University of Alberta

Breathing *In*:

Experiences of Adults with Chronic Pulmonary Illnesses

by

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A thesis submitted to the

Faculty of Graduate Studies and Research

in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta

Fall, 2005

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Abstract

This phenomenological study was undertaken to explore perspectives, perceptions, meanings and descriptions of breathing in adults who have moderate to severe chronic pulmonary disease. The approach of van Manen was used to explicate meanings and describe themes, through ongoing reflection, conversation, writing, and re-writing. The philosophical underpinnings of Husserl and Merleau-Ponty guided the analysis. Sixteen persons with chronic pulmonary disease were interviewed to elicit their experiences of chronic pulmonary illness.

Analysis of descriptions revealed that with pulmonary disease, the body metaphorically and literally loses its silence; calling attention to itself with noisy breathing, chest tightness or pressure, coughing, or wheezing. Sounds and sensations of the body are interpreted and evaluated as normal or as signals for concern. Feelings of panic, distress, and desperation were experienced when the person was unable to get air. Metaphors of attacks, drowning, and suffocating, and focus on breathing *in* further revealed the threat of acute shortness of breath.

Delineated as pulmonary or lung disease, chronic pulmonary illness is experienced holistically by the person. The body-in-the-world reveals the nearly invisible disease to self and others. Tempo and actions are altered; the person has to slow down, do less, and at times even has to stop. No longer lived in the now, in the moment-to-moment of life, breathing limits the body and self. Physical strategies are used to alleviate or prevent symptoms, such as pursed-lip breathing and avoidance of triggers.

This study is significant in understanding the delay for diagnosis of pulmonary disease, particularly emphysema and COPD. Sense-experiences such as coughing and wheezing are not purposefully unreported but may be attributed to smoking or aging and interpreted as normal. These interpretations of sensations limit early diagnosis and interventions, including delay of smoking cessation. Further insights and implications of this study include meanings of shortness of breath, which was differentiated as normal, chronic, and acute. These interpretations and perceptions influence daily activities and choices for emergent treatment. Understanding perceptions of chronic pulmonary disease enables prevention of acute events and ongoing lung injury, education regarding smoking cessation and exercise, and understanding of health care providers.

The accomplishment of an undertaking such as this lends to reflection upon the significant persons who have supported and encouraged me along this path until its completion. I am thankful to the many who have done so. My mother, grandfather, and sisters, who were models of learning. My children: Rebecca, who has just achieved her masters' degree, Claira and Andrew, who are completing their undergraduate degrees. My husband, for both his intellectual and very practical support. Several others have contributed to this accomplishment: Friends who have shared the experiences of undergraduate and graduate classes, faculty who encouraged me to take the "next" degree, those who taught with enthusiasm and relayed high professional standards, and a school teacher who encouraged me to attend university.

I thank my committee members Drs. Marion Allen and Max van Manen, and especially my supervisor Dr. Janice Morse, for their insight, expertise, and support.

In particular, I want to acknowledge the participants who shared their experiences. It is indeed a privilege to have met you, and your time and openness are appreciated as both were necessary for this research and further this understanding. Thank you.

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Chapter One

Overview of the Inquiry

Persons with acute or chronic pulmonary illnesses often experience difficulty with breathing, shortness of breath, or breathlessness, which may be labelled as 'dyspnea.' Dyspnea, a term which includes a variety of breathing symptoms, is not specific to particular disease states or clinical populations (Lenz, Pugh, Milligan, Gift, & Suppe, 1997). Despite common use of the term *dyspnea*, its meanings and definitions are unclear and indistinct.

Within acute and critical care nursing practice, the focus of respiratory assessment has been on technological and biomedical indicators, such as breath sounds, rate of respiration, oxygen saturation, parameters of mechanical ventilation, and oxygenation calculations. Although these indicators provide important and relevant information, self-report from patients is often not obtained. There is scant attention to psychosocial aspects or personal experiences that may occur.

Reflecting on Practice

In our natural attitude towards an object or phenomena, we hold theoretical perspectives and assumptions (Husserl, 1900/2001). As nurses, our attitude towards assessment and understanding of breathing is influenced by natural science perspectives, and informed by nursing knowledge and practice. When reflecting on my critical care nursing practice, I began to notice gaps, differences, and incongruences between the person seeking and receiving care and knowledge and perspectives of clinicians. As my attention to the subject of breathing continued, I became increasingly aware of language and assumptions held by myself and others, and began to question theoretical and knowledge perspectives that I held. Here are four exemplars from my nursing practice.

Are you short of breath?

I was assisting a patient up to the washstand for the first time after his myocardial infarction. He had a long history of Chronic Obstructive Pulmonary Disease (COPD) and was on 3 Litres/minute (L/min) of oxygen at home. We walked closely together, his elbow tucked under mine, my arm touching his rib cage. When we had taken about half of the 10 steps across the room, I noticed that he was breathing loudly, at a more rapid rate, had an audible wheeze, and was using his accessory shoulder muscles to forcefully inhale and exhale. I glanced over his shoulder at the monitor. There were no significant changes in heart rate, rhythm, or oxygen saturation. Wondering if we should pause, or if he might need more oxygen, I asked "Are you feeling short of breath?" He looked at me, frowning a bit as if questioning, said, "No," and continued on, slowly taking another step and breathing louder.

I was puzzled at his answer, but it was not the first time patients did not express symptoms that *I thought* they may be experiencing. I later wondered: Did I not ask the 'right' question? Was that his 'normal' experience and manner of breathing? How might he describe his breathing? If his breathing had become more difficult, how might he have expressed it? As shortness of breath? Or something else?

Why didn't you ...?

Two experiences, those of Stacey and George, occurred in which nurses perceived that patients delayed seeking help when they felt short of breath. Stacey was 17 years old, admitted to critical care with status asthmaticus. I heard one nurse ask another, "Why did she wait so long to come in? Why didn't she come in when she was feeling short of breath?" There seemed to be concern, puzzlement, and frustration in her voice. I also wondered: At what point in asthma does one decide to seek help? Is this experience with asthma different than another she has had? Did she *feel* short of breath? What was her perception of her breathing when she decided she did need help and came to the Emergency?

George was 63 years old, admitted to cardiac critical care with acute decompensated heart failure. He gained 3.5 kilograms in less than 5 days and had fulminating pulmonary edema. "Why didn't you take your Lasix® when you felt short of breath?" the nurse asked. He responded, "I didn't feel short of breath." As nurses, *we* perceived that he was labouring to breathe. We noticed his shoulders heaving to take in air, counted his rapid respiratory rate, heard his audible crackles, and saw his low oxygen saturation. We concluded that he *was* short of breath, and that he *felt* short of breath. But he did not. He came into Emergency because he was exhausted, not because of his breathing. I wondered: What did he perceive of his breathing? If he did not perceive he is short of breath, what does that mean to him? Not enough air? Difficulty with breathing? Why did nurses focus on his breathing when he did not seemingly notice or regard it as a concern or problem?

Short of breath?

In another experience, a critically ill patient expressed distress when I initially didn't think he was short of breath. Joseph lay in bed in an intensive care unit. At set volumes and pressures, the ventilator delivered sufficient minute volume to achieve normal oxygen and carbon dioxide levels. His respiratory rate was 22 per minute, tidal volume 500 millilitres. When I looked at the monitor, his heart rate and blood pressure were within normal limits, oxygen saturation was 95%, and I concluded that his breathing was sufficient. I might even have reported at shift change that he was 'not short of breath.' Going from the monitor to looking at his face, Joseph seemed distressed. Intubated and weak, he could not speak or write. I struggled to read his lips, distorted by the endotracheal tapes, to interpret his frown. He shook his head no to numerous queries: "Pain? Wife? Time?" Finally he nodded in response to: "Breathing?"

He felt as if he wasn't getting enough air, although from my perspective he was. His oxygen saturation, respiratory rate, and heart rate were all within 'normal' reference values. His tidal volume was sufficient for his size and age. His arterial blood gases indicated sufficient ventilation and oxygenation. His breath sounds throughout his lung fields were adequate. From the objective data, there was more than adequate air. But he *felt* as if he wasn't getting enough air. Only his face revealed the need to question further. There seemed to be a sensation of 'enough' and 'not enough' air or volume, independent of the objective and external values that we so carefully monitor. My assessment and monitoring all fell short of understanding or describing his experience and sensations.

Thinking further about assessment of breathing, I read in one chart, "patient is dyspneic" and wondered: What did the nurse perceive and then interpret as dyspnea? Did the patient indicate that he was short of breath? Did she observe some external sign? I began to consider sensations and experiences of what we, as nurses, call dyspnea.

Exploring the Literature

What do we mean by dyspnea? Does the term encompass or reflect aspects of the patient's experience or symptoms? Or is it objective indicators that indicate insufficient or difficult air exchange. Does it mean *difficulty* in getting air in or *inability* to get enough air in? May it have both meanings? Is dyspnea associated with rapid breathing? Or laboured breathing? In North American nursing literature, dyspnea is usually described as difficult, laboured, uncomfortable breathing and most often called 'shortness of breath' (e.g. Brown, Carrieri, Janson-Bjerklie, & Dodd, 1986; Gift, 1990; Lenz, et al., 1997). In medical literature, dyspnea is usually interchanged with breathlessness (Burki, 1980; Mahler, et al., 1996; Zeppetella, 1998).

Diverse Definitions

In addition to shortness of breath and breathlessness, the term dyspnea encompasses numerous aspects and meanings, including rapid breathing, laboured breathing, effort, work, heavy breathing, and unpleasant awareness of breathing (Brown, et al., 1986; Burki, 1980; Gift, 1990; Killian, Summers, Jones, & Campbell, 1992; Manning, Molinary, & Leiter, 1995; Zeppetella, 1998). Awareness of breathing is considered to occur as an unpleasant symptom of illness (Lenz, et al., 1997). However, based on these diverse descriptions, dyspnea is not *a singular* unpleasant symptom, but encompasses a variety of symptoms.

There is a wide spectrum of definitions for dyspnea, ranging from narrow and specific, such as the sensation of difficulty with breathing (Gift, 1987), to broad connotations of distress and discomfort with breathing (Killian, et al., 1992). Breathing effort is included by some authors in its definition (Burdon, Pain, Rubinfeld, & Nana, 1994; Turcotte, Tahan, Leblanc, & Boulet, 1993; Wasserman & Casaburi, 1988) and excluded by others (Roberts, Thorne, & Pearson, 1993). In nursing and medical literature, dyspnea at rest and on exertion is differentiated (Burdon et al., 1994; Brown, et al., 1986). Comparisons between rest and exertion, or health and illness, were not found in this review of the literature.

Unlike symptoms of pain or fatigue, many persons who experience breathing symptoms do not use, and may not even recognize, the term dyspnea. Furthermore, patients may adopt or reject descriptors of dyspnea that are predetermined by health care providers. In one study in which dyspnea was "readily defined" by physicians as "an unpleasant or uncomfortable awareness of breathing," patients chose "a host of phrases when describing their own sensations" (Elliott, et al., 1991, p. 826, 831). When asked about particular descriptors, patients may disregard common terms, including shortness of breath, and select several terms that seemingly conflict with another (Elliott et al., 1991; Gift, 1991). A variety of expressions and concepts have been used by patients to describe 'shortness of breath', includes tightness, cough, drowning, suffocation, fatigue, and nausea (Janson-Bjerklie, Carrieri, & Hudes, 1986). The proposal that "dyspnea is a term used to characterize a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" acknowledges its use by clinicians, and incorporates the diversity and complexity (Anonymous, 1999). However, this definition has not gained general acceptance or use, and it is argued that "there is no consensus about a definition of dyspnea" (Govindaraj, 2002, p. 662).

Breathing Symptoms

Several dimensions of symptoms are inter-related with, yet distinct from, one another, including intensity and quality, duration and frequency, and perceptions of distress (Desbiens, Mueller-Rizner, Connors, & Wenger, 1997; Lenz, et al., 1997). *Distress* is defined as the degree that the person is bothered by the symptom and incorporates the interpretation and assigned meaning of the experience, whereas the *intensity* of a symptom is the severity, strength, and amount experienced. It has been demonstrated in both health (Wilson & Jones, 1991a) and chronic lung disease (Carrieri-Kohlman, Gormley, Douglas, Paul, & Stulbarg, 1996) that the *distress* of 'dyspnea' differs from its *intensity*. The level of distress has been associated with perceptions on quality of life and decisions about seeking treatment, whereas intensity is the dimension most often addressed in assessment and research. There has been extensive effort to ascertain the intensity of dyspnea in acute episodes (e.g. Killian, et al., 1992; Mahler, et al., 1996; Moy, Lantin, Harver, & Schwartzstein, 1998; Turcotte, et al., 1990), but relationships between physiologic status and treatment effectiveness continue to elude us, in part due to the lack of clarity in assessing components of distress and intensity.

The enigma of breathing symptoms is augmented by the complexity of both known and unknown physiological and psychosocial factors. Perspectives range from simplification of central nervous system perception and brain stem integration (Wasserman & Casaburi, 1988) to that of a “complex subjective experience… [with] physical, psychological, social, and spiritual components” that contribute to the perception, reaction, and “total suffering of dyspnea” (Zeppetella, 1998, p. 323).

It has been surmised that there is a physiological imbalance between the demand for air and ability to breathe and meet that demand, thus air hunger is included within some descriptions of dyspnea (Mahler, et al., 1996; Wasserman & Casaburi, 1988). Other factors postulated to contribute to dyspnea are wide and varied: increased ventilatory drive due to increased metabolic demand, acid-base imbalance, increased right atrial pressure, lung inflation reflexes, nasopharyngeal and airway reflexes, capillary receptors, discordance in feedback between lung and chest wall, hyperinflation, receptors of respiratory muscles, airway receptors, airway inflammation, corticosteroids, and obesity (Elliott, et al., 1991; Manning, et al., 1995; Wasserman & Casaburi, 1988; Zeppetella, 1998). In actuality, there is still little known of the sensory and neural mechanisms underlying the sensation of discomfort of breathing (Anonymous, 1999; Burki, 1980; Comroe, 1964; Guz, 1977).

In nursing and medical literature, it is overtly acknowledged that dyspnea is a subjective sensation, that is, dyspnea is a symptom individually experienced and interpreted, not a sign or indicator objectively perceived by external observers (Brown, et al., 1986; Burki, 1980; Comroe, 1964; Gift, 1990; Moy, et al., 1998; Wasserman & Casaburi, 1988). Yet the term is scientific not everyday language, is used as an external label, and both objective signs and subjective self-reports are presumed to provide information. Patients have been labelled as impaired or poor perceivers of dyspnea

(Brand, et al., 1992; in't Veen, et al., 1998; Kikuchi, et al., 1994; Wasserman & Casaburi, 1988). Dyspnea is presumed to be measured through objective signs such as tachypnea (Wasserman & Casaburi, 1988), irregular respiratory rhythm or use of accessory muscles (in't Veen, et al., 1998; Mahler, et al., 1996; Zeppetella, 1998), and discomfort in carrying normal conversation (Burdon et al., 1994). These objective signs would be helpful if they were indicative of breathing discomfort. However, there is no simple, direct relationship between objective signs and the subjective sensation. Objective signs only *suggest* that the symptom may be present. Any combination of these signs may occur in either the presence or absence of dyspnea, and breathing symptoms may occur with or without any of these signs (Jenny & Logan, 1996; Zeppetella, 1998).

Although physiologically based, symptoms of breathing are not necessarily correlated with external, objective signs. Persons who were mechanically ventilated reported sensations of breathing discomfort, breathlessness, shortness of breath, and air hunger, despite normal vital signs, normal oxygen and carbon dioxide levels, and adequate tidal volumes (Jenny & Logan, 1996; Manning, et al., 1995; Powers & Bennett, 1999). Conversely, persons with airway obstruction, low flow rates, decreased tidal volumes, and abnormal blood gas values did not consistently self-report symptoms associated with breathing, including shortness of breath or breathlessness (Brand, et al., 1992; Chetta, et al., 1998; Moy, et al., 1998; Gift & Narsavage, 1998; Turner, et al., 1998). Assertions of necessary objective signs have demonstrated to be invalid (Jenny & Logan, 1996; Zeppetella, 1998). Yet when there was an absence of lactic acidosis, normal oxygenation saturation, and a lower heart rate than expected, complaints of shortness of breath have been described as "malingering for secondary gain" and "psychogenic dyspnea" (Wasserman & Casaburi, 1988, p. 506).

In addition to ratings of intensity, it is essential to obtain descriptors of breathing symptoms to assess the patient's respiratory status. For example, Moy and colleagues (1998) report that 8 of 25 persons with asthma were discharged from an Emergency Department with less than 60 % of predicted FEV_1. Seven of these 8 persons reported their shortness of breath as less than 1.5 on the Borg scale, however most continued to describe their breathing as tight or requiring work or effort. They concluded that these persons were not "poor perceivers," instead that "the language of dyspnea reflected the continued airways obstruction more clearly than the decreased overall intensity rating" (p. 752). Thus, although it is important to determine the presence and severity of the sensation (Kendrick, 2000), a self-report scale is insufficient to evaluate respiratory distress. Patients need to be observed, descriptors obtained if they are able to respond, and FEV_1 obtained.

It is recognized that the sensation of dyspnea is complex and multi-dimensional, with distinct experiences and differences related to physiological mechanisms (Mahler, et al., 1996; Zeppetella, 1998). There has been interest in subjective aspects of dyspnea, including possible differences in sensation experience. Govindaraj called for "information on the subjective aspect [and the] possible differences in the sensation experienced by subjects in different types of dyspneic states," but no one has yet addressed his query: "Is there any difference in the sensation of dyspnea between heart failure and emphysema, between asthma and pulmonary fibrosis?" (1987, p. 64).

Assessment and Evaluation

As a subjective symptom, dyspnea is evaluated through self-report, such as with the Borg Scale and a Visual Analogue Scale (VAS). The Borg Scale was developed to evaluate physical exertion and effort during exercise. Exertion is rated as a numerical value between 0 (nothing at all) to 10 (very, very strong – almost maximal). Persons select a numerical value which has a descriptor of intensity, such as 0.5 (very, very weak – just noticeable), 3 (moderate), 5 (strong), and 9 (very, very strong).

Borg commented that the scale "might be suitable" to quantify subjective symptoms "such as breathing difficulties, aches, and pain" (1982, p. 379). The Borg Scale was readily adopted and subsequently adapted to 'measure' numerous aspects of dyspnea. Two difficulties ensued. First, the scale was used without consistency between the intent and the descriptors. Second, contrary to Borg's assertion that "numbers should be anchored by verbal expressions that are simple and understandable by most people" (1982, p. 380), verbal descriptors are usually omitted from the scale.

Although Borg did not assert that breathlessness or shortness of breath could be reliably and validly measured with the category rating scale, the Borg Scale has become nearly a gold standard for measurement of dyspnea. It has been modified by numerous descriptors, including perception of breathlessness (Brand, et al., 1992), symptom tolerance (Chetta, et al., 1998), severity (in't Veen, et al., 1998), and discomfort (Moy, et al., 1998). Unfortunately, not only have the numerous modifications of this tool contributed little toward clarity or understanding of dyspnea, they are not always representative of the question. For example, *intensity* of breathlessness and *perception* of asthma symptoms was measured by a modified Borg Scale which was labelled *tolerance* of symptoms (Chetta, et al., 1998). Distress and intensity have inappropriately been substituted or exchanged. Patients were asked if they were "troubled by shortness of breath" but rated *intensity* through absence to maximal breathlessness (Brand, et al., 1992). Intensity of breathlessness was reported to be measured by rating symptoms from none to maximum bearable (Turcotte, Corbeil, & Boulet, 1990), which is more consistent with *distress* or *tolerance*.

A Visual Analogue Scale (VAS) is another self-report method used to quantify patients' symptoms. The usefulness of a Visual Analogue Scale was demonstrated in patients with asthma and chronic obstructive pulmonary disease (COPD) for ratings of shortness of breath, which were correlated to a numeric rating scale (Gift, 1989a; Gift & Narsavage, 1998). Important as these contributions are, there are weaknesses and issues in the use of the VAS for measurement of breathing symptoms, primarily related to inconsistency of terms. For example, dyspnea is most often *defined* as difficult or laboured breathing, but breathlessness or shortness of breath is reported to be *measured* (Gift, 1989a; Gift, Plaut, & Jacox, 1986). Gift (1989b) noted this inconsistency with regard both to differences in descriptors of breathlessness and shortness of breath and intensity rating. To date, in the majority of the published research, visual analogue scales and numeric rating scales continue to have different or conflicting descriptors attached to them.

In summary, a variety of subjective sensations, most often shortness of breath or difficult breathing, are translated, conveyed, and labelled as dyspnea (e.g. Gift, 1989a, 1991; van der Molen, 1995; Wilson & Jones, 1991a). Although it has been acknowledged that "breathlessness is a multi-dimensional symptom" and requires clarification of working definitions (Wilson & Jones, 1991a, p. 69), definitions and meanings of dyspnea remain unclear. Furthermore, descriptors of dyspnea are primarily determined from external and technical perspectives, without exploring meanings and interpretations from the perspective of personal experiences.

Understanding Breathing Symptoms

The paradox of the focus on assessment and measurement is that descriptions of breathing remain sparse and we have limited understanding of breathing symptoms from the person who has that experience. This gap has not gone completely unnoticed, as "a greater lacuna lies in the qualitative aspect of dyspnea ... with insufficient information on the subjective aspect" (Govindaraj, 1987, p. 63). Four studies were found in the literature in which descriptions were obtained through either semi-structured interviews (Brown, et al., 1986; DeVito, 1990) or open-ended questions (Govindaraj, 1987; Manning et al., 1995). Findings from these studies are particularly interesting in that each demonstrates the complexity of 'dyspnea' and need for further understanding due to inconsistencies of beliefs, practices, and experiences.

Apparently contradictory in their findings, these studies reveal the complexity of the experiences. When asked to describe 'the last time you were short of breath,' 29 of 30 persons with lung cancer used phrases about difficulty and effort of breathing, and about being tired or fatigued (Brown, et al., 1986). Descriptions of patients' feelings of being short of breath included coughing and wheezing (DeVito, 1990). Healthy persons on ventilators reported no sensation of breathlessness, yet had perceptions of air hunger and airway discomfort (Killian, et al., 1992). Despite the "widely prevalent acceptance that dyspnea in asthma is expiratory in character" held by clinicians, discomfort in asthmatics was experienced on inspiration (Turner, et al., 1998). These studies are significant both in their contribution to knowledge of breathing as a symptom and in the demonstration of the need for further research to understand and describe the person's subjective experience.

While recognized that nurses ought to understand the meaning of dyspnea for each patient (Roberts, et al., 1993), understanding continues to be overlooked in favour of measurement. Acknowledged that "dyspnea is a general term used to characterize a range of qualitatively distinct sensations" (Moy, et al., 1998, p. 749), there is no report of, much less consensus in, the literature as to what aspects and distinct sensations might be encompassed within that general term. Instead, emphasis is on measurement of a symptom of which we actually have very little understanding.

In pulmonary illness, breathing symptoms are prevalent, distressing, and contribute to health choices and quality of life. Decreased activities and quality of life are strongly associated with shortness of breath in cancer, lung disease, and heart disease (Bruera, MacEachern, Ripamonti, & Hanson, 1993; Jenny & Logan, 1996; Lee, et al., 1999; Lynn, et al., 1997; Roberts, et al., 1993). Breathing symptoms are cited as an important cause of suffering and disability in heart and lung disease (Roberts, et al., 1993), and linked to depression and possibly suicide in lung disease (Horton-Deutsch, Clark, & Farran, 1992). Some persons with pulmonary illness attempt to minimize the distress of breathing symptoms by decreasing their activities, resulting in two unfortunate consequences. Quality of life is reported to decrease due to altered activities and interactions, and an increased sedentary lifestyle leads to significant deconditioning and loss of muscle strength, assumed by person with pulmonary illness to be worsening of the disease (Burdon, et al., 1994).

In persons with asthma, perceptions and symptoms vary widely, and are postulated to contribute to undertreatment and near fatal attacks (Turner, et al., 1998). Breathing symptoms are not necessarily correlated to disease severity or objective measurements, yet labels are given and assumptions made, based on perspectives of breathing primarily from an outsider's perspective. Associations have been made between the severity of asthma and psychological disturbances, impaired perceptions, and lack of self-management (in't Veen, et al., 1998; Kikuchi, et al., 1994). It is asserted that near and actual deaths are due to denial, unrecognized psychopathology, and poor compliance (Kikuchi, et al., 1994; Turcotte, et al., 1993; Turner, et al., 1998). Yet how can perception of a subjective symptom be impaired? By negating patient perspectives, "we continue to discount the patients' report of symptoms...and insist instead that the caregiver is best informed about the ill person's needs and wishes" (Morse & Johnson, 1991, p. 3).

Little is known about experiences, perceptions, meanings, and interpretations of persons with chronic pulmonary disease. Gift (1987) put forward important research questions with regard to dyspnea: adaptation; progression; variation; components;

amelioration; and differences in disease and non-disease. Not only are there variations in experiences and descriptors for dyspnea, there may be other components needed for patient descriptors (Carrieri-Kohlman, et al., 1996; Gift, 1990). It is important both to nursing practice and patient perspectives of their illness and symptoms to define, delineate, and develop concepts, such as dyspnea, and to gain rich descriptions of patients' experiences for sensitive, thoughtful, and effective nursing care (Gift, 1990; Morse & Johnson, 1991; Morse, 1996). In 1980, Burki declared that "it is to be hoped that a better understanding of dyspnea will be achieved in the next decade" and that "specific therapy can be developed as it has for pain relief" (p.53). Nearly twenty-five years later, we continue to have limited knowledge of the symptom or interventions. It is both timely and necessary to increase our understanding of patient experiences.

To date, descriptors of breathing have been sparsely evaluated, primarily through investigation of predetermined descriptors developed by medical personnel (e.g. Moy, et al., 1998; Simon, et al., 1990). Relevant descriptors are necessary to describe and assess the variety of patient experiences and symptoms. Poor descriptors and assessment of health care professionals may impair assessment of breathing discomfort and unwittingly contribute to the acuity of the illness (Wasserman & Casaburi, 1988). Lack of understanding of symptoms of breathing inhibits assessment and interventions. Self-report surveys and interviews with cancer patients demonstrated that troubled breathing was unrecognized or unreported by nurses; inadequate assessment was related to gaps in nurses' interpreting and understanding the phenomenon (Roberts, et al., 1993).

Conflicting messages are given to clinicians who are urged to "be certain about the terms used to assess dyspnea" (Gift & Narsavage, 1998, p. 204) even though "dyspnea as a term does not easily lend itself to precise definition" (Govindaraj, 1987, p. 63). Symptoms need to be further described to gain understanding and sensitivity to the patient, and provide a basis for further exploration of duration and intensity of symptoms, and interrelationships among symptoms. Although assumed that 'dyspnea' is measured by self-report scales, this concept may, like pain or fatigue, require a multi-dimensional tool (Gift, 1987; Steele & Shaver, 1992).

In summary, although usually translated as shortness of breath, breathlessness, or difficult breathing, dyspnea has numerous meanings and interpretations by clinicians and researchers. Furthermore, despite the prevalence of chronic pulmonary disease, little is known of perceptions and perspectives of breathing symptoms experienced by adults with chronic pulmonary illness.

The Research Question

In the majority of the literature, the focus is on 'dyspnea' in persons with pulmonary illness, with the assumption that patients with pulmonary disease have some type of difficulty, laboured, or uncomfortable breathing. Some persons apparently learn to adapt, tolerate, or endure their disease process. Due to the significance of this symptom in illness, it is necessary to gain understanding of the meanings, clarify the language, and alleviate this symptom.

To further our knowledge, we must consider the limitations of objective data, put aside our assumptions, not simplify a complex and subjective symptom, and extend our understanding from patient perspectives. "To understand the patient's physical state, a nurse obtains measures of body temperature, blood pressure, and other indices. To understand the person requires the nurse to encourage his verbal disclosure of just what he is experiencing – his worries – his fears – his joys – just how the world seems to him, for he acts on the basis of how *he* sees the situation and the meaning it has for *him*" (Mathew, 1962, p.154).

A phenomenological approach is suited to uncover, reveal, and explore descriptors through meanings and experiences, and to appraise assumptions, clarify meanings, and increase sensitivity to experiences (van Manen, 1997). This study was undertaken to explore perspectives and descriptions of breathing symptoms. The population that was approached to obtain this data were those with moderate to severe chronic pulmonary illness. It was anticipated that this population would expand understanding of meanings and interpretations of dyspnea, and extend descriptors from patient perspectives. The phenomenological approach was expected to expand our knowledge of experiences of breathing in the chronic and acute phases of pulmonary illness, and to contribute to our understanding the extent of awareness and strategies for incorporation of symptoms into their daily meanings and activities.

The initial research question was 'What are experiences of breathing in chronic pulmonary illness?' As the study progressed, the question was expanded to 'What are experiences of adults with chronic pulmonary illness?'

Chapter Two

Approach to the Inquiry

As a nurse, I am particularly interested not only in the familiar acceptance of the body (Merleau-Ponty, 1962), but also disruptions in that state of being. Disease may lead to such a disturbance in our body; making us aware of that which is normally taken for granted. Reflecting on my clinical practice and observations, and the literature on pulmonary illness, I wondered: Does pulmonary illness disrupt the usual body awareness, the natural rhythm of breathing? Does breathing move into conscious awareness? What is it like to be short of breath? What perceptions and meanings occur?

Phenomenology is the method of choice when seeking to understand and elicit meaning of a phenomenon and the lived experiences of persons (van Manen, 1997). Hermeneutic phenomenology includes interpretation of the description: acknowledging that humans make meaning of the lived experience, and seeking to interpret that meaning through research (van Manen, 1997). For this study, a phenomenological approach was chosen to further our understanding of pulmonary illness by describing lived-experiences, both in the day-to-day being and acute episodes. This approach is expected to provide understanding and elicit meanings of a phenomenon within the context of everyday experience (van Manen, 1990; 1998) and strengthen connections between individuals' experiences and health professionals' practice.

Participants were deliberately sought who best represent living the experience. Clinical populations that maximize the phenomenon of breathing include persons with acute and chronic pulmonary illness. Chronic pulmonary illness was defined as ongoing, long-term lung disease. Participants had either asthma or COPD/emphysema. Excluded from the focus of study were participants with lung cancer, acute conditions, such as pneumonia, and extrapulmonary etiologies, such as cystic fibrosis and myasthenia gravis. Participants were primarily recruited through outpatient clinics to attain both variation and commonalities among participants, including age, gender, severity of illness, and etiologies. Sixteen persons with chronic pulmonary illness were interviewed, two of whom were interviewed a second time.

Participants with chronic pulmonary illness had either moderate to severe episodes of asthma or moderate to severe emphysema/COPD, as determined by pulmonary function tests. Consistent with the overlap and progressive nature of chronic pulmonary illness, several participants had a combination of conditions or diagnoses, such as asthma and COPD (See Appendix 1), or an additional diagnosis including bronchiectasis, chronic bronchitis, or pulmonary fibrosis. There were six females and ten males. The six persons with asthma as an exclusive diagnosis were between 35 and 60 years old, whereas participants with other etiologies were between 50 and 77 years old. All who had been diagnosed with emphysema had a history of smoking and were either on disability, unemployed, or had taken early retirement due to physical limitations; five were on home oxygen therapy.

Personal experiences, close observation, and phenomenological literature were also used as data. Two autobiographies and one book chapter were used for their descriptions of experiences with asthma: *Breathless: An asthma journal* (DeSalvo, 1997), *Catching my breath: An asthmatic explores his illness* (Brookes, 1994), and *Asthma as a personal experience* (Storr, 1979). Five persons with cancer, pneumonia, or heart failure were interviewed for contrast and comparison. Descriptions of breathing in health were also obtained for comparison.

Procedure and Ethical Considerations

Ethical review and approval were obtained through the Health Ethics Review Board, University of Alberta. In the clinics, the Registered Nurse informed potential participants of the study and provided them with an Information Letter; potential participants contacted me if they were interested in participating in the study. Consent to participate in the study was obtained prior to beginning the interview. Participants were assured of anonymity in the publications and presentations, that is, although quotations are used, neither names nor other indicators are revealed or associated with any data.

Gaining understanding of breathing was expected to require creativity, a wide lens, and diverse types of data that extended beyond my previous experiences or knowledge. The approach and question thus created the need to “go back to the ‘things’ themselves" through descriptions and observations (Husserl, 1900/2001, p. 88). Returning to the phenomena through descriptions of concrete, lived experiences reveals context and characteristics, and redefines them, enabling the task to "rediscover phenomena" through layers of lived experiences (Merleau-Ponty, 1962, p. 66).

