Strauss (1991), the framework was presented with reference to specific phases as outlined above. Later, Corbin (1998)
revisited the framework and emphasized the use of the framework to conceptualize the progression and course of illness over time, without being limited to the linearity or orderliness of the phases as originally outlined. Thus, the Illness Trajectory Framework, consistent with the findings of the study, serve to organize the COPD illness experience, and in doing so, required that the phases, as originally outlined, be reordered and omitted. Specifically, the data analysis identified a blending of the acute and crisis stages and a lack of a stable phase.

In this thesis, I endeavoured to identify the impact of those socio-medical factors which have shaped the illness experience of individuals with COPD. In the next chapter, the methodology is discussed and the study group and analysis is described.
CHAPTER THREE

METHODOLOGY

QUALITATIVE RESEARCH METHODOLOGY

To study the experience and meaning of chronic illness, a qualitative research approach was taken using semi-structured, in-depth interviews. Qualitative research is fundamentally concerned with understanding, meaning, and subjective reality (Stone, 1991).

Qualitative methods of inquiry have increasingly been accepted as a research approach within health sciences research (Sandelowski, 1986). Qualitative and quantitative orientations have different philosophical premises and purposes, lead to different goals, and thus require the use of different research methods and evaluative criteria (Guba & Lincoln, 1989).

ETHNOGRAPHY

Ethnography is a specific form of a generalized approach to developing concepts to understand human behaviours from an emic point of view. An emic viewpoint refers to information which is derived from the subjects’ view of the experience (Brown, 1995). The essential core of ethnography is this concern with the meaning of actions and events to the people we seek to understand. It provides a means of gaining access to the health beliefs and practices of a culture (Smith, 1996).

Ethnography yields detailed empirical data about the lives of people in specific situations. Another aim of ethnography is to develop hypotheses to develop and/or test a theory of a specific culture.
Ethnographic approaches to research have extended beyond the field of anthropology. Of the allied health professions, nursing has particularly recognized and applied the benefits of this methodological approach (Field & Morse, 1985). In the context of health, culture may be used in a broad sense. Culture, in ethnography, refers to the acquired knowledge that people use to interpret experience and generate social behaviour (Spradley, 1979). Thus, cultures may be defined by groups or sub-groups in a population linked by common experiences.

Ethnography yields detailed descriptive empirical data about the lives of people in specific situations (Field & Morse, 1985; Spradley, 1979). Multiple methods may be used including observation, interviews, genealogy, demography and life histories (Field & Morse, 1985; Spradley, 1979). However, the role of language and speech in revealing tacit and explicit knowledge is recognized as the essential part of all ethnographic fieldwork (Spradley, 1979). Indeed, much qualitative research is interview based (Britten, 1995).

**STUDY GROUP AND RECRUITMENT**

The participants for this study were community dwelling elderly people who had severe COPD. Disease severity was assumed solely on the basis of an individual’s requirement for prescribed oxygen. Thus, individuals with severe or advanced disease, as indicated by oxygen prescription, were targeted. Choosing individuals with severe or advanced disease, as indicated by oxygen prescription, is an attempt to obtain data spanning the fullest course of the illness experience as possible.
The study participants were required to meet the following criteria: i) 65 years of age or older; ii) communication abilities were not limited due to cognitive impairment; iii) English speaking; iv) with daily oxygen use requirements. A lack of any of the above criteria was the basis for exclusion from the study. All of the participants for this study met the inclusion criteria.

The study group was a volunteer sample obtained through professional contacts. All of the health care practitioners (physicians, physiotherapists, nurses, registered respiratory care practitioners) received a letter of introduction to the study (see appendix 1). The letter requested their assistance in identifying individuals who met the inclusion criteria. It also outlined the purpose of the research. Liaison health care professionals were also provided with instructions about how to approach potential participants (see appendix 2). Potential participants were given a letter of introduction to the study (see appendix 3) by the health care professional. This process was used to minimize the possibility of potential participants feeling coerced, or in any way bound to participate. It also clearly noted that as the referring practitioner, knowledge of whether or not the referred individual participated would not be provided back to them.

Physicians were my initial referral group. I met with physicians in their medical offices. They elected to provide their patients with the introductory letter (see Appendix 3) to the study through their receptionists or front desk clerks. This further removed their direct influence on patient. However, I believe that it may have reduced the potential number of study participants referred through the physician group. Only one study participant was referred in this manner. Due to
the low response, I initiated a one-on-one recruitment process of nurses and physiotherapists with whom I had previously worked.

As with the physician group, I met with these health care practitioners in their clinical settings and provided them with introductory letters for potential study participants. The introductory letters were individually and personally passed on to individuals who met the criteria by the recruiting nurses and therapy clinicians. Through this group, eight study participants were recruited. Part of the difficulty in obtaining participants through this second group was that all of these practitioners worked in teaching hospitals, and thus I had to make applications to their boards of ethics. This was a lengthy process which included personal interviews with research directors and ethicists of the facilities. I received ethics approval from two facilities after a period of six months, and two other facilities were still in process of ethics review when my data collection was completed, and my study almost concluded.

In light of the delays, I further explored yet a third group of clinicians for recruitment of participants. I approached three oxygen supply companies in the Durham region. I again met with the managers at each office to explain the purpose of the study and my request for their participation in recruitment of participants. The clinicians working for these companies were primarily registered respiratory care practitioners. Once approval for their participation was obtained through the managers, they involved themselves in the process of recruitment. I provided each oxygen supplier with a supply of my participant introductory letters which they took with them on their home visits and left with
potential participants. In this way, an additional fourteen study participants were referred and did participate in the study.

Every individual who was referred and contacted me, did agree to participate and was included in the interviews for the study. By the 18th interview, I was recognizing saturation in the data. However, due to the proximity of referrals of the last 5 participants, I proceeded with their interviews, not wanting to exclude anyone. I believe that the resultant 23 interviews provided a richly saturated volume of data for the study. Conrad (1987) had suggested that a minimum of 20 participants is needed to fully capture the range of illness experience. More recently (Conrad, 1994) has suggested that as few as 10 may be sufficient.

Participants

The sociodemographic characteristics of the 23 participants in the study are recorded in Table A. To summarize, there were 14 female and 9 male participants. They ranged in age from 60 to 87 years of age at the time of the interviews. The mean age of participants was 72 years. The marital status of the participants was as follows: 8 were widowed, 7 were married (living with their spouses), 4 were divorced, and 4 were single (never married). Of the 16 who were unmarried, 15 lived alone, and one lived with his son and daughter-in-law. Of the 23 participants, 14 lived in houses, and 9 lived in apartment or condominium complexes. All of the participants had smoking histories, and two were present smokers. All of the participants were oxygen dependent. The
Table A. Participant Demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Time on Oxygen (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65</td>
<td>F</td>
<td>W</td>
<td>12</td>
</tr>
<tr>
<td>2</td>
<td>79</td>
<td>F</td>
<td>W</td>
<td>24</td>
</tr>
<tr>
<td>3</td>
<td>82</td>
<td>F</td>
<td>W</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>72</td>
<td>F</td>
<td>W</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>63</td>
<td>F</td>
<td>M</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>82</td>
<td>M</td>
<td>S</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>69</td>
<td>M</td>
<td>D</td>
<td>36</td>
</tr>
<tr>
<td>8</td>
<td>68</td>
<td>F</td>
<td>M</td>
<td>24</td>
</tr>
<tr>
<td>9</td>
<td>60</td>
<td>M</td>
<td>S</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>75</td>
<td>M</td>
<td>D</td>
<td>10</td>
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<tr>
<td>11</td>
<td>75</td>
<td>M</td>
<td>M</td>
<td>60</td>
</tr>
<tr>
<td>12</td>
<td>70</td>
<td>F</td>
<td>M</td>
<td>24</td>
</tr>
<tr>
<td>13</td>
<td>66</td>
<td>F</td>
<td>D</td>
<td>24</td>
</tr>
<tr>
<td>14</td>
<td>70</td>
<td>M</td>
<td>M</td>
<td>12</td>
</tr>
<tr>
<td>15</td>
<td>87</td>
<td>M</td>
<td>W</td>
<td>24</td>
</tr>
<tr>
<td>16</td>
<td>69</td>
<td>F</td>
<td>D</td>
<td>12</td>
</tr>
<tr>
<td>17</td>
<td>72</td>
<td>F</td>
<td>W</td>
<td>24</td>
</tr>
<tr>
<td>18</td>
<td>71</td>
<td>F</td>
<td>S</td>
<td>12</td>
</tr>
<tr>
<td>19</td>
<td>81</td>
<td>F</td>
<td>W</td>
<td>18</td>
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<tr>
<td>20</td>
<td>79</td>
<td>M</td>
<td>M</td>
<td>18</td>
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<td>21</td>
<td>66</td>
<td>F</td>
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<td>12</td>
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<tr>
<td>22</td>
<td>80</td>
<td>F</td>
<td>W</td>
<td>30</td>
</tr>
<tr>
<td>23</td>
<td>66</td>
<td>M</td>
<td>S</td>
<td>60</td>
</tr>
</tbody>
</table>
period of oxygen dependency ranged from one month to 60 months, with the mean length of use 19.65 months.

**DATA COLLECTION PROCEDURES**

Data were collected through in-depth interviews using a semi-structured interview guide (see Appendix 4). The guide was pre-tested on a prior sample of seven individuals with COPD who met the same inclusion criteria. Adjustments to the interview guide were made based on its ease of use with the pilot group. The interview guide probed into the chronological course of the person’s illness experience. Each interview began with the statement “I’d first like us to talk about when you first noticed something was wrong”. The general topics then followed from the guide related to the meaning of noticing something was “wrong”, how events were made sense of, resultant consequences, actions in response to the consequences, seeking health care, concerns and expectations, the impact of diagnosis, coping with a medical label, relationships, adaptation to physical discomfort and strategies used to “get by”. Topics from the interview guide were then followed up as they came up. Each interview seemed to come to a natural close. When I thought it was complete, I asked each participant if they wished to add anything else about the illness experience, and I took my cues from there. Often, this was responded to in the negative, however, on two occasions, participants sought specific health care advice. I referred them back to their physicians and/or referring health care practitioner indicating that I did not have any specific information about their health status, and could not “treat”
them. This was readily accepted. All interviews were between 42 and 95 minutes in length.

I conducted all interviews at a time and location convenient for the participants following informed consent (see Appendix 5). Data were transcribed verbatim from tape recordings and written notes into a computer software program (Ethnograph © 1996) for data organization and ongoing analysis. Due to shortness of breath with prolonged conversation, participants spoke in short sentences punctuated by long pauses to “rest” and catch their breath. This is evident by the brevity in length of direct quotations cited in this thesis. I was aware of the physical effort required of the interview process and inquired, at intervals during each interview, of the need to stop.

THE DATA

The accounts of the 23 participants reflected the general areas of questioning of the semi-structured interview guide. The areas of emphasis of participants’ responses varied only slightly. The data included:

a) important elements of the participants' biographies, personal data such as work/education histories, living arrangements, social contacts and economic status,

b) health care interactions during their illness process such as events during hospital stays, feelings about those interactions and some unsolicited opinions about specific individuals or groups of health care providers,
c) participants’ feelings about their COPD illness and the impacts that it has had on their lives,
d) in general terms, participants’ perceptions of their life satisfaction and coping mechanisms, and
e) participants’ views about what may have improved their illness experience.

In presenting the data, participants’ words are quoted extensively to ensure that their own voices are heard regarding their experiences. Identifying information has been altered or omitted (i.e. participants and family names, place names and health care practitioners’ names) without changing in any way the meaning of what was said. They are either identified by fictional letters or generic terms. Participants’ occupations are also identified in general terms. These measures were taken to ensure anonymity of the participants and their referring health care practitioners and facilities. In some cases, I have omitted long anecdotal material or repeated detail from the quoted material in the interests of length and relevance, ensuring that meaning was not altered or lost.

Quotations are punctuated using these conventions: 1) three dots ... indicates a pause in speech; 2) bolded words are reflective of the participants emphasis; and 3) brackets identify generic terms used instead of specific place names.

DATA ANALYSIS STRATEGIES

The strategy of developing theories grounded in empirical data of cultural description is known as Grounded theory method (GTM). GTM can be
considered as a form of ethnographic data analysis (Field & Morse, 1985; Spradley, 1979; Strauss, 1987). GTM involves both an inductive and deductive approach to theory construction in that constructs and concepts are extracted from the data, and hypotheses are tested as they arise from the research.

GTM provides a useful set of research strategies for studying the experience of chronic illness (Chamaz, 1990). A modified social constructionist GTM, as outlined by Chamaz (1990), was used to analyze these data. It is a form of analysis that uses a specific highly developed, rigorous set of procedures to discern themes and issues based on the empirical data collected (Creswell, 1998; Schwandt, 1997). As tentative answers to questions are advanced, and concepts are constructed, the constructions are verified through further data collection (Schwandt, 1997).

GTM requires a concept-indicator model of analysis, which in turn, employs the method of constant comparison (Creswell, 1998; Schwandt, 1997). Empirical indicators from the data (in this study, actions and events described in the words of the interviewees) were analyzed for similarities and differences. From this process, underlying uniformities or themes in the indicators were identified, and coded categories or concepts were produced (see Table B). Concepts were then compared with more empirical data, and with each other to sharpen the definition of the concept and to define its properties.
Table B. COPD Illness Experience Codes

<table>
<thead>
<tr>
<th>Code</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset</td>
<td>Onset. How participants describe the start of their illness.</td>
</tr>
<tr>
<td>Real</td>
<td>Realization. How participants describe how they come to acknowledge their illness.</td>
</tr>
<tr>
<td>Cause</td>
<td>Cause of illness. What participants attribute as the cause(s) of their illness.</td>
</tr>
<tr>
<td>Blame</td>
<td>Blame. Participants’ negative interpretation of the cause of their illness.</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Diagnosis. What the participant states as his/her diagnosis.</td>
</tr>
<tr>
<td>Dx-reaction</td>
<td>Reaction to diagnosis. The meaning of the diagnosis to the participant.</td>
</tr>
<tr>
<td>Know</td>
<td>Knowledge of the condition. How participants define their understanding of the illness.</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Symptoms. Specific symptoms identified by participants.</td>
</tr>
<tr>
<td>Hospital</td>
<td>Hospitalization. How participants describe their hospital experiences.</td>
</tr>
<tr>
<td>Tx</td>
<td>Treatment. Specific health care interventions/activities identified by participants as treatment.</td>
</tr>
<tr>
<td>Advice</td>
<td>Health care advice. Participants’ perspective of health care advice received</td>
</tr>
<tr>
<td>Function</td>
<td>Function. How participants describe their abilities.</td>
</tr>
<tr>
<td>Chronic</td>
<td>Chronic course. How participants describe the course of their illness.</td>
</tr>
<tr>
<td>Crit-event</td>
<td>Critical event. Specific events participants perceived to be significant to their illness start</td>
</tr>
<tr>
<td>Action</td>
<td>Action taken. Specific action taken by the participant in response to their illness.</td>
</tr>
<tr>
<td>Control</td>
<td>Control over illness. Participant describes/perceived their control, or lack of control, over the illness.</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Acceptance or coping.</td>
</tr>
<tr>
<td>Futility</td>
<td>Futility. Participants describe a fatalistic or futile perspective regarding their illness.</td>
</tr>
<tr>
<td>Social</td>
<td>Social consequences of the illness.</td>
</tr>
<tr>
<td>Physical</td>
<td>Physical consequences of the illness</td>
</tr>
<tr>
<td>Emotional</td>
<td>Emotional/psychological consequences of the illness</td>
</tr>
<tr>
<td>Oxygen</td>
<td>Response to oxygen.</td>
</tr>
<tr>
<td>Shock</td>
<td>Shock. Participants’ perception of being unprepared, surprised, shocked.</td>
</tr>
</tbody>
</table>
Data collection continued until additional analysis no longer contributed to anything new about the concepts.

I coded the data on an ongoing basis as they were collected. After the first 4 interviews I developed a coding scheme. The codes evolved as each successive interview was concluded and analyzed, and as ongoing analysis revealed new themes in the data.

EVALUATIVE CRITERIA

One of the greatest obstacles to the identification of excellence in qualitative studies is the effort to evaluate qualitative studies using quantitative criteria (Burns, 1989). Authors often define qualitative research by comparing it to quantitative research (Creswell, 1998). Several groups of researchers, Lincoln and Guba (1985, 1989) and Erlandson, Harris, Skipper and Allen (1993), have recognized the inadequacy of this comparison and have established criteria for judging qualitative research which parallels that used in quantitative critiques.

Trustworthiness is defined as that quality of an investigation and its findings that make it noteworthy to audiences (Creswell, 1998). Lincoln and Guba (1985) developed four criteria and associated procedures, paralleling conventional quantitative criteria, that evaluate and ensure trustworthiness. These criteria, their quantitative counterparts, and procedures are outlined Table C. Trustworthiness speaks to methodological adequacy, and by establishing it, qualitative researchers can make strong claims to methodological safeguards that parallel those by quantitative researchers (Erlandson, Harris, Skipper & Allen, 1993).
Table C. Trustworthiness Criteria Standards per Lincoln & Guba 1985

<table>
<thead>
<tr>
<th>Qualitative Term</th>
<th>Quantitative Term</th>
<th>Criterion</th>
<th>Procedures for this Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Internal validity</td>
<td>Accurate portrayal of participants data in researchers’ analysis</td>
<td>Participant verification Review by thesis supervisor Triangulation</td>
</tr>
<tr>
<td>Transferability</td>
<td>External validity</td>
<td>Establish the degree of generalizability or applicability of the research across contexts</td>
<td>Thick description Purposive sampling</td>
</tr>
<tr>
<td>Dependability</td>
<td>Reliability</td>
<td>Ensure the process is logical, traceable and documented</td>
<td>Auditing Review by thesis supervisor</td>
</tr>
<tr>
<td>Confirmability</td>
<td>Objectivity</td>
<td>the data and interpretations are produced by neutral, readily discernable means</td>
<td>Auditing Memo taking (Charmaz, 1990) Review by thesis supervisor</td>
</tr>
</tbody>
</table>
The procedures as originally outlined by Lincoln and Guba (1985) and refined by Erlandson and his colleagues (1993) were applied in this study. The initial three interviews were reviewed by my thesis supervisor. She independently coded them and made specific notations of areas that I was required to obtain participant verification. In those cases, participants received follow-up telephone calls for data verification. These interviews were also triangulated with the seven pre-study interviews for consistency in data analysis and coding. This revealed a high credibility. As each successive interview was competed, the interview tapes were also re-audited to ensure consistency with the transcriptions of the data. Additionally, the data were compared to the memo notations made during the interview, and immediately following each interview. Each interview time, place and circumstance was recorded and all memos, files and related materials catalogued to ensure that the research process could be clearly documented to demonstrate a logical and consistent approach.

The sampling strategies used resulted in a sufficiently large sample of sociodemographically diverse individuals from this select population, and will contribute to the transferability of the findings.

The ethnographic approach utilizing grounded theory analysis, guided by the trustworthiness criteria, provided a consistent and credible process of data analysis and verification. Meaningful insight into the lived experience of COPD was achieved.
CHAPTER FOUR
THE COPD ILLNESS COURSE: PRE-TRAJECTORY AND CRISIS/ACUTE PHASES

In this chapter I will describe and discuss the pre-trajectory and crisis/acute phases of the COPD illness course, and the resultant unpreparedness that surrounds it. Much can be hypothesized from the data about the relationship between the illness perceptions and the natural course of the disease, hospitalization, diagnosis, oxygen therapy and the functional and social losses described. These socio-medical factors are also discussed. In chapter five I will discuss and describe the remaining phases of the COPD illness course: onset, unstable/downward, and dying, and the relevant socio-medical influences that occur during these phases.

In this study, participants identified a number of socio-medical factors that shaped and created differential meaning for them regarding their COPD illness. Participants identified hospitalization, diagnosis, oxygen therapy and their resultant functional and social losses as contributing to their understanding and meaning of their illness. The findings of this study are that the illness course differs greatly from the disease course of COPD.

THE COPD ILLNESS CRITICAL EVENT HOSPITALIZATION: THE BEGINNING OF THE ILLNESS COURSE

The illness experience is precipitated by a critical event hospitalization. The critical event hospitalization becomes the point in time that the COPD illness begins to ‘exist’ for participants. In speaking about their critical event
hospitalization, participants would reflect back to, and speak about their pre-COPD illness period (i.e. their pretrajectory phase). The critical event hospitalization also becomes the demarcation point between the pretrajectory and illness onset. Participants universally expressed “shock” (DG:892) in relating the significance of that critical event to their future health status, and their unpreparedness for the life changes that would follow. Mr. AA describes this well:

JST: Can you clarify what you mean when you say that being sick [diagnosed with COPD] was a real turn of events for you?

AA: I mean it was night and day. Night and day. I was the type of guy that was busy, day and night, day and night, busy, active ... nothing kept me from the work ... never sick a day. I go into hospital and I come out with this [points to oxygen tubing].

Hospitalization was a central reference point for participants in this study when describing the processes or events that contributed to the meaning of their COPD illness. Various aspects of hospitalization were important to participants’ meaning of illness. These aspects are length of stay, health status after discharge, treatment received, oxygen use, diagnosis, and for those who had been previously hospitalized, how they perceived that the critical event hospitalization differed from their previous experiences.

THE COPD PRETRAJECTORY PHASE

All of the individuals interviewed, when describing the course of their lives, and where their illness had impacted, did so in reference to the time before the COPD illness existed for them. Corbin and Strauss (1991) refer to this period in
the Illness Trajectory Framework as the pretrajectory phase. Prior to the start of my interviews, my bias had been that for individuals with COPD, the pretrajectory phase would not be particularly relevant to their overall illness experience. This assumption was made because, as a health care practitioner, I knew that COPD develops over decades, with an insidious onset of physical symptoms, often interpreted by individuals as the normal anticipated changes of aging. However, the data revealed that the pretrajectory phase was of great significance to individuals. Additionally, the data revealed that this pretrajectory phase of the illness course was interpreted in two distinct ways, either a period of “wellness” or a period of “other respiratory illness”.

**Wellness Pretrajectory Phase**

For a group of participants (n=6), their pretrajectory phase had reportedly been one of good health. These participants denied that any symptoms of disease existed prior to their critical event hospitalization and their COPD diagnosis. The critical event hospitalization was precipitated by a life threatening difficulty with breathing. Participants universally reported being unable to “catch their breath” while doing an everyday activity. This inability to breathe, on that particular occasion, was consistently unexplainable.

This group described their pretrajectory phase as a period of “wellness”. For many in this group, the COPD hospitalization is the first related to any lung pathology. These participants expressed “shock” and reported having held no previous expectation of the potential for their hospitalization, nor any expectation of the eventual outcomes. In several cases, participants were entirely baffled by
the “turn of events” (AA:L445). Take the case of DG who is recounting her first hospital admission:

JST: had you been in hospital before?