Specific concrete descriptions of moments or times of awareness of breathing were sought through conversational interviews. The opening question was very broad: "Tell me about your breathing…" The conversation, research question, and ongoing analysis were used concurrently to guide questions in the current and subsequent interviews. Not only *intentional* wonder (Merleau-Ponty, 1962, p. *xv*) of "What is it like?" was used in the analysis, understanding was sought through contrast by reflecting upon experiences and language and asking "What is this *not* like?" For example, my perceptions and interpretations of what it is like to feel short of breath, are *not like* those experienced by persons with pulmonary illness. Reflection and comparison was enhanced by comparison of breathing experiences of persons who did not have chronic lung disease, that is persons in health, or with diagnoses of heart failure, pneumonia, or lung cancer.

Additional text for reflection and phenomenological analysis included close-observation, literature, previous personal and clinical experiences, and expressions of language. The latter were explored and reflected upon to reveal assumptions and interpret meaning. Close-observation was used as breathing is experienced bodily, subjectively, and holistically, and meanings are embodied through gestures. Thus understanding was sought not only through formal, verbal language, but physical expressions and gesture, and vocalization of breathing. Attentiveness to expressions and gestures of participants, personal clinical experiences, and diverse literature (both artistic and scientific) were used as text and comparisons to further understanding of experiences with pulmonary illness.

The open-ended, conversational interviews were audio taped with consent of the participant. The interviews were conducted at the place of the participant's choice, either in their homes or at the International Institute of Qualitative Methodology, University of Alberta. Most chose to be interviewed in their homes.

Demographic data were obtained from each participant, consisting of age, gender, level and type of education, marital status, number of children, occupation, brief medical history, and medications, including use of supplemental oxygen. When recruiting participants, I attempted to ensure that each participant was able to recall and describe in depth the experience of breathing. However, although participants were willing and descriptive in their conversation, their descriptions of breathing were not in-depth. This in itself revealed aspects of the taken-for-grantedness and habitual nature of breathing. Data collection and analysis overlapped, with analysis beginning after the first interview. Collection of data was discontinued when no new themes or ideas emerge from the interviews, and there was enough data for a full and rich description of breathing in these chronic illness experiences.

Research Perspectives and Analysis

Phenomenology as research is the study of experiences of life, through attentive thoughtfulness, wondering, conversing, reflecting, and writing (van Manen, 1997). The philosophical underpinnings for this analysis were from perspectives of Husserl (1900/2001) and Merleau-Ponty (1962; 1964). Phenomenology was understood to be a systemic and logical description: "This phenomenology must bring to pure expression, must *describe* in terms of their essential concepts and their governing formulae of themes" (Husserl, 1900/2001, p. 86). Through description and reflection, phenomenological analysis explicates meanings (Husserl, 1900/2001; Merleau-Ponty, 1962). In this phenomenological analysis, central meanings were extracted and refined to relay themes of the experiences. Themes were viewed as unifying ideas and central meanings of the experiences, and are not necessarily *essential* to all participants.

This phenomenology as research included phenomenology as philosophy. Philosophical understandings from Husserl (1900/2001; Zahavi, 2003) and Merleau-Ponty (1962; 1964) were like a light that provided focus, attention, and contrast to enable the analysis, reveal assumptions, and delineate themes and themes. Perspectives from Merleau-Ponty (1962; 1964) provided insight into the body with pulmonary disease and contrast to the body in health. Reflective analysis on these lived-experiences included the existential philosophy of Merleau-Ponty, through considerations of the body, the body in the world, aspects of body-awareness, and body subjectivity-objectivity (Merleau-Ponty, 1962; 1964; van Manen, 1998).

One aspect of phenomenological reflection is the examination of our previous understandings, assumptions, and presuppositions. During reflection and analysis, the natural attitude of culture and tradition was continually examined: at times set aside, at other times suspended. In this analysis, there was purposeful and ongoing consideration of my assumptions as a nurse and a researcher. In addition, assumptions from the literature and of participants were reflected upon for comparison and contrast. In this approach to human science, phenomenological reduction was an ongoing endeavor to examine, scrutinize, and reflect upon these participants' lived-experiences of pulmonary illness, and explicate themes and themes.

Research Approach

The approach of van Manen (1997) was used for the analysis, which includes six interactive aspects for the inquiry and analysis of the data: Orienting to the phenomenon and explicating assumptions and pre-understandings; investigating experiences as lived, through conversational interviews; conducting thematic analysis and interpreting through conversation; attending to writing; writing in a strong and oriented way; and balancing parts and the whole. Thematic analysis was undertaken through the reflection process to uncover themes, elements, and motifs of the experience. Descriptions from language, including metaphorical analysis, were analysed for meanings and assumptions.

Interviews were transcribed and then read to ensure accuracy. Written descriptions and notes were typed, then verbal and written text analyzed through reflection and writing, with conversations with committee members, comparison of experiences, and consideration of phenomenological data, including literature.

The first aspect of analysis includes bracketing knowledge and assumptions that I held about breathing in illness. Despite my assertions of holistic thinking and mind-body connections, I initially directed my focus of attention and interest on 'breathing' in pulmonary illness, whereas participants spoke also of whole body experiences. After two interviews, it became apparent that experiences of pulmonary illness extend beyond 'breathing' symptoms. Subsequently, the question that guided the study expanded from 'experiences of breathing' to 'experiences of pulmonary illness.' Thus, the opening question of the interview was broadened to expand experiences beyond 'breathing' and I then took cues from the participant.

Meaning was explored through analysis to develop themes. The text of each interview was attended to as a whole and as main aspects of the whole. Phrases were noted that reflected or revealed aspects of the experience. Detailed attention was given to sentences about their meanings. Phrases were highlighted and notes made on each transcribed page. Anecdotes of participants' experiences were then written.

Approaches of intentionality, reduction, and reflection are necessary for a rigorous phenomenological science (Husserl, 1900/2001; Merleau-Ponty, 1962; van Manen, 1990). Intentionality is the conscious and purposeful orientation of the researcher's attention to the question and the phenomenon. Through reflection, the researcher becomes conscious and aware of present knowledge and assumptions, and is open to analysis. Reduction is the researcher's openness to gaining insight into diverse experiences, revealing themes, and making meanings explicit. In part, an attitude of wonder is adopted (Merleau-Ponty, 1962), subjective experiences and personal assumptions are examined, and pre-supposed theories, definitions, and concepts are set aside for comparison. The third aspect, reflection, is an active attitude and effort to grasp meanings, to describe, to comprehend, and to understand. We "practice reflection" (Husserl, 1900/2001, p. 90) through distance, description, and continuous regard, questioning, and comparisons. I contrasted and compared experiences and meanings, asking questions such as: 'What is that? What is it like? What is it not like? What is the underlying meaning of the text or description?'

The analytical research process of writing and re-writing was used to explore layers of meaning. Writing creates a reflective stance, a distance of thoughts and a necessity to re-interpret those words for understanding. Through analysis, distinctions and similarities were noted within and between experiences. Themes were articulated through reflection on contradictions, ambiguities, and differing aspects, and with ongoing awareness of assumptions, questioning of personal experiences, and attentiveness to participants' descriptions. To maintain a stance of orientation and intention to the research question, I upheld the overall question and subsequent areas of interest in the forefront of the study. The interviews were listened to and reflected upon to ensure that I had stayed attuned to the question and topic, alert to emergence of themes and insights, and open to the unexpected.

Throughout my analysis, I recorded notes and saved copies of the systematic process which enabled clarification of assumptions, reflective thinking, consideration of experiences, development of insights, and grasping of meanings and themes. Reflection on participant descriptions and additional text was ongoing throughout the analysis. As an example of analysis, I recall several months of struggling with a notion of 'limitations' and being unsure of the theme, the meaning, significance, and continuity. Re-reading thoughts on the body by Merleau-Ponty (1962) and then re-listening to an interview, I heard and understood a phrase that captured these experiences. *Doing less* was then developed as a theme to describe experiencing *The Body-in-the-World.*

To establish rigor of the phenomenological perspectives in writing and rewriting, I attended to the language of my writing and the participant descriptions, maintaining a wondering and questioning tone rather than a declarative tone. I strove to avoid adopting 'external' perspectives, such as nursing jargon, psychological analysis, scientific perspectives, and popular or politically correct phrases. The analysis and writing was tied to concrete experiences, such as using phrases and descriptions from the participants in both examples and development of themes. In this manner, I adopted a continuous regard for the lived-experiences, analyzing and describing with an "unnatural attitude" of questioning and wonder, adopting the "phenomenological thought-stance" (Husserl, 1900/2001, p. 90).

At times this stance of attending to language was difficult as participants used medical terminology to express aspects of their experiences. Later it became apparent that although the terminology may be common, underlying meanings and understandings were not. For example, participants described a decrease in "vital capacity" which was with regard to their capacity for activities of life, not the scientific meaning of lung volume.

Throughout the analysis and writing, I struggled with my inability to relay the distress, frustration, and effort of the participants' described and observed experiences. At times I wanted to present their interviews in their entirety, which might have resulted in interesting data, perhaps even stories, but would have fallen short of the analytic work of phenomenological inquiry. Acknowledging the difficulty and necessity to communicate results as a source of knowledge and to advance research (Husserl, 1900/2001), I continued in the work of reflection and writing as both process and product of phenomenological research.

Breathing has an intimate relationship with speech and expression. As children, we learn to pace our breathing and speech with ease, not conscious of the need to conserve air or parcel it out to complete a sentence. Learning to sing, we are more conscious of the relationship between breaths and voice, avoiding running out of air or taking loud breaths. Writing is not only an expression of thoughts and emotions, but an expression of the body. My usual writing style is that of long sentences, perhaps separated by colons or semi-colons; paragraphs that wind their way from one page through to the end of another. Reading my written text out loud forces me to stop and insert periods, as I could not pace the written words with the normal flow of speech, the long sentences and paragraphs leaving no time to inhale. In contrast, in this study, I found myself adopting the style of the participants. My writing became more abrupt. Perhaps wanting to recognize and capture their style of speech. The necessity of pauses to breathe and get more air before continuing on with their thought.

In a sense, this style of writing is a way of being with and expressing the limits of air in pulmonary illness. Partly adopted consciously. Partly unaware of the change in style. But is it only in speaking, in expressing that words are saved? Pauses made? Or perhaps the style is an embodiment of the illness, as DeSalvo describes:

> After I get asthma, I start writing very short sentences. Then I start fracturing my sentences. Like this. A friend tells me that my new way of writing is driving her so crazy, she can't read my stuff anymore. I sound like a moron. A sixth-grader. Can't I please, go back to writing the way I used to? For a couple of days, I try. I pull some sentences together; try semicolons, my by-no-unfamiliar friend. But it's impossible. My body, my breathing, are different. So my writing is different. I'm not the same self I once was. Not the self who can take in enough air to exhale long, deep, complex sentences. These sentences that chop and sputter their way through space are the only ones I can write now. (DeSalvo, 1997, p. 152).

There is an abruptness to this type of conversation that contrasts with the slowness of speech. With limited air, nouns, adjectives, and even verbs become less necessary or possible. Sometimes thoughts not able to be expressed in a complete sentence. Running out of air talking on the phone. Needing to inhale part way through the sentence. I find myself adopting the style in my writing, some ‘sentences’ are without verbs. Thoughts expressed within the limitations of pulmonary illness. To convey the experiences.

Overview of the Analysis

Themes of this phenomenological analysis are addressed in the next five chapters. Perspectives from Merleau-Ponty (1962; 1964) were used to convey experiences of persons and organize chapters; themes are expressed through words of participants. Aspects of experiences with chronic pulmonary illness include:

- Awareness of breathing and the body.
- Sounds, sensations, and signals.
- Experiences of breathing.
- Experiences of the body-in-the-world.
- Expressions of breathing.

Chapter Three

Awareness of Breathing and the Body

How do we usually experience our body? Moment by moment, day by day, most of us are not aware of or notice our body. Can you recall a recent experience of walking across the room, or perhaps sitting down in your chair? Perhaps it was only a few moments ago, but do you remember how your body felt? The movement of your arms and legs? Your sense of balance? Did you notice your breathing? Can you recall how quick it was? Whether it was loud or quiet? Perhaps you did not notice your body or breathing; your attention instead directed to the person or object that you were moving toward, or the thoughts and conversation you were having.

The person-embodied lives through time and space in immediacy and spontaneity, not continuously reflective of or about body actions or sensations. In this manner, life is lived moment-to-moment within the phenomenological or habitual body the self moving with motor, sensory, and perceptual habits with little conscious awareness of the physical body (Merleau-Ponty, 1964). Many aspects of the habituated body are unnoticed. Awareness of our body is nearly forgotten, continuously and silently passing under our conscious awareness, *passé sous silence* (Sartre, 1956).

In this ongoing mode of near self-forgetfulness (Sartre, 1956), the body is like a familiar presence, not needing to be noticed. We do not need to 'listen' to our body as we move through the world. We do not usually 'hear' our body as it maintains our being. In the moments of life, our body is usually unheard, not actually silent, yet not speaking or calling for attention. We are able to freely direct our intentions and attention outward, not toward the physical body (Merleau-Ponty, 1962). In this preobjective manner of being in the world, we live *through* and *in* our body, able to take our body for granted and engage our attention toward our activities, interactions, projects, and others (Merleau-Ponty, 1962, p. 92). The common and continuous sounds and sensations of our body go unnoticed.

It is not only the body that is not noticed or given attention. Much of our inward and outward world is unnoticed or ignored. Passing over our conscious awareness, other times moving into awareness. As I stop for a moment and reflect on this thought, I look up at our grandmother clock, seeing the pendulum swinging gently. Marking the passage of time. Only now do I hear the quiet tick-tick of the pendulum. A moment ago, although it was not silent, it was unheard by me. I think about times I have purposefully waited for the clock to chime the hour, only for it to slip by unheard or unnoticed. At times I even wondered if the clock had stopped. Then realizing, no, it was not silent. The sound of the chimes had gone unnoticed and now could not be recalled.

I recall a recent story of an acquaintance trying to sleep in her grandparents' living room. The continuous ticking and intermittent chimes of the several clocks that went unheard in the daylight became unbearably loud as she tried to sleep. She got up and crept around in the darkness, trying to find and silence each one. In those moments of heightened awareness, she could not ignore the sound of the ticking nor disregard the chimes. My thoughts return to the clock in my present space, and I realize that I have not heard its ticking or quarter-chime as my attention has gone to this memory. Perhaps this is how we experience some sounds and sensations of the body. The body is not literally silent, but unheard and noticed in the moments of life, until our attention is directed toward it.

Breathing is one of the many aspects of the body that is taken for granted. The awareness of breathing is somewhat of a paradox. Ongoing and repetitive, most breaths go unnoticed. Others are given attention and regard. We watch and listen for 'the first breath' of a newborn and for 'the last breath' that indicates life has ceased. As a mother and nurse, I have closely watched the breathing of ill children and adults. Listening in the darkness for the quiet breathing of a child drifting to sleep. Breathing rapidly in synchrony with the patient on a ventilator. Standing at the bedside with a family member, waiting and watching for the last breath.

In a lifetime between these 'first' and 'last' breaths, we take hundreds of millions of breaths in and out. At rest, adults breathe in and out about 16 times a minute: every minute of every hour, day, and year. A remarkable number of breaths. A thousand breaths an hour, 24 thousand a day, 10 million breaths each year. Most often, these breaths go unnoticed. We are not usually aware of our lungs inflating and deflating moment by moment. We do not notice the small effort of muscles contracting and relaxing. We do not often pay attention to the depth or interval of our many breaths. We do not consciously perceive the effort of respiratory muscles contracting and relaxing. We do not feel the flow of air in and out. Even if our breathing is not literally silent, it may be unheard by Self. We can go through a whole day without hearing, noticing, or paying attention to breathing. In contrast, a person with asthma may suddenly notice and reflect upon their breathing, feeling interchanged with hearing:

> On Sunday night I wasn't sleeping well. Over perhaps forty-five minutes of turning from one side to the other the sensation grew. Which is odd in itself: what was I actually *feeling*? After all, the muscles are there all the time, flexing and contracting, I suppose. Why don't we feel our breathing all the time? Or would that be too much background noise? (Brookes, 1994, p. 145).

Indeed, it would be too much noise to feel or hear the sounds of our breathing. Moment by moment, breath by breath. To be aware, to feel, and to constantly hear our body would not only be background noise, but intrude into the foreground. Such a disruption of the usual silence of the body. I try to imagine hearing every breath, feeling every heart beat, noticing my body sitting, standing, or lying. How cumbersome that would be. How tiring to have so many sensations felt, heard, noticed.

When I take in a big breath and audibly exhale, I may not even notice. Or I may feel the change in breathing or hear myself exhale. Or it may be a sigh that goes unnoticed. When that occurs, do I actually *experience* my breathing? Or am I experiencing changes in being that occur? The breath reflective of a thinking about my schedule, not an indicator of lung function or body activity.

Breathing is usually involuntary, the rate and depth of respiration regulated by independent autoregulatory respiratory centers. The regulation of breathing is of "*vital necessity*" (Buytendijk, 1974, p. 280); necessary for life, breathing is orchestrated by involuntary or voluntary centers in the brain. Located with other primary functions in the brainstem, breathing is dependent upon body needs and balances. Chemoreceptors respond to oxygen, carbon dioxide, and hydrogen levels. Regulation of chemoreceptors by the respiratory centers is neither perceived nor noted in our conscious awareness. Information is sent to the respiratory centers to modify breathing rate and depth.

Breathing is altered by activity, emotions, and events through these 'involuntary' centers, although not with deliberation, by choice, or even awareness. Control of breathing has been arranged to be automatic, unless we need or choose to alter it. Without delay, such as when a person is anxious or exercising, breathing is quickened. Awareness of person or existence is not required to breathe (Buytendijk, 1974). We do not have to be aware of the triggers that change our breathing. Indeed, we may not even be aware of the change. But breathing is more than the movement, rate, and volumes of the lungs. Not limited to a physical event directed to optimal balance of gases, "*man* himself breathes" subjectively (Buytendijk 1974, p. 281). Noticed or unnoticed by self or others, pre-reflective or reflected upon, breathing is an experiential aspect of being human.

The taken for grantedness of breathing is similar and dissimilar from the awareness of the body and other body functions. At any moment we can focus on or think about our breathing. Unlike the rhythmic beat of our heart, we may voluntarily interrupt the rhythm of our breathing. Interrupted, not stopped, we may hold our breath for a moment, but then soon must take another breath. Through voluntary centers in the cortex, we can alter the depth, rate, speed, timing, and sound of our breathing (West, 2000). Consciously changing our breathing so that it is noisier or quieter. Faster or slower.

Breathing is supportive and sustaining, necessary for body motion and life in this world. What if voluntary breathing was required? Imagine walking with a leg in a cast and having a continual attendance to and reminder of each required movement. Imagine how cumbersome it would be to deliberately plan and control breathing. What if breathing becomes noticed and loud, interrupting our being? When it is louder or faster than usual, it may become noticeable to self or Others. A high school student describes his awareness and attention to breathing. He *notices* his breathing, and feels he is *noticed* by others:

> I'm running down the hall. I've got to get to class. I'm not thinking of breathing. I go into class and I sit down. Everybody's quiet. Now I become aware of my breathing. If I really cared about not being noticed, I wouldn't be that loud, so I wouldn't feel like everybody is looking at me. In church, I can keep it quiet by paying attention to it, until I forget about breathing because it's normal.

Each breath watched and attended to until breathing recedes into the background, into normal. Quiet, shallow, slow, easy breaths are again unheard. No longer given any attention or notice.

We can become aware of our breathing, but can we 'be aware' of our unawareness of breathing? As I consider this question, I *become* aware of my breathing. I am aware of the groups of muscles that I use for each breath. I hold in my abdomen and breathe with my shoulders, then relax and breathe with my abdomen. I am attentive to the rise and fall of my breasts as my lungs fill and deflate with air. I am mindful of the air flowing down the increasing number and diminishing size of airways until it reaches the alveoli. In my mouth and throat, I feel the 'fresh' air that takes oxygen to the alveoli. I envision oxygen molecules diffusing immediately across the surface area as large as a tennis court. I marvel that a billion molecules of oxygen cross from the alveoli into each red blood cell to bind with hemoglobin.

Imagine, with each breath, billions of oxygen molecules move into thousands of red blood cells. In a quarter of a second, oxygen attaches to one of the four waiting iron arms of hemoglobin until nearly 100% are connected. With knowledge of biology and physiology, through reflective awareness and mindful action, I am attentive to the technicalities and wonder of breathing. But what of the subjective and experiential? What meanings and interpretations and perceptions are held?

I have now become very aware of my breathing, as you may be at this moment of reading. I cannot purposefully and voluntarily move back to being *unaware.* I wonder, can I breathe 'normally' while being aware of breathing? My breaths change. I slowly count as I breathe in. I notice that the time for breathing out is longer than breathing in. I breathe slower and deeper. My focus on breathing is moved to the foreground and other elements have receded to the background. I breathe. In and out. Can I be aware of my breathing without creating a change in breathing? It seems that as soon as I attend to it, it moves from the pre-reflective into a reflective experience.

Can we recall an experience of breathing when it was taken for granted? When it was pre-reflective? I can remember being at a coffee shop with my friend one morning several months ago. I can recall in detail the chairs, the music, the waitress, the taste of the coffee. Yet, when I try to recall my breathing, I can't remember it at all. I can remember walking to work last fall, the smell of leaves, the noise of traffic, but I don't remember my breathing. I can reflect on and describe my emotions, thoughts, and ideas in these moments, but not my breathing. When I look back, I am somehow aware that it was ordinary, nothing to remark upon or take note of.

I can recall experiences of breathing when I had become aware of it. I can remember walking quickly to an appointment, hearing myself breath loudly, feeling my chest hurting a little, thinking about being out-of-shape after a winter of sitting while reading, writing, and reflecting. Moving from pre-reflective awareness into reflective awareness, my perceptions of breathing were interpreted within the context of my whole body and self. When we *recall* an experience, we call it back or bring back memories of the experience into our present thoughts. How can I *call back* the sensation or experience of breathing that silently passed by completely unnoticed, experienced in my body but given no first thought or conscious awareness?

When breathing is brought to our attention by the body or by others, we may immediately notice and recall it. When student nurses are taught to assess breathing, they are reminded, 'Don't tell patients that you are going to count their respirations.' This caution is not intended to hide the task of counting breaths per minute, but to make the count more accurate. When the patient becomes aware of the observer counting, breathing is immediately noticed, and the rate and depth are often altered. It appears that as soon as we are nudged to thinking about or being aware of our breathing, it then changes. It is as if we cannot evoke our pre-reflective experience of breathing.

Although not heard in our conscious awareness, the body is not actually silent. The body is, in some sense, 'speaking' in our moment-to-moment being in the world (Merleau-Ponty, 1962). Sensations from the inner and outer world are not merely 'received' by the body; sense-experiences communicate between the body and world, making it a familiar setting of our life (Merleau-Ponty, 1962). In this study, the term sense-experiences is used to describe experiences of awareness or noticing the body within a context of place and time. Sense-experiences are interpreted as more expansive than sensations, which are included within sense-experiences. For example, tightness of the chest is both a sensation and a sense-experience, wheezing might be better understood as an auditory sense-experience, and not keeping up a spatial sense-experience of the body in the world.

Although the body is unnoticed and unheard, it is not consciously ignored nor is it actually silent. Sensations of the body are just beneath or in the background of our conscious awareness. When we are disrupted or consciously attend to the moment, we move from this pre-reflective awareness of our body (Husserl, 1900/2001, p. 207). In that moment, for perhaps only a moment, we become aware of our body, our mannerisms, or movements. We may even say we become *self-conscious.* Consciously aware of our body, our physical actions or movements, of the self in our body and in the world. At other times, we may purposefully focus our attention on our body, such as when learning a new activity or slowing down breathing to relax.

When obtaining descriptions of breathing from healthy persons, breathing in its taken-for-granted, pre-reflective state was not recalled or described. Descriptions of experiences were of moments when breathing came to their attention: times when breathing was deliberately thought about; times when it was difficult or unusual. Nor did participants with pulmonary illness describe breathing when it was unnoticed. Descriptions of experiences were when breathing was disrupted, noisy, or brought to their attention. It is only in the moments when "taking note" of the sensation that their experiences become "objections of inner perceptions" (Husserl, 1901/2001, p. 209). They then may be assessed, discussed, reflected upon, and described.

Breathing, Wheezes, and Cough

With pulmonary disease, breathing may be noticed either when it is heard or felt. Breathing may be noisy, or wheezes or cough may occur. Each of these sounds has physiological and physical understandings that may or may not coincide with the phenomenological experiences.

Pulmonary disease is often categorized as restrictive and obstructive (West, 2000). In restrictive disease, air is restricted from entering the lungs, resulting in decreases in vital capacity, tidal volumes, and total lung capacity. There are numerous etiologies of restrictive disease. Some arise from the lungs, such as fibrosis; others are structural, such as scoliosis. An increase in elastic work is required to overcome static recoil pressure and expand the lungs. Even with increased effort and work, tidal volumes are limited, and minute volume is more dependent upon respiratory rate.

Obstructive disease has fewer etiologies, with COPD/emphysema the most classic cause. In this type of etiology, air is obstructed from exiting due to damaged airways and loss of elasticity. Increased effort is required to exhale, increasing the dynamic compliance and further inhibiting expiratory air flow. Small airways collapse and air is trapped, resulting in increased residual volumes. The trapped air continues to diffuse oxygen and carbon dioxide, decreasing the alveolar oxygen pressure and gradient. Collapsed airways may not reopen, further trapping air, and increasing dead space. Not only is alveolar ventilation compromised, diffusion is impaired due to alveolar and capillary damage. These factors result in significant mismatches in ventilation and perfusion.

These categories are not discrete. Inflammation, mucous, and bronchial constriction of asthma tend to obstruct air from both entering and exiting, and restrict chest expansion and tidal volumes. In either category of pulmonary disease, exertion increases respiratory rate and work of breathing to meet the body's oxygen needs. These increases in rate and effort increase the demand for oxygen, and may no longer 'match' the body requirements.

Wheezes are an audible whistling sound that is heard either on inspiration, expiration, or both. They are rarely heard in health, although they may occur with forced expirations. Wheezes may be so quiet that they are only heard with a stethoscope, or be loud enough to be heard easily by another. An adventitious or extra lung sound, they are due to narrowed airways, such as bronchoconstriction or mucous obstruction. Numerous etiologies may result in wheezes, but most often they occur in asthma or obstructive lung disease (Meslier, Charbonneau, & Racineux, 1995).

Cough is a sound and sensation that is not limited to pulmonary disease. Defence mechanisms of the lungs protect the body from harmful substances by coughing or sneezing, alert the body through smell, and defend the lungs with cilia, mucous, macrophages, and bronchoconstriction. The cough reflex is complex, and little is known about the physiological, neurological, or anatomical aspects. In addition to cough, the defence system includes the muco-ciliary system and bronchoconstriction, that is, narrowing of the airways. Cilia are small protrusions that move particles up the airways. Mucous production both initiates cough and enhances removal of the irritant or foreign substance. Bronchoconstriction is postulated to promote coughing by increasing the velocity of air flow. Mucous production and bronchoconstriction are elicited by different pathways and receptors than coughing, but irritants may trigger the three to occur simultaneously.

Cough is a forceful exhalation, occurring involuntarily in response to stimulation of cough receptors in the airways. As a reflexive and defence mechanism, coughing ejects foreign substances, objects, or toxins from the respiratory tract. Although most commonly activated by mucous, toxins, or irritants in the airways, the cough reflex can be initiated by a variety of stimuli, including large breaths, severe hypoxia, cold, or heat (Widdicombe, 1989).

There are a variety of mechanical and chemical cough receptors located throughout the lungs, from the trachea to the small airways (Braunwald, 1994). Although less numerous in the small airways, receptors in these airways may be more sensitive (American College of Chest Physicians, 2003). With time or exposure, cough receptors may adapt and become less sensitive to irritants. It is hypothesized that there are numerous cough receptors outside the airways, because cough may be triggered by pressure in the eardrums, sinuses, pleura, diaphragm, and stomach (American College of Chest Physicians, 2003). The neuroanatomical pathways of the cough reflex are debated, but the vagal nerve is postulated to carry impulses to induce coughing to a diffuse cough 'centre' in the brainstem. The motor response to the reflex is transmitted through the phrenic and spinal motor nerves to the respiratory muscles.

Cough has been described as a "concrete" symptom because the "subjective sensation is accompanied by an objective manifestation" (Kroenke & Harris, 2002, p. 801). Thus from a health care perspective, "cough can be a sign as well as a symptom" (Irwin & Madison, 2001, p. 813). Several participants perceived cough to be expected with smoking or essential to clear secretions, thus cough is not necessarily interpreted as an indicator of disease or experienced as a symptom of illness.

We can voluntarily cough, taking in a deep breath and forcefully exhaling. Taking deep breaths and coughing post anaesthesia and surgery clears toxins, but more so increases alveolar ventilation and re-expands the lungs. Coughing can be replicated voluntarily. We might 'fake' a cough, 'pretend' to cough, or 'force' a cough. A deliberate cough may be used as a signal – to announce one's presence in a room, to discretely gain attention, or to interrupt a conversation.

Whether voluntary or involuntary, the ability to cough depends upon many factors such as muscle strength, cognition, and pain. The force of the cough depends largely on the volume of inspired air and the force of expiration, which requires effort to create static recoil pressure. The larger volume of air stretches the expiratory muscles and increases the force of exhalation. Cough is beneficial in clearing secretions, except those initiated by irritants, not mucous production. When mucous is removed, it is then described as an effective or productive cough. Thus, coughs are classified as effective/non-effective, or productive/non-productive, depending upon whether mucous is expelled.

The effectiveness of the cough is largely dependent upon two aspects: the ability of the person to increase lung pressures, volume, and flow; and the consistency of the mucous. High volumes on inspiration and high pressures on expiration are required to maximize flow through the airways (West, 2000). Clearance of mucous is not only dependent on air flow, but also the amount and viscosity. Weak inspiratory muscles will decrease the volume inhaled and force exhaled. If the mucous is too viscous, or the cilia are inhibited, movement of mucous into the larger airways is limited. In chronic pulmonary illnesses, respiratory muscles may tire, cilia are inhibited or destroyed, and more viscous mucous is secreted in excess. Each or any of these will result in a prolonged but less effective cough effort to remove the mucous.

Breathing Awareness

As breathing rate and depth are automatically controlled by the brainstem, it is considered 'normal' to *not think about* breathing (West, 2000). Indeed, in the moments of life, we *normally* or *usually* do not think about, attend to, notice, or control our breathing. Rate and volume are adjusted in response to levels of carbon dioxide, hydrogen, and oxygen. In this manner of being, there is a familiar acceptance with breathing and with the body (Merleau-Ponty, 1962), and there is no first or second thought given to breathing.

What is *normal* about not thinking about breathing? Is it *not needing* to notice nor attend to breathing that is normal? Is it that it is *not normal* to think about breathing, or do we *normally not think* about breathing? It seems to be normal to not have to think about breathing, or have to consciously increase or decrease our breaths to meet the moment-to-moment demands for air exchange.

Possibly 'not thinking about breathing' is that we do not notice when breathing is ordinary. I might become short of breath while climbing a couple of set of stairs and notice my breathing, but I don't really have to think about it, control it, or monitor it. Taking rapid or deep breaths I might say that I'm 'out of breath.' Breathing is not quite ordinary in this moment. It is noted and remarked upon. But is it not still normal? On the contrary, in this context, my perception is that feeling short of breath *is* normal, expected, and usual. The increased rate or depth of breathing is interpreted as normal.

What does it mean to 'think about breathing'? Or 'not think about breathing? Is it that we don't *have to* voluntarily control breathing or consciously don't notice breathing? For at times we may choose to think about our breathing. In relaxation or meditation 'exercises' there is often a conscious awareness of breathing, and it is normal to control or notice our breathing. In activities such as Yoga, Pilates, or Tai Chi, breathing is purposefully focused upon, and the person consciously alters depth and rate.

It is not necessarily *abnormal* to focus on breathing to control the rate or depth, to synchronize it with an activity, or to relax. Athletes may focus on their breathing before or during the event. Conscious awareness of breathing is used to gain control and improve performance. When I explored breathing in health, this person described her attention to breathing when swimming. Her breathing is consciously brought to the foreground of her awareness, focused on to synchronize with her body movements:

> Cold water makes me breathe faster so I ease my body slowly into the water. Slow down I tell myself. I push off the end of the pool and start to warm up. I am completely aware of my breathing. Don't exhale too slowly and miss the timing. Don't exhale too quickly and lose the oxygen. Don't swim too quickly and lose too much energy. I am concentrating solely on my breathing. My body shoots through the water like a torpedo. My fingers dip back into the water; I count 'one' and force the air out through my nose. My body passes through bubbles of

> escaping air. My left arm reaches forward. 'Two.' All the air is gone from my lungs. My body rolls slightly to the left, I turn my head to the right and breathe in. 'Three.' I continue to count, 'One, two, three, one, two, three' to get into a rhythm and to relax.