DG: never!

JST: so it was a big event?

DG: so I told everybody that [laughs heartily]

JST: and what did they say?

DG: Well I think they were beginning to smile really, because the first one I told, then the second one I must have told, and then the next few would tell me, 'we know you have never been in hospital' [laughs]. So I think it was treated as a bit of a joke, and [trailed off].

JST: Having never been in hospital before, and then going in suddenly for this [COPD], how did that make you feel?

DG: It was a shock really ... but after a while, you know, after a while ... I ...it had to be.

JST: How long were you in the hospital?

DG: Two weeks.

Similarly, LS reported:

“I was never sick, never a problem at all ... oh sure I was getting unable to do like I used to do but ... you know ... I was no spring chicken ... we all get old.”

For LS, typical of other participants who reported a “wellness” pretrajectory, or non-illness state, there is some acknowledgement of a retrospective gradual loss of function, or difficulty with breathing that they associated with normal aging or smoking. LS’s response is an example of the intersection of interpretations of
aging and disability that Wilkins and Cott (1993) had discuss in their paper relating aging, chronic illness and disability. LS held an expectation of loss of function with aging, therefore her changes in function were attributed to the aging process. LC rationalized or normalized her symptoms differently. LC recounted:

“Well I was taking care of dad [her deceased husband], as I says [said], and that was a lot a [of] work. I’d be up early and to bed late, and after a few years of that I just couldn’t do it no more. But I did ... I mean he was a big man to have to get in and out of the tub would put me to huffing. But in those days I smoked eh, ...it was a way to relieve the stress. And the smoke would cause the coughing.”

VV also noted:

“It is easy to know that you you’re getting older, every five years or so I would notice that I couldn’t stay up all night, or drink as much beer, or walk as far on weekend hikes, this [your functional abilities] changes as you grow older. So, I wasn’t thinking, I’m sick so I can’t do this or that. After all, we all get old! And I wasn’t sick!”

AA was a participant who was very adamant and thorough in his descriptions of his pre-illness state.

JST: You had never been sick before this?

AA: Not a day, well, I would get a cold now and then, the usual stuff for anyone, but never really sick – you know, not sick sick.

JST: Had you ever been in hospital Mr. A?

AA: Not a day... not for me, I mean except for when my kids were born and I would visit the wife.
JST: So when you started to feel short of breath and you eventually went to the doctor and he told you you had COPD and he drew the circles

AA: yah, yah

JST: How did you feel about that?

AA: Well, a little shocked, because I said is it bad? You will never get rid of it he said, and this doctor is always good.

Further probing did not dissuade Mr. AA from his assertion that he was an extremely healthy individual prior to his currently acknowledged illness.

Although, most participants who reported “wellness” pretrajectories would concede, upon probing, that what they considered normal aging or the results of smoking, may have indeed been due to the COPD, several did not hold this view.

MW recounted her impressions:

“I would pick one up [cigarette] and put one down, pick one up, put one down, and coughing in the morning was part of that – and it was like that for years and nothing about that was anything to worry about –a smokers cough, and lack of exercise was how I thought about it [increasing cough and decreasing function].”

The experience of “wellness” during the pretrajectory period places significant meaning on the illness course that follows.

Other Respiratory Illness Pretrajectory Phase

Acute Hospitalizations

For the majority of participants who had histories of repeat hospitalizations prior to the COPD critical event hospitalization, these hospitalizations were not
noted as COPD, but rather as other respiratory related illness of an acute and
time limited nature.

Those prior hospitalizations are characteristic of an acute episode of
COPD. An acute episode is characterized by a marked and fairly rapidly
developed inability to breathe. In this condition, individuals are unable to move,
let alone perform even the simplest of tasks. Medical management of COPD is
largely aimed at symptom control and improving oxygenation during the acute
episode (Petty, 1988; Mador & Tobin, 1995). Thus, for an acute episode of
COPD, management would involve antibiotics, short-term oxygen therapy and an
emphasis of returning the individual to a medically stable state (Mador & Tobin,
1995). For the study participants, these prior hospitalizations were not
connected to their COPD.

Participants experienced prior hospitalizations that were sporadic and
generally of shorter duration than the critical event hospitalization. Additionally,
participants viewed these hospital experiences, and much of their treatment that
they received during those “other respiratory related illnesses” or ‘non-COPD’
hospitalizations, as passive and minimal intervention experiences.

JA reports:

“I didn’t have to do anything! They would
take care of me. They would make sure
everything was okay.”

EM relates:

JST: what happened on those [non-COPD] visits
to the hospital? Can you describe those ..

EM: Well, they were, good, really good to me
there, and they got to know me. You get to know when people are really needing your help, no? they would take good care of me for a few days, two or three, then I would go home.

JST: And what sorts of things happened when you were there?

EM: I would get a, how you say, intravene [IV] here [points to forearm], sometimes a little oxygen, first day, then when I get better, i go home.

TA is also specific about his pre-COPD hospital stays for his “other” illness.

TA: I would be in [hospital] for 1 or 2 days, until I was well again, got my wind back. It would be a variety of things that could set me off – allergies and the weather even. I would be in and out, good as new!

JST: and what sorts of things, what happened while you were in hospital on those occasions?

TA: Oh, you must know, they give you special medicine that you inhale through a mask – that gets you right almost right away. Then you take a day or so for them to, observation, that you’re back on track.

JST: Can you remember anything else? Well, for example did you get any advice while you were there? how did you know what to do to perhaps not end up there [in hospital] again?

TA: Oh, well of course they tell you what to avoid like working too hard outdoors and such. That’s all they could do really. I didn’t know when I would be back.

The treatment described by participants can be summarized as care administered to them as passive recipients. Additionally, the duration was not considered significant. Participants reported that any hospital admissions, prior to the critical event hospitalization, was only for a “few days” (SV: 316).
Another issue identified by participants was the lack of health care advice or information received during prior hospitalizations for "other respiratory illnesses". RP stated:

“They would always let me know when it was better again. I would be told about taking my antibiotics.”

BN stated:

“They never said much. I could never be sure about what was what ... sometimes I wanted to know what to do when I get home, but the impression I got was everything was fine now.”

These comments suggest that health care advice received related primarily to the immediate life threatening situation, with a lack of information about maintaining health once discharged home. It is possible that information was provided, but due to the oxygen deprivation these individuals would have experienced, the information was not retained. It is also possible that information was provided, but was not relevant to their illness experience once they returned home.

The health care advice and discussions about health, during these other respiratory related conditions, were referenced back to their immediate near death threat with no link to a chronic disease state. This is likely unique to COPD, in that the acute state is such a marked difference from the chronic stable state.

In the disease stage prior to end stage disease, between acute episodes, the individual may have difficulty with breathing, but usually associated only with
certain activities or exertion. Despite some limitations, they are still able to do many things that are important to them.

None of the participants, however, view their current illness state as a continuum of chronic illness progression of many years. EM's response is typical when asked about his impressions of the potential of this:

"No. it wasn't something that I can say happened. This thing [COPD] is not what I have lived with, I should know this, no?"

Participants further assert that they did not receive any health care advice that indicated that those experiences were part of a chronic, serious condition.

Ms. BA is a 71 year old woman who acknowledged to me that, recently, she had been wondering about her past history of 'problems' and if they could be related to her current health status. She recounted a series of 'set backs' in her health that seemed to make it harder and harder for her to function. She reports leading a very sedentary lifestyle with little physical activity. Her main activities related to house cleaning, which she reports became gradually more difficult for her to manage. This was significant to her because she took a lot of pride in her home, and despite her health, would push herself to complete her activities.

Ms. BA related:

"Just about 15 years ago I noticed a difference in my breathing, and my daughter-in-law said to me, as we were walking up one day, to the foot of the door, she said 'boy are you ever as shaky'. [COPD] that's what it was, I'm sure. And just after that, I could see different incidents, to indicate that there was a problem, although I could get by."
When asked if she had been to the doctor in that 15 year period, she responded yes, but she had not raised the problem of her breathing, and her physician didn’t mention it either. She further stated that it was only two years ago that she learned that she had emphysema from a respirologist who “was the only one who ever put a name to it”.

Thus, the pretrajectory phase is described as a period of “other illness” or “wellness”. These findings are significant because they indicate that, unlike the onset of the disease course, which is slow and steady, the start of the COPD illness course was perceived to be sudden and marked. Thus, long after the lung pathology has started, and long after the start of initial signs of disease, the start of illness occurs.

**Shortness of Breath and Functional Loss**

Participants’ accounts of when they first noticed something was wrong reveal a sudden awareness of a decreased ability to breathe, which resulted in the inability to perform a specific, desired activity. The response of DG is representative of participants when asked when they first noticed that something was wrong:

“Coming up stairs. When I got up my friend said ‘sit down, you should go to bed!’, because I really couldn’t breathe. And then I seemed fine later. I suppose it gradually, you know, cleared, and then, um, my son and his wife and granddaughter came and I was fine that evening. They didn’t notice anything, and I didn’t. But then in the morning, when I got up, I just couldn’t breathe again. And, um, I think we called the doctor, I think Dr. ____ said go to the hospital, and that was the start of it really.”
Similarly, PP reported:

"... because everything was okay, and I was okay, so 'till a year last April and then it was what happened, when I lay down in bed at night, I couldn't get my breath ... so I was sleeping in one of those chairs." (points to a recliner chair)

The decreased ability to breathe, or shortness of breath, is noted with respect to its interference with activity. The activities interfered with were reported as those activities routinely performed in the lives of participants prior to the critical event. Those reported include walking, dressing and lifting things, as well as a variety of housekeeping tasks such as vacuuming, laundry and cooking, as well as errands like grocery shopping and banking, as well as socializing. Participants would report a perceived sudden inability to perform certain activities. For example, YJ stated:

"Like I used to love to go dancing, you know, when there was a wedding up North I would go over there, but I couldn't dance, because I couldn't breathe. I just, would dance for a little while, that's all, I had to sit down, so I couldn't."

SV also reported:

"I was operator. Machine operator. And I was sitting whole day. But as soon as I walking, or you know, dressing myself or doing something, so I felt short of breath."

Also BA:

"... at that point I could do most anything, it was the different things I could not do I found hard for me to do, like wash floors, wash walls, cleaning windows, this kind of thing ... I found, oh, I would be in the bathroom, I take the dust mop to clean the floor and all the hairs off the floor and
I would have to sit down on the toilet ... it was ridiculous you know ... I mean, having to sit down because you're dusting!"

Each participant characterized this loss of function as significant. However, the loss of function alone was insufficient to mark the onset of the recognition of serious, chronic illness. Participants typically attempted to relate the shortness of breath and loss of function to other things. YJ noted the following:

“Well, I was working in the factory, and I was working with aerosol cans and other pesticides and all that then. While I was working there I noticed it was hard for me to breathe. But I was smoking at the time too, but then I had to quit, so I did quit smoking. Because I thought, you know, that’s Asthma, more like my aunt and my sister, and I thought, well, like there’s nothing I can do about it, so that’s why”

BB related it to aging:

“Well I realized that this (problem) was in my lungs, I was becoming an old man.”

Upon further probing into his expectations of aging and its potential impact on his breathing, BB had the following to say:

“I can’t expect to do at 60 what I did at 20. The effort, it takes more out of you. That’s natural. You’ll see a 60 year old huffing and puffing whereas a young guy is doing the work like it’s nothing!

The above statements illustrate that participants typically hypothesized about the cause of their shortness of breath. They related it to such things as smoking,
work-related exposure, or aging. However, others, despite smoking histories, could not offer any explanation.

EM was uncertain:

“Well, it didn’t mean much of anything. I really didn’t know what was going on you know.”

Some participants also reported that they were not alarmed by the loss of functional ability in everyday activities because they were still able to function generally at a very high level, and there were not other signals that something more serious was wrong, or would occur. SV explains:

“No, I wasn’t okay, but I didn’t go to the hospital because I was working, you know, and I didn’t want to lose (time off work), and it wasn’t so bad.”

Similarly BB explains:

“I’ve always had control of those shortness’ (shortness of breath in “other” illness). I was able to set back a while and relax and let it pass. Or even when I had to go in (hospital), it was a short trip to be fixed right again.”

Although all individuals identified a gradual worsening of their shortness of breath, there was a marked dichotomy in the data as to the timeframe in which individuals first noticed something was wrong. Many noticed the change in their breathing years previous to their illness recognition, while others noticed the change immediately preceding their illness onset. Participants in the former category identify the signs of their gradually worsening disease process as shortness of breath, but did not associate this historical pattern with their current
illness state. Those apparently distinct episodes were explained and made sense of in a variety of different ways. JN stated:

"That I'd let myself get badly out of shape, ah, and it was just a matter of, ah, getting back in shape and I'd be fine, and, ah, so that's how I rationalized the whole thing."

The illness course described post pretrajectory was common to all participants. Therefore, regardless of whether or not an individual had reported a "wellness" or "other respiratory illness" pretrajectory phase, their subsequent descriptions of the remaining phases did not differ in substance.

Regardless of the timeframe reported, the start of illness would require more than shortness of breath and functional loss for these participants. Illness onset required the additional factor of hospitalization.

THE COPD CRISIS/ACUTE PHASE CRITICAL EVENT

For both these groups of participants, it was clearly important to describe this period of "wellness" or "other illness", because they perceived it to greatly contribute to their current illness interpretation. Participants use the pretrajectory phase, and their perceptions of that timeframe as an explanation and justification for the "shock" and unpreparedness for their COPD illness experience. Without the understanding of disease progression and chronicity participants felt that the COPD illness experience was marked by a sudden and unexpected onset.

Participants acknowledged that this hospitalization was "different" and that there was much fear expressed over this event. LB explained it in this way:

LB: I was used to the odd visit in [to hospital] over the years, but nothing like this. First off, I didn't bounce back at all. I went in
feeling badly, really not good, and came out feeling only this much [places two fingers close together] better.

JST: Can you say, why do you think you felt that way? Um, not much better?

LB: I knew now that I was sick. Boy, I knew if this was as good as it gets, things aren’t good.

JST: How did you come to that realization?

LB: Everything that happened to me there said that this time it was different. For one thing, I came home with this [points to the oxygen tank].

For LB, he drew on his past experience and how critically ill he was now as marked by the need for continued oxygen. WN also noted that this hospitalization was different due to health care providers’ immediate concern for her life:

“I could tell by the way they kept coming in, and coming in, it seemed like every few minutes to see if I was still alive. I was! Then, it settled down and I could hardly get people to come see me when I wanted to”

LT referenced her significance in terms of her fears about changes to her health status post discharge. She stated:

“... it was difficult to know, know that.... Well really be certain about the big picture. I just could tell that I wasn’t going to be lucky this time. I might look Like Fran [a neighbour] with her little green cart [wheeled walker]. But you know I didn’t get one of those, I went home with nothing at first”

BM is clear about his fear about death:

"I just wanted to get through this. They kept say to me ‘it’ll be okay’, but I had this fear that it might not be.”
PM as well relates around the fear:

“It was like wanting to come up for air, and then just realizing it isn’t up to you. It’s up to all the people around you. The first few days was such a commotion. Then, later it was calmer.”

Participants believe that full “recovery” from this event would not happen as on other occasions. RP describes this very well:

“I’ve had good care over the years. My doctor would get to the hospital before I did. That’s the kind of doctor he is. He would get there, and in a few days I would be home with antibiotics. That would be the end of it.”

SV reported:

“It wasn’t. I was always able to come back. I would be in hospital, or see my doctor at home, you know, in those days they came to you too, well, it was never anything serious that lasted more than the usual flu and cold season. I would get some bad flu, but come right back from it.”

EM also had a similar experience:

“My wife was always saying how I managed so well, especially with being on the road. You have to be in pretty good shape to ride the big boys [trucks] because you had 12 to 16 hour shifts. If you felt bad, you couldn’t do the shift and you didn’t get the job. Even when I come down with something, I could do the shift. It didn’t keep me down.”

Participants also comment on the treatment during this critical hospitalization. SV described her critical event hospital stay:

SV: It was all specialists and more specialists. They are just asking me how do I feel, they are listening to my lungs, taking blood pressure, and
then when they listen something, they give me these antibiotics or prednisone, and prescribing the medication what I'm on, that's all you know ...

JST: So being the first time that you were there for so long, for more than ten days were you, how did you feel about that?

SV: I think I had to be, you know.

JST: And you were there for roughly ten days, what did they do for you over the ten days?

SV: They gave me oxygen, and then medication, antibiotics.

JST: And what sort of other things did you do? What kind of health care people would you see when you were in hospital over the ten days?

SV: Oh, I had the specialist.

JST: The respirologist?

SV: Yes

JST: Did you just see your doctor there? or did you see other health care people take care of you?

SV: no, no, the doctor.

JST: Just the doctor?

SV: The doctor.

For many participants, length of stay was considered significant.

RP reported:

"I had been in before, but only for a few days. Never 10 days. 10 days!"

LS stated:

"I didn't know what to expect, but I was in
hospital so long over this."

For others, of note was their requirement to participate in activities not previously required of them. BN identified it this way:

"After a while they kept coming to get me to go for walks. I had to learn how to put this [nasal prongs] on my nose, and I thought, 'why are they bothering with all this?, I'll be rid of it soon.' But, of course, it [the oxygen] stayed with me."

BB noted:

"At other times I didn't have to do a thing. I guess its like family, the longer you stay, the more you got to do. I had different people coming to get me to walk, and to take me to breathing classes."

Related to the above, for many participants, the expectation of follow-up treatment, at home or another facility, was very significant to their illness meaning. DG reported:

"Having never been in hospital, I just dreamed about being at home. I kept asking, 'when am I going home?' and I think they were avoiding me, because it wasn't the day before I was leaving that I knew I was going to the other place [Rehabilitation facility] for another 3 weeks."

VV noted:

"I didn't know I was coming home with this [oxygen], and that _____ was going to arrange for someone to come out to the house."

Participants spoke directly about this critical hospitalization as being the beginning of a markedly diminished health state leading to a downward slope of illness. PP expands on this:
“After being in the hospital that time [critical event hospitalization], they said I needed to go to ______ [Rehabilitation Facility] to get beefed up. I was so weak. I needed that.”

MW also remarks:

“That was the start of the end.”

LC stated:

“I knew that I was sick. I was sick for good.”

AS noted:

“It was just knowing, for many reasons, but a feeling for sure, just coming on, that this was it. It must be close to feeling like death is waiting at the door for you.”

TA was certain that:

“For this one, a cure was not in the cards.”

The data above are suggestive of a realization among the participants of the fact that following this critical event hospitalization they would not be “cured” (TA: 1678).

JA was also a particularly poignant story teller on this point. This 70 year old man had recounted a history of hospitalizations for “breathing trouble” and “allergies”. When asked to describe his “breathing trouble”, he was clear about experiencing “suddenly unable to catch breath, and then they would take” him to the hospital. He reports numerous short hospital stays over a 10 year period, but characterizes that “breathing trouble” as different than “this” [COPD]. This difference is never fully articulated, but when pressed, he explains in this way:

“I can tell you that I always knew it [the breathing problem] would pass ... I would be sure to, sure of
They never said I needed the oxygen or anything. 
... I could do things and go on. This is a serious sickness 
that you don't get better ... it doesn't pass."

Such was the case of BB. Mr. B is a 60 year old retired truck driver. He 
is a gentleman with a 45-pack year history of smoking, and reported that he had 
experienced episodes of mild shortness of breath for years, for which he used 
"puffers" regularly. Mr. B reports that one morning he awoke not feeling quite 
right. It was his turn to do the laundry, the facilities for which were located in the 
basement of his two-story home. After two or three trips to the basement with 
armloads of laundry, Mr. B began to experience shortness of breath from which 
he could not recover with the use of his puffers. Mr. B asked his wife to call an 
ambulance to take him to the hospital. At the time, he was certain that after a 
short stay in emergency, he would return home. He had been through this 
before. However, taken to hospital via ambulance, and after his emergency 
room assessment, it was determined that he should be admitted, and his hospital 
stay lasted 8 days. Mr. B marks this event as his "critical" hospitalization.

"I was never knowing I had anything wrong. I 
wasn't sick until after that day, ..... that day I 
came home ... before that I was okay."

Mr. B had been hospitalized on numerous occasions for "breathing troubles". 
Yet, when I probed, he did not associate those prior health problems with the 
specific hospitalization in which he marks the start of his illness. He further 
asserts:

"I was never as bad as this. That other breathing 
stuff is one thing, never left me really sick. This is 
a serious breathing trouble."
Many participants staunchly asserted that their prior illness states had been separate and distinct entities relative to this COPD illness which with they are currently faced. This is reported, at times, in seeming conflict with histories of repeated short acute care hospitalizations for “breathing trouble”.

PM stated:

JST: When you look back now and consider that you were in hospital quite a bit, over the years for breathing, that that may have been related to your COPD illness, what do you think?

PM: I don't think that [prior illness] had anything to do with this! I, I don't think I ever thought of that before exactly, but no ... it was just a breathing problem.

JST: can you be more specific, try to describe your previous breathing problem?

PM: I would have an attack where I couldn't breathe, and would have to be rushed to the hospital. Often a couple a times in the summer months this would happen. I think it was allergies, you know from plants and such, that was the trigger.

JST: oh, okay. Would it always be in the summer, or did you have breathing problems at other times and in different ways, was it different, did you always have to go to the hospital?

PM: No, I mean I couldn't ever push myself anyhow with the breathing. Mostly summer trouble, but sometimes with the cold weather my breathing would act up too.

JST: and what did you think caused your other breathing problem?

PM: well, the weather and such, just what I said.

JA further clarified this issue:
“Oh I always had the allergies real bad, always had the allergies problem. In a summer I could be in there [the hospital] three, four times. But never for this.”

Also of note was BN’s comments:

“I mean smoking can, does kill you. But when you are smoking and getting the odd cold or cough, that’s one thing … this is another.”

Others reflect back on their past histories and can concede that it may relate to their present status. SV noted the following:

“I wonder is the job had a cause in this… sometimes, you know, I wonder this. I was never very active, all my life, didn’t give myself any exercise”

Similarly, YJ reported:

“Well, I was working in the factory, and I was working with aerosol cans and other kinds of pesticides and all that then. Then I went to an allergist and he told me I have allergies. and then I had to start taking puffers, but I worked there for fifteen years. While I was working there, while I was working there I found it hard to breathe. But I was smoking at the time too. So I blamed it on the cigarettes too. But then I had to quit, so I did quit smoking. Was it 20 years ago maybe now.”

Mr. RP’s responses explain his past health state with his current.

JST: And you’ve had pneumonia years before?

RP: Yes, a couple of times … So [this time] I had no idea. I thought maybe I had pneumonia. That’s because I’d had pneumonia before.

JST: Oh, I see, okay. And now you were in hospital, and you just got out about a week ago now?
Before that, you say, did you ever have problems before that with your lungs?

RP: No.

JST: Never?

RP: Never had.