In this experience, breathing is not taken for granted. Breathing is purposeful, with a concentration on rate, depth, and timing to maximize efficiency of the body. Each breath is coordinated to body movement. There is a conscious attentiveness to slowing down and pacing the breaths, to save energy and time. This attentiveness lends toward establishing a rhythm of breathing with the actions of the body. Another person describes thinking about breathing:

> Usually, breathing is like your heart, you don't have to think about it. In swimming or running, you have to think about breathing. When I'm going for a run, at first I have to be aware of my breathing. I regulate it in tune to my stride, to get into a groove. Later when I'm running, I'm still pretty aware. All I can hear is my breathing. It's the only time I hear myself breathing. It's intrusively loud. It's in my head. I keep my stride. It's what I'm most intensely aware of.

What does this runner hear? His breathing? Or his breathing in pace with his body. He does not seem to *run out* of breath, but *run to* the rhythm. Many runners learn to pace breathing and stride. As with the swimmer, this runner describes breathing as a rhythm for his body. Breathing is like a metronome, in which his stride is regulated with a rhythm. He uses musical phrases: "in tune", "into a groove". Attuned to the body and in tune, breathing *paces* and is *in pace* with the body. We speak of the body as being in tune (Buytendijk, 1974; van Manen, 1999) when harmony and rhythm are attained.

In Husserl's notion of *anormality*, an experience clashes with that which is anticipated, typical, or usual (Zahavi, 2003). In pulmonary illness, breathing sounds may be noticed when they are not usual or typical. Noticing breathing moves from that of the lived-experience into an object for reflection and interpretation. In chronic pulmonary illness, coughing, wheezing, and breathing may be noticed and reflected upon. In the next chapter, I explore sounds and sensations of pulmonary illness, and how they are perceived and interpreted.

Chapter Four

Sounds, Sensations, and Signals of Pulmonary Illness

In contrast to experiences in health, participants with pulmonary illness speak of sounds and sensations of breathing within the context of the unusual and abnormal. The body metaphorically and literally loses its silence. The body calls attention to itself through sounds and sensations of breathing, coughing, and wheezing. Sense-experiences such as chest pressure, tightness, or pain are experienced. The person moves out of the lived experience into a self-reflective awareness of the body. Sounds and sensations are reflected upon, interpreted, and meanings and significance are given. Themes of sounds, sensations, and signals of the body are *Noticing Breathing and the Body, Interpreting Normal, Revealing the Invisible,* and *Demanding Attention.*

Noticing Breathing and the Body

When breathing and body sensations are noticed, they are interpreted with various meanings and perceptions. Before diagnosis of chronic pulmonary illness, breathing may have been noticed and interpreted as normal within the context of meanings. As the disease worsened or upon diagnosis, meanings and interpretations changed. Themes of *Noticing Breathing and the Body* are:

- Never thought anything about it
- I can feel it
- Much more aware
- Clearing my throat

Never Thought Anything About It

As we move day-to-day in our healthy, habituated self, sensations are perceived and interpreted within a number of possibilities regarding context and history (Merleau-Ponty, 1962). Body sensations, such as breathing quickly when walking quickly up the stairs, may be noticed and their significance and meanings interpreted. Perhaps the sensation is considered to be normal and "not given a second thought." Sensations may be ignored when considered to be temporary or ordinary, such as "flu-like symptoms" experienced by Jake:

> I was staining a friend's deck. And I'd be out there pushing the roller and finding I was stopping more and more often. And I'd have to stop and go sit in the shade for quite awhile. And I just thought, 'Here's these flu-type symptoms showing up again in the middle of the summer.'

With chronic pulmonary disease, sounds of breathing or sensations of the body may not have immediate meanings of illness or disease. Sensations of the body move into conscious awareness, and may be reflected upon. Possibilities are sought; interpretations are explored. For several participants, smoking and aging were within the possibilities of meanings, and the sensations were interpreted as normal within these contexts. Feeling tired was interpreted as aging or being weak, as this participant with emphysema describes:

> When I walked back to my room, which was only ten feet or something, I walked against the wall because I thought I was gonna pass out. I felt awful weak. I don't think it was the breathing so much. Just weak.

When sensations are noticed and then attributed to aging or smoking, they may be ignored or even not be thought of again. Gregory had breathing difficulties for 15 years before being diagnosed with severe asthma and COPD:

> I had hay fever every spring, but never really thought anything too much about it. And then I used to wake up in the middle of the night and I had a hard time breathing. But I didn't think anything about it and just kept going. And I also noticed people would say 'Come on, speed up, can't you walk any faster?' And I'd be hiking or something and I noticed I was short of breath. But I didn't attribute it to anything because I smoked then and figured that was the culprit.

Ed had many sensations that he interpreted as signals of getting old: short of breath, cough, fatigue, difficulty walking, slowing down, and difficulty breathing. He noticed but does not "complain" as he did not interpret these as signals of disease or illness.

> I celebrated life all the time. I drank and I smoked. I went out had a great time. And it was all energy expending. But all of a sudden, I just thought I was just getting old. I had not complained about it at all, because I mistook the symptoms. I didn't think I was sick. I just thought I was old or I was getting old. And this is the way old people feel. But my god, I didn't realize. I'm not exactly a dullard.

> And I think I've got my wits about me. But it never occurred to me that my lungs were shot. It never occurred to me. I didn't know.

Only after diagnosis and upon reflection was wheezing interpreted as indicators of disease. Ed described, "I had indications before I even knew that it was my lungs. When I had to cut the grass outside here. When I used to take the garbage out to the back alley and I would be (*makes wheezing sounds*)."

Jake speaks of "noticing" his breathing and feeling "dead tired" when doing physical work. He attributed his breathing and fatigue to being older than the others.

> I was noticing. Like when I would do yard work. And I started to do more physical work and that's where I really found out how limited I was. I was working with young kids that were 21 years old, and I would come home and would be dead tired.

Excluding those with asthma, all of the participants in this study had a history of smoking. Coughing was another sound and sensation that was noticed and interpreted as expected within the context of smoking, even named by some as 'a smoker's cough.' Paul describes his cough as if it was expected: "Every smoker, smoking longer than 30 years like me, 40 almost, has a cough because the mucous does not extract by itself. It was just to extract the mucous." For some, the cough was described as "pretty bad" or a "hard cough." The cough is not completely disregarded, yet it is not considered to be a signal for concern. Betty has smoked for over 30 years. She noticed, and yet didn't notice, her almost constant cough. Was it normal? Expected? Shaped by the context and meanings of smoking, it is understood and labelled as a smoker's cough.

> I thought it was a smoker's cough. Because it was almost constant. It was constant like a little cough. And then I would get, like just these (*Coughs*). I can remember my cough got so bad for awhile that it actually hurt my ribs to cough. And when I had my chest x-ray there at the hospital, I remember the resident looked at me and said. 'Did you fall, or do you know? Your ribs are cracked.' And I said 'No.' And I kind of looked at my husband and I thought, 'Did I fall down?' And he said, 'No.' And she said 'You know, sometimes you can cough so hard that you actually crack your ribs, so maybe that's what you did.' And I said, 'I was coughing pretty badly.' So that's how hard I was coughing.

With chronic pulmonary diseases, there may be ongoing lung damage which is subtle and disregarded. Prior to diagnosis of emphysema, Jake gave an example in which others noticed his breathing, but it was not perceived as significant or of concern:

> I used to walk up the stairs all the time. I was fairly physically fit. And I would smoke with my secretary we'd go down to the parking garage and back up five floors. And she'd say, 'Boy, you're really a huffing and a puffing.'

Even when noticed by others, sounds and sensations are easily disregarded with no *thought* of illness. Instead, they are attributed to common, everyday understandings such as smoking or aging, and interpreted to be normal within these contexts.

I Can Feel It

In acute episodes of pulmonary illness, attention and focus shifts from the outward world and activities inward to breathing and the body. Unlike the purposeful focus on breathing described in health, attention to breathing is not to enhance physical activity or mental relaxation. Breathing or wheezing or coughing is heard by self or others. Tightness, pressure, or pain may be experienced. The sounds that are heard and the sensations that are felt are unpleasant and associated with illness. Jake describes sensations that he experiences with emphysema:

> I feel like I have the flu. I just don't feel well. But on the other side I don't breathe well either. So that flu like symptom gets me down. I will get aching ears. Up in my jaw bone. I would work and in the middle of the day I would get those symptoms. Everything worked fine for four hours and half way through the day, and then all of a sudden I would feel these symptoms. Chills and aches. I would just feel terrible. And I would feel like, 'What am I doing here?'

Valerie also experiences diverse sensations with asthma:

> It's a bad sensation, that pressure and tightness. The tightness comes first. If I can relieve it, the shortness of breath doesn't bother me. If I can get rid of that sensation that someone's sticking their high heel into my sternum, then that's better.

Wheezing may be experienced as a sound, a sensation, or both. Wheezing is often likened to whistling, and several participants used musical terms or instruments in descriptions of wheezing. Wheezing was described as discordant and noisy, not pleasant or soothing. Valerie describes her wheezing as "an off-tune musical horn" which "really varies in intensity and sound." Wheezing may only be noticed by the person when it is audible, as Barbara describes:

> I don't remember wheezing a lot. I only noticed it if it was audible. When I am wheezy, you can hear my lungs. It's like a pipe organ. I'll hear that breathing in my ears. Like a ringing. Just like a ringing in the ears. Oh, my lungs are usually noisy. Last time Dr. G. said, 'You know there's no noise in your lungs anymore.' I said, 'You mean I shut off the pipe organ?' He says, 'I can't hear it.' So, he seemed to be quite pleased. Even danced (*Laughs*).

Several participants differentiated aspects of hearing wheezes. Wheezes were heard in their head or through their ears. Mary describes an asthmatic reaction in which "I wasn't audibly wheezy but I could hear it in my head." Some participants described listening to themselves breathing to detect an audible wheeze, perhaps when exposed to an allergen or when feeling tired. Others suddenly heard themselves breathing or wheezing, as this person described:

> I can hear myself wheezing. Sometimes I'm reading a book and I think, 'What's that noise?' I know I can hear a noise and I'm not sure what it is. And it's myself wheezing.

Although medically defined as a sound, wheezes are not only *heard* as a sound of the body. They may also be *felt* as a sensation:

> When I get wheezy I can probably feel it more than someone else can hear it. If I can hear it, it's very, very low. Occasionally if it gets really bad, my wheeze is loud enough that somebody else around me can hear it. But most of the time, it's more of an 'I can feel it.'

Breathing is noticed not only when it is heard. Sounds and sensations are not necessarily differentiated as I might as an outsider. Breathing fast or wheezing may be felt, not only heard.

Much More Aware

In health and at rest, breathing is very quiet, not usually heard from even a short distance. The usual sounds of breathing may only be heard with a stethoscope or by placing our ear directly on the chest. Air moving through the large airways sounds hollow, and then whispers as it moves through the small airways. On exertion or with exercise, breathing may be heard. Taking in large breaths, breathing loudly, we might hear the sounds of the increased air flow through the trachea.

In chronic pulmonary illness, awareness of breathing is more than a disruption in the silence. After diagnosis, sense-perceptions are interpreted within a context of meanings of disease. Breathing fast or noisy is no longer understood as aging or smoking. There is an increased awareness of and attention to breathing.

Betty no longer takes her breathing for granted. It is as if her breathing moves in and out of the shadows into the foreground of her consciousness. The pre-reflective, taken for grantedness experience of breathing is lost. Breathing becomes more of a near continual awareness.

> Instead of being unaware of my breathing, I'm never unaware of my breathing. I live with it everyday. Instead of it being in the background and just sort of running along. And when it worsens, all of a sudden it becomes very, very noticeable. It raises to a higher level in my consciousness.

It is not just breathing that may move into conscious awareness. Noticing breathing brings into awareness actions that can no longer be taken for granted, and a consciousness of the struggle to do that which is no longer easy but difficult. Perhaps there is a conscious awareness to take short rests, to pace the body to breathing.

> You should take your breathing for granted, and I don't. I'm kind of always aware. I'm just much, much more aware. It's kind of always there. And aware of sort of taking a break because I get a little short of breath. I make sure I sit down a lot more. I'm always kind of thinking how to save my breath I guess. And I'm just conscious of it more. Just more conscious of it.

With severe emphysema, Jake notes that "With those restrictions on, certainly I know I took everything for granted." Now it is not only breathing that is a struggle, a difficulty, not taken for granted:

> I don't consider myself getting any better at this point in time. I wasn't going to let myself get completely run right down, to start struggling again. I have to reinforce myself with things, to motivate myself with, day in and day out. To think of it continuously. It's just like breathing. So easy to do when it's not (*pause*) difficult for you.

Gregory also has severe emphysema. When he is sitting or resting, he is unaware of his body or breathing. Everyday exertions force his breathing and body into his conscious awareness, and he notices his breathing:

> When I sit I'm fine. No problem. My oxygen levels are about 94, 95. There are times at night, I notice. When I lay down, brush my teeth, wash my face, hands, lay down on the bed and I'm (*puffs*). I can hardly breathe, just that little bit of activity (*pause*) and I think, 'My gosh, what's going on?' I sit on the side of the bed and do some pursed breathing and that helps, just slowly. That, I've noticed more than anything.

For persons with pulmonary illness, awareness of breathing may move into their conscious awareness as they hear themselves wheeze or notice they are making an effort to breathe. At other times, breathing, coughing, and wheezing demand attention, forcing the person to rest or acting as signals for concern.

Indicators of Trouble

Outward indicators of pulmonary disease reveal the disease not only to self, but others, such as when the person is gasping for breath, shoulders heaving, striving to take in air. In acute or severe episodes, there may be visual and audible signals that reveal the disease to self and others. Several participants remarked that family members, friends, or partners noticed their breathing:

> He would say, 'Slow down, I can hear your shortness of breath from going up the hill.' He was very aware of it.
>
> I could hear him wheezing as we climbed the one flight of stairs to the bedroom. I looked over and noticed that he was using his shoulder muscles to breathe. I asked, 'Are you feeling short of breath?' He frowned, 'Oh, that's what it is. I was really feeling tired.'

Laboured breathing, prolonged coughing, or loud wheezing are not just sensations experienced by self, others may be alarmed or concerned by such events. Barbara has "indicators of trouble" that signal infection or pneumonia: a worsened cough, a fast heart rate, feeling tired, and getting nervous. Interestingly, she does not *feel* short of breath, a symptom which clinicians anticipate as a sign of pneumonia:

> Of course I cough until I'm exhausted. And my heart rate is going whoop (*moves hand into air*). (*Coughs extensively).* That, for instance. I've been coughing like that now for about, oh, a good month and a half. But I don't feel short of breath. I've been tired. Oh I've been tired in the last month. No ambition. I'd just as soon lay down and sleep. I know it when I'm running into trouble. I know it before. The first sign is I don't want to eat. And I'm awfully tired. And nervous. Especially nervous. Jumpy. That's the first sign. As soon as I start coughing badly, they do the culture. And my son warned them, 'As soon as you see her acting strange, you get her on an antibiotic because she's been through it so much I know exactly what she's like.' He knows all the signals.

Coughing, wheezing, or raspy breaths may be heard by an Other; the rapid or forced breathing may be seen. Others may not only notice the sounds of pulmonary illness, they may recognize the need for intervention. Others may not only notice, but also experience concern for the person who is struggling to breathe, or recognize the signals to slow down or seek help.

Revealing the Invisible

To maintain life in our body, it is necessary that we eat, drink, and breathe. Eating and drinking are visible, public activities, sometimes occurring in social occasions or for celebrations. Eating or drinking are not usually continuous or urgent activities. We might choose to fast for a period of time, or even 'forget' to eat until we suddenly realize that we have not had lunch. Unlike eating and drinking which are visible in both activity and substance, "breathing is necessary moment to moment, the commodity supplied by respiration is entirely invisible and almost intangible" (Miller, 1978, p. 144). Moment by moment, the living body must renew its vitality and life through breathing. We might forget to have lunch, but never 'forget' to breathe. We might 'hold' our breath for a moment, but only a moment.

Breathing and air are nearly but not completely invisible. If we turn our attention to breathing, we can see the chest move. The outward actions of breathing are inconspicuous at rest, but often obvious with exercise by the movements of the chest and shoulders. When we exhale into the cold air, we may remark that we "see our breath." In times of temperature inversion, excessive humidity, or pollution, we may 'see' the air we breathe. In contrast to breathing and air, the components and exchange of oxygen and carbon dioxide are quite invisible, and only conceptual. We might perceive that the air in a room is 'stale,' but the concentration of oxygen and other gases are felt, not seen.

As with breathing and air, chronic pulmonary disease is nearly invisible. The cellular injury that occurs with COPD, emphysema, fibrosis, or asthma is unseen within the body. A significant portion of lung dysfunction and damage may occur before the body shows indication of the changes or it is noticed by self. Although the acute or chronic inflammation and bronchoconstriction that occur are not outwardly visible, there may be visible indicators that also go unnoticed by self and others, such as a slight change in colour, a quicker respiratory rate, an expansion of the chest.

Merleau-Ponty (1962) describes the body as a visible expression of the self. In this mode of being, aspects of the inner and outer self are seen. Feelings, thoughts, and sensations are expressed by the body. The body is also a visible expression of the physical self. As air is required with activity, moving through the world may disclose the inability to breathe, and thus pulmonary disease becomes visible. In this manner, injury, inflammation, and infection are revealed. Yet these outward indicators are not necessarily interpreted by self and others as illness or disease, as described in these themes of *Revealing the Invisible*:

- Nothing the matter
- Awhile to understand
- A good gauge
- Wearing oxygen

Nothing the Matter

At first glance, the body may not visibly express pulmonary illness to others; the inner sensations and perceptions not visible in the outer appearances of the body. How does an 'invisible' disease become known? How is it seen? Karl has severe emphysema and cannot pick up his cat or get a cup of coffee without stopping to breathe. Yet, his illness may be invisible to others:

> In the van out there I have one of those disability plaques. And lots of people see me drive up and they think 'There's nothing the matter with that guy.' But I walk from the parking stall to the store and as soon as I get inside the store I'm stuck. I have to stop because I can't breathe.

Karl's illness becomes visible when he becomes short of breath and has to stop. Unable to even sit and rest, he stands and leans on a table, a chair, a fence. These are visible signs to others who then see and 'know' that he is 'in trouble.' It seems that they *see* his trouble, his difficulty. Yet his illness is not really known or seen:

> I've been out walking in a mall, and I just stop and catch my breath before I can do anything again. A lot of people don't realize when I'm breathing like that I prefer to be standing. Like I'll stand at the end of the table here and put my hands on the table. It's easier than sitting down and trying to breathe. I've had people come up to me and say, 'Are you okay, are you okay?' And all I can do is nod my head. I just I go with that. But they can catch on that I'm in trouble. They know it.

Pulmonary illness is *felt* more than *seen*. The alterations in airways and gas exchange are invisible to the Self and to the Other. The lungs are hidden from the view of self and Others, thus injury and inflammation are not outwardly seen. The illness experience includes invisible sensations, such as shortness of breath, chest tightness, and weakness. Other aspects of the illness experience are visible or audible, such as medication inhalers ('puffers'), supplemental oxygen, force of breathing, and rapid rate of breathing. One participant's partner describes that she can see it when he uses his puffer:

> He really doesn't confide in me. He keeps it to himself. He doesn't want me to know about how much difficulty he is having. He tries to hide his condition from me and in doing so he hides it from himself. I can see it sometimes when he takes his puffer out.

Not confiding, explaining, describing helps to keep the illness invisible. I wonder, how can you hide that which is invisible? That which is felt, not seen?

Even if the person perceives that something *is the matter,* the invisibility of pulmonary disease may delay diagnosis. Ed went to several physicians before being diagnosed with emphysema. Both Mary and Valerie had delayed diagnoses of asthma, despite their distress with shortness of breath and cough. Not the visible but the audible are indicators of asthma. Indeed, prior to 1979, when it was demonstrated that cough could be the only symptom of asthma (Corrao, Braman, & Irwin), the presence of a wheeze was considered to be essential for the diagnosis of asthma. Twenty-five years later, wheezing may yet be regarded as necessary for the diagnosis of asthma and given more importance than coughing. Wheezing continues to be considered as the primary indicator of bronchoconstriction (Bickley, 2002; Irwin & Madison, 2001). However, neither cough nor wheeze is necessarily present in asthma or COPD. For some, cough may not occur whereas for others, cough is their most significant symptom and they may or may not have wheezes. In this manner of expectation and understanding, chronic pulmonary diseases remain invisible and underdiagnosed. Asthma in particular may be difficult to diagnose as Pulmonary Function Tests (PFT's) may be normal and wheezing may be present or absent (Irwin et al., 1998).

DeSalvo (1997) struggled for many months with cough before being diagnosed with asthma. Her cough persisted and worsened. It was accompanied by sensations of fatigue, shortness of breath, and headaches, which were perceived as signals of illness. But wheezing was absent and thus the disease was not named for months:

> I try to ignore the trouble I'm having breathing, the coughing attack that has continued, unabated, for the past two hours. If I'm going to get better, I think, I must listen to what my body is telling me. Except for the wheezing, I am sure that what I have is asthma. Incessant coughing. Thick, sticky mucous I can't clear fast enough. I have come to the hospital because of a coughing attack so severe and prolonged I almost lost consciousness. I have waited over an hour and a half to be seen, hunched over, head down, sucking air, counting my breaths to calm myself. "I think I have asthma," I tell him. For months, I've had a nagging suspicion that what I have is asthma. "No wheezing," he says, "so it can't be asthma." Long pause. "Are you going through a bad time? Making yourself hyperventilate? Have you considered that this might be hysterical?" (p. 2, 3).

Most often, it is not the cough *per se* that is a signal for concern, but other sensations and experiences, including worry about its cause, exhaustion, insomnia, or pain (Irwin et al., 1998). Valerie "only" had cough and shortness of breath. She sought medical care because she had a cough, seemingly since she did not have the classic wheeze of asthma, diagnosis and treatment were delayed. Was nothing the matter?

> I tried for several years to convince doctors that I was asthmatic. And they kept saying, 'No.' And they'd look at my chest and they'd say, 'No, there's no wheezing. You're not asthmatic.' And it wasn't until I insisted and finally went for PFT's, that they said, 'Well, you are sort of an allergy and exercise induced asthmatic.' And when I finally saw Dr. J., he said the number one sign of asthma is not wheeziness, but coughing. And of course that's what I did a lot of, and shortness of breath.

Other physicians "looked" at Valerie's chest. Not seeming to listen to her chest or to her, not hearing the signs of illness. Perhaps Dr. J. really listened to her, not only attending to the absence of wheezing in her breath sounds but to the presence of her cough, her descriptions of shortness of breath, and her distress and frustration.

Awhile to Understand

If an illness is not visible, how will others know? What signs and signals tell others? Shortness of breath, tightness, and wheeze are invisible. To be understood, the invisible needs to be spoken, described. Valerie verbalizes her illness to Others, knowing they can't see and don't understand.

> In the choir, women wear perfume and I tell them, 'I can't sing, I can't come, I can't breathe.' And they don't understand. It's hard for people to understand unless they've either seen it or they know somebody who has asthma or they've had it themselves. It's almost that they think that I don't really get that distressed. And when I do get distressed I feel it way before, way before others can see it.

Explaining and describing makes the invisible understood in part. But not feeling, not seeing, can we really understand what it is like to have asthma? Or pulmonary fibrosis? Or emphysema?

> It takes people awhile to understand what the situation is. Takes a lot for people to understand what the hell I have. Everybody can say emphysema. But do they really know what it is? Or how it has affected my lungs? They know it is a lung disease created by the smoking, but it's not lung cancer, it's emphysema. It's a slower process of killing you. They didn't really understand the severity and the level until last year. My brother really couldn't fully understand this when I started to explain it to him over the telephone. He said 'I didn't realize you were that bad.' Even one of my best friends, he just didn't understand it until I explained it to him. 'I didn't realize you were that bad.' (*Long pause*).

The invisibility of pulmonary illness seems to make it less known to others and less understood. Is it not quite 'real' to others when the distress is not visible? One participant describes an experience with her asthma:

> I was in hospital in a 4 bed unit and I didn't know the lily was there. I came in and went to sleep. In an hour I was in terrible distress and I went out and I said to the nurses, 'I can't breathe.' And the nursing staff didn't believe it initially until I got really bad. And then they believed because they had seen it and they had seen me in my distress.

What did the nurses see? The effort of the body? The rapid breaths? Did they hear her distress? Although educated to assess breathing, they did not initially see or hear the signs of asthma or recognize her distress. The experiences of 'emphysema' or 'bronchoconstriction' are not easily grasped or understood, the acute distress not understood. As participants' meanings of shortness of breath and distress are not derived "from our experience as embodied subjects" (Merleau-Ponty, 1962, p. 236), they require articulation and description.

A Good Gauge

Sensations of pulmonary illness are not visible, but outward signs of disease can be seen and heard. Respiratory rate is counted; peak expiratory flow and oxygen saturation ('sat') are measured. These objective measurements may be used as visible indicators to self and Others, perhaps as a gauge for activity or risk. Gregory is recovering from a cold and infection:

> My sat level is usually 96. The other day it was 89 to 91. At the present moment I'm not doing any exercise because I went down so low that I think to do any at this time would be detrimental. So I'm gonna wait until I've got my saturations at a higher level. It's gotta come up a little bit.

Oxygen saturation seems to be regarded as an indicator of illness. A fact, not a feeling. Timothy looks at his oxygen saturation and determines he's "fine," as if he cannot know he is fine without seeing an indicator:

> I went out and bought my own oxygen monitor, so that I can look and say, 'Well gee, if I'm 96%, I'm not keeling over.' So if I'm 96%, I'm not keeling over, I'm not turning blue, I'm not going to Emerg. 96 is a lot different than 76. It reinforces the fact that 'Hey, I'm doing fine.'

However, oxygen saturation is not necessarily a reliable indicator of acute inflammation or injury, nor does it reveal the person's *feelings* and *sensations* of illness. In the presence of normal saturation, there may be sensations of an urgency or difficulty in breathing. For Valerie, even when her oxygen saturation is normal, *she* is not fine.

> I wouldn't go to Emerg unless my actual life is threatened. They're so used to doing the sats and maybe seeing the sats plummet. The first thing the nurse does, she takes my sat and she says, 'Your sats are good.' My sats are always good. It's not the oxygen. I know I'm in trouble. I'm wheezing. I have no reserve. I don't want to wait until my sats aren't good. I honestly don't know the next time I'd go to Emerg. I honestly think someone else would have to call. *(Long pause).* To go to Emerg, I'd have to be blue in my finger tips and not be able to say a word.

Some persons with severe chronic disease may perceive that they are fine when sitting, however their oxygen saturation falls the moment any activity is initiated and they are halted. At rest, the oxygen level is "very well" but the body is not well or fine. Thus, the technical instrument both reveals and conceals aspects of pulmonary illness and injury.

> As long as I don't do any physical activity I'm fine. My oxygen level stays very well. Around 95, 96. But the minute I start doing anything, they go to 90 or lower.

Storr (1979) argues that the body may be "deceived" when it is at rest, and that a flow meter "reveals" the truth:

> One can suffer quite a large diminution in one's respiratory efficiency without being fully aware of how great that reduction is... When lying in bed or sitting still little oxygen is needed, and it is easy to be misled as to how difficult it may be to get more oxygen when that is required. I am sure I am not alone amongst asthmatics in having often woken in the morning with a conviction that an attack of asthma has almost subsided only to find that, when I get out of bed to empty my bladder, I am far more breathless than I had supposed. A peak flow meter will reveal the true state of affairs.

Not only is oxygen saturation perceived to be a visible indicator of illness. The body's demand for oxygen may be used as a gauge, to reveal how the body is doing. For Jake, his use of oxygen seems to reveal good days and bad:

> I have had really good days. A good gauge for me is when I do not have to use my oxygen, off and on for quite a while. When I know I can get away without it. And at that point of time, it always makes me wonder, 'Why am I wearing the oxygen?' I've been able to get up and walk out of that place, up a set of stairs, walk to the car, and no major inconvenience. Other nights I've been struggling to get up the stairs with the oxygen on.

What is the 'true' state of the lungs? Of bronchoconstriction? Is it the objective criteria of peak flow or oxygen saturation? Or is the 'true' state the person's experience?

Wearing oxygen

For some persons with chronic pulmonary illness, supplemental oxygen therapy is part of their illness. Oxygen is not only used, it is outwardly worn on the body. Oxygen tanks, tubing, and cannula are *seen* and the invisible disease becomes visible. In some manner, being on oxygen may alter activities, expectations, and interactions of self and Others. Gregory notices that since he starting using oxygen, others open doors for him. His illness is indicated to others, it can now be seen. Timothy, a young looking man in his 50's, does not look ill at first glance. Yet he has severe emphysema and is waiting for a lung transplant. At times, he wears his oxygen, even when he may not "need" it or even use it.

> I put the cannula on, but don't turn the oxygen on. I feel that others are thinking, 'He is a healthy guy. Why isn't he helping us?' I don't want to explain that I can't lift. Or why I can't help.

Wearing his oxygen tubing outwardly reveals to Others that Timothy is ill, whereas his severe emphysema is otherwise invisible. It is not the use or need for oxygen, but the wearing of the tubing and cannula that shows his disease to Others. In this manner, being seen with oxygen is having the illness seen; making visible that which is ordinarily invisible. In contrast, Jake also uses his oxygen intermittently, even taking his oxygen off so he is *not* noticed:

> I just stop. I rest with my hands on my hips and I inhale as much oxygen as I possibly can. I pretend I'm looking at something. I don't know who I'm fooling. (*Laughs and coughs*). I'm embarrassed to be seen with a breathing apparatus on. So typically I turn my head the other way. In the drug store I don't mind so much, because they're used to me. But going in the big store, or even the bank, I'm more embarrassed. A lot of times I take my oxygen off once I am inside the store, because I don't want to be seen with it, going around the store. I get very conscious when I get on the bus. I take it off right away. Because I'm not moving around, I can sit there. I can ride 20, 25 minutes. I can survive that long without the oxygen.

Oxygen is not like a puffer, which is used intermittently and possibly hidden from others. Jake takes his oxygen off to keep his illness invisible. Are the people in the drug store used to *him*? Or is he used to *them* noticing?

The oxygen tubing and the noise may be *seen* by others, and seen by self as a nuisance. Timothy "ended up on oxygen" after pneumonia. For him, oxygen seems to be something that is saved as a backup, only used when necessary. Like a crutch, oxygen is a visible aid. Perhaps like a crutch, it may be set aside when no longer needed.

> I spent four days in the hospital with pneumonia. They wouldn't give me any puffers, so I ended up on oxygen. I came home, and of course I had to have oxygen. I still have the oxygen but I only use it at night. I'm gonna get rid of it, I don't need it. If I have my puffer, I'm okay. I feel quite fortunate. I see quite a few people and they have the oxygen on all the time. I think you could quite easily accept getting the oxygen on a full time basis. Oxygen is fine as long as you're there but as soon as you get off it and you go to exert yourself, I mean, you can't! You have no backup in your system. And it's like a crutch, or it could be.

Although oxygen is a visible indicator of lung disease, others may not *see* the illness. The person still needs to disclose verbally the symptoms, the feelings, and restrictions of pulmonary illness.

> When I came back from Vancouver I had the oxygen on all the way. I got up out of the airplane and it was unbelievable. I may as well have been exhausted. I got out of that airplane after 2 hours total and walked out the exit and had to stop right away. And then kept on walking. And the further I went, I could feel the tension in the back of my neck from struggling to breathe. Even with the oxygen. I finally got down the stairs. I must have been the last guy out of there. And my daughter came to pick me up and had been there waiting for me. Her car is in a no-parking zone and she's in a hurry. And I said, 'Don't run so fast.' I had to say that on several occasions.

There are different perceptions in this experience. The daughter needs to hurry and get back to her car. Perhaps she *sees* her dad on oxygen and thinks he too can hurry, or *doesn't see* the oxygen and forgets he cannot rush. At times, on good days, Jake can go without oxygen. When he rides on the bus he takes off his oxygen. Now, after a 2 hour plane trip, he is exhausted. Has to stop. Is struggling to breathe. It is unexpected to them both that he is so exhausted. Phenomenological and physiological understandings are in synchrony; perspectives and perceptions of father and daughter are not. Although pressured, there is a decreased amount of oxygen pressure in an airplane, and subsequently a decreased availability of oxygen even though the percentage of oxygen is approximately the same. By the end of the flight, his arterial oxygen pressure and saturation will have dropped, leaving little or no reserve for his walk into the terminal and to the car. Struggling to breathe, he is *unable* to hurry.

In summary, the ill body loses its near-silence, calling attention to itself as a diseased or disobedient body (Morse, Bottorff, & Hutchinson, 1995). In chronic pulmonary illness, the silence of the body is interrupted or disturbed when the ease, quietness, and rhythm of breathing is disrupted and noticed. The near-invisibility of pulmonary disease may go unnoticed by self or Others. Other times, the usual state of being is disturbed, and the body and breathing are reflected upon, noted, watched, and remarked upon.

Interpreting Normal

Sounds and sensations of the body may be interpreted with meanings and understandings of what is typical and usual, with perceptions of *normal* and *not normal.* The abnormal may be noticed and reflected upon, or the sensation compared to that which is considered normal. Themes of *Interpreting Normal* are

- *A breathing problem*
- *That kind of short of breath*
- *More or less normal*
- *Clearing my throat*

A Breathing Problem

When breathing is noticed as fast or noisy, when sensations worsen in intensity, or when actions of self are compared to others, meanings of these experiences may be interpreted as normal and attributed to aging or smoking. When not interpreted as normal, other meanings were sought.