JST: Wow, so besides pneumonia.

RP: That's right. I only had pneumonia.

Mr. RP went on to confirm his diagnosis of emphysema and chronic bronchitis.

So I further explored the presence of other signs of COPD.

JST: Okay. Did you used to cough at all? Regularly?

RP: Oh, quite a bit, yeah. That was from smoke.

JST: From smoking? [nod from RP] How long did you smoke?

RP: Fifty years.

JST: Five, zero, 50?

RP: Fifty years.

JST: okay.

RP: a pack a day.

JST: a pack a day. Do you still smoke?

RP: No.

JST: when did you [quit]

RP: ten months now.

JST: ten months you haven't? What made you stop?
RP: coughing.

JST: aha

RP: and breathing, and I had a friend coming from England that didn’t smoke.

JST: didn’t smoke?

RP: No.

JST: oh I see,

RP: and I stopped.

JST: but your smoking hadn’t stopped you from being very active?

RP: it put me into a stop right now.

JST: it put you to a stop now. You blame your, this on your smoking?

RP: on smoking and from my job, sure.

Mr. RP was a transport truck driver. He continued to sum up his thoughts this way:

"Thirty six years. But you know, they didn’t really think about gasoline and smoking, and ear plugs then. No. No."

For Mr. RP, the first time that he noticed something was wrong was 10 weeks prior to my interview, which he reports, corresponded with his diagnoses of emphysema and chronic bronchitis. Mr. RP expresses confusion and shock that his health status could have so suddenly deteriorated.

SUMMARY

For the participants in this study, the COPD illness experience is marked by an acute care hospital stay following a sudden onset of shortness of breath
producing near death circumstances. This critical event is distinguished from any other hospitalization that the participant may [or may not] have experienced until that point. This critical event, this specific hospitalization is the one in which the notion of illness is formed. Every participant recalls such a critical event. The specific details of the critical events, just prior to hospitalization, vary from individual to individual. However, common to each recount is an absence of the realization, at the time of events, that this hospitalization would be significant in any way. The case of TA illustrates this point:

“No way, no way would I have known it would come to this. I’d been in [hospital] before you know, I knew what, I thought I knew what it was gonna be. In and out ... but not this time.”

TA is a 70 year old man with a 35 pack year history of smoking and reports of annual episodes of shortness of breath which cause him to go to the emergency room of his local hospital. He acknowledged use of “puffers” for many years. His story is one of a repeated history of acute exacerbation of COPD. This makes his assertion in the previous statement very significant. It demonstrates that “medical history” does not necessarily equate with personal history or experience.

Throughout the interviews, the theme of unpreparedness was revealed in the participants’ discussions about the critical events that brought them to the hospital, and their eventual realization, through that critical event, that they had a serious lung disease. For DG, as with the majority of the others, her words clearly define the emotion experienced:

“It was quite a shock really... but after, you
know, after awhile, I ... it had to be."

This universal unpreparedness of participants for illness and disability may be partly explained from their reports of their pretrajectory phases. Participants who reported wellness pre-trajectories, attributed their gradual loss of function, commonly to what they perceived as 'normal' aging, but also due to smoking and lifestyle. Participants who reported other respiratory illness pre-trajectories viewed their breathing problem as a series of discrete acute episodes that were always 'cured'. In both groups, there was no recognition of chronic illness. Thus, participants were unprepared for the start of illness and the significantly altered physical status that would follow.
CHAPTER FIVE

COPD ILLNESS COURSE: ONSET, UNSTABLE AND DYING PHASES

COPD ONSET PHASE

Much of the characterization of the illness experience was centred around participants’ reactions to their use of oxygen. Participants in this study presented with the clinical signs of advanced lung disease. Thus, they exhibited signs of shortness of breath with activities such as moving from sitting to standing, or prolonged speech. Some individuals reported chronic shortness of breath even at rest. Accordingly, all of the participants in this study were considered oxygen dependent, and thus had medical prescriptions for long-term oxygen therapy.

Long-term Oxygen Therapy

For participants, the use of long-term oxygen therapy was universally linked to the critical event hospitalization and illness start. The oxygen, like the illness, is ever present as a constant reminder of loss. MW confirmed:

“This [oxygen] came as part of the breathing sickness package. It [points to the oxygen tank] tells me, ‘you’re not doing so good.”

As did SV:

“You have to remember your sick, because if you don’t, you trip over this cord [oxygen tubing] and it reminds you.”

Participants expressed their perceptions that health care providers in hospital viewed oxygen use as an unwelcome requirement. LT’s statements provide an overview of those provided by many participants:

“[respiratory therapist] tried to be very
positive, she was wonderful. But I thought for a minute that she was the one who was gonna cry, not me! I remember telling the nurse that it was going to be ok. I wasn't thinking that at all. But you make it worse for them it you act like you can’t cope with it all.”

Participants' perceptions of health care providers' reactions to their oxygen use contributed to what participants noted were minimal discussions around the likely duration of use, implications of use on the disease course, and prescription specificity. TA noted:

“If I could have really asked questions, and really felt comfortable with it, it might have helped.”

As did DG:

“When they set me up they didn’t say how long it would be, or if I really needed it.”

Similarly EM:

“Do you know if I can take it off sometimes?”

Specifically, the significant aspect of COPD illness noted by participants was the need for oxygen in the home. The majority of participants had indicated that they had temporary and short-term use of oxygen during prior hospital stays. They had, therefore, identified oxygen use with being very sick. When “well” or “cured”, the need for oxygen, in their prior experience, had been removed. Therefore, for many participants, the need for oxygen use in the home marks a significant health change for these individuals. AA states:

“I was shocked to need this. I said ‘is it this bad?’, and the doctor said, ‘you will never get rid of it [the oxygen], and this doctor is always good.”
This issue is further informed by BA:

“Oxygen is like saying, now you are really sick.”

Specifically, some participants link the use of oxygen to a poor prognosis and an indicator of disease severity. For BA again:

“Oxygen is like saying you are just hanging on.”

Similarly DG reported:

“The oxygen was a bad sign.”

The use of oxygen in the home places many physical and social demands on the individual with COPD. It not only marks the change in health status for this group, but also marks the need for significant change and adjustment in other domains of their lives. As such, participants’ need for oxygen in the home reinforces the sudden and dramatic perception of change in their health status and further emphasizes that they have a chronic illness. Thorne (1993) illustrates how factors, such as equipment use, serve as markers for recognizing chronicity.

YJ reported that:

“When I went to ______ [Rehabilitation Facility] I had really wanted to go home, but they said no, I was too weak. I am still weak. When it was time for me to finally go home, I begged them to let me stay a little longer … I had no … I was worried about going home and managing for myself. I was very sick now.”

LT stated:

“I didn’t realize at first, but I slowly began to know that my life was gonna change. Did it ever!”

PM also noted:
“It was a big shock [just being in the hospital], but I just knew the biggest shock was coming, how I was going to cope when I got home.”

WL is emotional as she recounts her experience:

JST: Can you describe the difference in your health since then [first hospitalization for COPD]?

WL: It’s been a big change for me. I live here [pointing around the bedroom] now. I have more trouble than ever with walking and talking and taking care of myself. Before this I would do a bit of house cleaning and be, have to catch my breath. But now, I can’t even walk over there [across the room] without needing to rest ... or worried about making it over there at all.

JST: What has changed? Can you describe ...

WL: Everything. This [oxygen] keeps me going, but it also keeps me back. Now I need this [oxygen] just to get by ... I can’t even think about cleaning, I concentrate on breathing!

Despite varying levels of oxygen prescription, each described a dependency on the oxygen for sustenance of life. This dependency, although acknowledged, was not always welcomed. AA would repeat throughout the interview:

“These damn things [nasal prongs], they are so irritating sitting up in your nose like this.”

These comments note the recognition of long-term oxygen use as a significant event, and a constant physical reminder of their illness state. With this constant reminder of illness, unlike in their pre-trajectory, participants were unable to dismiss their signs and symptoms as ‘normal’ or anticipated results of aging or smoking.
Diagnosis

The issue of diagnosis was identified as a critical factor influencing the illness onset for participants. The term labeling refers to a social process by which individuals or groups classify the social behaviour of other individuals (Bond & Bond, 1994). For the participants in this study, the diagnosis or label itself, was less significant to participants than the manner in which it was presented, the timing, their understanding of it, and their perceptions of others’ feelings about it. For participants, these factors related to diagnosis signified illness onset by precipitating change after their critical event hospitalization. For participants, these changes, noted once discharged to home or another facility, brought about the realization for them of COPD illness.

Although all individuals in the study were identified by their referring health care practitioners on the basis of the inclusion criteria, including an identified diagnosis of COPD, very few participants used that or an associated diagnostic term when asked of their diagnosis. With prompting they usually recognized the term Emphysema, with only a couple individuals able to explain the pathology.

MW stated:

“I have breathing problems that are deteriorating.”

SV reported of her diagnosis:

“The breathing isn’t good.”

MW informed me that:

“They [the doctors] were quite up front. They had to say ‘we don’t know what is what’, ya know? So nobody was saying this is your diagnosis and your prognosis, and
this is the way it’s going to be.”

What was evident in discussions was a degree of discomfort around how individuals came to be labelled, or not. A lack of diagnosis, advice, or meaningful communication by their physicians in the early stages, at times in contrast to a not clearly understood later diagnosis, was identified by participants as significant to their illness perception. MV further noted:

“... and I have a very vivid memory of that [discussion about diagnosis] because I didn’t feel like I could get out of bed for about a week, I was there in a fetal position crying – I thought I’d never smile again.”

DG compared her diagnosis discussions on previous hospitalizations relative to her critical event hospitalization in which she received her diagnosis of emphysema:

“In the hospital, I was more lead to believe it was asthma. I know when I did get a bad cold I had to watch for bronchitis. I know that. I mean that’s been for years. That’s [pause] but in the hospital I think I was lead to believe it was asthma. But Dr. ______ told me it was emphysema.”

JST: What’s the difference to you? What does it mean to you the difference in these?

DG: Well I know with [pause] Emphysema there is no cure, is there? Asthma, I think [pause] I don’t know if there’s a cure, but there’s, I don’t think it’s quite so serious as the other.

JST: So emphysema seems more serious to you?

DG: hmm hmm [yes].

JST: and, um, when they use that word ‘Emphysema”
did that change anything for you?

DG: Yes, it bothers you.


DG: [long pause] Um, [long pause] it's hard to say. Yeah, well you know you feel it's probably the worst, the worst it could be kind of thing.

Physicians may not be able to provide a definitive diagnosis of COPD until advanced disease, therefore they offer probable diagnosis. This leaves individuals wondering about their outcomes and leads them to believe that they have a less serious condition, and thus, makes it harder for them to cope.

If an early diagnosis is provided, it may have held no meaning for an individual in the absence of obvious physical debility. The diagnosis may be provided in such a manner [timing is later and definition and prognosis suspect] that individuals are unable to relate that diagnosis to their recent state.

Participants also express confusion around their COPD diagnosis and its meaning for their future health. LC stated:

“I didn’t know what it would mean for my future.”

WL noted:

“It [the diagnosis] didn’t help me know what was going to really happen to me.”

Miscommunication around diagnosis would lead to miscommunication about management and prognosis. With questions unanswered, individuals were left to assume the worst, or seek additional information.

RP stated:
"I wanted to know everything. I would be wanting to meet with my doctor to get the information."

JN said:

"I would ask one person, and then the next, just looking for answers. No one wanted to tell me anything, either way."