> I remember what my breathing was just before I got diagnosed with asthma. I remember because it was abnormal. I was sitting in math class, and my breathing got tight and more difficult. I felt slightly light-headed. I didn't know what was wrong. I put my head down in my hands and focused on taking deep breaths. Needless to say, not paying attention to class. Eventually I felt better. This happened a few more times and I eventually saw Dr. Q and he said I had asthma.

Several participants spoke of the normal of others or the normal 'before' illness or before diagnosis. When doing physical work, Jake noted he was running out of breath "a lot more than normal." Comparing himself to others seemed to nudge his awareness of both body and breathing. When snorkelling, it was not his breathing that he noticed as not normal, but that he was unable to keep up to his wife:

> I'd look ahead and there she is way ahead of me. I got to thinking, 'Well I'm not struggling for breath under here. I'm breathing what I thought was normal, but I obviously wasn't keeping up to a normal person.' Things kind of hit you in the side of the head like that. You become very conscious of stuff like that.

Sensations and sounds of breathing may be interpreted as something that is not normal. Perhaps as a problem to be fixed, controlled, managed, or solved. For some, the problem, the 'thing' that is no longer normal, is breathing. Ed described his lungs as machines that no longer working normally. Gregory described knowing his breathing as not being normal, but a problem that worsened over time.

> All I knew it was a breathing problem. It wasn't until 15 years later, I was having a hard time breathing and my wife took me into the Hospital and they said, 'You just got him here just in time.' I was admitted to the pulmonary ward, and Dr. Z looked at me and said, 'You've got asthma! We'll fix you up.' When I found out I had asthma, I felt relief in the sense that now I knew why I couldn't breathe at three in the morning. It was just a total relief of concerns that I had 'cause I used to hate waking up at night and couldn't breathe.

There is a notion here from the physician that a breathing problem can be solved or fixed. Some persons were told that a particular medication would 'fix' them. "Ventolin® fixed me up right away," says Adam of his exercise induced asthma. The breathing 'problem' is not actually fixed with medication, but his breathing returns to normal and he perceives himself as fixed up.

In expressing illness as a breathing problem, I wonder if problems come and go? Do they worsen as well as get fixed? Thom says, "When I have asthma" as if he doesn't have asthma at times. Brookes (1996, p. 39) gives his perspective of asthma, not something that needs to be fixed, but perhaps something that will go away:

> When we're not actually suffering an attack, most asthmatics don't *feel* ill—we certainly don't like to think of ourselves as having a chronic and incurable illness—and, hoping against reason, we prefer to believe that our illness will simply go away by itself.

Breathing may be perceived as a problem, one that is intermittent or can be fixed. Although it is noticed, and perhaps compared with self or others, there is minimal distress or concern.

That Kind of Short of Breath

It is normal to feel short of breath at times of physical exertion. When exercising, we may notice that we are breathing rapidly, taking larger breaths, or trying to catch our breath. We may even slow down or stop our activity, and feel a little uncomfortable if we need to take large breaths in. But somehow this has a sense of normal. It is readily interpreted as the usual, typical, expected occurrence with exertion, with our present activity. If I am climbing six sets of stairs and feel short of breath, I may pause and rest a moment. I am not concerned that there is something wrong, that there is something abnormal. I am not distressed that I feel short of breath. I do not consider that my lungs are damaged. Instead, I perceive the sensation as normal and interpret that I am out of shape, that stairs are hard work, or that I was going too quickly. My perception of my breathing is immediately interpreted within perceptions of my fitness and the context of exertion in climbing the stairs.

Metabolic demands are increased in exercise or exertion, subsequently we increase our minute volume, breathing more quickly and deeply to meet oxygen requirements and expel carbon dioxide. It seems normal to feel short of breath if we're exercising and perceive that we are out of shape. My colleague started an exercise class and mentioned, "I am really out of shape, and I'm so short of breath." In contrast, with chronic pulmonary illness, shortness of breath and condition may be interpreted and understood within the context of the amount and type of exertion, yet not be considered normal.

> I don't notice my breathing on a regular, normal day. In day-to-day activities in sales or housework or golfing, or something with moderate output, it doesn't seem to affect me. We live in a walk-up and so from the basement to our apartment is 3 flights of stairs, and when I do the stairs carrying things, I'm a little (*pause*) short of breath at the top of the stairs, and I always think to myself, 'Damn, that's not right. I shouldn't be short of breath coming up that little ways.' So, there's a daily event in my life, where it comes into my consciousness with what I consider minimal exertion, where it shouldn't, and it never used to, but there it is. But that's from being out of condition, as well as aging, as well as some damage to my lungs.

For some persons with pulmonary illness, there is a common shortness of breath, perhaps experienced with walking or talking, and a different kind of shortness of breath that is acute and severe. Neither is normal. Timothy describes being short of breath:

> When I'm walking sometimes I can get short of breath, but then I'll stop, and I'll do some pursed-lip breathing, and then I'm okay. That kind of short of breath is probably the common one. And then the other one, what I mean by short of breath, is I can't breathe. And that's when I go to the hospital. My chest is so tight that I can't do anything. I can still speak but it is very hard.

To me, it is not really normal to be short of breath while walking. To have to stop. To pay attention to breathing. But for Timothy, it is common and seems even normal in his description. Ed perceives that being breathless with exertion is normal, but it is different with lung problems:

> You would be breathless if you had been walking fast or running or something like that. And you know that you've been doing this physical exertion and you're not getting the breath the way you normally do. But that's got nothing to do with lung problems. That's got to do with the normal business of the body reacting to the exertions. All that means is you're trying to get the air in that you need. It's what the body can normally deal with and so you get breathless.

"All that means" seems to relay that the type of breathlessness with extensive exertion is normal, in contrast to breathlessness experienced with emphysema. The everyday meaning of shortness of breath experienced with exertion is not that which is experienced with illness. Shortness of breath is not *just* breathing more deeply or quicker. Perhaps there is a sensation of not getting enough air, as Mary experiences:

> Feeling short of breath is an inability to get enough air in. When I am short of breath with asthma, it isn't being out of shape or that type of increased, heavier breathing. No matter how hard I try, I just can't get enough air in. I've had the sensation of knowing what it's like to not be able to breathe. To not get enough air in.

In pulmonary illness, there is an emphasis on breathing that seems different than the 'normal' shortness of breath. There seems to be more of an uncertainty of body and breathing. The abnormal is not getting enough air, in trying to take in a big breath and getting only a little breath. Normal sensations of getting enough air or of air flowing into the lungs are altered.

More or Less Normal

For those who experience moderate to severe chronic pulmonary disease, difficult, laboured, and noisy breathing may at times be perceived and interpreted as normal. Activities, expectations, and anticipations may be modified, and that which was not normal may become normal. Wheezing, coughing, and breathing recede into the background, no longer remarked upon or perhaps even noticed. Peter considers that he is "quite normal" in his breathing. During the interview, his breathing was very rapid, with a quick and audible indrawing of air. As he spoke, he paused to breathe between phrases. He becomes tired and short of breath with speaking, walking or lifting:

> I don't suppose I'm ever actually panting. (*Pause*). Not normally. (*Pause*). After sitting down now I'm pretty well back to normal. (*Pause*). I really get very short of breath. (*Pause*). If have overextended myself. Doing things (*pause*) I get tired I guess. Even talking to you I get out of breath. I like to think that I'm quite normal. (*Pause*). And even though I'm normal today (*pause*) in the evening I might put my oxygen on (*pause*) because I've been out shopping. (*Pause*). And doing this, that, (*pause*) and the other thing.

For persons with chronic pulmonary disease, there may be as a sense of normal experienced in this moment or day or activity. This normal is differentiated from that of health. "Breathing normally" and "normal breathing" were phrases used by many participants when I would not interpret their breathing as normal. Their breaths were large and prolonged, or rapid and shallow. They used their shoulder muscles to breathe, paused or coughed frequently, and had audible wheezes or noisy exhalations. Perhaps they get accustomed to or familiar with the experiences and sensations of illness? It is as if the unusual, atypical and not normal become the usual, the typical, and normal.

Bill has a continual rattle in his chest both felt and heard. They have become normal little noises. When I had an older car, there were many rattles, and I soon came to think nothing of them as they were not of concern. They were not normal noises, just ignored or even unnoticed. In chronic pulmonary illness, there may be a nearly continuous rattle, wheeze, or vibration that is noticed but is not a signal for concern. Always there, it becomes normal unless it gets louder:

> It's the asthma that's causing most of the problem right now. It's always there. Some days it's bad and other days it eases off a bit. I can hear it all the time when I'm breathing. I notice it all the time. It's pretty noisy. I can hear it. I can feel it. It rattles. The old vibration. Right now I can really feel it. I can feel the pressure and the vibration in there. It sounds like a brass band (*Laughs*). When it's bad others can hear it too. Some of them say 'I can hear you coming down the hall!' (*Laughs and wheezes*). I can hear myself too.

Barbara's breathing is noisy not only to me and others, but also to herself. Like the rattle in my car, the noise is not a concern and she doesn't really pay attention.

> I feel pretty good now. Even with that rattle in there now I feel alright. It doesn't bother me that much. It's there. The noise never goes away. It's annoying. But I don't pay much attention to it. It's more or less normal. I think for some people with asthma it clears up at times. Mine never clears up. For me it's normal. It's there all the time. It's always there. I always have to hear the noise.

It as if the unusual becomes nearly usual in illness and that which is not normal is perceived as normal or nearly normal. From an outsider view, it may seem that one may become accustomed to illness as being normal. DeSalvo feels that she has become "so used to living with discomfort" that "I've forgotten what wellness feels like" (1997, p. 25). Using an inhaler, feeling a tightness in the chest, hearing breathing may become expected and usual, even familiar. Timothy, who has asthma and COPD, notices his breathing, not quite ignoring it but not needing to really pay attention to it, "To be honest I haven't really paid attention to it. I have so many little things and I blame it all on old age."

For the person with asthma, the perception of 'normal' breathing is an indicator that the attack has lessened or passed, even if other sensations are present:

> I sat on the table for an hour and a half, unwinding, my muscles unwrapping themselves until I was no longer a clenched triangle but could sit back against the pillow as the external world returned. I felt as if I had been inside out. The staff was as surprised that a major attack had passed so quickly. Within two hours I was shaky, but breathing normally; at 4 a.m. I shuffled out to the lobby in lime-green hospital slippers and took a taxi home (Brookes, 1994, p. 12).

As I read Brookes' account of the passing attack, from my perspective as a nurse, I would not perceive that he was breathing *normally*. I imagine hearing a fading wheeze, seeing the muscle tension, noting the accessory muscles, and would interpret his breathing as forced or laboured, but not normal.

Sounds and sensations may move into aspects of normal, but much of living with severe pulmonary illness is not normal. Jake "battles" his breathing, infections, fatigue, and depression. "It really, really, really bothers me because it doesn't allow me to participate in a lot of normal things." There is a sense of normal and not normal as he describes going out on a cold day to get milk.

> The cold air restricts the passages quicker. I find I'm out of breath a lot quicker than usual. I'm okay down around 10 to minus 1. But minus 15 and colder, it just hits me like a brick wall. When I get hit with both, the cold and normal lack of ability to deal with it, they're just (*whooof*)! I was stopping out there one day, and it was minus 15 with the wind chill factor, and I had my hood up and I had my scarf around my nose and mouth, and I had to turn my back to the wind. I couldn't go on. I had to stop. I almost turned around. I almost went right back home. I thought 'Oh-oh. Why am I subjecting myself to this ridiculous cold? Well, yeah, I needed milk.' (*Chuckles and coughs*). I can watch people out there and they just trudge, trudge, trudge, trudge along at a normal speed, and bang they're into the store. And there's Mr. Stop-30-times or something like that.

At that moment when he couldn't go on, the task is thought about and disrupted. The synthesis of his activity within time and space is disrupted (Merleau-Ponty, 1962). Perhaps that which *is* 'normal' for Jake is his activities. Even though it is cold outside, he walks to the store to get milk, whereas other participants stayed indoors when it was cold. Some seldom went outside for months, planning doctor visits for spring and fall, and remaining inside for most of the winter. Would Jake recognize the *not normal* if he did not try to participate in normal, everyday activities such as going to buy milk?

Bill has asthma and pulmonary fibrosis, he notices his breathing almost all the time, is "quite often" short of breath, and sometimes wakes up, "gasping for air." His perception of control is that his asthma is "tamed down a bit" and he has not had an acute attack requiring emergency care:

> It was very severe when I first got it. I was into the Emergency at least four times a year. It was very severe. And then, I'd almost get blacked out, the colour started changing on me. But over the years it seemed to settle down a bit. I haven't been to the Emergency for a long time for an asthma attack. They got it pretty well all under control now.

Ed describes that he "normally has a lot of the breathing difficulties" and that his breathing is normal at rest. Abnormal breathing is an indicator of pneumonia. When I listen to the tape or recall the interview, I remember his breathing and would not consider his breathing normal. The loud, raspy, wheezy breaths are very audible. Every breath seemed forced as he used accessory muscles to inhale and then exhale. But does he *feel* the effort and work that I perceive? Or perhaps his wheezing and noisy breathing have become so common that they are perceived as *normal*. This *normal* breathing is disrupted by any activity or exertion. Getting up quickly from a chair causes him to feel short of breath and he has to stop to get back to his normal:

> My breathing is very difficult. I'm practically at the point where I really can't do anything too much physically. The desire to do it is there. The will to do it is there. And there are things I'd love to be doing. But the moment I start doing it, my lungs protest. And I am fairly immediately short of breath. And I have to sit down and get back to normal breathing.

Karl described many 'normals' with severe emphysema. He has to stop to catch his breath with any small exertion and has a low oxygen saturation. He can drive all day, or walk around "as usual" with a walker. In contrast, everyday things are not normal and he uses various strategies to keep breathing normal. Imagine having to stop in the shower between washing and rinsing to get "back to normal."

> I get soaped down sometimes and I can't even rinse off. I just gotta fight to control myself. To get everything regulated again and back to normal. Then after that I get rinsed off. Then I gotta fight again to turn the shower off. And then I'll end up just standing there. Drip drying for about five minutes or so. Before I can actually grab the towel and start drying myself.

Unlike breathing in health, it is not just stopping to catch one's breath that is required and experienced. When the normal breathing difficulties worsen in severe emphysema, focus and effort are required to fight the panic, to think about breathing, and get "back to normal":

> I'm just breathing. Well, I'm actually fighting the panic. I just have to keep saying 'Okay I'm not doing anything, I'm sitting here, I'm just trying to control, to get things back to normal.' And I was I was leaning on two watering cans. Just leaning on them and using them as a brace so I could calm myself down and get my breathing going back to normal and working properly again. It feels like I can't get it in. But it's actually in reverse. So then I've got to stop and think. Well, I'd better start using the pursed lip blowing it out, and blowing it out, and blowing it out. And finally I get myself calmed down and then I can start to breathe normally again.

In chronic pulmonary illness, some breathing symptoms and difficulties may become normal, expected, and even taken for granted. Yet these too are differentiated by various situations and comparisons. Medical treatments partially relieve illness symptoms, which lends to comparison with 'normal' symptoms. Jake feels that use of steroids move him into a "falsified normal" as he has more energy, less symptoms, and an increased appetite. This false normal enables him to compare normal and semi-normal. In his *false* normal, he again feels that he can breathe, that his body is in tune with his self:

> I've really felt the effects of prednisone in the last 3 or 4 days. It always gives this false hope. It gives this good feeling. And I certainly do feel a lot better when I'm on it. I feel like I kind of return to falsified normal. I always call it falsified normal. I'm not sure I know what it does, but taking a steroid, I feel enhanced. When I come off that stuff, I always feel regret, 'cause it actually makes me feel like I'm almost semi-normal for awhile. Where I can breathe. Where my lungs are wide open. The rest of my body feels in tune with me.

It is considered *normal* for body and self to be "in tune" with one another, not discordant in sounds or dyssynchronous with actions. In chronic pulmonary illness, breathing difficulty is usual and expected. Noisy or rapid breathing, wheezing, coughing, pausing may become normal breathing.

Clearing my throat

Throughout these interviews, several participants coughed repeatedly, seemingly not noticing except once or twice when they coughed extensively over a longer time and then verbally 'excused' themselves. When listening to the taped interviews of several participants, I hear a frequent heavy coarse cough throughout, which seemed to increase the force of their breathing and lengthen the pauses in the conversation. Often the person did not seem to notice the noise or disruption of the cough. Does the sound and sensation of coughing become taken for granted and go unnoticed?

Cough differs from many symptoms in that it can be seen and heard. The subjective sensation may not be consistent with the objective sound heard by an outsider. For example, I perceived that Ed frequently coughed and the transcriber inserted frequent *(coughs)* into the manuscript. Yet seemingly he does not perceive that he coughs frequently. Can 'cough' be seen, heard, and interpreted as coughing, yet not noticed or regarded by the self as a cough? Or is it that the word that we assigned as outsiders has a different meaning? Ed expressed a difference between coughing and clearing his throat:

> The doctor was asking me, ‘Do you cough very often?’ And I said, ‘No, no. You know if I cough, it may be 3 or 4 times a day.’ And he says, ‘Well, why do you say that? I’ve heard you cough 6 times since you’ve been here in the last hour.’ And I said, ‘That wasn’t coughing. You call that coughing? I call that clearing my throat.’ He said, ‘No, no, you were coughing to clear your throat.’ I said, ‘Oh, well, if you’re going to say that is coughing, then, God knows how many times a day. I’m always trying to get my throat clear.’ I don’t cough all that much. Maybe a couple of times. But that was when I was really coughing. This business of clearing my throat or clearing a little bit of phlegm out of my throat, which I do regularly, I don’t call that coughing at all. He does apparently.

Perhaps there is a change in interpretation of meaning and significance of the frequent coughing sounds, or the cough is so usual that it is longer noticed or perceived. The sound and sensation of coughing move into the background, no longer noticed.

Demanding Attention

With chronic pulmonary disease, injury to the lungs may occur slowly over time. Sounds and sensations may be subtle and easily ignored, or interpreted as normal within the context of smoking or growing older. With increasing severity of the disease, or with asthma which may occur as moderate to severe in each episode, sounds or sensations of the body are no longer just ‘noticed.’ The body *demands attention*, sending signals of concern and warning. Breathing and the body cannot be silenced or ignored. Themes within *Demanding Attention* are:

- *Gasping for breath*
- *A warning*
- *Can’t ignore it.*

Gasping for Breath

In health, when we exercise strenuously or exert ourselves, immediately and without difficulty, we take larger breaths more often. This change in breathing may be noticed or unnoticed. In pulmonary illness, the immediacy of being out of breath and catching one’s breath may be more than just noticed. Rate and depth are no longer spontaneously matched to the required need. The body *demands* attention. There is a conscious awareness of the need to get air into the lungs and oxygen to the body.

Breathing is reflected upon and evaluated, and at times planned for and organized. There may be pain on inspiration, trying to get air into the lungs. The person *has* to think about breathing.

> I'm out of breath. So it's the deep gasping thing. It's trying to think of saying 'open you little alveoli' and there's pain. There's a feeling that I'm not getting enough oxygen that I need to get, that I need to physically think of pulling it deeper into the lungs because it feels like it's not reaching the bottom. But on the breathing end, it's having to think about getting it into the bottom of the lungs.

In our usual way of being, we live in the 'now' – we don't think about the immediate past, each moment leads to the next (Husserl, 1900/2001). When we pause and reflect on the moment, on the now, we might *think about* the next moment, the future no longer immediate and unanticipated. Some participants experienced this loss of the immediacy as they wondered how and what it will be like to not be able to breathe. As they analyzed and reflected on their body and breathing, they no longer lived in the moment. For example, Jake will suddenly "find" himself needing to stop, to hang on, to catch his breath:

> I'll find myself hanging on the shower door. I'll hang on to it to catch my breath. (*Pause*). In between shampooing or something like that. In the shower this morning I was at that one point. (*Pause*). And I thought, 'What's restricting me?'

Is he ill at *that* moment when he reflects on his body and situation. Was he not ill the moment *before* when his body and situation were not thought about, noticed, reflected upon, and analyzed?

In this manner of being, there is not just an awareness of breathing or recognition of an increased rate and depth. It is not the 'normal' sensation of being short of breath experienced with exercise or exertion. There isn't an assurance or reliance of getting the next breath or enough air. There may be sensations of a shortage of air, a decrease in air flow, or difficulty and frustration in breathing, as described by Betty:

> I guess I just wonder if I am ever going to catch my breath. Before I was diagnosed with asthma, I just assumed that I would catch my breath. And with asthma, it feels like I'm not. Like I'm not going to be able to catch my breath. It's different. That heaviness in my chest is different. Running and being short of breath before was different. I was getting air. But it's almost as if no matter how big of a breath I'm taking, I'm only getting a little breath. Even if I'm gasping I'm only just getting a little breath.

Normal shortness of breath was differentiated by several participants. Adam compares his shortness of breath with exercise asthma to that experienced by a normal person:

> It's like trying to breathe through a straw, or lying on my back with somebody pushing on my chest while I'm trying to breathe, or somebody standing behind me holding me around the chest tight and then I'm trying to breathe quickly because I'm short of breath. That's much different than what a normal person would feel like if they ran a couple of blocks, and so they're a bit out of breath. It's just that they need more air quicker and so they breathe faster. Breathing a little heavier and a little faster for maybe a minute, but able to regain their breath. Feeling a little short of breath, taking half a dozen or a dozen quick breaths and then they're almost back to normal again. They don't feel the tightness in the chest and don't feel like they're having trouble getting the air in. They don't feel like they're not getting the air when they're breathing.

In chronic pulmonary illness, it is not only breathing that demands attention. The person may experience pain, burning, effort, difficulty, heaviness, or tightness in their chest. Depending on the person, not the etiology, these sensations are interpreted as worsening of their illness or episode:

> A shortness of breath comes on first. I don't have a particular tightness in the chest or anything. It's just that I'm breathing heavier and the next thing I know I'm starting to wheeze a bit. If it's really bad and bothering me, I focus on my breathing. If I'm really wheezed up then I tend to focus on the breathing until it gets down to a manageable level. I feel like I'm actually having trouble getting oxygen. I can feel my chest muscles or my lungs or whatever working hard to pull in and push out.

Sensations are not only of breathing, the lungs, or the chest. Many sensations of the body call out to be noticed. Brookes (1994, p. 3-4) describes the onset of a severe asthma attack.

> At half past midnight, my stomach suddenly felt uneasy. Within a few minutes my entire metabolism changed. My sinuses were swelling, stiffening, filling up, my ears and cheeks getting hot, my spine and my chin itching. Everything was closing in around my throat and chest; I felt a tightening internal claustrophobia, a sense of metabolic urgency rapidly mounting toward panic. I already knew this was no ordinary asthma attack.

The demand for attention at times is sudden, with little notice. Interpretations are then made and meanings sought for the sounds and sensations of the body. Is it pulmonary illness or another cause? Hearing himself breathe, Brookes (1994, p. 266) is relieved to interpret his noisy breathing as anxiety, not asthma. As he lies beside his girlfriend, he does not *catch his breath,* but *catches the sound* of his own breathing.

> On Sunday night I wasn't sleeping well anyway. It's hot, the pollen count is high—I hate this season. By 4:30 I was aware of my breathing. It didn't occur to me that I was getting asthmatic; it was like realizing you're lying on something in your pocket, and not being able to ignore it. [Suddenly] I caught the echo of my own breathing in the hollow of my shoulder and discovered to my surprise that I was asthmatic. This could have been a sign of anxiety, but luckily I made the opposite assumption, exclaimed, 'Good grief! I'm wheezing!' and reached for the Albuterol inhaler, thinking, *Of course*. The house was incredibly dusty, the air was full of pollen. How could I have been so stupid? A minute later I could lie down and hold her, feeling several shades of relief.

Asthma, intermittent in nature, is listened for and interpreted by the audible sounds of breathing or wheezing. At these moments of awareness, the sound or sensation are reflected upon. Awareness of these sensations "makes these experiences objects of inner perceptions" (Husserl, 1900/2001, p. 209). Breathing and the body are no longer taken for granted, but focused on. Thinking about breathing and the body is necessary. The person moves from experiencing self and body as subject-object to an increased awareness of the body and self as object-subject. The element of concern needs to be assessed and interpreted: is the demand for attention something that can be ignored or is it a warning that must be regarded?

A Warning

Sounds and sensations may be perceived as warnings, as signals for concern. Breathing may not be noticed and immediately understood. One participant with asthma describes: "I often don't consciously notice it right away, but when I do it's like a bell goes off and I realize that's why I was feeling off." Other times, breathing is noticed and interpreted in the severity of an asthma attack. For Valerie, sounds and sensations are indicators of warning and prevention:

> So for the tightness I use Ventolin® and I have to wait it out or ignore it. If something else is going to make me more short of breath, like going to choir, then I'll use the Ventolin®. If I'm going to be exposed, or walking, or exerting, then I use the Atrovent. I don't cough routinely, and if I'm coughing, then I use the Atrovent. If I'm wheezing I know I'm in trouble. I've gone way down the line.

In emphysema or fibrosis, wheezing is also perceived as an indication of congestion or inflammation. For Timothy, wheeziness is a warning that signals worsening of his emphysema and possible pneumonia.

> I didn't feel wheezy, but obviously I was wheezy. I can feel wheeziness. If only a slight wheeziness then I can usually clear it. I can feel that and that scares me because I don't want it to get worse. And my saturation level was probably down.

Cough may also be perceived as an indicator or warning. No longer defending the body, coughing announces disruption or acts as an indicator of illness or complications. Noticed by self, or by others, coughing may be interpreted as a signal of a complication such as pneumonia or warning of an allergic response. Jake 'discovers' that he has an infection by coughing and pain in his chest and lungs:

> What was so prevalent last week was coughing. Trying to catch my breath in between the coughing. And this is where I discovered I was getting something. I knew I had something in me. When I start to cough and I feel something in there that's hurting my chest or my airway, I know I'm getting some kind of chest cold.

We might say that cough 'heralds' an acute attack or infection. In this manner, coughing 'announces' a concern, speaks for the body, and signals a warning. Unlike the discrete cough used to announce one's presence in a room, the persistent cough of illness may be exhausting and frustrating. Incessant coughing may cause alarm in others, as they listen with concern. Barbara's cough which is initiated by dust, dry weather, infection, or even talking, is a concern to others:

> I was coughing and coughing. The dust. And especially the weather. My mouth was so dry in the throat. That's what makes me cough mostly is the irritation in the throat. The administrator and the Registered Nurse heard me coughing. They came in and said, 'Barbara, you've got to get out of this room.' Oh, I was choking and coughing. Yet I didn't feel short of breath. (*Coughs extensively*). Like that, for instance. I've been coughing like that now for about a good month and a half. In fact, they did a culture last week. I was coughing so bad and they checked out my blood gases. (*Pause*). (*Coughs extensively*). See, as soon as I get excited talking I'll start to cough. Well, it's good a way for me to get it to come up. Because I can feel a factory down there manufacturing infection. I seem to just harbour infection in the lungs. I don't think there's a bug in Canada that don't say, 'Well let's go and visit Barbara Jones.'

In chronic pulmonary illness, cough may announce bronchoconstriction and inflammation. In this manner, cough signals an acute event. In COPD and emphysema, coughing may be a signal of the chronic 'progression' of the disease, the increase in lung damage. Continuing to escalate, this cough is not easily abated. Ed reflects on his cough and that of his sister:

> (*Coughs*) It's been getting progressively worse. (*Coughs extensively*). Excuse me (*Pause*). It's getting progressively worse as time goes on, obviously. I do get congested. I have to avoid getting things like colds and pneumonia or anything like that, because that's when it really, really attacks me. My sister died years and years ago of bronchiectasis. And that was a terrible sight to see her. She'd be sitting up. She could never lie down. With all these pillows around her. And she had this handkerchief in front of her. Hardly without it. And she hardly ever stopped coughing. I thought, 'My God. What a terrible, terrible life to lead.' (*Pause*). She coughed her life away I think.

It is not only the noise or interruption of coughing that is an offence. Phlegm and mucous are produced, and described as offensive or disgusting. With emphysema, phlegm *needs* to be cleared and needs to be looked at as it is a sign of infection:

> You saw how I was coughing, well that was minor to what the coal miners used to go through. They really had a terrible job in getting this phlegm up and out. It was like trying to get rid of concrete, I'd suggest. I've got Kleenex in every room, and I just thank god, because I can remember that there the miner's wives used to have to wash the handkerchiefs of these poor buggers, that would constantly cough up sputum and the only way that they could do it was with this handkerchief, which presumably had to be boiled and stuff like that. You know, the whole thing is just horrifying. Quite often the only way that they would do it is to go outside and just spit the phlegm out on the ground. Anything to get it cleared. Like right now I have quite a bit of phlegm. And it's fairly loose. I suppose the antibiotics are doing something which is good. Because sometimes it's very tough to clear it. It used to come up and it used to be very dense. Now it's very loose. It's very bubbly And the phlegm, I have to look at it. What colour it is. All the time.

Ed perceives that his brain warns him of the problem that needs to be fixed. He may feel a sense of panic as he needs to breathe:

> When my lungs suddenly fail on me, something happens to the machinery. There are little warning lights that come on and the brain sets me into a bit of a panic. I think I panic because the brain is telling me that's something's wrong and it's got to be rectified. That's just the brain reacting exactly the way it is designed to do say, saying, 'Hey, listen, there's problems happening. You've got to sort it out. Now get it done.' And I say (*breathes in audibly*).

With pulmonary disease, there is a disruption in air flow, alveolar ventilation, and oxygen exchange across the respiratory membrane. Diffusion of oxygen is impeded by an increased distance and decreased surface area for gas exchange. Breathing noisily, wheezing, or coughing are warning signs of lung disease, injury, or inflammation.

Can't Ignore It

Imagine having severe pulmonary disease: frequently or nearly continuously aware of your breathing. *Having* to think about breathing. Trying to ignore the sounds of the body. Can we ignore that which is demanding attention? Ignoring a sound or sensation of the body is not the same as silencing. It is consciously trying to push it back into the background of awareness; trying to not listen or think about breathing: "Now that I know this is asthma, I can relatively pass off these episodes by taking some deep breaths and pushing it into the background."

How can sounds or sensations be ignored? Attention directed to other thoughts yet in the same moment, there may be a sense of waiting and listening. Waiting to hear if it will worsen. Waiting to hear if the Ventolin® will ease the sound and sensation of the tightness and wheeziness.

> I have on occasion been in a situation where I hadn't had the Ventolin®, or I thought, 'Oh, it will go away. It'll go away' and hadn't taken the Ventolin® early enough. And then I ignore it. And if I ignore it, then it's more difficult to get on top of it. So I may have to take four puffs. Two and then wait a bit and then two more. And there's a level of anxiety there because I always think, 'Well, what if it doesn't go away?'

To ignore something has various meanings. We can fail to notice something, refuse to acknowledge it, or give little attention to it. In this context, there is a conscious intent to give little attention to the sensations or disregard them unless they worsen. In this sense, the person does not refuse to acknowledge the sounds or feelings, but attempts to put them into the background of their thoughts. The sound and sensation are not actually unnoticed and ignored. Valerie has frequent and serious attacks of asthma; she feels the tightness and may *try* to ignore it by tolerating the symptoms.

> Last year I would have had different criteria to take the Ventolin® for wheezing. But the serious attacks are now from other medications. So now I'm also more tolerant as it gets worse. So for the tightness I use Ventolin® and I have to wait it out or ignore it.

However, at times, breathing is not just brought into awareness through wheezing or coughing, and ignored. The ill body is not easily silenced nor ignored, even though one may try:

> I try to ignore the trouble I'm having breathing, the coughing attack that has continued, unabated, for the past two hours, the slamming inside my head, my fatigue. For the next few seconds, I try to ignore this body I inhabit that has declared war on me. Try to notice the changing sky. Ignore the chronic cough, the pain in my chest, the lump in my throat, the rasp in my breath. And can't. (DeSalvo, 1997, p. 2).

In an acute attack, breathing, wheezing, or coughing may no longer be ignored. They demand attention as described by two participants, one with emphysema, the second with asthma.

> If I have a bad attack then it would get a little scary. I can't breathe, I have no breath. I can't ignore my breathing. There's no way I can ignore it. I'm gasping for air (*makes gasping noise*) which is really worse. And so I have to sometimes tell myself, 'Stop, take (*breaths deeply*) slow.' Obviously I can't do that when I'm in the middle of an attack, but I do what I can.
>
> Once when I was working in the café, a lady came in with some strong perfume and I just started coughing, hacking. I was choking. I couldn't breathe. I don't know how to describe that, except for what I've already said I guess, it's a little scary and I get tingling all over, because of the lack of oxygen. Fortunately the owners were in there at that time and I just said, 'I'm going out.' I just had to go right outside to get fresh air, to get away, and do a few couple puffs on my inhaler. And then it's just, I don't know how to describe how I felt, just that I knew I had to be outside where I could get fresh air and do some Ventolin.