BA also:

"... and I rather suspected it [a serious diagnosis], but no one would come right out and say it. Until he [the doctor] finally said it. He never really said 'you have Emphysema'. But in his conversation with me, he would say things like, ah, 'Emphysema patients' and this kind of thing so, you know. I clued in that he was referring to me. ... I think perhaps he was afraid of having a severe reaction. ... they're [doctors] afraid that they're [the patients] not going to be able to handle it ... and I guess there's a lot of people who couldn't.

AS reported:

"When you are very sick, people are afraid to look you in the eye and tell you the truth. You have to discover the truth for yourself."

PP reiterated:

"Not knowing is the problem with how you look at the whole thing."

It is possible too, that because COPD refers to a cluster or combination of diseases, there may be a lack of consistency among the varied health care providers who these individuals interact with, and thus confusion for the individual. This uncertainty in diagnosis may be the cause of some of the unpreparedness associated with the COPD illness course identified in the data.

Regardless of the timing or method of diagnosis, after the critical event
hospitalization, participants reported being faced with what they see now as a totally debilitating condition.

Thus, for participants, there are multiple factors related to diagnosis and life change due to the COPD illness that marks the illness onset.

**COPD UNSTABLE PHASE**

**Unstable Phase**

Participants described the COPD illness experience as an unstable condition of constant discomfort, physical effort, and loss. The functional losses are characterized as dramatic and sudden: BB noted:

"I could lift 250 pounds with no problem before. It was like yesterday I could do that. Now I got to be careful not to lift my grandkids."

LS:

"I would like to get up and make the tea, make toast for myself. Those take too much [effort] now."

RP:

"I was just dancing in Tenerife! And the women there! I was doing a lot of that too [sex], but now I can’t walk from here to there [points to the front door, approximately 3 meters away]."

Certainly, a prolonged hospitalization for an acute episode of COPD would leave an individual with residual functional losses that may be perceived to be in excess of their previous state, or their noted gradual decline. It is understandable that a hospitalization period of even two weeks, mostly bedridden, for someone who has severe cardiopulmonary compromise, would
leave that individual in a very weakened, deconditioned state. If the individual is not referred on to a reactivation program, or does not receive rehabilitation in the home, they are less likely to regain their function given that they now have the additional limitation of oxygen use. Additionally, many participants reported receiving health care advice to “take it easy” [YJ:2318], “don’t over do it” [RP:986], and “slow down” [BA:684]. There is an indication that these directives were taken literally, without understanding the context in which that advice was most likely given.

BA reports:

“It’s important to not get to that point again when it’s lights out. This means being careful not to do too much.”

YJ said:

“They tell you to be really careful. Sometimes I try to clean, then I stop if I feel the heavy breathing coming on.”

Thus, participants report their uncertainty around not only how much to do, but also specifically how what they do will affect their disease and their prognosis.

For example, DG:

“I went to a movie, and I noticed the tank was empty by the end, but I don’t know for how long, so I wonder what that means? Do you think I should tell the doctor about that?

Participants sought my advice about “appropriate” levels of activity and impacts on their need for oxygen (PM:678-754; BB: 1844-1897), their suitability as lung transplant candidates (EM:2015-2044; JN:1567-1578), and my experience, if any, of individuals living “long” lives after the start of COPD illness
(SV:998). To each question I redirected participants back to their physicians. These questions illustrated participants’ uncertainty around different aspects of their illness.

Further Functional Losses

Universally common to all of the participants’ meaning attached to their illness experiences, is the significance placed on the functional losses that occurred as a result of COPD.

Functional losses are described in terms related to their perceived prognosis and how they feel about their illness. For AS it is interpreted in this way:

“As time goes on, I find myself more and more trapped in this chair, and just in this room. I realize that it will only get worse.”

Similarly, PP reported:

JST: Are you as active the same, more or less than when you [became ill]

PP: Less. A lot less.

JST: A lot less?

PP: Yeah. Most of the time I lay in this damn chair and sleep. I don’t have any energy to do much else.

Thus, if the individual with COPD perceives their health status as futile or hopeless, the motivation to be more active is absent. The spiral of deconditioning and decreased activity that is typical throughout the disease course would be accelerated after the acute phase.
For participants, each subsequent hospitalization, since the start of their illness, did not conclude with a return to their pre-hospital states. For this group, each subsequent hospitalization has left them more debilitated and fearful of the extent to which their illness state can worsen. WL explained it this way:

WL: Three months later I was back again. I knew it was gonna be bad. That time it, it was shorter [length of stay] than I expected, but I was worse off when I left.

JST: How do you mean? What makes you say that?

WL: I couldn't move after that. I sit right here [pats arm of chair]. Before that, I could at least get around to make myself a cup a tea. I can't do that anymore! I worry I'm gonna go from here, straight to there [pointing toward the bed, which is in the living room], and then into the coffin!

Even those participants who were just at the start of their COPD illness, interpreted the illness as the start of a declining process. LT reported:

"I don't think this is for the better. This isn't going to get better."

Similarly PM stated that:

"I'm waiting now. Today I can do this much, tomorrow, I don't know what I can do. Some days are better than others ... but I really don't have what I would call good days now. They, the days get slower and slower, worse and worse."

All participants, whether re-hospitalized since illness onset or not, describe their illness experience as generally unstable. Some of the previously reported data illustrate the fine balance that most participants feel that they walk between
having and losing the ability to breathe. MW had difficulty expressing her thoughts about her illness.

MW: It's not something that you wish for anyone. I can tell you ... I can try to accept this now, I can say ... to everyone ... I, this can, it's not the worst that can happen to you ... but ... you, you know it is.

JST: hmm. Why do you say that?

MW: All the time I have this [oxygen] to deal with. Then the dryness and discomfort here [points to nostrils], and everything is a big effort. I don't know how this is living.

MW continues to describe her illness experience and relates it to being a "prisoner" in her home, and sometimes a "prisoner" in her living room, and at the "worst of it, a prisoner" in her living room chair, where she spends the majority of her day. Another participant, AS, is a married woman. She describes the meaning of her illness in this way:

"You only know it's going to be worse. You wait for a good time, a good day. You wait and wait. I can't do nothing no more. Nothing. My husband has to do everything for me, I can't even make the bed. Everyday, I can do less and less. I keep getting worse."

For LC, her illness is viewed similarly.

"How can this be living? I am, no, no one can know what it means. I go in [hospital], I come out and everything is different. It's never been the same. I can't do anything now."

When probed, participants are clear in making the point that their health states after the start of illness was markedly decreased. They cite significant
loss of function and discomfort caused by the necessity of the use of oxygen.

The “crippling” [LB:1256] functional loss was universally commented upon.

For most of the participants in this study, this phase of their illness was associated with the need for coping. VV summed it up in this way:

“i just get by. you have to cope with it all, or else it becomes, just, it becomes too too much. you have to say, this is the way it is, now get on with it!”

Similarly YJ:

“I do what I have to do [laughs]. Yeah, yeah! That’s the only way I think you can survive these days [laughs].”

For YJ, despite the description of an illness with significant physical discomfort and loss of function, in the end, she could qualify her responses to minimize those impacts, and convey a clear message that this was preferable to death.

For others, coping was clearly more difficult, and their perspectives had already shifted to the final trajectory phase of dying.

**Social Impact**

In addition to the functional losses and impacts reported by participants, of note were also the social losses and impacts. The data indicated several different social impacts. Participants identified what could be termed as a self-imposed social isolation: BN stated:

“At first I thought of travelling, and getting out, not the same as before, but something, but it is such a big production with the Wheeltrans and the planning. I don’t bother anymore.”

MW noted:
"I don't even like my family to see me like this."

LT tearfully recounted the following:

"We celebrate birthdays in threes in my small group [of friends] – three of us born this month... I really thought about it, back and forth, about being able to set it all up. Make all the plans to be in on it, but it wouldn't have been right. We can't even go to _________ [restaurant] because I can't get in with this [wheelchair] – it won't take it [not wheelchair accessible]. And I don't have the energy to walk it in from the parking, so I just decided that for the first time .... I won't be there. It's not fair to them or me, but it has to be."

WL similarly stated:

"You have to ask yourself if all the planning and special effort will be worth it [the outing]. Usually I'm so tired, it takes me two days to feel okay again. It's not too many things that I feel I really have to get out for now."

These statements illustrate that individuals identified their illness as a barrier to social interactions or activities.

Additionally, participants described more consequences of having COPD that they viewed as externally imposed. DG recounted:

"I never thought of being embarrassed. I thought of it [the oxygen] being a nuisance, but not an embarrassment. But that [being stared at by a grocery clerk] just planted the seed."

DG's comments relate to the stigma associated with the visual declaration of disability that the oxygen represented.

BB noted also:

"I have some great friends, but they can't help me with this stuff [oxygen tank and walker],"
they have their own problems – arthritis and so forth. They want to help, but can't, and I don’t have someone who can just take me about – if I did I would go out more often”

JN also commented on the burden of equipment: While oxygen, as an assistive technology, is required to sustain life, and is thought to improve quality of life, it also requires support and creates different challenges for individuals (Locker & Kaufert, 1988).

“Some taxi cabbies are great, they help and make it easy for you. But you’re still left on the sidewalk and have to push the cart [walker] with the tank in it on your own. I can never be sure how far I will get, and where there’ll [will] be a seat or a good Samaritan to help me out”

This statement summarizes common stories of critical factors that participants identified of self image, stigma and the reaction of others.

Many participants also commented upon the impacts of their illness on family and friends. VV noted:

“It's harder for my daughter. She, you can see her suffering every time she looks at me. We are close.”

PM:

“I feel like a burden to them [family] now. My son bought my house from me, but I’m here as part of the bargain. No bargain there!”

WL stated:

“The kids have been great. My daughter calls or comes by once a week, and the other one [daughter-in-law], ______, she comes every other week or so. But it's hard for them you
know, with families of their own too.”

BA noted the impact on friends:

“I think it’s hard to ask that much of them [friends], I mean they have kids and grandkids and what not as well. Friends shouldn’t have to always be doing for you – it makes things very unbalanced. I don’t have any kids of my own, and some of their kids come by, but I feel bad about it, but lucky too. I can’t imagine what I would do without the help.”

Each of the above demonstrates characteristics of chronic illness reported in the literature. LC’s recount is an exemplary example of biographical disruption discussed by Bury (1982), VV and YJ spoke to struggling with illness (Charmaz, 1987), and reflections on stigma and uncertainty were provided by DG and JN. Each of these social factors influenced the illness experience and the meaning of that experience on the lives of the participants.

**THE COPD DYING PHASE**

The dying phase of an illness trajectory is the final phase characterized by a straight downward plunge (Strauss & Glaser, 1975). In this phase, the focus is still on functional and social losses, illness coping. For some people, the focus on death anticipation is greater than that on illness coping.

A dying patient is generally regarded as one in the final stages of his/her life. Dying is regarded in a narrow biomedical view, largely indistinguishable from death (McCue, 1995). In this narrow biomedical view, dying is merely a failure of medical diagnosis and treatment (McCue, 1995). Dying is a predictive term, indicating the likelihood that someone will die within a socially defined time perspective (Bond & Bond, 1994).
The process of dying is an unwelcome part of medical care, viewed as the endpoint of inadequately treated or non-treatable disease or injury (McCue, 1995). To be dying places a framework of interpretations around the individual which influences social activities (Bond & Bond, 1994). Thus, a dying perspective will greatly reduce the options and interpretations of the illness experience for individuals with a chronic illness (Bond & Bond, 1994), such as COPD. Four of the twenty-three participants had entered the dying phase of their illness experience.

For those participants who articulated this phase, each had a primary support person or persons who were very much involved in their care, and aware of the meaning that their illness had become to them. Probing and follow up around this meaning was not helpful in identifying why these particular individuals had progressed in their illness experience to this phase. Nor did an analysis of their demographic data related to age, time since diagnosis, oxygen use and prescription, and marital status separate these individuals from the others in the sample.

To be dying places a perspective around the illness experience which greatly reduces the options and interpretations of the illness experience for that individual (Bond & Bond, 1994).

LC's remarks support this point:

"Oh, I don't know about the future. I've even said to _____ [daughter], it's a terrible way to, [think] you know. And sometimes, I feel so tired I lie down, I don't care whether I wake up."
BA was also particularly poignant in her views:

“There’s not much I can do about it I guess. It’s [death] coming for me. I get very depressed. There are days when I rat [rack] my brain (think about it constantly) last week with that. And believe it or not I was sitting in the kitchen, thinking of all the different ways I can kill myself … now that’s bad. But … this thing is killing me for sure … that’s no way for someone … [trails off].”

After a period of extended silence, BA concluded:

“I don’t like this … situation. It’s [living with COPD] is not living really.”

**SUMMARY**

It is evident that much of the meaning of the COPD illness experience that participants reported is linked to a variety of socio-medical influences. The data support that the medical processes involved in hospitalization, medical management and treatment, diagnosis and communication were interpreted by participants and shaped their illness meaning. Similarly, participants’ perceptions of the functional and consequent social impacts of their illness also shaped and influenced their illness meaning.
CHAPTER SIX
DISCUSSION AND CONCLUSIONS

In this chapter I will summarize the findings of this study, and discuss how these findings are situated in the larger illness experience literature. I will also discuss the study's limitations and recommendations for practice and future research.

SUMMARY OF FINDINGS

There is a dual nature of acuity and chronicity attached to the COPD illness experience. This duality is highlighted by the nature of the pre-trajectory phase. There exist two pre-trajectories for the COPD illness experience; in which individuals report being "well", and another in which individuals report experiencing "other respiratory illnesses". Common to both of these pre-trajectories is the absence of the notion of chronic illness.

These pre-trajectory phases correspond to the early stage, or mild to moderate lung impairment phases, of the disease course. It can be argued, from the findings, that either health care providers did not recognize the presence of pathology during this phase for participants in this study, or more likely, that they did not acknowledge the presence of pathology as part of a chronic disease process. Due to the gradual nature of symptom presentation, it is also likely that participants overlooked early symptoms in an attempt to keep their bodies functioning as best they could and, by doing so, define their lives as normally as possible.
This pre-trajectory phase of the COPD illness experience held significant meaning for these participants with COPD. The pre-trajectory phase left individuals unable to prepare for chronic illness. It resulted in universal perceptions of the onset of their illness as sudden, and the consequences previously unpredictable. It created a greater challenge for adaptation and preparation for chronic illness.

Secondly, there exists a great time differential between disease and illness onset in COPD. The disease pathology is known to exist for decades prior to the acknowledgement of illness. This may be due, in part, to the gradual nature of the initial symptoms of COPD, and the tendency for individuals to attempt to ‘normalize’ or explain their symptoms away. It may also be explained by the acute, episodic nature of this illness, and the acute care focus that health care providers place on this disease.

Additionally, the process of diagnosis of COPD has little attached meaning to the COPD illness experience. Unlike other chronic illnesses, the process of, and eventual diagnosis of COPD, in and of itself, did not hold significant meaning. In fact, few participants could articulate their diagnosis, or medically interpret it. This is partly explained by the reported lack of discussion of diagnosis with this group of participants and their health care providers. This lack of discussion may arise from the generality of the term COPD, or from health care providers’ perceptions of how the diagnostic label of COPD may impact on their patients.
Lastly, this ambiguous response to the COPD diagnosis, and health care providers' implicit acceptance or facilitation of this ambiguity, creates a great deal of confusion, shock and uncertainty for the individual with COPD. Individuals with COPD do not acknowledge a chronic illness process. This shapes their response to illness, and their expectations and coping abilities.

Throughout the interviews, the theme of unpreparedness was evident in the participants' discussions about their realization that they had a chronic lung disease, the critical events that brought them to the hospital, their eventual diagnosis, the oxygen use and the resultant social and functional consequences of the disease.

Although COPD develops over decades, with an insidious onset of physical symptoms, all but one participant indicated an unpreparedness for the critical events and expressed a perceived sudden onset of their illness. Study participants experienced COPD onset as a sudden, discrete acute incident. In many cases, participants seem entirely baffled by the "turn of events". They are able to hypothesize about the causes, such as smoking or work related exposure. However, with further prompting, they often denied this to be the cause, and could not see the link between those activities over time.

Other participants would describe another 'non-COPD' chronic illness that they saw as distinct from this "new" illness COPD. In these cases, the distinction was made between an illness that was acute in nature and only minimally functionally limiting, to what they see now as something chronic and totally
debilitating. The unpreparedness theme evolves from the dual acute-chronic characteristic of the illness experience.

In this study, I identified a number of the socio-medical influences of the COPD illness experience, and the impacts of those influences on the understanding and meaning of the illness as an acute/chronic condition. These data support that the medical processes involved in hospitalization, medical management and treatment, diagnosis and communication were interpreted by participants and shaped their COPD illness as an acute, then chronic entity. For example, all of the participants indicated shock or surprise with the need for continual oxygen use after the critical event. In the early phase of the trajectory, oxygen use was either absent or short-term, thus re-affirming the acute care emphasis and character for participants. After the critical event, the requirement for long-term continuous oxygen use was a significant marker for participants indicating chronic illness. It served as a concrete and undeniable symbol of their chronic illness state.

Diagnosis is another complex aspect of the unpreparedness theme linked to the duality of the illness trajectory. The literature reports that the individual with COPD is typically diagnosed while in their fifties or early sixties. The participants in my study ranged in age from 60 to 87 years of age. Only three individuals reported a diagnosis that preceded their critical-event/realization of their illness in the early acute nature trajectory. Therefore, the absence of diagnosis in the early illness trajectory adds to the negation of a chronic illness state and disease progression. The medical acknowledgement and affirmation of
chronic illness, through diagnosis, comes late in the COPD illness trajectory. It comes too late to create understanding of the chronic and progressive nature of the disease.

Similarly, participants' perceptions of the functional and consequent social impacts of their illness also shaped and influenced their illness meaning of COPD. Early functional decline was characterized as minimally limiting and gradual. As such, it was made sense of as change due to aging and/or smoking, and perceived as 'natural', or expected. In the pre-trajectory, when acute episodes of “other respiratory illness” existed for most participants, participants report full functional recovery post acute episodes, and the resumption of all functional and social activities. Functional status and social impacts are not reported as significant then. The acute illness having been fully resolved or ‘cured’. This is in contrast to their ‘new’ illness, COPD. Participants report a significant loss of functional abilities, which contribute greatly to a decreased level of social activity after the onset of COPD. These functional losses and social limitations largely contribute to chronic illness recognition for participants. This acute-chronic duality within the COPD illness trajectory is the significant finding of this study.

**STUDY LIMITATIONS**

I interviewed participants only once and retrospectively examined changing illness meaning of COPD. Following participants prospectively, over time, would have allowed an examination of the unfolding of the COPD illness experience as it occurred.
Another study limitation was that neither health care practitioners, or family/significant others, were interviewed. The perspective of health care practitioners would greatly contribute to the understanding of the medical influences on the COPD illness experience. For example, an understanding of physician interpretation and decision making with respect to diagnosis discussions with individuals with COPD would contribute to our understanding of the impacts of diagnosis for this group. Similarly, a study of health care practitioners’ attached meaning to the diagnosis of COPD and their perceptions and assumptions relating to the COPD illness experience would further inform our understanding of their role in shaping the illness experience. The perspective of family and caregivers of individuals with COPD would create understanding around the unique influences of the acute/chronic COPD trajectory duality on the relationships and dynamics between individuals with COPD and their support networks.

THEORETICAL CONTRIBUTIONS OF THE STUDY TO THE LITERATURE

The study highlights the dual nature (acute/chronic) of the COPD illness trajectory. In this next section, I will situate the findings in the sociological chronic illness literature.

Acute and Chronic COPD Illness Trajectory

In viewing the course of illness as an illness trajectory, we acknowledge the individual and social context of disease (Wiener & Dodd, 1993). The Illness Trajectory Framework allowed me to examine not only the physical factors of COPD, but also the impact of the consequences of the disease and its effects on
the lives of individuals involved. The findings highlight the utility of the Illness Trajectory Framework in describing illness as it unfolds.

The notion of trajectory, in the sociological chronic illness literature, has been depicted as a varying but inevitable decline (Glaser & Strauss, 1963). The trajectory patterns of chronic illness have been depicted as having a progressive decline (i.e. terminal cancer), or as an up and down trajectory (i.e. rheumatoid arthritis). There have been brief discussions in the literature of illness trajectories that are “relatively stable” punctuated by acute episodes of distress or decline. For example, Charmaz (1991) briefly notes that some people with rheumatoid arthritis, whose condition only affects them periodically (i.e. acute exacerbations), view their condition as acute, stating that they ‘sometimes’ have rheumatoid arthritis. In this study, I have demonstrated the acute and chronic aspects of the COPD trajectory and the socio-medical influences which shape this trajectory. For example, unlike other chronic illnesses, the acute exacerbations of COPD that punctuate the long periods of relative stability are extreme life threatening events. Thus, from a medical perspective, although a chronic illness, medical interventions are predominantly focused on episodes of acute respiratory failure. This pattern of medical intervention may be one factor shaping the lived experience of COPD. While the study has shown how COPD has acute and chronic aspects to it, do individuals with COPD adopt sick role behaviour? The findings of this study would indicate that the answer to this question is yes. I will use Parson’s Sick Role to illustrate how individuals with COPD can be viewed to adopt the sick role, and thus may be treated by health care practitioners with an
acute short term care focus, rather than a chronic illness focus.

**Sick Role Theory and COPD**

Talcott Parsons developed the concept of the sick role to describe the expectations of people in a society which defines the rights and duties of its members who are sick. The sick role was intended to be primarily an analytical concept for differentiating behavioural expectations from criminal and sick people formulated at the institutional level of analysis (Twaddle, 1979). Parsons (1975) asserted that illness is not merely a state of the organism and/or personality, but comes to be an institutionalized social role. Therefore, Parsons (1975) identified three primary criteria for accepting the social role of being sick. Firstly, is the assertion that being in a state of illness is not the sick person's own fault, and that he should be regarded as the victim of forces beyond his control. The illness is viewed as involuntary (Gallagher, 1976). A second feature of the sick role is the claim of exemption from ordinary daily obligations and expectations (Parsons, 1975). The third criteria is the admission that being sick is undesirable, and in doing so, seeking health care measures to maximize the chances to facilitate recovery, or if the condition is chronic, to subject to its proper management (Parsons, 1975). Furthermore, the person in the sick role was viewed as a passive participant who was expected to cooperate with the physician expert and comply with the physician's advice (McCormick, Min & Conley, 1995; Segall, 1976).