Several participants described acute experiences in which they tried to ignore their breathing, and others intervened. Betty tried to ignore her distress, not speaking of it to others. She was taken to hospital when a guest and then her son became aware of its severity:

> I could barely make it up the stairs. I kept holding back because I didn't want to spoil my son's New Year's party. I was just kind of crawling upstairs. I thought, you know, this could be it. If I don't get something soon I'm not going to be able to breathe. Period. And finally somebody was in the kitchen, getting a drink or whatever and they said, 'X, I think your mom needs you!'

Another participant recognized he had breathing problems, and although not quite 'ignoring' it, he did not recognize the severity. Instead, his wife "detected" the serious of his breathing problems and called the ambulance:

> I had a pneumonia. One night we been out to dinner (*Coughs*) and halfway through, I felt like the wrath of God, and I said, 'I got to go home. I'm really having breathing problems.' And got me back here. And then my wife detected that I was more seriously incapacitated than even I thought I was. So she phoned me in, I came with the ambulance, and took me in (*Coughs*) into ICU. And I was there for 6 days I think, while they were presumably getting my lungs working again.

Sense-experiences of pulmonary illness are sensations and sounds of the body that are noticed when they disrupt the usual taken-for-grantedness of the body. These sense-experiences may be disregarded or interpreted as normal within the contexts of smoking or aging. Other meanings of abnormal may be given, and these sense-experiences become signals for concern and act to reveal illness to self and others. In moderate to severe pulmonary illness, sense-experiences of breathing, wheezing, and coughing are not only noticed, at times they demand attention and cannot be ignored.

Chapter Five

Experiences of Breathing

In chronic pulmonary illness, breathing is no longer automatic, taken-for-granted, and effortless. New patterns of breathing are learned, and breathing is often conscious and voluntary. Work and effort are perceived in needing to breathe, and at times, sensations of being unable to breathe are experienced. There are three major themes in breathing with chronic pulmonary illness: *Learning to Breathe, Work of Breathing,* and *Can't Breathe.*

Learning to Breathe

We don't remember learning to sit up, stand or walk. We see babies 'learn' to do these actions, faltering and unsteady, gaining strength and surety. We don't need to learn to breathe. Our first breath is automatic and involuntary. Unlike other actions such as walking, breathing is not learned by trial and error. The first breath is just taken. Without thought or effort, respiratory rate and volume match metabolism and necessary oxygen and carbon dioxide exchange. A moving body demands more oxygen and produces more carbon dioxide than one at rest. When I get up and walk across the room, that change in activity demands more oxygen. Immediately and in synchrony, my intercostal muscles are activated to expand the thoracic volume. Without thinking about it, or sometimes even noticing, I breathe at a faster rate. The increase in rate and tidal volume increase alveolar ventilation, facilitating oxygen and carbon dioxide exchange. 'First' in the alveoli, then quickly and sequentially, oxygen is delivered via the systemic circulation to the muscles. I don't have to think about taking a different type of breath, don't feel my heart rate increase, don't notice my body asking for and delivering increased amounts of oxygen.

Other times, we may think about our breathing. Rate, volume, muscles can be attended to and modified. We may focus on breathing as a form of relaxation, perhaps to slow our *selves* down. We may even say that we 'learn' to breathe in some activities.

Athletes and dancers 'learn' to breathe to maximize their performance by pacing themselves, breathing with different muscles, focusing on air flow. Body movement programs, such as Pilates© and yoga, require learning to breathe, focusing on flow of air and muscle use. Of course in these instances, we are not really learning to breathe, instead we are learning to breathe in a certain rhythm or with particular muscles. Learning to breathe in these experiences has meanings of enabling the body and self to relax, to function, and to excel.

In pulmonary illness, changes in the conducting airways and alveoli disrupt the natural pattern of air movement in and out. The body demands gas exchange yet the automatic breathing pattern inhibits getting adequate air. Conscious and voluntary breathing patterns may be learned, optimizing air flow through attention and focus. What is it like to learn to breathe in pulmonary illness? Is it to pace their body as does the athlete? Is there a focus on the body and breathing? Themes of *Learning to Breathe* are:

- *The way it feels*
- *Breathing the right way*
- *A cat chasing his tail*

The Way It Feels

The objective self *knows*, thinks, analyzes, reflects, and interprets, whereas the subjective self *feels*, experiences, and perceives. Knowing and feeling are seamless in pre-reflective experiences, whereas other experiences occur in which knowing and feeling are not equivalent and may be contradictory within the same experience. Walking across a suspension bridge, I experience severe vertigo. *Knowing* I will not fall does not eliminate the *feeling* that I may fall. In this and many of our experiences, intellectual knowledge conflicts with sensations of the body. With experiences of breathing in chronic pulmonary illness, knowing and feeling may not be fused into one perspective. Some participants *knew* that the difficulty is breathing air out, while *feeling* the panic, distress, or effort in trying to breathe in.

Storr's intellectual perspective as a physician contrasts with his experiential description of a severe asthmatic attack: "As every asthmatic knows, breathing out is more difficult than breathing in; and the more the bronchi are obstructed by spasm and swelling, the more difficult it is to force air *out* of the lungs." Yet on the same page, he describes a severe asthmatic attack "I was in bed, panting away, wholly absorbed in the question of how I could get enough air *into* my lungs (Storr, 1979, p. 7, italics added for emphasis). However, not every asthmatic *knows* that breathing *out* is more difficult or necessary. The focus is on breathing *in:* "Breathing in is inspiration, clutching for the straw of air. Breathing in is the beginning of life, the first gulp as the diver reaches the surface. No asthmatic works to breathe out" (Brookes, 1996, p. 9).

In COPD and emphysema, air is perceived as being restricted from entering, although it is physically obstructed from exiting. Ed indicated that "I used to think that if I could just tug enough air in, I would be fine. I didn't know the problem was exhaling." It seems that how 'he used to think' is how he *felt,* when he *didn't think* about breathing. Breathing sensations were perceived through body. His current perceptions are re-interpreted with cognitive information from others. He incorporates his beliefs of smoking and carbon dioxide damage with the need to learn to breathe:

> I never learned until this whole mess started for me that the most important thing about breathing is breathing out. Nobody had ever told me that. And I used to think in terms of 'So long as I can pull the air in, I'm going to be in great shape.' But what I was doing was not exhaling. And I'm a very shallow breather anyway. And the carbon dioxide, I suppose, was doing its damage because I wasn't getting rid of it.

The knowledge imparted from others, the "they" of medicine and nursing, contrasts with the knowledge of the body. Intellectually knowing he needs to force air out, Karl perceives that his body needs to breathe *in*:

> They say you're supposed to breathe in through your nose and breathe out through your mouth. Well, when I'm in a panic attack for breathing, I don't do that. I breathe in as much as I can to get in there and then I have trouble blowing it out. It feels like I can't get it in, but it's actually in reverse. They tell me anyways that's the biggest problem, I can't get it out.

For Bill, feelings of being unable to get air and of working to get air in are dominant. What he *knows* is what he *feels*:

> I'm a little short right now. I'm working a little harder to get the air in and out. They tell me, 'Not in and out, it's getting it out.' I don't know much about that part. It seems to me, I'm trying to get it in. I'm working to get air in. They told me it's getting it out. But it seems to me it's hard gettin' it in! Because that's the way it feels, to us. It's starting to get the air in, that's the way, not get it out. And the medical people tell me, 'It's getting it out.' But it feels like getting it in 'cause I'm always taking a (*audible big breath*) big breath trying to get it in. They don't understand that part but they told me so, so I go along with it. I guess it's not coming out so I can't get it in.

From pulmonary function tests, we 'know' that air is trapped at the end of inspiration. Trapped air increases the dynamic compliance, airway collapse, and work of expiration. Air must be forced out. Feeling as if needing to take bigger and bigger breaths, the lungs hyperinflate, further limiting air entry. Our present physiological and intellectual knowledge is not consistent with that the sensation that is experienced.

Not only the perceived experience may differ between knowing and feeling. The measured capacity of the lungs may not be the same as that felt by the person. Knowing that his 'measured' vital capacity has improved does not match Jake's subjective experience of his body:

> I've been tested every four weeks where you see the capacity in the inhalation levels. My tests came back and those levels showed no decrease, in fact a slight increase. Yet, I personally feel like I don't have as much there. I find I don't have much left in reserve, I come home and crash. I'm made to stop. And I feel like I don't have as much capacity to keep on going. I feel like I'm reaching down to the very bottom of my lungs. I'm made to stop and I feel like I don't have as much capacity to keep on going. I have to stop and try to reach way down and see what I can get in there. And sometimes I don't feel like I can get a lot in there, or anything is being absorbed. Maybe the body just demands too much of what's left of the lungs or whatever capacity.

In the moment of *the being short of breath*, a disconnect between subjective and objective time may be perceived. Feeling, knowing, thinking, and telling are used to relay perceptions of time:

> I feel that I'm only breathing once every three minutes and that's not fast enough, but I know that I'm breathing a lot faster than that. It's thinking I have a limited amount of time to actually do something about this. Although I know that I will survive. Thinking about the steps that I have to do, and knowing. I could tell you that it probably takes me 30 seconds to get breathing again, but it feels like five to ten minutes before I can actually slow that down.

In this experience, the objective stance is the counted seconds and minutes of time. Feelings of breathing too slow, of limited time, the long time to get breathing again are reflected upon, and the subjective time is contrasted with the objective.

Jake also felt that he might be getting too much oxygen. Like feeling the need to breathe in, too much oxygen is not consistent with our current physiological knowledge of the body:

> At one point of time I felt maybe the oxygen was inhibiting me. I was forcing it in too fast. It was my thinking that maybe I was getting too much of a gulp and then not being able to inhale it, or store it, or whatever. But I've been corrected. They have told me that there's no way in God's green earth that you're going to get too much oxygen.

Knowing and feeling may conflict, particularly within experiences of breathing *in.* Although restriction and obstruction primarily affect *expiration*, the subjective experience is that of difficulty on *inspiration.* Even when cognitively 'knowing' that they have too much air or that the difficulty is with expiration, it is perceived as needing to breathe *in* or to inhale *more* air. When more gas exchange is needed, the person with asthma, COPD, or emphysema may rapidly gulp in air or gasp in large breaths. Air is trapped in the alveoli, and subsequently limits lung expansion.

Breathing the Right Way

In health, expiration takes little or no effort. Although airway diameters are decreased, friction work is minimal and the elastic recoil of the chest promotes air flow. In most types of chronic pulmonary disease, resistance in the airways increases the amount of friction work that is required on both inspiration and expiration. In COPD or emphysema, high compliance, loss of elasticity, and collapsed airways require a significant increase in the effort to breathe out. In asthma, bronchoconstriction and mucous plugs increase resistance on both inspiration and expiration. In either etiology, the force of expiration may be insufficient, leading to trapping of air within the alveoli.

Learning to breathe requires slowing down the rate and focusing on breathing. Pursed-lip breathing promotes prolonged and forceful expiration which decreases air trapping and enables larger breaths to be taken. The is a purposeful focus on breathing may or may not alleviate the sensation of feeling short of breath, as Jim described in emphysema:

> It starts out as feeling short of breath. I sort of use ways of dealing with shortness of breath. And then I go to pursed-lip breathing and try and slow my breathing down. And I try and breathe in through my nose and out through my mouth and all that good stuff. And the concern starts when I get to a point where I say, 'This isn't working.' Frankly that raises alarms. And the way our bodies are built it obviously raises the first alarm in the fight or flight response. So I sit there and I say, 'Gee is this it? What usually works isn't working. What could I do?'

Jake also has severe emphysema. He perceives that there is a problem restricting the air going in, and that he has trouble retaining air. When this occurs, he tries to breathe "correctly" or the right way. Remembering and doing so is not easily adopted or attained, particularly when it is most needed. Learning to breathe requires conscious, cognitive effort, and he often "finds himself" gasping, not able to breathe:

> It feels like it's not retaining it. I believe there's not enough collecting there. I try to practice this pursed mouth method where I breathe through my nose. But when I get into those situations, I find I'm gasping for breath through my mouth. Or I'm exhaling and nothing. I know I haven't retained anything. It's just going (*ssswoop*). Nothing's staying in my lungs. If I'm relaxed, I do the right type of breathing. Whereas when I forget about it, I immediately expend my supply of oxygen (*breathes in sharply*) and I'm struggling and I'm blowing out through my mouth. (*Breathes out*). Like that. And there's nothing being retained. I'm panicking, so I'm going (*breathes in and out loudly and quickly*) type of thing. In the meantime I'm wearing myself out doing it. It's just a matter of (*pause*) mind over matter by being able to tell myself too continually to strengthen or fortify the thought of breathing the right way. And when I do slow it down, it actually helps the stress, with the rhythm.

Although the 'right' way of breathing can be learned with practice, it does not seem to be the natural rhythm of the habitual body. Mind over the body, thought and attention are required "to change the breathing habit." Knowing, thinking, and doing are not in synchrony as "the faster I gulp, the more energy I use and the less I inhale. The less I keep in." Another person with emphysema describes struggling to breathe "the right" way:

> I don't pay enough attention to what I should be doing right, to correct these problems with my breathing. Something I took for granted all my life and then all of a sudden it's pinched off. It takes me a long time to relearn something. To train myself to do the right thing. I'm really struggling with that. But I just let other things get in my mind. It's so easy to disregard it. I can remember a couple of instances, where I went over the top. And the shortage of breath really got short and I was really panicking. And the worse it got, the more anxious I got. It's very difficult to concentrate on those when you're feeling anxious. I was struggling so much. Even after having taken the Ventolin®. I was getting no relief. I was just puffing and puffing and struggling to breathe. Doing it all the wrong way. Sucking it in and blowing it out of my mouth. Not regulated like with the pursed lips business. I just wanted to live. I was gulping air.

Breathing the right way must be learned. It may feel opposite to that which is usual, and requires attention and focus, which may be difficult to attain in moment of acute distress.

A Cat Chasing His Tail

Learning and knowing how to breathe is difficult to do when gasping for air, and concerned about wanting to live. The normal or natural response with anxiety is an increase in rapid and shallow breathing, which is the opposite of the required type of breathing. Thus, "one must school oneself to breathe as deeply and slowly as is possible even whilst in the throes of an attack" (Storr, 1979, p. 11). Gasping and puffing and struggling increases the body's need for air, which is not matched by the perception of attaining it. I try to imagine how difficult it might be to relax at the same moment when struggling for air. Feeling I have to get more and more air in. Trying to interrupt the struggle to get air. Feeling anxious. Trying to relax.

> I've felt anxious trying to breathe. It was like a cat chasing his tail. One was chasing the other. And I realized what was happening, so I went and laid down and did my best to relax. And it seemed to work after about half an hour.

Like a cat chasing its tail, feeling anxious and struggling to breathe go round and round. Learning to breathe can interrupt the spiral, the never-ending chase after the elusive breath. Darlene uses counted breaths and *thinks* about pulling air in deeper into her lungs. Her counting has a rhythm as well as a pace: "Doing eight counts in. Hold eight counts. Eight counts out. Hold eight counts." With acute asthma, she feels that she is breathing faster, "not getting enough oxygen," and that "it's not reaching the bottom of the lungs." Learning to slow down her breathing has eased the spiral of perceptions:

> Being able to have strategies to control it makes me feel better about it. Probably reduces the psychosomatic spiral with it. When I first had asthma, quite a lot of it was 'I can't get air. Oh god I can't get air. Oh god...' and then it was spiralling in on itself. Having at least some things to deal with that resolved that.

For those with asthma, leaving the environment or using a bronchodilator may interrupt the cycle of needing to breathe and feeling unable to breathe. The focus is on getting air, and getting enough air:

> At the time, all I can think about is the struggle for air. I'm not aware of anything but *not* being able to get air. I'm not feeling my feet. I'm not thinking about hitting a baseball. I'm just totally focused that 'I can't get enough air.' I don't think of anything else. I get into this little, inward spiral of concern, and I suppose the agitation probably exacerbates it. It was never a case of trying to get the next breath, it was a case of consistently (*pause*) not being able to get enough. And there's a subtle difference there somehow. It's not that I need one big breath, it's that I'm more and more shutting down and I can't get enough air, and I can't do anything about it. Until finally it got so bad, that the only thing I could do about it was to remove myself from this environment and get the fresh air to stop the cycle.

The need to take in air is experienced. Regardless of objective knowledge or having learned to breathe, the cycle of trying to breathe in without sufficiently breathing out may continue.

> I feel like there's somebody gradually pushing on top of my chest and pushing down and pushing down so that I can't catch my breath. I can't breathe in fully. And I'm not supposed to not breathe in. It's breathing out that's the problem. But of course when I get myself sort of wrapped up in this condition what I do is that I just (*breathes in sharply*). And no matter how I try to do the pursed lip breathing thing, I'm still full of air and I can't get rid of it. And then I can't breathe in because I'm already full.

Although considered important in alleviating symptoms, many participants had not learned pursed-lip breathing techniques from health care providers or learned them late in their illness experience. One participant with known and severe emphysema learned pursed-lip breathing in hospital from a patient:

> The guy kept insisting that's the way you breathe. There was another gentleman in there, an older gentleman, but he was getting exacerbated like I do. And he was breathing, exhaling, considerably more. He wasn't retaining any thing. So you learn something. So here's a guy that's 70-something teaching a guy that's 80-something – with a 53 year old listening – how to breathe.

Another participant with COPD/emphysema had not yet learned pursed-lip breathing or other strategies to exhale. She has been told the problem is breathing out, but has not learned to breathe it out. When asked her about breathing exercises, she said her doctor wanted her to learn it when "going to rehab" but she had to quit smoking first:

> J: (*Makes small quick breathing noises*). No, it's more like (*makes gulping/hiccup noises as trying to breathe*). And taking it in, because what happens is I can't get the oxygen out of my lungs, so therefore there's no more room to take anymore in, I guess, I don't know. But that's what they tell me, that I take air in, my intake of air is not too bad but the taking it out is not good. So I keep oxygen in so I guess that's not good. So I'm trying to suck more in, when really I need to be trying to push it out I guess, I don't know. I've never really thought of it.
>
> C: Has anyone taught you the exercises to try and push it out?
>
> J: Um, not yet. Dr. Q. is dangling a carrot, as he says. He said that he would get me there, but first I have to quit smoking.

Pursed-lip breathing or purposefully slowing their breathing rate were strategies used by several participants to regain their breath. As pursed-lip breathing may relieve both the distress and difficulty of breathing, it should be taught early after the diagnosis of COPD, which did not occur for several participants.

Work of Breathing

The force and effort required to expand the lungs are described as the work of breathing (West, 2000). In health, there is little impedance to air moving in and out of the airways; the majority of 'work' is to expand the chest and promote air flow on inspiration. When taking a relaxed breath in, only a small amount of force is necessary to overcome static recoil pressure, and stretch the elastic fibres, expanding the volume of the lung for air entry. On expiration, the elastic fibres recoil and the lungs deflate. A small amount of friction work is required to move air through the airways on both inspiration and expiration. The natural recoil of the lung is greater than the friction work, thus expiration is considered to be passive and without effort. In health, even when large breaths are required with exertion, inspiration work is minimal and usually perceived as effortless. We may take in large breaths, using more muscles to expand our lungs at an increased rate. Is this breathing perceived as requiring effort? Interpreted as work? I think back to a moment of riding my bike or climbing stairs and remember taking large breaths. I noticed my louder or quicker or deeper breaths, but did not perceive an effort to breathe.

With moderate to severe chronic pulmonary disease, increased work of breathing is required for everyday activities. Even at rest, breathing may be laboured, required increased effort to inhale and exhale. With an acute attack of asthma, extensive work of breathing is necessary. Narrow, constricted airways increase friction work and decrease air flow during inspiration *and* expiration. Inflammatory fluid and cellular changes markedly increase the elastic work required, forcing the respiratory muscles to work harder for a smaller result in air entry. In emphysema and COPD, damage to the elastic fibres decreases expiratory recoil, which increases the work required to exhale. Airway collapse or mucous plugs increase the friction work on expiration, and air is trapped at the end of inspiration. Breathing becomes hard work, even with minor exertions. The themes of *Work of Breathing* are:

- *A big chore*
- *Real work*
- *Worn out.*

A Big Chore

With acute or chronic lung injury and inflammation, increased effort is required to breathe. With asthma, in the midst of everyday activities, Valerie experiences "struggling, making an effort to breathe." Ed "normally has a lot of breathing difficulties" as his lungs "won't do its bloody work." Perceptions of work are not limited to the lungs; effort is not limited to breathing. Ease is lost, awareness is extended to the body, and work is required to breathe:

> My breathing is very difficult. I have to stop and hold on and work at getting breath into my lungs. Air into my lungs. It was hard work. I really had to work at it to get it done.

Work of breathing is more than the small force required to move air in and out. The work of breathing is perceived with exertion or may limit activities. With exercise-induced asthma, “even something as simple as golfing will bother me.” For others, work of any kind is no longer possible

> I always worked on automobiles. Worked out. Played sports … curling, baseball, football, golf. (*Pause*). I miss it. (*Pause*).

Karl describes himself as “always a hard working man,” now taking a shower is “a real, real chore.” Work is not only ‘big’ things, but ‘little’ everyday activities: “Basic things like taking a shower, going to the bathroom, all of a sudden doing every little, everyday things that you do normally become a chore.” The work of breathing may not be perceived until everyday activities become a chore or a challenge that takes energy and effort. For those of us whose breathing is effortless and easy, it may be difficult to imagine the effort that breathing requires in pulmonary illness. Can you imagine when taking a shower becomes a chore? That drying off afterwards is hard work? When breathing impedes nearly every activity, they become work that requires effort and energy:

> In regards to the breathing it just gets to the point that I can’t do anything. Basic things like taking a shower. Going to the bathroom. Doing every little, everyday things that you do normally (*pause*) all of a sudden become a chore. And a big chore. They’re very hard on me. Everything I do uses energy. And Dr. G was talking to me the other day and he says, ‘For me to breathe and you to breathe, you use twice as much energy to breathe as I do.’ In other words, everything I do is work.

In health, we don’t think about the work of breathing that is required for our day-to-day activities, such as walking up a flight of steps. With pulmonary illness, with the required effort and the ensuing fatigue, these activities may become work. Awareness of breathing work and effort move into awareness of self, and influence decisions on use of medications or changes in activities. Bill takes his Ventolin® when he feels that his chest is heavy, there is pressure, and he is “working” to inhale. The medication ‘works’ to dilate the airways and subsequently decreases the work of breathing:

> I take the Ventolin® when she starts getting like this. The breathing gets difficult. And the chest is a little heavy now. I can feel a bit of pressure. Not much, but just a bit. I can feel it. I’m working a little bit now.

Work is not just the effort of moving the chest muscles. It is as if there is effort in even feeling the sensations of breathing.

> There's a heaviness in my chest and then that feeling that I've got to start breathing. That I've got to start working harder at breathing. It definitely becomes work if I don't take the Ventolin®. (Adam)

It is not only 'physical' exertion that increases the effort and work of breathing. One person with asthma notes that "Talking and laughing, getting upset or crying, anything that forces my air is hard to control, despite all the efforts." Activities are planned to save effort. Effort is taken to control breathing and eliminate triggers. Effort is required to breathe, to relax, to slow down. Ed says that he "works through the panic." To relax becomes an exercise that demands work, attention, and practice:

> I had this one relaxation exercise where I started at the top of my head and I worked down. To my toes (*Coughs*). Try to make everything feel heavy. I always start at the top of the head, through the head, and gradually work down and try to concentrate on that. To relax, rather than let the anxiety take precedence over what I'm trying to do. It's difficult. It takes a lot of practice.

Real Work

Work is more than paid or unpaid jobs. In moderate to severe COPD or emphysema, everyday activities become real work:

> And I went out to the little greenhouse this morning. Just to water a few tomatoes. I got a little hand pump watering unit out there. And it is a real job. Just to water a few tomato plants.
>
> Little things. If I have to get up and go to the bathroom or come out and get a cup of coffee or to do anything. Then bingo, I'm working again.

The work of breathing may impede paid or unpaid work. Several participants retired because of their illness. The effort of breathing and everyday activities is their work. Minor exertions become 'real work.' Previous physical efforts can only be remembered, not recovered.

> I'd love to work. It's no fun sitting here alone, for the better part of the work day week. But if I have an opportunity to go to work but I don't think I could. The way I have felt in the last 11 months I don't think I'd have the stamina or I could sustain it. I think of all those years, of some of the work I did. Working life and how much physical work I did day in and day out. I built a house practically on my own.

Not working does not have the same meaning as not working with 'retirement' or 'relaxing.' In the context of pulmonary illness, not working is involuntary, neither chosen nor something to look forward to or be celebrated. Jake's inability to work at a physical job has decreased his activity level, and is felt as a loss, as a pity, not a celebration. The emphasis on breathing and fatigue points to physical aspects, but work is more than the body. The person and self that worked is no longer able to be occupied in paid and unpaid activities.

> Obviously since finishing work, my activity level has dropped, which is a pity because I get bored. If you're going to be active, then you need something to do. I hate this. I hate it with a passion. I really do.

Gregory "quit work" about five years ago. He "loved" his job but didn't want to go to work anymore. Tired when he was there. Exhausted when he got home. Today, he is on continuous supplemental oxygen. Taking his time, he is able to do some of the 'work' of the house. The work of other activities he'd like to do is no longer possible:

> Some days are better than the others. If I'm doing something in the house and I get tired I sit down for a minute. Two minutes. Get up and get at it again, as soon as I catch my breath. Today I made the bed. I did the dishes. I'm going to vacuum this afternoon. There are things that I'd like to do, that I can't. Which makes me mad. Working on the car, I enjoyed that. Now my son does it all. I went over there the other day and he was working on my car. I tried to start but I couldn't do it. It made me so darn mad that I couldn't work on it.

Worn Out

Some participants mentioned feeling tired with severe emphysema or after an acute asthmatic attack. Although necessary to clear secretions, extensive effort and exertion are required to cough. With a dry, persistent cough, this work is of little or no 'benefit'. When I think of some*one* as productive, I have a notion not only of effort but contribution to life, work, society, and human welfare. With a productive cough, there is indeed effort, but benefits may be absent or not in proportion to the work. Mucous becomes tenacious in pulmonary illness and difficult to expel. The effort of coughing becomes exhausting, troublesome, frustrating, and with little results. Ed describes his coughing as “trying to get rid of concrete.” Jake experienced cracked ribs from “coughing or trying to, 'cause I wasn’t clearing all the phlegm and stuff like that.”

When there little removal of phlegm, coughing seems to have no apparent purpose. It is a waste of energy. It seems to escalate distress. No longer is cough beneficial to protect the airways. Nor as a defence of the body. Coughing occurs without necessarily clearing the secretions.

In the past I’ve had a cold and cough for several days. The cough is annoying, tiresome, wearing. Waking up at night coughing. Stomach muscles hurting. Imagine a cough continuing for months. Worsening at times. How must the body feel with a cough that is so persistent? Ongoing? Imagine what it might be like to cough like this. To be tired and terribly short of breath from coughing. To have broken ribs, headaches, nausea, and still continue to cough and cough and cough. The person’s chest may feel tight, or blocked. Short of breath. Not only is the need to cough more common in pulmonary illness, greater effort is required. Imagine coughing for hours or intermittently through the day. Everyday. Brookes writes that he spent two hours clearing “an accumulation of phlegm” (1994, p. 209). Barbara coughed frequently throughout the interview, and spoke of the exhaustion, and inability to clear her lungs, “I can’t get it up. I know there’s something there but I can’t cough it up. And I cough until I’m exhausted.”

The fatigue and frustration of the effort of coughing are part of the work of breathing in pulmonary illness. Sometimes, Jake doesn’t realize that he has gotten “very exacerbated from coughing.” He needs to cough to clear his chest, but is worn out. Sometimes from coughing. Sometimes from the infection. Or are they really this distinct? He likes to use an inspirometer because it helps get the phlegm out, but when he most needs to clear his chest, “I’ve hardly used it at all because I’ve felt so worn out.” When phlegm builds up, it is not only the coughing that is troublesome. He feels the tightness and soreness of his chest, and feels more tired:

> The tightness holds me back more than anything. It seems to (*Clears throat*). I've got a frog in there or something in there right now. I don't know. The air is not going in properly. It's blocking something. It's there now. It makes me tireder. It's a phlegm that's in there. And it just will not come out. I've tried this morning to get it out. But so far it hasn't come out. But when it does come out then I feel like a new person. I can go ahead and do something. But if I have it I don't feel like doing nothing. I just wait until I get rid of it. My problem with the difficulty in breathing is the soreness in the chest and the phlegm or whatever it is.

The body may feel worn out with the effort and work of breathing. Feelings of tiredness may be prolonged after an acute asthma attack:

> I spent a good half hour or forty minutes really struggling to breathe, so it took a fair amount out of me. I felt fairly tired after that. Just physically tired, even though by then it had gone away.

Physical tiredness and fatigue were not distinguished from the work of breathing by some participants, whereas others spoke of feeling tired and not having enough oxygen or air: "All of a sudden I started feeling tired. Oxygen went down to 83. I could hardly make it to the washroom."

The effort of breathing and coughing in acute events maybe perceived as real work. The person may need to rest at short intervals within their daily activities or longer intervals after acute episodes. The effort of breathing includes, but is not limited to, inspiration and exhalation of lung volumes. Effort and work were perceived by the self. For some, the work of breathing impeded other activities that required exertion, even everyday activities of walking, showering, or talking.

Can't Breathe

Breathing is far more than the movement of muscles and air. *The first breath* and *the last breath* define the beginning and end of life. Breathing has had connotations of life and vitality since descriptions and reflections of early philosophers. Anaximenes, a Greek philosopher around 550 BC, proposed that air was the main element of the cosmos, and the body renewed its vitality from moment to moment by drawing breath (Miller, 1978). In the 4th century BC, Plato and Aristotle identified the necessity of warmth for life; Aristotle assumed that breathing cooled the flame within the heart. Glen, a Roman physician, postulated that the heart created heat to produce a substance for movement and sensation, and that breath both fanned this process and provided an essential ingredient. These conceptions of warmth and energy were the basis for biological aspects of breathing until the 16th century (Miller, 1978).

Our understanding of breathing and the symbiosis between air and life is relatively recent. In the 1640s, the first "problem" of the Royal Society of London was "the nature of air and the part it played in both breathing and combustion" (Miller, 1978, p. 150). Not until the late 1700's was oxygen differentiated within the air that we breathe, and in the late 1800's understood as necessary for production of energy. Knowledge of breathing and respiration has increased greatly in the past century. Concurrent with expansion of understanding of aspects such as gas exchange and cellular metabolism, breathing continues to have associations of inspiration, life, vitality, and energy.

We have a basic understanding of the body's requirement for oxygen. This understanding is an intellectual knowing, not a knowing of the body or of sense-perception. Not thought about, the atmosphere, air, and oxygen are taken for granted. We don't envision our need for oxygen, nor recognize our need for a continual and sufficient supply of oxygen. If I don't have a sufficient amount of oxygen for aerobic metabolism, I likely don't notice. Perhaps I am a little stiff or sore the next day. I immediately interpret that I am *out of shape,* not that I am *out of oxygen.* I really have no understanding of the need for oxygen. To be short of breath and not able to get the air and the oxygen that the body needs seems much different than that experienced in pulmonary illness.

There is an "unremitting regularity of breathing" and "one usually breathes without a second thought" (Miller, 1978, p. 144). Indeed without a first or any thought, we breathe. When this rhythm is interrupted in pulmonary illness, it not only that attention is drawn to breathing. It feels as if breathing is stopped. Sensations may be experienced of not being able to breathe. The themes of *Can't Breathe* are:

- *A terrible distress*
- *Almost a panic*
- *Can't get the air in*
- *Time slows right up.*

A Terrible Distress

In 'vital' and 'vitality' there are connotations of animated, full, invigorating life. Of necessity. Sunlight, water, and air are all vital for life. Air and breathing are not an option, but a necessity for life. Without air, life ceases. Without air, movement ceases. The person without air may literally stop with the feeling of being unable to breathe. Karl is "fine" when he is sitting, resting, but "as soon as I go to exert myself I can't. I can't breathe."

Vital signs are the assessment of temperature, heart rate, and respiratory rate. Intertwined, these signs of life and vitality are indicators and determinants of oxygen delivery and consumption. Life requires ongoing exchange between the physical body and atmosphere. Air of the atmosphere contains sufficient oxygen to maintain life. In acute episodes of feeling unable to breathe, there may be a sense of desperation and distress. Coughing may worsen the sensations of not being able to breathe. Having to force air out at the same time as trying to gasp it in. Valerie describes one asthma attack in which:

> My chest couldn't expand, I couldn't push the air out fast enough, and I would cough and cough with no apparent reason. In an hour I was in a terrible distress. At that point it's already past control. I was getting so short of breath. I was coughing. I've used up all my Ventolin®. And I went out and I said to them 'I can't breathe.'

The need to breathe is urgent when the body is not able to get its breath. Air is immediately available, yet not available. Barbara feels that her lungs won't open and she can't get enough breath:

> My lungs spasm. They tighten up. I can't breathe. I just can't get enough breath. It's just no way. My lungs won't open up. To have my lungs spasm, that's when I really get short. Let's face it. I just don't breathe. And I know I've got to breathe and yet I can't do it because my lungs is all screwgied up. That's an ungodly feeling.

Feeling that they *can't breathe,* the world may shrink to the lungs and breathing. The person is physically situated in the world, but somehow the rest of the world diminishes, "As if there is a tunnel and at the end of that tunnel is air." As Ed described, when one can't breathe, one centers inward, not outward: "It seems then that my whole body gets centered in those lungs and I just can't, I just can't breathe (*coughs* *extensively*)." As Mary described being inward centered, she reached her arms out in a circle. She cupped her hands, and pulled them into her sternum as if she is pulling air into her lungs.

> Whether it's wheezing or shortness of breath, I am very much inward centered. I turn inward because I am quite focused on relieving it. If there was a group of people around, I would go away to deal with it. To manage it. I'd leave the crowd and go into the washroom or something and take my inhaler. I wouldn't be moving outwards and say, 'Help me with this!' So, if I am wheezy or something, I am always needing to just be by myself.

The centre of being and life is in breathing. We even might envision the chest as the centre of the person; the lungs and heart central to life. Focusing on breathing is essential:

> Sometimes my wife says, 'Are you okay?' and I don't even answer because I can't. Doesn't make much sense maybe. I can't do anything. I can't answer her because sometimes I just can't breathe and I can't say to her I'm fine or I'm not fine. When I was in the hospital when I had that pneumonia the nurses would ask me 'Are you OK?' And I was on oxygen in there and I still couldn't answer. I was too busy surviving to speak.

When feeling one *can't breathe,* acute distress and anxiety may be experienced. The person is centered on breathing, unable to speak or interact, perhaps not even able to be with others. DeSalvo (1997) gives us a glimpse of calming her breathing. The focus is on her breathing. Not her pounding, tightening, tingling, clogging body.

> My worst asthma attacks now come at 1:00 a.m. When I awaken, heart pounding, chest tightening, throat tingling, mucous clogging, I don't even need to look at the clock to know what time it is. My house, at one in the morning, is quiet and still, and I am trying to calm my breath.

Perhaps focusing on breathing, calming down breathing, eases some of the anxiety, the panic, and the physical sensations of the body and self. Alleviating the panic enables one to move back into the present moment and grasp an immediate future.

Almost a Panic

At times, we may disregard or ignore sensations of the body. Other sensations "demand attention" when they raise alarm or decrease activities (Miller, 1978, p. 46). With the demand for air, there may be a forceful awareness of breathing, and nearly a panicky feeling. Unable to breathe. Unable to catch one's breath between coughing. Unable to get air in. Most would interpret these sensations as a threat to life, with a sense of distress and alarm. A desperation for air may be perceived. Panic, and yet not quite panic, is experienced:

> I'm almost panicky. I just wonder if I'm ever going to catch my breath. Even if I'm gasping, I'm only just getting a little breath. I'm taking these huge breaths, but I don't feel that air moving in there. And that's probably why I get panicky.

Sensations and images are experienced and understood within a context and "horizon of meaning" with significance and relatedness interrelated (Merleau-Ponty, 1962, p. 18). In the suddenness of an asthmatic attack there may be an apprehension of the next breath, or the next moment. As Valerie describes, "It's almost a panic and almost instantly I'm short of breath. And I'm terrified because I don't know where this one will go." Urgency and distress may be felt when one can't breathe, to feel time is limited. In describing her experience of breathing with asthma, Sasha recalls that each attack "was the worst one" and feeling as if she was "running out of time" (Clarke, 1992).

In almost a panic, it is as if the wholeness of mind-body is disrupted. Intellectually, one may know the next breath will occur. Physically, the body may not *know* or *feel* the certainty of the next breath. There is an immediate necessity of getting air:

> Not being able to get your breath is a bloody awful experience (*forcefully*). It's not a painful thing. It is a panic thing. I get this feeling, 'Well, here it is. I've done it.' It is simply, 'Am I going to get the next breath?' Even though intellectually I know – breathe in and breathe out and it will work itself. But I don't do that when I'm fighting for breath. All I can think of, 'Shit – this is it.' (*Forcefully through clenched teeth*). And I quite often do get into a panic like that. I suspect that no matter what the dimension of the panic is I would slowly come out of it naturally, but I don't know that or at least my psyche doesn't know that.

Knowing and not knowing. In the midst of feeling panic, Ed recognizes the necessity to breathe, perhaps that is part of the anxiety and struggle. Thom also described an asthmatic attack as desperate and "almost panic":

> I felt, I don't really want to say panic. Boy, it's hard to articulate this. *(Pause) (Forcefully)* Desperate. And it's just a sense of, almost panic, because I can't get air. I know I need it. And there's nothing I can do about it. Desperate is the best word I can think of. I'm desperate to get air. I need it and I can't get it. And there's nothing I can do. I was so frustrated that I couldn't reach my hands in and open things up. It's inside and it's not working. Desperate. Yeah, desperate when I couldn't get air. And angry.

It is a kind or almost a panic. Yet "panic" does not quite capture the sensations of desperation, anger, frustration, concern. Not a panic of injury or death, but a panic and need for air. A need for breath to live is also experienced in COPD/emphysema:

> I woke up literally almost panicked because I couldn't breathe and I was fighting for air. I could feel myself closing up inside, and it just got worse and worse as the night progressed. And so it's a struggle, and (*pause*) I know from feeling my body that I'm short of oxygen, that I'm struggling and I can't get it, so of course that just sets up more angst and agitation.

The distress may be exacerbated if medical help is not available. One participant described having an asthmatic attack while camping "was like a nightmare. Here I'm safer because I know I'm not far away from oxygen or that kind of thing." Another described running into trouble on an airplane. Either camping or in an airplane, the person is physically unable to get to a hospital for help. The sense of "trouble' intensifies:

> We were on an airplane coming home from visiting friends. And suddenly on the plane, I couldn't get my breath. I had some kind of a struggle going to the washroom on the plane, and I couldn't get the toilet to flush properly or something like that. By the time I got back to my seat I was quite desperate. The airplane experience was frightening. Simply because it was on an airplane. At home, I can be in the hospital in 5 minutes, if I last that long. Up in an airplane I'm in real trouble.

Availability of oxygen or Ventolin® may ease a sense of that panic. When oxygen is at hand, or the Emergency Department nearby, some of the sense of concern may be alleviated. Storr (1979, p. 11) has supplemental oxygen nearby:

> In a very severe attack, oxygen is often valuable. I myself have a cylinder in my bedroom. Although I seldom need to use it, it is a comforting presence, and has in fact been invaluable on more than one occasion.

There may be an understanding and recognition that the body needs oxygen, not only air. Oxygen is no longer easily attainable from the atmosphere. Being able to turn up the oxygen tank at home, or to get to the hospital quickly, feels safer. The availability of supplemental oxygen is described as helping to breathe, alleviating some of the panic:

> I was at such a point that my airways were completely clogged. The airways sealed right up. And there was nothing getting in there. I was struggling to breathe. I couldn't feel the airways open up. They weren't letting anything in there. I thought if I couldn't get any air, if I couldn't any get relief on oxygen, I would die. So my wife had to call an ambulance to get me oxygen. There was some relief naturally from the oxygen. Something else is helping you. The oxygen is there helping you to breathe.

Can't Get the Air In

Regardless of the etiology, many participants described moments when they perceived that they were unable to breathe in. Others expressed that the air they did attain didn't have enough oxygen or wasn't processed by the lungs. Darlene describes trying to get more oxygen in asthma:

> I can't get the air in. Cannot get the air in, can't get the air in. Can't process the oxygen out of the air that I am getting, so it feels like I have to breathe faster to get more oxygen in, but that's not working either. I breathe faster for sure because I feel like I'm trying to gulp air, and I'm not getting enough.

Within these experiences of not being able to get enough air, there is an immediate awareness of the necessity to breathe. And perhaps an uncertainty of breathing as no longer is the next breath, or the next moment, taken for granted. Attention is directed to trying to breathe. Getting enough air. There is an urgency, or desperation, to breathe. The body is seen in parts, the lungs as objects. The "brain" is aware of the *necessity* to breathe, knowing the lungs are not able to get air:

> When I have asthma, and everything is shut down, it's not shortness of breath. It's one of the worst feelings I've ever had. It's lying there and gasping, knowing there is nothing I can do. My brain knows I can't get air. I'm consciously aware that I can't get air. I understand that my bronchi are closing. I can't reach in and rip those bastards open. And it's a desperate thing to know that you can't get air and you can't do anything about it. It's a desperate thing.

Imagine the desperation of trying to breathe and feeling unable to take in air. To open the lungs. To take enough breaths.

> I'm out of breath. So it's the deep gasping thing. It's trying to think of saying 'open you little alveoli' and there's pain. There's a feeling that I'm not getting enough oxygen that I need to get, that I need to physically think of pulling it deeper into the lungs because it feels like it's not reaching the bottom. It's having to think about getting it into the bottom of the lungs.

Oxygen in the atmosphere is no longer taken for granted. Sometimes one must stop, to breathe oxygen: "I just stop. I rest with my hands on my hips and I inhale as much oxygen as I possibly can." There may be a perception of a limited supply: "When I forget about breathing, I immediately expend my supply of oxygen. And I'm struggling and blowing out through my mouth. (*Blows*). Like that." Breathing faster or deeper to get more oxygen. Yet feeling as if there isn't enough air, as if there isn't enough oxygen for the body:

> When my asthma is bad it feels very, very inflamed. Feeling like the lungs are on fire. That I can't get the air in. A feeling of not being able to get my breath. Not being able to catch, hold, and use the oxygen. Feeling that I can't process the oxygen out of the air that I am getting. I probably more gulp breathe when I'm trying to capture all that oxygen and send it down. Trying to get it deep. Sometimes I breathe quickly. It feels like I have to breathe faster to get more oxygen in, but that's not working either.

I have noticed the staleness of air in its smell. I might even go for a walk to get 'fresh' air, coming back ready to work again. It seems different than not getting enough oxygen as Darlene described with asthma:

> There are times when I'm not breathing deeply or times when I get colds or a flu that it feels like I'm not getting enough oxygen to the brain. When I have a cold and I'm congested, I feel like I'm breathing, but the air isn't doing me as much good as it normally does. I'm getting it but it's not going through! That I'm not getting enough oxygen. It just feels like I'm not getting the same benefit out of each breath that I am when I don't have a cold. That I'm not milking as much oxygen out of the air.

Darlene's perceptions of getting air but not enough oxygen have a physiological basis in that decreased alveolar ventilation or impaired perfusion decrease oxygen diffusion. She may be getting air in, but not getting enough oxygen to the brain. Ed also perceives that he is not getting enough, even though he may be getting enough air:

> The lungs is a machine that by design is supposed to separate the oxygen and the carbon dioxide. Emphysema is not that you can't get the air into your lungs. It's the difficulty of the equipment. The bloody machinery of the lungs is not working correctly. The lungs cannot do the work that they're supposed to do. That is to sort the carbon dioxide out from the oxygen and run the oxygen into your body. So the oxygen's not where it belongs and where it's desperately needed. And to get rid of the carbon dioxide, which is a poison. And if I'm not breathing properly, particularly breathing out correctly, then the machine is going to suffer because of it. I'm breathing in all the air I need, but the lungs aren't refining it the way it should. And the lack of oxygen is absolutely crucial. I'm not getting the oxygen that I need and that of course makes me feel generally feel rotten. The bloody machinery of the lungs is not working correctly and the lack of oxygen is absolutely crucial. When I was on oxygen it relieved a lot of the breathing difficulties that I have normally.

Our understanding and language of the world affect perceptions (Merleau-Ponty, 1962). Some participants incorporated scientific and medical language in their descriptions, at times with their own perceptions and interpretations. Oxygen is perceived as precious. Perhaps even scarce. Does this intent to inhale oxygen reflect an intellectual knowledge of the need for oxygen? Or does the language describe the person's subjective perception of the need for oxygen? Feeling and knowing may differ, yet intellectual and physiological perspectives may be in synchrony.

Time Slows Right Up

Feeling unable to breathe or get enough air, the complete focus is on breathing. The world may get a little smaller. And time a little longer. Seeming to take forever to catch one's breath, nothing else matters in these moments:

> When I'm short of breath, I just stop and hold myself. It's absolutely helpless. When I can't breathe, it's awful. Time slows right up. It feels like I'm never going to get through this. I'm just thinking of my breathing. I don't really care about the rest of it. Because if I can't breathe, what good's the rest?

In these moments of trying to breathe and not getting air, time is subjectively experienced as slowed down or slower than objectively known time. Waiting for the next moment, for symptoms to subside, time is not seconds ticking or minutes passing. The moments of experienced time lengthens.

> I'm out of breath. I gotta stop and catch my breath before I can get do anything. Generally it will be a minute or two. And it starts to come back. It seems like it slows down 'cause it seems to take forever to get your breath back. And it's not really that long. I know that for a fact. But it seems that everything is in slow motion.

Time also slows down for Timothy when he can't breathe: "It's a five minute ride from my house to Emerg, which is like five hours long." Knowing for "a fact" that time is not that long, yet time is prolonged when lived. It is as if when air is running out, time itself is limited or running out (Clark, 1992). Within the moments of time during an asthmatic attack, there is a body sense of time and rate. Breathing may be rapid, yet perceived as slowed. Interestingly, the person is "running out of air" and time is running out; both expressions describing the immediacy and acceleration of needing to breathe:

> Time starts stretching out. And I may feel that I'm only breathing once every three minutes and that's not fast enough, but I know that I'm breathing a lot faster than that. Thinking about the steps that I have to do, and knowing. It probably takes me 30 seconds to get breathing again, but it feels like five to ten minutes before I can actually slow that down. It's really a grave thing, although I know that I will survive. It's thinking that I have a limited amount of time to actually do something about this.

The need to breathe is instant and immediate; treatment is not. Relief with oxygen or bronchodilators takes time. "When I get the oxygen, or even the Ventolin®, it takes awhile for it to work. It's not instant." Moments of waiting for breathing to ease are not instants in time. There may be an awareness of time passing, a sense of waiting as if there is a pause of self in the world. "I just wait for it to go. I just calm down and let it pass." In that moment, time moves from lived time to time that is reflected upon. With an acute asthma attack, Valerie waits, struggling to breathe, and time is prolonged:

> Time is affected. It seems an eternity. It seems so long. Sitting in Emerge for five hours seems so much longer. I focus on my breathing. Struggling to breathe takes so long. Waiting for drugs to kick in takes so long.

An intentional attentiveness to time may be used as a strategy, counting breaths, slowing down. Some may slow down their breathing, counting the inhalations and exhalations, prolonging the moments of breathing:

> Since I've gotten asthma, my own relationship to time has changed completely. There is nothing that makes you as conscious of time present, and time future, as not being able to breathe. Moment by moment by moment, the asthmatic is aware of the breath. Moment by moment by moment, the asthmatic waits for the breath to ease, knowing that one day, perhaps this day, it might not. (DeSalvo, 1997).

For some, an end to time may be perceived, the next moment is no longer imminent. Sensing that the next breath may not come, Timothy feels helpless, unable to grasp the next breath and the next moment:

> Not being able to breathe is probably one of the most helpless feelings. You can hurt your arm or hurt yourself physically somehow. And it's painful, but you can still walk. When I can't breathe, I feel the end is coming. And one day it is gonna come. But it's the most helpless feeling.

We speak of a moment as if it is nearly instant, perhaps asking someone to wait 'just a moment.' How long is a moment? A second? As quick as a heart beat? How long is the moment when the person can't breathe? Feeling they *can't breathe* and consciously knowing they *must.* When waiting for that next moment, waiting for the next breath, struggling to get the next breath in, each moment may feel as if time is lengthened.

When I take a breath in, I never consider the instant movement of air between inner and outer self. For the person who can't breathe, air does not seem available. Thom extended his arms and cupped his hands outward saying with asthma, "It feels like the air is out there, and I can't get it. I can't get it in here." The air is distant. Perhaps too the next moment is no longer imminent. The moment as difficult to catch and hold as the air that is needed to be breathed.

Experiences of breathing in pulmonary illness are *more than* noticing sounds and sensations of the body, needing to learn or work to breathe. It is not 'just' a perception of being short of breath, the persons may perceive they *can't breathe.* There is a difference in the descriptions of persons with pulmonary illness who *can't breathe.* There is a sense of desperation. A demand for air. For life. A halting uncertainty of the next breath.

In this chapter, I have described awareness of the body with chronic pulmonary illness. Breathing is frequently noticed, for some the taken-for-grantedness is lost. Sensations and signs of pulmonary illness are perceived and interpreted. For the person with emphysema or COPD, within the familiar environment of home and the enclosed horizons of walking to the door or across the room, life may seem nearly normal. Then suddenly, at any moment, any exertion disrupts the self. For the person with asthma, an allergen or exercise triggers bronchoconstriction. Regardless of the etiology, that which was normal or near normal is no longer normal. The self moves from subject-object to object-subject, and the body is reflected upon and interpreted. Breathing becomes work. Effort and attention must be made to breathe correctly, to slow down, and to expel air. Acute distress and desperation may be felt when struggling or waiting to get the next breath.

Chapter Six

Experiencing the Body-In-The-World

Not usually reflected upon, the physical body is the means of self being in the world. In the moment-to-moment, we live in subject-object awareness of the body. Not necessarily a dichotomy nor "two mutually external terms" of subject and object (Merleau-Ponty, 1962, p. 102), we hold in-between perspectives of the phenomenological, experienced, subjective body and the physical, reflected upon, objective body. In this manner, self and body inhabit space and time in the now, with a "fusion of soul and body" within experiences (Merleau-Ponty, 1962, p. 85). For the person with pulmonary illness, it may not only be that the body and breathing is noticed or demands attention. There is a discord between body and intentions, no longer a simultaneous fusion of events. The body moves into conscious awareness, body and experiences may be reflected upon as objects.

Sense-experiences are communications between body and world that present it as a familiar setting, not merely receptions of the world to our body (Merleau-Ponty, 1962). The experience of our senses is part of the embodied self. This chapter addresses ways of being in the world that are disrupted with pulmonary illness. Altered tempo and actions of the body are described in the themes of *Slowing Down*, *Doing Less,* and *Have to Stop.*

Slowing Down

In moderate to severe chronic pulmonary disease, with some activities, it is no longer possible to increase rate and depth of respiration to sufficiently meet oxygen needs of the body. Unable to speed up breathing, the body and self must instead slow down. Persons with pulmonary illness may find themselves slower than they were. Slower than others. Out of tempo with others. Out of tempo in the world. Aspects of slowing down were more predominant for those with moderate-severe COPD/emphysema, although they were also revealed in descriptions of experiences with asthma. The themes of *Slowing Down* are:

- *Can't keep up*
- *Slow it down*
- *Move too fast*

Can't Keep Up

Our immediate perceptions and interpretations enable us to interact with the world in its familiarity. In pulmonary illness, slowing down may be noticed, reflected upon, and interpreted. The person may slow down when pulmonary disease is not evident or known. Slowing down might be noticed when compared to Others or the prior self. For example, when holidaying in Mexico, both Jake and his wife noticed "how slow" he was. Recognition moved into reflection upon his body and breathing:

> I was swimming and snorkelling. Doing pretty good. But in comparison to my wife, I was twice as slow. She couldn't believe how slow I was. You don't forget how to swim. Or if you've snorkelled before you don't forget how to flip your feet and stuff like that. But I wasn't traveling. I'd look ahead and there she is way ahead of me. I got to thinking, 'Well I'm not struggling for breath under here. I'm breathing what I thought was normal, but I obviously I'm not keeping up to a normal person.' Things kind of hit you in the side of the head like that.

Swimming in the warm ocean is not Jake's familiar context, yet in his visual and spatial sensations, it is not the world perceived and interpreted as unusual. It is not his body movement that is unfamiliar. He hasn't forgotten how to swim or snorkel. What he notices is that he is slow in comparison to his wife. Noticing, Jake is attentive of his breathing, which seems normal.

In the daily context of our lives, the "living system of meanings" creates immediate recognition and understanding of experiences (Merleau-Ponty, 1962, p. 131). Noticing his wife ahead, not keeping up, familiarity and meanings are disrupted. With the onset of illness, unfamiliar sensations must be interpreted, and new meanings developed. Before being diagnosed with pulmonary disease and given a medical meaning, perceptions of slowing down are interpreted within the context and knowledge. The slower change in pace does not make sense. At 47 years, Jake interpreted slowing down as growing older:

> I was doing a lot of slowing down, but I was getting up in age. I would have been 47 years old. So you don't run as fast as you used to or you don't push the lawnmower as fast as you used to.

After diagnosis, within the context of illness, recognition and acknowledgement may be given to the body as not being able to keep up. The person with emphysema cannot keep up with the Other, despite will or effort. As Peter describes:

> My wife and a good friend go to a mall every morning for a small walk. When I walk the mall I don't do any power walking. I don't try to keep up with them. And I stop very frequently.

Perhaps starting at the usual pace or the speed of others, the body is unable to keep up. Others who go at a faster pace than the one with illness may not perceive or attend to the asymmetry of tempo.

> I'll start walking at the same speed as the people I'm with are walking. And I can't sustain it. They don't notice that I'm in trouble. And I have to say to them, 'I'm sorry, but you're going to have to slow down because I can't walk at that speed.'

Unable to keep up, this person calls upon others to slow down; others tell them to go ahead at their pace. It is not immediately evident that Others cannot maintain their pace. I would not expect to run with a marathon runner and keep the same pace, but perhaps walking is more ordinary. We usually can pace ourselves walking with others. Slowing down a little or speeding up a bit we walk with others. With moderate to severe chronic pulmonary illness, walking moves out of the ordinary. The person with pulmonary disease must slow down and is out of tempo with others. Not able to keep up. Sufficient air is required to 'keep up' or maintain the pace of others. If others do not slow down, slowing down lengthens distance as Others go ahead at a different pace.

> If we would go walking, my daughter would say, 'Come on dad,' and I said 'You go at your own pace. I can't walk as fast as you guys can.'
>
> It used to be my wife could never keep up to me walking. Now I can't keep up to her. She takes off and I just let her go. There's no way I could keep up to her if I tried.

As a nurse, I often have to consciously slow down in order to match my pace to that of an ill patient. This conscious attentiveness was experienced with a participant whom I met and then walked with to the interview room. Trying to slow down to the pace of his walking and breathing, I took small, short, slow steps. Moving at less than half of my usual speed. Part way down the corridor, I asked, ‘Am I going too fast? May I carry his knapsack with the oxygen?’ Not sure if his answers of ‘no’ were from politeness, I consciously slowed down further. When we arrived to the interview room, he indicated that he needed time to catch his breath: “When we walked through the corridor I started to get short of breath, because we were quite fast for me.” Not inattentive, slowing down, yet unaware of his pace, I had walked *too* fast for him. We walked neither to his tempo or mine.

In contrast to slowing down, acute episodes within chronic pulmonary illness are often sudden and urgent, demanding a quick response. The haste that is necessary is unable to be attained. The person is unable to speed up, to keep up to the demands of the illness, and Others may be asked to hurry. Brookes (1994) describes a major ‘attack’ of asthma in which the acceleration and urgency of the attack required an increased tempo:

> Everything was closing in around my throat and chest; I felt a tightening internal claustrophobia, a sense of metabolic urgency rapidly mounting toward panic. I already knew this was no ordinary asthma attack. Three times since I’d turned thirty, something entirely different had happened, a sudden, overwhelming assault that stormed through my whole body, seizing my throat and suffocating me. This felt like one of those asthmas. I woke Barbara, my girlfriend. She had never seen a major asthma attack before; I knew that it would probably be more frightening for her than for me. From the outside, the sufferer of asthmatic anaphylaxis looks as if he is collapsing inward, drowning in an invisible sea of himself. “In the car,” I said, trying to show calm, measuring my phrases to fit the amount of air that I could muster. “In the glove compartment. Is my epinephrine syringe. Please go and get it. Right away. Here are the keys.”
> Alarmed, she dressed hurriedly and ran out.
> The attack was accelerating.

He slows his breathing. Slows his speech. Time is running out. He calls upon his girlfriend. She must hurry. He cannot. Even at the same time that the body demands one slow down, speed is most necessary.

Slow It Down

Part of slowing down is consciously attending to speed and pace of the body. Forced to slow down. When we speak of pacing, we attend to both speed and time. In aerobic activities, we want to set a pace that challenges the body but maintains oxygen supply. A runner described being aware of his breathing to pace his body, "I regulate it in tune to my stride, to get into a groove." He uses musical phrases: "in tune", "into a groove." It is as if his breathing becomes his metronome to regulate his stride, not his running that determines his breathing. Buytendijk (1974) and van Manen (1999) also speak of breathing as being in tune. It is not the sound of breathing that is in tune, but the harmony between body and movement maintained by a rhythmic beat. Breathing is rhythmical and in synchrony with the body.

Pacing of activities and breathing are conscious, reflective actions. In pulmonary illness, breathing cannot be quickened so the body must be slowed. Activities are avoided or done at a different speed. Slowing down may be conscious and purposeful as experienced with asthma: "Now, I just go slowly, take my time. I have to modify my activities and rest." Moving slowly, taking time to rest, activities take more time with emphysema:

> If I'm doing something in the house it takes me quite awhile. I just go slow. When I get tired I just sit down for a minute. Two minutes. Get up and get at it again, as soon as I catch my breath. I take a long time to do it!

The pace of moderate to severe chronic pulmonary illness is much slower than the busy, quickened pace of everyday life. In my everyday activities, I feel rushed at times. Trying to do many things within a day or month. As if life and my body are accelerated. Not breathing quickly, I might feel that I need to 'slow down and take a big breath.' To slow down, and take 'my' time. It is as if there is a natural 'rhythm' of breathing that is paced to our lives and a subjective sense of timing and intervals. Many times, we may not perceive or consider the rapid speed of our lives. For DeSalvo, slowing down with asthma revealed her rapid pace of life:

> I never before realized how impatient I am, how unable to allow change to come in its own good time, how much I rush through life, how little room I give myself to breathe (1997, p. 60).

Jake remarks he is cautious to "go at a pace" in the shower. Jake describes himself and his friend as "not feeble or anything. We just suffer from the same type of thing. Where we just can't breathe quick. So can't walk quick." It is not only walking and other physical activities that might slow down. Jim must slow down or halt his conversations. I imagine him talking on the phone as he did in the interview. A few words at a time. Many short pauses. Consciously taking time:

> There aren't many conversations that I can carry on in a normal fashion. Where I'm not conscious of the fact that I'm pacing a conversation. It seems to be more when I'm talking on the phone. I'll just say to somebody, 'Gee, you know, I'm running out of air. You start talking and talk for awhile. Or let's hang up and talk later, after I get my breath back.'

In health, with exertion or anxiety or speech, we breathe faster to increase our minute volume. In chronic pulmonary illness, slowing down breathing may be a very conscious, deliberate act. There is not an immediate involuntary match between breathing and body. Rapid and shallow breaths are the opposite of what is required. Needing to breathe slower, feeling the need to breathe faster, slowing down requires focus and effort:

> I use a lot of pursed lip breathing and when I have panic attacks. I got to fight it. I gotta fight it down. To try and slow down. To try and get my mentality back into thinking straight and normal breathing again.

Karl feels he does go slow. Some nights it is as if he cannot go slowly enough. Tired and out of breath, he concentrates on slowing down his breathing:

> I don't go fast. I go slow. When I sit I'm fine. No problem. I try to do as much pursed breathing as I can. There are times I notice at night. I brush my teeth, wash my face, and hands, lay down on the bed and I'm (*puffs quickly in and out*). I can hardly breathe. Just that little bit of activity. I sit on the side of the bed and do some pursed breathing and that helps. Just slowly.

In moderate to severe chronic pulmonary illness, breathing cannot be quickened to attain or maintain a faster speed. Breathing demands that the body slow the tempo of moving.

Move Too Fast

We live at a certain pace, by habit or intent in our external world. With chronic pulmonary illness, the body may try to go too fast, and is then reminded to slow down. Peter forgets to slow down at times when he goes for walk. For him, his speed is a speed walk. It is as if he can't get used to slowing down. Not used to his body at a slower tempo. With other things on his mind, forgetting upon slowing down, he goes too fast:

> I've not learned to pace myself. I think that's a big part of my problem. When I get out there to go walking, I speed walk. Well, speed walk for me. I go too fast the first length. And then I tire myself out and I have to do those little stops in-between. So every once in a while I just have to make sure I slow up. So I can at least walk so to speak. When I get going too fast then I'm out of breath and I'll have to lean against something to catch my breath. And I understand all that. So I just have to slow up. I find there's something missing. I will not absorb this, or I will not retain in my memory, the ability to go slower. And then the whole outcome is I get tired. Tired before I should. With my life I have so many other things to worry about that I don't pay enough attention to what I should be doing right. To correct these problems with my breathing. I have other things dwelling on my mind.

Gregory's automatic, habitual sense is to walk fast. His body does not remember to slow down. He automatically starts to walk fast when his breathing is good; other days he is very slow:

> I'm aware of my breathing. When I'm walking I notice. I try to do as much pursed breathing as I can. I used to walk fast. I find that when it is good day then I'm walking fast, automatically. On the other hand, if my breathing is not good, then I'm slow as molasses.

Starting to rush, to go 'too fast' or perhaps at a 'normal' pace, the body is quickly slowed down by breathing. At the beginning of my interview with Karl, he bent down, picked up the cat, and took two steps and stopped for a moment, breathing deeply. He then walked the remaining four or five steps across the room at a slower pace. In the interview he reflected upon that moment:

> Everything a person like me does, I have to do very slow. And I've never been one to be slow. Picking up that cat and bringing him back, I started rushing. And the minute I do that, I'm finished.

Moving quickly has immediacy. Rushing seems to have different meanings and interpretations with pulmonary illness. Perhaps moving at a usual speed becomes rushing. Darlene has exercise-induced asthma, and notes that "My breathing is a bit laboured because I was rushing from the bus and I was rushing up the stairs." It is as if her body has a sense of rushing.

In health, respiratory effort occurs with "exorbitant consumption of oxygen" related to "strenuous muscular work" however "under normal circumstances, breathing keeps pace with our exertions" (Miller, 1978, p. 170). With severe emphysema, the body can not rush nor does breathing keep pace with exertion. Perhaps starting to move fast, to do everyday "little things" the body is immediately slowed down. Unable to go fast, Karl has to take his time:

> If I take my time, I'm fine. I don't get much warning. I just do some stupid little thing. Like moving too fast. That will trigger it.

Not going too fast is perceived as taking more time. Bill describes, "It takes me a little time to really get going in the morning." Darlene feels she is slowing down. It seems that she is not quite in synchrony with the tempo of herself: "It feels as though all my responses are slower. That I'm not getting enough oxygen. That it takes me a little longer to do things." Ed is unable to exert himself at any speed. His lungs demand that he slow down. Unable to run the journey of life, he is now slowed down to a crawl.

> I had gone into a very, very deep depression. (*Coughs*). I think it was a case of me sitting around thinking, 'I've had such a terrific life. (*Pause*). And if this emphysema thing is going to slow me down like this. And I'm going to have to give up this and give up that,' I thought to myself (*coughs*), 'What's the hell use in hanging around, with that kind of incapacity? I might as well, you know, get on the journey that is still to be run as it were, and let's get on with it.' That's the way I used to live. Slowly I came out of that very black pit. (*Coughs*). But I slow down to a very slow crawl now.

Living with pulmonary illness may inhibit the intentional, the habitual, anticipated, and expected ways of moving through the world. In COPD and emphysema, it is as if the self retains the pre-illness tempo. Not accustomed to the slowing down of their momentum, the self conflicts with the body. Gregory "knows" that he must "slow up." If he forgets, he is reminded by his body. Going too fast, he is soon out of breath and must slow down or stop. In contrast, Barbara has slowed down. She is unable to be rushed:

> I don't notice being short of breath during the day. I do get short of breath sometimes. If I go out walking quite a bit. Especially with my son, I have to turn my tank up, because I get too short of breath. Or if I get agitated. Or somebody tries to rush me. 'Come on, hurry up. We've got to go. We're going to be late. Come on. Do you have shoes on? Do you have this on?' God give me strength. That agitates the life out of me.

The body that has pulmonary disease or acute inflammation is unable to maintain the speed of that of the healthy body. Before diagnosis of COPD or emphysema, the slowing down of the body may be noticed, reflected upon, and compared to normal. Slowing down is not necessarily voluntary. When pressed to "hurry" up, persons with pulmonary illness are unable to do so, and instead are compelled to maintain their own pace set by their body and breathing.