Despite criticisms (Gallagher, 1976; Segall, 1976; Twaddle, 1979) of the sick role theory in its limited application to chronic illness, the above mentioned
criteria can each relate to an individual with COPD due to the acute nature of its early trajectory. As previously stated, the clinical disease course of COPD is characterized by periods of stability of symptomology punctuated with acute exacerbations (Snider, 1995). Encounters with medical intervention are usually restricted to those episodes of acute exacerbation. During periods of respiratory stability, the individual with COPD tends not to seek out medical intervention (Miller, 1992; Williams, 1993). We know, from the findings of this study, that the presence of disease is not acknowledged by individuals during this pre-trajectory phase. Chronic illness is not acknowledged by the individuals with COPD, nor does it appear to be acknowledged, or effectively communicated, by the health care practitioners who are involved in their care. Hence, the notion of chronic illness is not formed. For individuals with COPD, the COPD illness trajectory is acknowledged by a critical acute event which is followed by the introduction of long-term oxygen use, which serves to signify the presence of chronic illness. Thus, the argument is made that this treatment pattern satisfies the acute care focus of sick role theory.

The first criterion of social acceptance of the sick role as the notion of involuntary victims of disease (Parsons, 1975) may be applied to individuals with COPD. The majority (60%) of individuals with COPD can be shown to have active or past voluntary exposure to the primary risk factor of smoking (Pride & Burrows, 1995). However, it has only been in recent years that the ill effects of cigarette smoking has been made known to the public, and legislation has mandated written public warning labels on tobacco products and restricted public
smoking areas. For many years, smoking was a very acceptable social custom. Individuals chose to smoke, not to become sick. Even when diagnosed, many individuals lack knowledge of the meaning of their disease, and the implications of past or present smoking practices (Miller, 1992). The findings of this study support this. Either the link to smoking is not acknowledged, or individuals with COPD experience helplessness in stopping a lifelong habit previously socially condoned and encouraged (Williams, 1993). These factors tend to absolve the individual with COPD of initial responsibility of disease onset as evidenced by acute treatment practices for even those individuals who are active smokers.

Exemption from daily obligations and expectations is arguably the easiest criterion for the individual with COPD to meet. As breathing is a fundamental requirement for the sustenance of life, and shortness of breath is a characteristic result of progressively decreasing activity, it is reasonable to conclude that the individual, family, and health care providers would support and accept reduced functional activity especially after an acute episode. Additionally, given their age individuals also had aging as a socially acceptable reason for slowing down.

Lastly, is the acknowledgement of undesirability of the disease state, and the obligation to seek medical treatment (Parsons, 1975). The very urgency of breathlessness drives acute care intervention. The emphasis on acute care management promotes individuals to adopt the sick role relative to COPD.

RECOMMENDATIONS FOR PRACTICE AND FUTURE RESEARCH

Health care providers who are involved with individuals with COPD must ensure that an illness experience perspective informs their practice. It is important
to acknowledge that, as a health care provider, your actions and interactions with an individual with COPD are likely to hold different meanings for that individual. One strategy that may be employed to acknowledge this is to invite individuals with COPD to relate their illness experience to you during your interactions with them. Checking meaning with respect to disease progression is important to gaining understanding of how an individual perceives their health state. For health care providers, the framework of acute care illness applied to individuals with COPD may explain the findings of fragmented care, incomplete health information and shock and isolation reported by participants in this study.

Future research should investigate health care providers, particularly physicians, view of their perceived impacts on the COPD illness experience. Additionally, a study of the factors impacting on health care providers in their response to COPD, and working with individuals with COPD, may facilitate our understanding of the biases or assumptions we bring to those encounters. Particular attention must be made to the assumptions held around diagnosis in COPD. Issues related to the potential impacts of perceiving chronic illness as acute versus chronic are complex. For example, we do not know if the dual nature of the COPD illness trajectory impacts on the coping and management skills of individuals with this disease. We do not know if, or how, the dual nature creates barriers or facilitates adaptation to illness acceptance and the use of assistive technology. We do not know if COPD is best characterized within the literature on aging with disability, or acquiring disability in later life.
CONCLUSIONS

It is important to examine how conditions are identified and acted upon. An understanding of the illness experience of persons with Chronic Obstructive Pulmonary Disease will enable health care providers to understand the implications and subjective outcomes of their interactions with these individuals.

The findings of this thesis served to extend the literature on the illness experience of COPD, and the illness experience and chronic illness literature. The major findings of this study that are different from much of the existing literature on COPD and chronic illness relate to the illness trajectory acute/chronic quality, the acknowledgement of chronic illness, the impact of diagnosis, and the resultant sick role implications for this group. These findings have important implications for health care practice and management of individuals with COPD.
REFERENCES


Gerhardt U. "Qualitative Research on Chronic Illness: The Issue and the Story". Social Science and Medicine, 30(11):1149-1159, (1990)


Orona C.J. "Temporality and Identity Loss Due to Alzheimer's Disease". *Social Science and Medicine*, 30:1247-1256, (1990)


APPENDIX 1

LETTER OF INTRODUCTION TO STUDY - HEALTH CARE PRACTITIONER

Dear Colleague:

I am asking for your help in identifying potential participants for my thesis research project entitled “Health Care Professionals Management of Chronic Obstructive Pulmonary Disease, and the Impact on Individuals Lived Experience”. This research project is part of a Master of Science degree requirement of Jackie Schleifer Taylor, who is a Physiotherapist and full time graduate student in the Department of Rehabilitation Science at the University of Toronto. This project is funded in part by the Ontario Respiratory Care Society and the Royal Canadian Legion.

The purpose of this thesis research project is to investigate the illness experience of the individual living with Chronic Obstructive Pulmonary Disease. The informants for this study will be community dwelling elderly presenting with severe Chronic Obstructive Pulmonary Disease. Disease severity will be assumed solely on the basis of an individual requirement for prescribed oxygen.

The study informants should meet the following criteria:

i) 65 years of age or older;
ii) communication is not limited due to cognitive impairment;
iii) English speaking;
iv) with daily oxygen use requirements.

A lack of any of the above criteria will be the basis for exclusion from the study.

Data will be collected through in-depth interviews using a semi-structured interview guide that will be pre-tested. I will conduct all interviews and collect all data following informed consent. There are no risks involved in the research with respect to the participants. The personal in depth interview guide is semi-structured in nature. This type of interviewing is a standard method used in studies of a sociological nature. This interview schedule, in a modified version, has already been used in pilot interviews conducted as a requirement for a graduate course in Qualitative research methodology.

If you are aware of individuals who meet the study criteria and may be interested in learning more about the study, please provide them with the attached letter of introduction. When approaching potential participants I would ask that you use the enclosed introduction to ensure that individuals recognize that they are under no obligation to call. If you have any questions please do not hesitate to contact me (699-8586).

Sincerely,

Jackie Schleifer Taylor, Graduate Student, University of Toronto
The liaison health care practitioner/receptionist will say the following to eligible participants:

I am inquiring about your interest in participating in a study about your experiences living with Chronic Obstructive Pulmonary Disease (COPD). If you are interested in hearing more about this project, I can give you an information package.

I would like to emphasize that you are not consenting to participate in the study at this time, but you are expressing an interest to find out more about it. I will not know whether you have agreed or not to participate in the project as this information will not be communicated to me. Whether you would like to learn more about the study or not will have no bearing on current or future treatment.

APPENDIX 2

INTRODUCTION BY LIAISON HEALTH CARE PRACTITIONER/RECEPTIONIST
APPENDIX 3

LETTER OF INTRODUCTION TO POTENTIAL STUDY PARTICIPANTS

Dear Madam/Sir:

I would like to invite you to participate in a research project entitled “Health Care Professionals Management of Chronic Obstructive Pulmonary Disease, and the Impact on Individuals Lived Experience”. This research project is part of a Master of Science degree requirement of Jackie Schleifer Taylor, who is a Physiotherapist and full time graduate student at the University of Toronto. This project is funded in part by the Ontario Respiratory Care Society and the Royal Canadian Legion.

The purpose of this thesis research project is to describe the experiences of individuals living with Chronic Obstructive Pulmonary Disease. It will also illustrate how health care experiences are perceived by those who receive health care services.

The information from your interview will provide clinicians with greater insight and knowledge of experiences of individuals with COPD. This information will help improve health care services for individuals with COPD.

The information from your interview will provide clinicians with greater insight and knowledge of experiences of individuals with COPD. This information will help improve health care services for individuals with COPD.

Information will be collected through face to face interviews lasting between 45 to 90 minutes. The interview will be held at a time and place convenient for you (for example your home).

If you wish to participate in this study, or learn more about it, please contact me at 699-8586 as soon as possible. If I am unavailable, please leave a message for me so that I may call you back at a time convenient for you.

Thank you in advance for your help.

Sincerely,

Jackie Schleifer Taylor
Graduate Student, University of Toronto
APPENDIX 4

INTERVIEW GUIDE - COPD ILLNESS EXPERIENCE

The purpose of this interview is to gain a better understanding of the illness experience of individuals living with Chronic Obstructive Pulmonary Disease, and to determine what factors, if any, you feel may have specifically impacted on your experience.

[ ] = information for committee members only

I would like to start with when you first noticed something was wrong [i.e. inability to walk as far, shortness of breath, etc.], and progress to the present.

1. First notice that something was “wrong”.

Probe if necessary.

   When did you first notice that something was wrong?
   What made you think that something was wrong?

2. The meaning of #1.

   What did this mean to you?

3. How events were made sense of (theories or explanations utilized).

   What did you understand to be the cause of these events?

4. Resultant consequences (biopsychosocial).

   How did these events affect you?

Probe if necessary.

   How did you feel?
   What changes occurred?

5. Informant actions in response to the consequences.

   How did you react to these changes?


   When did you first seek medical attention?
   Why?
7. The impact of diagnosis.
   When were you first diagnosed?
   What was that like for you?

8. Coping with a medical label.
   Has the diagnosis itself affected you?

9. Concerns and expectations of medical care.
   Do you feel that the diagnosis means the same to health care providers as it does to you?
   How do you feel about the health care you received initially?
   How do you feel about the health care that you received throughout the years?
   How do you feel about the health care that you receive now?

    Has this illness affected your relationships?

11. Adaptation to physical discomfort.
    Do you have physical discomfort?
    Can you describe it?
    Do you get used to that?

12. Strategies used to “get by”?
    How do you manage?

I would like to finish up by asking you if there were anything else that you would like to say.

THANK YOU.
APPENDIX 5

CONSENT FORM FOR PARTICIPANTS

I have been invited to participate in a research project entitled "Health Care Professionals Management of Chronic Obstructive Pulmonary Disease, and the Impact on Individuals Lived Experience". This research project is part of a Master of Science degree requirement of Jackie Schleifer Taylor, who is a Physiotherapist and full time graduate student. This project is funded in part by the Ontario Respiratory Care Society and the Royal Canadian Legion.

I understand that the purpose of this thesis research project is to describe the experiences of people living with Chronic Obstructive Pulmonary Disease. I understand that I have been invited to participate in this study because I have a diagnosis of Chronic Obstructive Pulmonary Disease.

I agree to participate in an interview lasting 45 to 90 minutes, and to the interview being tape-recorded and written notes taken. I understand that the interview will be conducted by Jackie Schleifer Taylor, graduate student. I understand that, if necessary, I may be contacted once by telephone after the interview if clarification of the information from the interview is needed.

I realize that the results of the interview will not benefit me directly, but the information from my interview will assist in providing a greater understanding of the lived experience of individuals with severe COPD, and how health care experiences are perceived to impact and influence that experience. This information will be useful in guiding health care initiatives for this population. I realize that a summary of the results of this study will be available to me if requested.

I understand that in any publication of the results of this study, I will not be identified by name, and any other identifying information will be changed or deleted.

I understand all of the information, which has been given to me about this study and that, if I have any questions, I may contact Jackie Schleifer Taylor (699-8586).

I understand that my participation in this study is voluntary and that I am free to refuse to answer any of the interview questions for whatever reason. I may also withdraw from this study at any time.

Participant's Signature    Interviewer's Signature    Date