Doing Less

Merleau-Ponty (1962) alludes to the body "the vehicle of being in the world" (p. 94); as embodied-subjects, "we are in the world through our body" and in the body we act and move through the world (p. 239). In this manner, there is an outward view of self toward the world, grasping events and activities. We are not continually self-reflective of our body as an object; our attention is toward the world and others. With chronic pulmonary disease, in contrast to this natural momentum of body and life, movements and activities become limited by breathing and the body. Breathing limits activities, the body and self must do less. Themes of *Doing Less* are:

- *Diminished capacity*
- *Conserving energy*
- *A static kind of life.*

Diminished Capacity

In chronic pulmonary illness, activities may be restricted to minimize sensations of the body. At other times, activities are restricted because of insufficient energy and required effort. Not only air is restricted or obstructed, the self and the body are also limited. Restricted from participating in previous events. Obstructed from physical activities. There is less *capacity* for air, for breathing, for life, for activities. Jake speaks of his capacity: "At that time I was 55% capacity compared to a regular human being. Now I'm down to less than 30, 20's." Is it only lung capacity that decreases? Or a broader capacity as a human in the world that is altered?

> Not being able to breathe and do the things you want to do is hell. Ah, it restricts. My capacity is compromised, and I can't do a lot of things 'cause I don't have volume.

With severe COPD/emphysema, the body is limited in projects and interactions by the decrease in lung capacity. The *self* is limited, restricted, obstructed. As capacity for breathing is limited, actions are limited, the body, self, and way of being-in-the-world are restricted:

> In regards to the breathing it just gets to the point that I can't do anything.
>
> It's reduced my ability to do anything to virtually zero. To heck with cutting the grass. Even putting the hose out on the lawn, I have to wrestle with it and it leaves me short of breath. It's amazing what I can't do anymore. It's extremely limiting.

Situated in both a physical and social world, limitations of pulmonary illness envelope family, friends, and other relationships. It is not only *I* as self that is restricted, but the *we* of self and Other:

> The social side of my life is practically nonexistent. I hardly ever go out anymore for social occasions. I will go if it's something of some momentous and of importance to me. In the old days, I'd go to a party 3 times a week. I very rarely go out at night now. When my wife and I go the theatre, we go to matinees. When we go to the movies, we go to matinees.

Jake has "become very conscious" of capacity. "I want to be able to have at least 50% of the total capacity back, versus less than 30 in each lung." It's as if not only the capacity for air or breathing is decreased, but also the capacity to recover from illness.

> In early 2000 I got a bronchial infection and went into the hospital. That's where I discovered how limited my capacity in my lungs was. It had dramatically dropped. And like this past couple weeks where it's been minus 15 or colder, I've noticed it has been a lot harder on me. Which to me means maybe my lung capacity is even worse than what I thought it was. Things kind of hit you in the side of the head like that. You become very conscious of the relation of capacity and stuff like that. This last month has been frustrating because in early December I got a cold and it didn't disappear for three to four weeks. I find my recovery rate is a lot longer than before. I don't know what or why but it is. My recovery seems to diminish with or decrease with the diminishment of my lung capacity.

With more severe pulmonary disease, the physical world changes. Still situated in place and time, their world of possibilities and distance becomes a bit smaller. Doing little things. Not going far. Plans and expectations become limited in scope:

> I struggle but I do feel better when I exercise. If I keep busy. Doing the dishes. Helping out around the house. Make the bed. Little things. That makes me feel better physically and mentally. I feel better when I get out into the car. I still drive. I don't go very far. There are things that I'd like to do, that I can't. Which makes me mad. I don't have a bright future or whatever. I don't have any big plans. I just take it as it comes.

In this northern climate, the horizon is restrained by distance and seasons. Karl had only been out of the house seven times between the New Year and May, "I haven't been for walks because of the weather. I can't get out in winter. With the cold." He schedules his physician appointments for spring and fall. Timothy ventures out in the cold for 2 blocks and feels like he must crawl to get home:

> It's hard to breathe when it's cold. Last winter, I went to Safeway and it wasn't that cold. But it was cold enough. And this last block coming home, it was just like crawling on my hands and knees.

It is not only with COPD/emphysema in which a decrease in capacity is perceived. Darlene reflects that with exercise asthma, "there are things that I probably avoid now more subconsciously than consciously just because I know, I'm not going to feel very good if I do all that." The lack of air and the inability to breathe obstructs activities and restricts choices in exercise asthma or acute asthmatic attacks:

> I felt like something was obstructing it, something was blocking it, knowing I needed more capacity, more air. It was almost like being in a confined area trying to breathe in air but there was none left (Mary, asthma).

Others purposefully limit their activities: "What I usually do is try and restrict it to 2 blocks. Going down the street. Just going around the block." Barbara has defined distances. Shorter in spring and fall, longer in summer on nice days. Trying to go further than this, distances extend. Blocks feel like miles:

> I usually walk that parking lot right down to the back and right back up this way. When it's nice in the summer, I used to walk 4 blocks. (*Coughs*). When my son comes I swear we walk 10 miles. One day I heard an ambulance whining in the distance, and I said, 'For god's sake, hail that ambulance to take me back to X because I don't think I can make it.' Oh I was so beat.

There may even be a decreased capacity for speech. In severe pulmonary disease or in an acute asthmatic attack, speech may be restricted by lack of air: "I've even been short of breath when I was talking on the phone. I've run out of air talking on the phone.

I've just had to get off." Breathing limits expression of thoughts, emotions, arguments, and views:

> I run out of breath when I talk so I stop. Even at my friend's 80th birthday, I got up to say something and I was so short of breath I had to cut it off.

Imagine the frustration of not getting the breath to carry on a discussion, to put forth your arguments:

> If we get into a discussion where we vehemently disagree on the subject matter, then I get really frustrated. I have to give up the good fight because I can't get any breath. I can't get the breath to get it done anymore.

A decreased capacity is experienced as limiting activities, including walking, speaking, traveling. No longer freely able to spontaneously and freely engage in their desired intention, they are held back by breathing and their body.

Conserving Energy

Decreased capacity of the lungs limits mobility and changes the way of being in the world. Actions are understood and described as taking energy, taking air, whereas doing less saves energy or minimizes fatigue. When Jake noticed he was falling behind his friends playing golf, he took a cart instead of walking:

> I was playing golf and noticed I was falling behind quite a bit. These guys I used to play golf with were all 30 years old. Quite a bit younger. I would be 40 something at that time. And they were saying, 'Oh, come on old man!' It's no fun huffing and puffing and then catching up to them and then have to tee off, or something. So I figured it was my age and I started to use a cart a lot more often.

Physical limitations are frustrating, and perhaps more evident than emotional exertions that tax the body. It may be easier, or at least more apparent, to conserve energy in numerous physical tasks than limiting intellectual or emotional exertions.

> If it's a physical thing. I know there are things that I can do to combat it. I don't go out on a five mile walk and I'm not running around like a madman. I conserve my energy and I only use physical energy when it is essential that I do so.

Attention is directed to conserving energy. New habits may be developed and modifications made to everyday life and activities to save energy:

> When I go to bed at night I always go in the bathroom. And I take off my pants. And I have a hook right beside the bed. And I walk in the bedroom and I hang them up there. Every morning when I get up I make a habit just to do the reverse.

> I've got my greenhouse set up out there. I can sit on the rail so I can dig in the ground. I just sit down and use one of those little hand trowels. And that's what I do if I'm doing any digging. That's the only way I can do it. And I've got a little hand pump watering unit out there to water a few tomatoes.

> I'm no longer buying shoes with laces. I buy slip-on shoes. And I buy those nice long shoe horns so that I don't have to bend over to put my shoes on. Because bending over and standing up I gotta take five minutes after that to catch my breath again.

Energy and air are scarce and precious. Saved for the moment. Not able to be saved for the future, like saving for a holiday. More like having to give something up or cut back in times of economic constraints.

> We've learned to cut back what we do. We don't do the big party thing anymore. We don't travel much anymore.

Energy is allotted and spent. Sometimes it runs out, and the person is not able to do anything more:

> Once a month my cousins and I meet and have lunch. I had to cancel the last one because when I got up in the morning I just knew that it was a bad day and I couldn't do it. And when I do go out for that luncheon I'm finished for the rest of the day. I can't do another damn thing for the rest of the day.

Energy must also be saved in the acute period of an asthmatic attack. Valerie does not speak. Every word requires energy and air. She *says* less as she *has* less air:

> When I'm that bad with the asthma, it's less energy and less air I have to talk. The shortness of breath. To breathe, the tightness. I would point. Every word I can save, I save air.

Oxygen, energy, and air may be conserved by doing less. With severe illness or in acute episodes, the body demands that less activities be done.

A Static Kind of Life

In moderate to severe obstructive and restrictive disease, doing less is experienced moment-by-moment, in day-to-day activities. The body limits motions and actions: "As soon as I go to exert myself, I can't. I can't breathe." With exercise or allergen induced asthma, doing less includes avoiding triggers, preventing attacks, and altering activities to minimize distressful sensations:

> I try to have a protective environment. Tonight I'm suppose to go to a book club, but she has dogs, and they'll bother me, and I'll know that I'll come home and not be able to sleep, and it's not worth the struggle to breathe and that shaking.
>
> I can get out of breath going up stairs. I no longer run for buses in cold weather. It's not necessarily the heavy breathing that worries me. It's the pain in the lungs afterwards.

Compelled to do less, yet not having diminished desire, willingness, or interest was frustrating for many participants. Two participants described that "It's hell" to live with emphysema. "Not a nice way to live" said another with asthma. Frustrating to be severely limited by exertion. Being held back by the body:

> The frustrating thing is not being able to do what I want to do. Kicking against the brick of suffering this ridiculous, bloody disease, and not being able to get on with whatever it is I'm suppose to be doing. The idea of never going on a stage again just grabs me. Never to have the concentration, or the energy to direct a play. It takes a lot of energy and a lot of concentration. And long hours. Into the middle of the night quite often. And I just can't do it anymore.

With severe chronic pulmonary disease, doing less is not a life of ease and relaxation. Respirations are not 'free' and 'easy' as experienced in health. Previous activities are not interrupted for a short time and returned to, nor are they set aside or replaced by something else. Hobbies, work, pleasures must be given up. From personal illness or injury experiences, many of us can imagine the frustration at needing to put aside leisure activities or physical exertions, such as carrying groceries. I try to imagine what is it like to have these limitations continue everyday, extending even to the ordinary. When the body limits activities as described by Karl:

> I've got a computer in the back room there and I play on the computer just about every morning. When I'm on the computer and just do nothing, I'm fine. I want to do something and I start to do it and my body just says, 'No, you can't do it.' It's hell. I sit around. What am I gonna do?

In the absence of illness, without noticing, we move through the world in a series of thoughts and experiences. If I want a cup of coffee, I merely stand up and go to the kitchen to make one. These day-to-day movements are seamless and flow unpremeditated. These intentions are disrupted with the presence of pulmonary illness. Instead of being in the world in which movements, meanings, reciprocities are not explicit or thought about (Merleau-Ponty, 1962), activities are planned or limited. Not going to choir because of perfume. Unable to go outside in extreme temperatures of humidity. With severe pulmonary illness, it is more than the body that is disrupted. Self is in a body that limits that which the self desires or intends:

> It's purely the breathing. If I could breathe easily and properly, everything else would fall into place. The frustrating thing is not being able to get on with whatever it is I'm supposed to be doing. I just can't do it anymore. I just can't do it. I just can't do it.

Sometimes in the busyness of our lives, we may contemplate or dream of a life of leisure, with less activities and responsibilities. But is it really doing less? Perhaps it is a life of doing different activities that we desire such as hiking or gardening. Doing less for the person with chronic pulmonary illness is not relaxing or taking one's ease. It is not voluntary. The person with asthma may want to go for supper, to sing in the choir, to visit friends, but is unable to do so. For the person with severe pulmonary disease, as soon as they go to exert themselves, they *can't*. Examples from three persons with emphysema depict feelings of being constrained by breathing and the body:

> It really, really, really bothers me because it doesn't allow me to participate in a lot of normal things. I'd love to work. I lose touch with a lot of things. I lose touch with communication and people. It's no fun sitting here alone for the better part of the work day week.
>
> Things I used to do, like go out fishing and stuff like this. I had boats and all my own fishing gear and it's all gone now. Given it all away. Cause I just can't do any of it. The last fish I caught I was with my son and that was three years ago this 24th of May weekend. It was only a 5 lb fish. And it was all I could do to get that fish in the boat and so that's when I give my boys all my equipment. I gave away thousands of dollars of equipment. I can't do any of it.
>
> I had an old truck and mechanic's tools, but I had that feeling at the time that I will never use those tools again. And there's a couple of things I wound up selling. I have a bag of golf clubs in there. And I look and them and I go hmmm. I don't think I'll ever hit a ball with them. I really kinda get demotivated and I feel like I get depressed.

Movement is a specific way of entering into relationships with others, with the world, with object, with activities (Merleau-Ponty, 1962). Being mobile in the world is a way that we connect with the world, with others. When disrupted, or limited, our way of being in the world has changed. With pulmonary illness, it is changed in present and future. The life that is lived is more static, sedentary.

> I'm practically at the point where I really can't do anything too much physically. The desire to do it is there. The will to do it is there. There are things I'd love to be doing. But the moment I start doing it my lungs protest. And I am fairly immediately short of breath. And I have to sit down and get back to normal breathing. All there is in life now is going to the movies or watching TV or reading books. It is going to have to be a static kind of life. I've been a physical participant in a hell of a lot of things. None of which are available to me anymore. I am much more static than I'd like to be.

Desires and activities may be reflected upon as lost. Comparisons are made of what could be done and now can't, as expressed by one participant with COPD, "I feel angry quite often. I like to golf and I couldn't golf. I used to curl and can't do that anymore." The *self* has not changed with the body. Instead, the body changes the actions of self. Yet, the self, in and through the body, is not longer quite the same person. DeSalvo expressed that "I'm not the same self I once was" (1997, p. 152). Desire is not in synchrony with mobility.

> I do get short of breath. It is frustrating. I'm the type of person, I just want to go, go, go. Like, just let me go! And I've got something holding me back. It's annoying. It's kind of like I'm not the same person I was.

The static life may be frustrating. Ed described having to be content with "the lesser things" of life:

> They keep telling me from different directions that I'm going to have to give up this and give up that. Slowly I came out of that very black pit, (*Coughs*) to the point where I could reassess those things that they were trying to tell me. And accept the fact I cannot expect that life is going to be what it used to be. And I'm not going to be able to have the level of life that I used to have. I'm going to have to be content with the lesser things. And not want to do things that intellectually I know I can't do. And stop moaning about it.

Another participant described being held back: "There's so much stuff I would like to be doing in the house and I just can't do it. I would never let things go the way I do now. I can't do it. And I do feel useless."

In contrast to several participants who expressed anger and frustration of the sedentary life, Barbara expressed little frustration. She has a long history of asthma, emphysema, smoking, and has been on supplemental oxygen for several years. Going to make tea, she takes her time. Getting out the tea bags. The tea pot. The milk. She moves her walker between two cupboards. Her oxygen tubing trails across the floor. Perhaps, her oxygen tubing and walker enable or remind her to *slow down.* To take her time. To not move *too fast.* Not frustrated unless rushed by another, she maintains her new pace. Her disease seems almost a part of her self.

> I used to get a little frustrated years ago. But not anymore. I just put up with it. It used to bother me at one time but not anymore. I suppose if I got a real bad attack I might get a little upset about it. But the way it is now, I've had it so long it, it's grown on me. It's part of me. As I would say, 'It's part of me. I put up with it.'

Doing less was both required and anticipated by several participants. The body not only sets the pace and requires the person to slow down; some activities are restricted by the presence of pulmonary illness. Other activities are avoided to conserve energy or minimize triggers or allergens.

Have to Stop

In our day-to-day being in the world, our acts are moments in a manifold of time, actions, and awareness (Merleau-Ponty, 1962). These moments are continuous in a series, with each instant projecting to the next (Husserl, 1900/2001, p. 207). In this manner of being in the world, time is seamless between instants and moments are not reflected upon as objects. The next action and moment are imminent, not consciously thought about or planned. Living in the world and in the body, intentional acts are immediate, spontaneous, and instantaneous (Merleau-Ponty 1962, p. 141). The next action is not always consciously thought about or attended to; the body is in situation and moves through the world. I might see a bird out the window and get up to have a closer look. There is a spontaneity and immediacy of being, seeing, and moving as I go quickly to the window.

In this manner, we live in the here and now; in the givenness of the present (Husserl, 1900/2001). Each moment has its previous attitudes and movements for the subsequent moment; each movement or moment leads to an expectation of the next (Merleau-Ponty, 1962). In pulmonary illness, this seamlessness of moments may be interrupted. With an acute asthmatic attack or severe pulmonary damage, the person may *have to stop.* No longer able to move through the world, the immediate future is disrupted. The themes in *Have to Stop* are:

- *All of a sudden*
- *Standstill.*

All Of A Sudden

I observed several moments in which participants seemed to suddenly stop. I try to imagine the suddenness of having to stop in the middle of an everyday activity. Karl stood up and bent over to pick up the cat. As he started to come back to upright, he suddenly stopped part way. Looking ahead, he took several large breaths in and out. Ed got out of his chair and started to walk the six or seven steps across the room. After three steps he stopped. Breathing loudly, he stood in the middle of the room. Barbara was looking for a tea bag. She manoeuvred her walker little by little until she reached the dresser. Leaning on it, she opened the drawer. Suddenly she stopped, straightened up and took six or seven deep breaths. Then she slowly leaned over again and got the tea bag.

Everyday activities, and in one moment, the body stopped every other outward action except breathing. The person stopped talking. Stopped moving. These many movements are no longer completely spontaneous. Actions are limited, not directed by interests and engagements, or intentions of self. Having to stop may be sudden and abrupt.

> I've run out of air talking on the phone. And I just had to get off. Whatever you're doing you have to stop.

In that moment, the self no longer focuses outward. The body must stop. The conversation must stop. The person *must stop.*

> When I go to the doctor, my wife drops me off and parks the van. And I'll go into the hospital. Generally just inside the door there's some wheelchairs sitting around in there. Most times what I've done is I'll grab one of them as a walker. But the last couple times that I've been there, there hasn't been one. So just walking from the front door to the elevator, I have to stop. I get halfway! I don't have a choice but to stop. Completely. Whatever I'm doing I gotta, I have to stop.

The person may be 'fine' one moment, if doing nothing physical. Then in the moment of activity, instead of immediate spontaneity of the action, the person has to stop:

> When I'm on the computer and just do nothing, I'm fine. But if I have to get up and go to the bathroom or come out and get a cup of coffee or to do anything then 'Bingo' It's just not good. I have to stop.

In these moments, being in the world in the body is suddenly disrupted. Abrupt, interrupt, disrupt. All have *rupture*, 'to break,' as part of their meaning. What is broken in this moment of having to stop? Time *between* the immediate past and the immediate future may be *inter*rupted. The seamless interplay of past-present-future moments ceases. No longer is time experienced subjectively as a continuous series of instants of the now with immediate past and imminent future. Suddenly terminated, without smooth transition to the next moment, being and moving are interrupted. Karl notices the abruptness of having to stop:

> When it does happen it generally comes on quick. I don't get much warning ahead of time. And I have to stop.

At one moment, self is walking down the street or across the room. In the next moment, the body is stopped and a new future must be taken hold of. The next breath needs to be grasped. To be caught. As if breaths and moments could be reached out for and seized. These moments of self-awareness become distinct. The instant becomes an object in time, the pre-reflective moves into reflective experiences. The spontaneity and immediacy of the body is disrupted:

> Anytime I get involved in something that requires some exertion, if I don't think about it ahead of time, then I end up having to take the Ventolin® to stop the onset of the problem.

Having to stop is not *just* an awareness of the body, or call of the body. Even if the body of habit begins to move forward, the body of that moment is limited by lack of air, and the person must stop. In these moments, self is *in* the body yet seems no longer in synchrony and union *with* the body. Self is unable to continue with the activity. The moment is disrupted. The flow of life and movement are interrupted or re-directed.

Having to stop is at that moment. In an instant of time. If Ed forgets to take his Ventolin®, his body tells him in *the moment* of exertion:

> Sometimes I can miss one Ventolin®, but the problem with that is the moment I do something physical, boy does it tell. It's very difficult for me to ascertain if I'm sitting down quietly reading or watching television. But the moment I do something physically, I know, 'I've let it go too long. I'd better get the inhaler before I do anything.'

At that moment, the ongoing action of moving through the world is no longer "simply lived through (*erlebt*) unthematically and prereflectively" (Merleau-Ponty, 1962, p. 26). The moment is reflected *upon,* not lived *through.* Conscious attention is directed toward breathing, catching one's breath. The body of that moment is stopped: "I stop. And I just breathe."

Merleau-Ponty described the body as "two distinct layers, that of the habit body and that of the body at this moment" (1962, p. 82). Many of our acts and actions are of the habit body. Not thought about. Immediate and spontaneous. In pulmonary illness, when *not* thinking, the habitual body may move too quickly or attempt an action that is not possible.

> When a thought occurs to me that something's got to be done, I get up and I go for it. But I've hardly gone across the room, when all of a sudden, I can feel my lungs refusing to do the job that they're supposed to do. My lungs are protesting. Slow down. Quit what you're doing because I can't stand it. So very often, if I'm not thinking, I still attempt to do things that physically I'm incapable of doing because of the condition of my lungs.

Diagnosed ten years ago with severe emphysema, Ed may yet move at his previous way of being. Without conscious awareness, he moves part way across the room, and then is suddenly halted. The body of the moment is stopped, impeded by the physical body and its need for oxygen. When the body of habit starts to act, to move, the diseased body is unable: "As soon as I go to exert myself, I can't. I can't breathe." In a moment, the body not only speaks and is heard. It protests, commands, demands, as Jennifer described: "I push my lungs to the limit and they say, 'Stop, we won't take it anymore.'"

The lifeworld changes for persons with severe pulmonary illness. Thinking about breathing, planning activities, pacing actions, the immediacy and spontaneity of being in the world is disrupted. Not continuously thinking about breathing, the self starts to go forward however the body comes to a complete stop. The life of intention is disrupted and actions must be modified.

Standstill

In our usual day-to-day activities, "under normal circumstances, breathing keeps pace with our exertions" (Miller, 1978, p. 172). With strenuous exertions, we might slow down, even come to a stop. But the 'immediacy' of that kind of stopping seems very different than that experience in pulmonary illness. The episodic nature of asthma has the body being stopped in an attack. With COPD/emphysema, breathing may not automatically keep pace with minimal exertion, or with everyday activities. No longer involuntary, moving has to be thought about, and intentionally kept in pace to breathing ability. Suddenly, in a moment's time, there is no air, no breath. The body is brought to a stop. To a standstill. It must stand still. Perhaps in the middle of a mall. Or the middle of a road. Hardly able to keep upright, the person may lean on that which is available, a table, a gate, or a railing. Jake describes:

> When I get outside, I've already gone up a little short flight of stairs. And I always have to stop outside that door. And lean on that iron railing, until I have recovered. I'm outside. I recover and start walking down the sidewalk there. I typically never get as far as that fencing up there with the building. I stop again. And recuperate. And then I build up a little bit more energy and the second wind and I stop right outside the door and try to get up enough steam. One day last week, when was it 30 degrees here, I stopped more.

The body with pulmonary disease is both predictable and unpredictable as a vehicle to move through the world. Ed has emphysema which is a "progressive condition" yet "I never know, on any given day, what I'm still capable of." Knowing when and where he has to stop, sometimes Jake is able to walk to the store and back. But not always:

> Some days, I walk out there and right away I get to the end of the sidewalk and I have to stop and kind of collect myself, slow down. Other times, I can just walk out there and bang, walk right over to the drug store and back, no problem. I don't know what it is, or what is hitting me like that. But I walk out there on those days and I'm embarrassed because I'm just standing there. I'll stop 15 times, even with the oxygen! I find that I never quite get enough out of the portable oxygen. I just don't seem to get enough. Even though I've got it cranked up to four [L/min]. Although I should only be on three. When I'm exerting any physical effort it never seems to be enough. So I have to stop. For a few minutes.

Not only shortness of breath, coughing may stop the person with chronic pulmonary illness. Everything except the coughing halts:

> Coughing can get wicked. Everything comes to a standstill. And I have to stand there and cough and cough and cough. I don't have any energy or stamina to do anything else, but to get that over with right now. It's not like I can walk away and just (*imitates coughing*). It is a full-functioning-stop-dead-type of cough. I sometimes feel like I'm just going to choke myself or choke off whatever air supply there is. And it's usually short lived. But there'd be occasion when I was still smoking, when I had these coughing fits where I would be starving for air. I didn't know if I was going to stop coughing or not. Long enough to be able to get a lung full of air. It just went on and on and on.

When brought to a standstill, there is a sense of being forced to stop. Not choosing to stop. Karl describes that when he is short of breath, "All I can do is stop. Whatever I'm doing I just stop. I just can't do anything else." His body is no longer mobile, no longer moving through the world: "I'm just gasping. I'm down right gasping. I can't move. I flop in a chair and that's it. I stay there." Gregory is stopped at times: "When I walk from the parking stall to the store, as soon as I get inside the store, then I'm stuck. I've got to stop and catch my breath before I can do anything else. Before I can get around." Everyday motions and actions are impossible for Valerie when she is short of breath. She has to stop to breathe:

> I ended up being so terribly short of breath that I couldn't walk three steps. Couldn't get up and down the stairs. I can't even go to the bathroom at night. Even climbing a flight of stairs I have to stop to breathe.

There is a suddenness, unexpectedness, and unreliability of the body coming to a standstill, having to stop. Forced to stop. A sudden stop. As if the lack of air or oxygen immobilizes the body. No longer mobile, the body is brought to a standstill.

> I remember being in Victoria (*coughs*) on a conference and I was climbing up and down the hills. And all of a sudden, I just had to stop and hold onto somebody's gate until I could get my breath rhythm back. And hold on. And work at getting breath into my lungs. Getting air into my lungs.

Some persons may anticipate having to stop. Setting aside the body of habit, the body of the moment, thinking about breathing and pacing the body. Walking in the mall, feeling short of breath, Bill slows down and "I'm looking for a place to sit down." Karl is usually "fine" walking half-way across his sitting area. If he forgets to stop and tries to walk completely across, he is out of breath. Has to stop. Standing and leaning on the table, waiting to catch his breath:

> I'll walk half way to the sitting area we have back there and then I'll stop again and then I'll walk over there, and I'm fine. But if I try and do it in all one push, then I get out there and I'm out of breath. I just stop and catch my breath before I can do anything again. Generally in a minute or two it starts to come back. When I'm breathing like that I prefer to be standing. I'll stand at the end of the table here and put my hands on the table. Because it's easier than sitting down and trying to breathe.

The body not only comes to a standstill, the person may be unable to stand. Ed describes having to stop right in the street, not even able to reach the other side: "I was visiting in Banff, when suddenly, in the middle of the main street, I had to go down on one knee, and get my breath." Karl also described a time when "I was just on my knees. I couldn't breathe. It was actually putting me down. I couldn't do anymore. I just couldn't." Gregory often has to stop, which in his home is "frustrating" whereas outside his home "sometimes it gets to be a panicky thing" and he bought a walker to sit down on:

> It's two blocks to the corner store over there. I used to be able to walk over there. But when I did that I'd have to stop about five times on the way over there. To catch my breath. I'd just run out of steam. So I got the walker. I can always sit down on it. Without that walker I'm beat. I can't go anywhere.

Holding on to a gate. A fence. A table. Sitting down. As if even keeping upright by one's self, without assistance, takes too much work. The body is completely stopped. This is a remarkable contrast to the *phenomenological* body which is described as in "constant relationship" with the world (Merleau-Ponty, 1962, p. 340). In our habitual body, activities are spontaneous, and "movement is not thought about" (Merleau-Ponty, 1962, p. 137). In the taken for grantedness of being in the world and moving through the world, there is a spontaneity, a "simultaneous patterning of body and world" (Merleau-Ponty, 1962, p. 189) of our bodies, emotions, thoughts, whereas with pulmonary illness, the phenomenological, pre-reflective experience of the body is often disrupted. The physical body is noticed and reflected upon. Movement is frequently thought about. Breathing is noticed and focused on. Space and time are experienced subjectively. Distances may increase and time slows down.

Doing less, slowing down, coming to a standstill, pulmonary illness is no longer invisible. Jake becomes very self-conscious. Noticed by self and others:

> I become very self conscious. I can't stay up with my grandson *(pause.)* If I'm having a bad day even walking. I'm very embarrassed sometimes when I go over to the store here. In the winter time, it was real tough. I'm trying to breathe and the cold air is even worse, cold air is terrible for me. And I would be stopping out here and I'm sure people would be thinking, 'What's that clown doing stopping out there in the middle of the winter with 2 bags, or 4 bags of stuff?'

With chronic pulmonary illness, breathing is not automatically synchronized with the activities and pace of life. If the person moves too fast, breathing cannot keep up to the speed of the body. The person may notice the body is slowing down. Perhaps may consciously set a new tempo, slowing down the body, slowing down breathing. Brookes (1994, p. 158) remarks on emotions, feelings, activities, and breathing:

> You'd think such a connection between emotion and breathing would have made its way into the language because poor lung function has such a dramatic effect of our emotions and our appearance. The asthmatic can't run, skip, jump, dance; we're reduced to a hunched shuffle. We lose the confidence of calmness: so much asthma occurs at night when we're trying to relax, giving us tension and anxiety rather than peace and quiet. We can't be authoritative or fluent; we seem to retreat into ourselves, to be stubborn, hard-headed, willful, uncooperative. Our condition looks more like a behavior *[sic]* than an ailment. From the inside it makes it all the harder to adopt the put-on-a-happy-face remedy of the wellness instructors. We've lost our breath, and perhaps it's no coincidence that in Latin *spiritus* means not only "breath" but also "life" and "spirit."

Perhaps Brookes does not speak on behalf of all persons with asthma. But he reveals that the loss of breath is more than a momentary inconvenience. With moderate to severe symptoms, the body and self slow down, does less, and at times even has to stop. The world is reduced in time and space to the next breath.

Is it only breath that is 'lost' or some part of self? Losing one's breath is more than just 'shortness of breath' or 'breathlessness' as experienced and understood in health. Running out of breath, being short of breath, losing one's breath. All describe a way of being in the world and with others. Slowing down and doing less are not choices of the moment or of being. It is different than the gradual, and perhaps even welcome, doing less and slowing down that we might think of attaining over time, children becoming more independent, a less demanding work environment, a restful holiday. Slowing down and doing less limit sensations. To reduce distress. In health care, we may call it 'Managing symptoms.'

At most times, the body is not the direction of our attention. We are in the moment of the *now*. Interactions with others, activities engage us. Yet we live and move through this world *in* our body. We grasp the world *through* our body. With a limited capacity for breathing, for air, for volume, there may be a limited capacity to engage in actions and interactions. The world and self are open in a new way of being and possibilities. Ease of mobility, habits of moving through the world, and spontaneity of movement are disrupted.

It is the body in the world that reveals the damage and disruption of pulmonary disease. When the customary world is no longer possible, disability is revealed (Merleau-Ponty, 1962). The person with emphysema is not able to jump up and take in groceries. The person with asthma does not go out to a friends' home where there is a cat or dog. The lungs limit the body; the body limits activities. The body is in the world, but the way of being in the world is altered.

Chapter Seven

Expressions of Pulmonary Illness

Expressions are signs, indications to direct attention and indicate meaning (Husserl, 1900/2001). We name and define objects through words and phrases of language which may not necessarily encompass the total meanings of that object or experience. Meaning is not complete within the word or phrase, "the relevant concrete reality is rather the total experience of the understood expression" (Husserl, 1900/2001, p. 133). In this way, meanings do not reside in things or words, but in the presentations and judgments (Husserl, 1900/2001). For subjective experiences, meanings of an expression or word are uttered and understood within the context of the person and the circumstances (Husserl, 1900/2001).

How might we understand or grasp the sensations or experiences of others? Others' inner experiences such as pain and anger may be partially understood through speech, but the object or experience can never coincide with speech (Husserl, 1900/2001). Thus, an act of interpretation and perception is performed. In this manner, language indicates objects and provides meaning, yet at the same time it is limited and words are unable to completely describe experiences (Husserl, 1900/2001; Zahavi, 2003). Perhaps language is more limited for experiential phenomena or sensations, such as breathing and 'shortness of breath.' Breathing is similar to other regulated functions of the body which are obscured and distorted when language separates body and personal subjectivity (Buytendijk, 1974). We cannot really describe our breathing until we attend to it or notice it, and even then words may elude us. We are accustomed to being unaware of our inner aspects of heart, lungs, intestines, and kidneys: "Designed to work without conscious instruction, these interior systems are at a loss for words when they try to speak up for themselves" (Miller, 1978, p. 41-42). Words may indeed be very limited to portray sensations in the chest that occur with asthma, indigestion, or angina, and be described as pain, tightness, or discomfort.

Descriptive phrases and comparisons were used to express or describe that which is not easily portrayed: "*As if* a cat sat on my chest." "I feel *as if* I can't breathe." "I would feel *like* there was a weight." "*Like* someone was standing on my chest." "*Like* my chest couldn't expand." In their use to describe sense-experiences, these phrases both reveal aspects of the sensation and the limitations of the words. *Almost like* was also used, indicating that the usual meaning of the word does not quite capture the sensation: "It's almost like, not a gurgling sound, but a wheezing that I can feel more in my chest than hear it."

'It's almost like' and 'as if' are cues that the phrase is not the same indicator, not the same sensation, as when the expressions is used everyday: "It's a sort of a...I can feel a very slight sensation in my chest, followed immediately by a *(deep breath in)*, as if I'm trying to catch my breath." Other times, words were not used to describe experiences of breathing. As if there are no expressions of language for the sensations or actions, participants substituted words with sounds by breathing loudly, coughing forcefully, inhaling sharply, or panting quickly. There may not be phrases or words to express the sensation.

Expressions of language do not merely say something, but say it "*of* something" (Husserl, 1900/2001, p. 114). When the *some thing* is subjective, a lived-experience, words and phrases may have different or several meanings, depending upon context and use. Misunderstanding occurs when we assume that we share definitions and meanings. We interpret expressions within our own context of experiences and culture (Merleau-Ponty, 1962). We cannot assume that words and phrases of pulmonary illness have mutual definitions, nor that there are reciprocal understandings of meanings and interpretations.

Exploring expressions of language expands their meanings, reveals subjective experiences, and explicates misunderstandings and assumptions that may occur when language is interpreted from one's own experiences. Analysis of language through reflection and comparison enables further understanding of lived-experiences of pulmonary illness. Everyday expressions have underlying meanings. Metaphors are used to contrast and reveal sensations and images. The body is revealed in language of space in time. In this chapter, three forms of expressions of pulmonary illness are explored: *Everyday Expressions of Breathing, Metaphors of Breathing and the Body,* and *Spatial-Temporal Expressions of Illness.*

Everyday Expressions of Breathing

Breathing is given significance in our day-to-day language and there are numerous expressions of breathing in the vernacular. Many of these expressions extend beyond breathing and the lungs to experiences within a context. Are these everyday meanings shared by those that have pulmonary illness? In this section, the following everyday expressions are discussed and contrasted within the context of pulmonary illness:

- Out of Breath
- Catch My Breath
- Save Your Breath
- Take My Breath Away
- Take a Big Breath
- Taking a Breather
- Don't Hold Your Breath
- A Breath of Fresh Air

Out of Breath

Sprinters explode down the track. Not a single breath is taken. Breathing is excluded from mind and body. They are not 'out of breath' until the race is done. Basketball, hockey, baseball, and football are activities with intense physical demands and exertions. Yet, athletes often do not run 'out of breath' in playing these sports. Is it only physical condition or the focus of attention? Attention is not on the body but on the game. A high school student describes running during a basketball game:

> I'm running in the game. Breathing fast. But I don't pay attention to it. There's just the game. Usually I'm in good enough shape and I'm not aware of my breathing. When I'm really tired, I'm out of breath. My limbs feel heavy and my lungs feel sore. I feel the inside of my lungs from breathing so hard. When I was sick last week, I noticed my breathing. I thought 'I can't run anymore,' but it was more being tired than out of breath. I don't remember ever being out of breath when I'm not tired.

During the game, there is no awareness of breathing and the body. Instead, his "primary occupation was in and with the world" (van Manen, 1998, p. 11). He runs, but does not run *out of breath.* On reflection, he considers his breathing as fast. In the moment of the game, the rate is not really noticed nor given significance. His subjective understanding of breathing is his physical conditioning and state of being, not effort of breathing or insufficient air in his lungs. When breathing is noticed, significance and meaning are to the body, not the lungs. The *body,* not the lungs, is ill or out of shape.

In chronic pulmonary illness, running out of breath has different meanings. *Out of breath* is not experienced with extensive exertion or distances as might occur with a swimmer or runner. Meanings and experiences of being *out of breath* differ with moderate to severe pulmonary illness. It is in the everyday activities that the person becomes *out of breath.* Speaking in a conversation. Rushing for a bus. Walking up the stairs. Going across a living room. Breathing cold air. In exploring these experiences, we gain an understanding that "space, time, and the world are as we 'live' them" (Merleau-Ponty, 1962, p. *vii*). Speed and distance are as they are lived, not measured. Subjective experiences and meanings of going too fast or too far and being out of breath in pulmonary illness contrast with everyday meanings:

> Let's say a normal person ran a couple of blocks, not full tilt, they just ran a couple of blocks. And so they're a bit out of breath but in that case, they tend to be able to regain their breathing just by breathing a little heavier and a little faster for maybe a minute. They're just out of breath and so they'll breathe harder and faster, and the air's still flowing in and out freely. I think the difference is that in that environment they don't tend to feel like they're actually having trouble getting oxygen. When it's bad for me, the best description I can give is I'm trying to breathe through a small straw. There's not enough air flow. When it's really bad, the air isn't flowing freely. And that's where I can feel my chest and my chest muscles or my lungs working hard to pull in and push out.

When persons with chronic pulmonary illness are out of breath it is not within the context of maximum exertion. Running out of breath may also be experienced as running out of time (Clarke, 1991, p. 133). Not just needing to catch their breath, they have no air, can't breathe. Not running but walking, and feeling as if they have run out of breath.

Short of Breath

Running out of money or space may leave one 'short' of either of those resources. Being 'short of breath' may have various meanings, such as the way of breathing or the insufficiency of air:

> The breaths are short, so they're not the *(breathes in and out loudly and deeply).* Not from the diaphragm kind of deep breaths. They're the trying to get in and out on a fast basis. For me that would be to quickly breathe and not deeply. But short of breath, when I think of it a different way, like I'm short of money, I'm short of breath, is very similar, as well.

Being *short of breath* is used in similar contexts as *out of breath.* I wonder if there is a sense of different immediacy with being *out of breath* than being *short of breath*? We can be *short* of money or *out* of money. From these perspectives, I might consider that being *short* of breath is less demanding than being *out* of breath. Less frightening. Less necessary. This early assumption is corrected when a person with asthma asks me to imagine the sensations experienced with being short of breath: "Imagine someone sitting on your chest and their hands on your throat. That's what it feels like." Another says:

> Envision yourself either lying on your back with somebody pushing on your chest while you're trying to breathe or somebody standing behind you holding you around the chest tight and then you're trying to breathe quickly because you're short of breath. That's much different than a normal person who's just a little short of breath. It's the tightness in the chest, and I feel like I'm having trouble getting the air in, not just that I need more air and so I breathe faster.

I can try and imagine those sensations. Short of breath, a phrase that I spoke so casually as a nurse, gains new meanings. In saying *out of breath* or *short of breath*, we use the same phrases, falsely thinking it is the same experience as experienced in health, but actually it is completely different. I perceive no limits to the availability of air. Air flows freely in and out. I have enough air for everyday activities. In chronic pulmonary illness, the body is unable to obtain it, to catch it, leaving one short or even out of air:

> Knowing I needed more air but it wouldn't come in. No matter what I did. It was like something was cut off. I felt like something was obstructing it, like something was blocking it. It was almost like I was in a confined area where I was trying to breathe in air but there was none left.

In experiencing being short of breath, there are perceptions of difficulty, of frustration, of effort, of distress, "I'm struggling. I'm making an effort to breathe. It's not the same as short of breath."

Catch My Breath

Hiking or skiing in the mountains, I have often paced myself, pushing onward to the next corner or to the top of the incline, before stopping to catch my breath. I drop my pack. I do not attend to the view. I just breathe. Somehow the body is invigorated, but is it breath that is caught? Is it the body that catches itself, that takes or captures a rest? At that moment, everything but the heart and lungs are resting. Oxygen is caught up into my leg muscles; eventually I am able to talk with fellow climbers and move on.

This physical need to catch our breath can be readily observed as I did in the last 10 minutes of a high school basket ball game. The home team was short of players and had played hard, keeping up or even ahead. The center point ran up the court and back, time and time again. The whistle blows. He goes off the court and collapses on the bench. His head and chest bent down, his limbs sprawled out. Across the court, I can see easily see his rapid, deep breaths. In-out-in-out-in-out. Suddenly he looks up as his coach murmurs. He jumps off the bench. He substitutes in and is back, running in the game. When on the bench, his whole focus seems to be on breathing. Catching his breath. Even the game recedes for a moment. Then he is back into the game. Reaching, throwing, sprinting. He seemingly has 'caught' his breath.

How can one catch something as elusive as breath? Unlike a butterfly, it cannot get away. We can catch a cold by breathing in the virus. But catching our breath is quite different. Everything and everyone recede and wait. We just breathe. We may even use the expression when we are rushed and busy with mental work, needing to stop and catch our breath. Somehow, once it is "caught", we are energized and ready to go again.

I might hear a colleague say, 'It's been such a busy day. I'm going to sit down and catch my breath.' Taking a break or relaxing, to 'catch my breath' is pleasant, but not necessarily compulsory. In this way, we don't really need more air, nor to make an effort to catch our breath. It is a way of relaxing and collecting one's self, not air. What is it like to catch one's breath in chronic pulmonary illness? Not voluntary or pleasant, and effort is required to try and catch one's breath:

> I'm not going to be able to catch my breath. That heaviness in my chest is different. Running and being short of breath before was different. I was getting air. It's almost like no matter how big of breath I'm taking, I'm only getting a little breath. Even if I'm gasping I'm only just getting a little breath. And the work of breathing is so much more. It takes so much more effort.

Not only effort but a sense of desperation may be experienced with trying to catch one's breath, either with severe emphysema, "I thought I was going to die. I just could not catch my breath" or in an acute asthmatic attack: "It feels like I can't get enough air. It's not just heavy breathing. No matter how hard I tried I couldn't get enough air in."

Save Your Breath

Saving our breath has elements of keeping silent, of not disagreeing, perhaps even of futility. We may be told to *save your breath* when we cannot change circumstances. Arguing, worrying, waiting, all take energy and increase the need to breathe. Breath is not wasted but saved when we comply and agree. But when air is plentiful, how can a breath be taken, held, caught, saved? With millions of breaths in a lifetime, how can we 'save' any breath for another time?

In severe pulmonary illness, activities are decreases or modified to decrease the need for air. In this manner of *Conserving Energy,* they *save their breath.* It is more physical than the mental or emotional aspects. Motion requires energy and energy requires air and oxygen. Speech may be limited, and the person silenced by the physical need to save their breath. Activities are paced and rests are taken:

> I'm just much more aware, and sort of taking a break because I get a little short of breath. I make sure I sit down a lot more and I'm just conscious of it more. It's kind of always there. I'm always kind of thinking how to save my breath I guess. I have to do this and this and this and this. So I rest here because I have to do this and this and this and this or whatever.

How can breathing be conserved? May it be saved as we might save money by spending it very carefully? Allotting it only to necessary items or events? Talking, laughing, crying all take energy and might be minimized to save one's breath. Energy-conscious of breathing, activities are planned, organized, and limited to "save air."

Take My Breath Away

In the expression *to take my breath away*, breathing is associated with strong emotions, not physical exertion. I remember walking to the edge of the cliff and looking over the vista, quickly inhaling and holding my breath. My breath is not taken, but held for a moment. I imagine if I came across a horrific accident, I might take a quick breath in and hold it momentarily. We say that these types of emotions and sensations *take our breath away.* We may hold our breath and gasp, for a moment not breathing, but of course, our breath is not actually 'taken.' It is more of a signal and a pause that expresses our emotions and self in the world.

Breath may be 'taken' away in asthmatic attacks or acute infections. There is no air. It is not a pause or expression of emotions. No breath may be taken in. If one's breath is taken away, can it be returned? Betty has *lost* her breath with asthma:

> Just my normal sort of day-to-day stuff causes the shortness of breath. I still get short of breath if I walk up stairs or whatever, but my breath comes back. That's the difference. At one time I'd lose it, and I just didn't think I was going to get it back. I just couldn't seem to get it back.

Another participant has gone to Emergency as he hasn't been able to *get* his breath – where has it gone? "I have had trips to the emergency 'cause I just couldn't take a breath. I just couldn't get my breath."

Breath or air can literally be taken away when we forcefully exhale. Yet in the next moment, we usually take another breath in, not thinking about breathing. In pulmonary illness, breath becomes more tangible, as something that can be conserved, taken, shared, or even lost.

Take a Big Breath

When a person is angry or worried, we may say, "Take a big breath and relax." We might take a big breath when we expect bad news. During painful procedures, I have directed patients, "Take a big breath. In and out." What is occurring when we take a big breath? Does it relax us? Perhaps it distracts. Or re-focuses. When people engage in relaxation and meditation strategies, they focus their attention on breathing, often taking deeper and slower breaths. Where are these breaths 'taken' from? What is gained when a big breath is taken? Perhaps the focus on the body moves us away from the concerns of the world.

Other times, we may not be aware of having taken a big breath. We collapse on a chair and take a big breath. We finish a project and give a big sigh. Are we aware of our breathing as we exhale that big breath? Or is it more an awareness of our experiences? Our being? Sighing, the change in breathing becomes "an expression of a bodily *lived* and personally *experienced* situation" (Buytendijk, 1974, p. 290).

How might we feel if we couldn't take a big breath? When taking even a small breath is a "big effort":

> With asthma, it's almost like no matter how big of breath I'm taking, I'm only getting a little breath. Even if I'm gasping I'm only just getting a little breath. And that's, the work of breathing is so much more. It takes so much more effort. So, I guess because I'm constricted. Yeah, like a big effort. Like I'm taking these huge breaths, and I know I am, but I don't feel that air moving in there. And that's probably why I get panicky.

In acute asthma or severe COPD/emphysema, tidal volumes are limited and the person is unable to take a big breath. Unable to relax, perhaps even becoming panicky as they can't get a large breath.

Taking a Breather

'Taking a breather' is an expression that describes taking a break, having a pause or respite. Imagine two men strenuously hand-sawing planks out of a log, each man straining at the end of a 6 foot rip saw. The constant exertion taxes their bodies to the limit. Nearly at the end of himself, one man sighs and says, 'let's take a breather.' In our modern world, this expression is not common and its use is more often connected to our mental state, not to physical extremes. Use of this expression is a signal to pause, to change our activity, or pace ourselves with others. Perhaps to settle our thoughts or clear our minds.

This expression was not used by participants in this study. The meaning of taking a break from the physical exertion is seen in the experiences of pacing. Of stopping to rest for a moment. Not taking a break from extensive exertion, but everyday little tasks such as washing dishes or potting plants, “I’ll have to sit down and stop and take a break in between.” Breaks might be planned to enable the tasks to be done. Stopping to rest.

> I make sure I sit down a lot more. If I have to do this and this and this and this, so I rest and sort of take a break because I get a little short of breath or something like that.

Consciously aware of taking little breaks and being short of breath again contrasts with the everyday use. In the vernacular, taking a breather connotes a change of pace, an interlude for the self rather than a focus on the body and breathing.

Don’t Hold Your Breath

When waiting for something to happen, we are sometimes told ‘don’t hold your breath.’ Holding one’s breath creates pressure and tension within the chest and takes work. Perhaps we shouldn’t hold our breath because we don’t need to add more tension to that of waiting? Does releasing our breath release tension? Or is it that holding our breath is a marker of time, as we can only hold our breath momentarily or for a limited time. While trying to hold our breath, we acknowledge that it is futile to wait.

Holding one’s breath may be voluntary or involuntary based on emotional or physical demands; the physiologic mechanism is not well understood (West, 2000). We may ‘hold our breath’ for a moment waiting for good news or watching a frightening movie scene. But when we take a breath we do not hold it for long, and may not be aware of holding it until it is released. For instance, I remember watching a climber descend down a rock face of a mountain. I was not aware of holding my breath. When his last hold was reached and he was safely at the bottom, I breathed out and then in. Then I noticed that I had been ‘holding’ my breath.

When we hold our breath, we prevent the body from doing what it can and should do (Buytendijk, 1974). Then voluntarily or involuntarily, a breath is taken. We can continue holding our breath for a time, but exhaling is eventually “forced” by the need of the body for breath to occur (Buytendijk, 1974, p.183). In this manner, holding one’s breath is limited. We can’t hold it for long before the body demands that we breathe.

When *learning to breathe*, to slow their breath down and exhale longer, persons with pulmonary illness may consciously *hold* their breath. Counting and holding.

Breathing out through pursed lips to expel air that is held. Trying to hold on and breathe. In these experiences, meanings and interpretations of holding one's breath are within the body, not the emotions and thoughts that are suggested in the everyday use of the expression.

A Breath of Fresh Air

While walking in the tropics on a cool evening my friend took a big breath in and said, "I love this air, I can't get enough of it. It's so *fresh.* I wish I could take it home." Suddenly, I too was aware of the air that a moment ago was unnoticed. It seemed moist and light. I took a deep breath in and savoured the air with that breath. But as I did so, I also become aware of other sensations: the slight breeze on my cheek, the unfamiliar palm trees, and the cobbled streets. What is it that makes one want to take a big breath in a certain type of air? The smell? The weight? The freshness? The warmth? The expanded awareness of other sensations?

We describe qualities of air: fresh, stale, warm, cold. I think about noticing types of air. I can recall the sensation but do not recall if these types of air affected my breathing or body. If there is a pleasant or unpleasant smell, I may take a larger or smaller breath. But it is the sensation of smell, not of breathing that I notice or I focus on. If the air is stale, I may notice the smell, not thinking about a decrease in oxygen.

Delighting in 'fresh' air, we may notice the smells and scents of the air around us. Not taking in air but sensations. A woman shares an experience of breathing 'in' the air of a flower shop:

> Entering the flower shop, I stop. I become aware of the fragrance. My nostrils flare with the opening of my lungs. I inhale the scent and want it to permeate my whole body. I close my eyes to immerse my being in the moment. The cool moist air is fresh, laden. It stirs my senses. I drink it in. Take it in slowly, and then hold it. I feel that I can't breathe in the air in deeply enough.

In this moment of taking a breath it is not the oxygen or body that is breathed. It is as if more sensation of the world is taken in through the breath. Taking in a breath of fresh, scent-laden air encompasses the aesthetic. Breathing offensive air is also more than gas exchange. With an obnoxious smell, we want to take as little air as possible. We interrupt breathing. Not taking *in* a breath to stop smelling. A teenager describes the outhouse at camp:

> It's horrible. I take a big breath outside and then go in. I hold it and hold it and hold it, until I can't any longer. My lungs are going to burst, but I can't take a breath in. So I start to slowly, so slowly exhale. And I feel relief. Even though I'm not taking air in, I'm breathing. My brain is fooled, thinking it's breathing. I slowly, slowly exhale, trying not to take a breath in until at last, I'm outside and can breathe.

Wanting to take in the smell of the air, we extend and expand the breathing *in*. The teenager prolongs breathing *out* to stop taking a breath. When taking a big breath, not just air is taken in, but smells and substances of the air. For the person with asthma, scents and smells may not be as easily categorized as pleasant or offensive. Jennifer holds her breath when she walks down the aisle to buy soap. Not offended by the smell, she instead holds her breath as she is "scarcely able to breathe." With asthma, scents may not only be an inconvenience or offence, but an irritant and a threat. For Valerie, perfume is a trigger for an asthma attack, "In the choir women wear perfume and I tell them, I can't sing. I can't come. I can't breathe." DeSalvo (1997, p. 25) also relates the threat of perfume as a threat, as a weapon:

> As I sip a wine that doesn't contain sulfites, the maitre d' seats a very well-dressed woman next to us who, I swear, has taken a bath in very expensive perfume. Perfume that, to her, is an enhancement of her charm. Perfume that, to me, is a potentially lethal weapon. I tell myself to ignore it, that I'll be fine. But my eyes start tearing, my throat starts closing, I'm coughing, I'm suffocating, I'm drowning.

Qualities of air may be noticed in pulmonary illness. Cold, humid, dry, warm. Air may be difficult to breathe: "The cold air feels difficult to breathe." Several participants described qualities of air that they breathed. Some wanted 'fresh air' or a breeze:

> I think I'll be better now that it's getting nice out, I can get out. I can get in the fresh air.
>
> At the nursing homes, they don't even have one little air hole that you can close and seal off yourself. The air conditioning, all that does is blow dust. But the fresh air. (L*ong pause*). My father-in-law, his lungs were bad. He smoked nearly all his life. And he was quite a wheezy and he'd sit in front of the window, with a nice breeze coming in.

Without fresh air, no air or bad air may be perceived and interpreted as being difficult to breathe:

> There are a couple of stairways in the building that are really bad for oxygen. There's no air. The air feels like there's something, a quality in the air, that is difficult to breathe.

The body that needs more air is revealed through several expressions: running *out of breath,* needing *to catch my breath,* and feeling *short of breath.* The context and use of these idioms in everyday use again have very different cultural and experiential meanings than in pulmonary illness, with perceptions of frustration or distress.

Underlying meanings of taking and holding are within the expressions *take my breath away, take a big breath, taking a breather, and don't hold your breath.* Breath is more than air in these expressions. The invisible substance of air is given honour and recognition, as if taking and holding a gift. Emotions and spirit are reflected in these expressions of taking and holding. Meanings are of the whole person, not just breathing and the body.

Metaphors of the Body and Breathing

How might we understand that which we do not experience? We might try to imagine sensations and feelings through description. Storr (1979, p.11)) expresses visual and sensory images of torture with an asthma attack:

> In various parts of the world, mechanical interference with respiration is a well-known method of torture. In many prisons, those who are being interrogated have their heads plunged under water, which is often full of excreta, until they are nearly drowning. Another well-tried technique is to lie the victim down and pile slabs of stone on to his chest until it becomes more and more difficult for him to breathe at all. I can imagine exactly what such a prisoner feels.

Not having asthma or breathing difficulties, unlike Storr, I cannot "imagine exactly" feeling these forms of torture. But with this description, I can partly imagine and understand sensations and distress that may be experienced in an asthma attack. How else may we understand that which we have not experienced?

The use of metaphor is another type of expression and description that may promote understanding of a concept, evoke meanings of phenomena, or provide sensations of an experience. Through imagery, metaphors enable different ways of seeing or perceiving a phenomenon, particularly experiences that are not easily described literally (Black, 1962; Ortony, 1975). In expressing thoughts and sensations, metaphors enable us to comprehend some aspects and hide others (Colwell, 1997). Tightness is a sensation that may be experienced in asthma. A metaphor evokes a sensation and a different understanding of the word 'tight': "That pressure and tightness. That sensation that someone's sticking their high heel into my sternum."

There are several perspectives or views of metaphors, the majority of which extend from Aristotle's notes on rhetoric – the form of speech that is intended to persuade. In metaphor, there is a transfer of meaning by analogy. Giving a name that belongs to something else creates clash of meanings, described as a twist or trope of the ordinary meaning of the second noun (Beardsley, 1962). Metaphor is perceived to be more complex than analogy, with underlying meanings that must be interpreted by the reader or listener. The listener must recognize the conceptual and literal incompatibilities, and interpret meaning through characteristics or themes of the secondary noun (Black, 1962). The construction and interpretation of metaphors reveals perspectives of physical and social experiences, and cultural and personal perspectives (Lakoff & Johnson, 1980; 1999).

Ricouer (1975) argues that metaphor is not just the noun within the sentence; it is the statement which requires a perception of resemblance within the sentence and context. Meaning is greater than just substitution; interpretation is required to exclude and include meanings within the semantic relationship. Metaphor is less explicit than simile, with "a chance to instruct and to provoke inquiry" (Ricouer, 1975, p. 26). Perceptions and comparisons that are not articulated lend to its elegance and power in creating meaning or evoking understanding. To interpret a metaphor, it must be recognized that the "speaker *intends* the expression to be taken nonliterally" (Pavio, 1979, p. 176). *Intended* ideas or concepts are interpreted by the listener through comparison of characteristics and underlying ideas. In metaphor, "language, perception, and knowledge are inextricably intertwined" (Ortony, 1993, p. 2). The strength of metaphor as an expression is its associated implications, some of which are selected by the hearer as relevant, others are elaborations. The system of implications and comparisons suppresses some details and emphasizes others (Black, 1962), both revealing and distorting aspects of reality (Colwell, 1997).

Although Beardsley (1962) suggests inclusion of cognitive and emotional aspects, mental interpretation is required to differentiate or interpret what the sentences states and what it suggests. There is an underlying assumption of mind-body separation in the emotional and corporeal meanings. From a phenomenological perspective, nuances of meaning are not restricted to cognitive or visual elements; metaphor may also elicit perceptions of emotions and physical sensations. Indeed, metaphors are considered to be useful when the thought or experience *cannot* be described literally, to represent features of an experience or represent images or body sensations. Thus, taken for granted experiences or sense-data, such as breathing, may be better understood when conceived and expressed through metaphor. Metaphors may not necessarily be weakened if the listener does not have a shared understanding of experiences. Their strength is in the possibilities of capturing the imagination, evoking a body sensation, or provoking curiosity. When language does not readily reveal experiences, such as breathing, metaphors may evoke understanding of emotive, cognitive, and corporeal experiences. Metaphors used in descriptions of chronic pulmonary illness were:

- *Drowning and Suffocating*
- *Concrete and Molasses*
- *Attacks and Battles*
- *Running Out*

Drowning and Suffocating

Ricoeur and Black argue that not all metaphors require perception and interpretation, and not all enrich vocabulary or understanding. Idioms are "dead" metaphors used in everyday language with immediate grasp of their common and conventional meanings. With some idioms, the metaphorical term is used, even though another "literal equivalent" word is "readily available and equally compendious" (Black, 1962, p. 33). For example, if we say "Richard is a lion," it is nearly directly taken to mean Richard is brave. In this use, no other aspects of "lioness" or themes of being a lion are brought forth, thus the image is more of decoration than expansion. For those familiar with the metaphor, little or no interpretation is required and little meaning is lost with exchanging the non-literal to the literal phrase.

However, interpretation of everyday metaphors revealed underlying meanings and assumptions within the context of lived experiences of pulmonary illness. Drowning and suffocating are everyday metaphors used for emphasis or hyperbole. For example, we might say that a hot and stuffy room is 'suffocating' or that we are 'drowning' in data or 'drowning' at work. In these instances, we share the meaning of 'drowning' or 'suffocating' within these everyday perspectives to describe sensations or perceptions. Thus, the meaning and use of the word is taught to us by our previous experiences (Merleau-Ponty, 1962).

The conventional and cultural meanings of these metaphors are very different than their use in personal and experiential meanings in pulmonary illness. DeSalvo tries to relay her distress when stopped in traffic on a hot and humid day. Her husband misinterprets her meaning from a conventional use of the metaphor. Suffocating is not intended to be literal, nor is its use within the exaggeration of the everyday. Within the context of an asthmatic attack, the metaphorical expression is intended to evoke an image of threat, feelings of desperation, and physical sensations of distress:

> "I'm suffocating," I gasp to him, and he doesn't understand that I meant this literally. "What do you expect me to do?" he asks, irritated. "Nothing's moving." (De Salvo, 1997, p. 54).

The *intended* meaning of metaphor is misunderstood because the idiom is *perceived* in the meaning of its conventional use. Recognition and interpretation of this metaphor requires attention to "the *particular circumstances* of its utterance" (Black, 1962, p. 29). Meaning has to be reconstructed or interpreted from the context and the speaker's intention, considering both parts and the whole. Use of drowning and suffocating metaphors in pulmonary illness denotes little air and greater sensations than the lungs. For Adam, the onset of asthma is "an overall feeling that I'm beginning to suffocate a little bit. I'm a little bit light headed cause I'm short of oxygen."

When these expressions of *drowning* or *suffocating* are used in a non-conventional manner, the interpretation requires attention to the context of the expression and the experiences of the speaker. The "commonplace utterances" no longer have "ready-made meanings" (Merleau-Ponty, 1962, p. 213) in pulmonary illness. Sensations are not *felt* or *understood* unless cues or extended knowledge from speaker and context are used to interpret meaning.

Meanings with the everyday use of drowning are confined to a sense of submersion, such as 'drowning one's troubles.' The more literal definition of drowning as death due to submersion in water and asphyxiation is closer to its use as a descriptor of asthma or emphysema. What might if feel like to be drowning with asthma or COPD/emphysema? Drowning and suffocating threaten the breath, perhaps even life. Not just a discomfort as in the everyday use. There may be a sense of desperation, panic, the inability to take a breath, the risk of losing life. Ed expands on meaning of drowning:

> The best way to describe it is drowning. People tell me, and you read in books, that drowning is really on the whole, quite a nice experience. And I can't for the life imagine why anybody would think not being able to get your breath is a nice experience. (*Forcefully*). It's a bloody awful experience.

Instead of creating understanding, meaning may be minimized, distorted, or trivialized by the use and interpretation of metaphors. When using and analyzing metaphors, it is the attributes of the "system of associated commonplaces" that provide meaning (Black, 1962, p. 40). For the metaphor to be effective, it is not so important that the commonplaces are true, but that they should be readily and feely evoked. Inclusion of comparisons and possible meanings are part of interpretation, but not all commonplace or dictionary meanings will be contained within the intent and interpretation of the metaphor.

Concrete and Molasses

With novel or 'live' metaphors, non-literal meaning is less easily substituted, there are underlying and subtle meanings rather than conventional meanings, and context is required for understanding. As with a poem, one may discuss and interpret meaning, it cannot be literally translated or easily paraphrased. The listener or reader is required to select, emphasize, and organize aspects using a system of implications and associated common uses of meaning (Black, 1962). Newly invented metaphor is seen by Ricouer (1975) as a phenomenon of discourse; interpretation is selection of meanings that are compatible with the context.

The descriptions of lived-experiences were re-read with attention to metaphors. These metaphors are of the body, not ‘the lungs’ as a separate or localized location of breathing. Ed, who has severe emphysema, described his everyday work experience as “I was walking through concrete.” Reflecting upon an asthmatic attack, Darlene said, “I was walking through molasses.”

Yet these metaphors are indeed descriptions of *breathing*, not ‘just’ *walking*. I can imagine the person walking, and the clash of image and sensation as they walk not through air but concrete or molasses. As I listen to their expression, the metaphor provides a sensation and image. I feel the difficulty of moving through concrete or molasses.

Concrete is strong and firm, intended to walk *upon*, such as in its use for a sidewalk or driveway, not walked *through*. The use of concrete in similes depicts the force of its impediment: “It felt like I was trying to breathe through concrete” and “There’s this phlegm building up in the top part of my chest here and it’s like trying to get rid of concrete.” The difficulty of moving against the immoveable is portrayed Ed’s frustration of living with emphysema. I perceive a brick wall with mortar or concrete that blocks him from his life as he would live it. Kicking against the brick seems both futile and difficult:

> It’s all this business of kicking against the brick of suffering this ridiculous, bloody disease, and not being able to get on with whatever it is I’m suppose to be doing. That’s frustrating.

Molasses has different characteristics than concrete. It is thick and tenacious. Impeding ease and freedom of walking. Molasses may be stiff and slow to move, as reflected in Gregory’s description: “If my breathing is not good, then I’m slow as molasses.” These metaphors of concrete and molasses give us body sensations and perceptions of difficulty, struggle, effort, heaviness, weariness, and frustration.

Attacks and Battles

Metaphors of war or conflict were often used by participants with moderate to severe pulmonary illness. They *fight* for air or breath, use medications to *combat* their symptoms, and worry about colds and pneumonia *taking a hit* on them. One person with emphysema paces his activities to "*strengthen*, to *fortify*, to *save* myself." In severe emphysema, the "fight day in day out to continue just to breathe" is seen as wearing, exhausting, frustrating. The body may tense up and ready itself for battle:

> My wife says what I do a lot is tense up. And she will say, 'Relax.' And I have to say, 'I can't bloody relax.' Sometimes at night I sit on the side of my bed and I'm rigid all the way through. I always tense up if I've got to battle for something.

Asthma is often described as an attack. Brookes likens the sounds and attacks of asthma to *crise*, the French word for "attacke": "it *is* a crisis, and the word's hissing exhalation, its vowel clamped down by a sibilant consonant, echoes the asthmatic's wheeze" (1994, p. 32). Crisis indicates the significance of an attack. Not just distress but danger, as an offensive force, "a sudden overwhelming assault that stormed through my whole body, seizing my throat and suffocating me" (Brookes, 1994, p. 4). When "the attack showed no signs of subsiding," Storr suddenly realized he was in danger (1979, p. 4). In an attack of asthma, DeSalvo (1997, p. 2) sees the body not as friend but foe:

> I try to ignore this body I inhabit that has declared war on me… I am trying to live with this illness that has invaded my body, and fight it, and figure it out, alone.

These notions of battle and danger are revealed within other descriptions of chronic pulmonary illness experiences. Numerous metaphors portray attacks on the body, and the battle, fight, and struggle to breathe: "when my lungs close down I have to fight for something that normally just happens." Vulnerable to attacks, to hits, fighting to breath and fighting infections:

> What the hell do I have to fight all this off? I don't know what it is, or what is hitting me like that. Now that I've been through two sessions of infection or viruses or whatever (*Coughs*) I find that I'm vulnerable. It's not just from the breathing. It's from my overall immunity to an extent. I'm kind of predisposed with those types of feelings, as well as the infection, as well as the breathing. Like I'm battling two things.

Infections are part of the attacks on the body that need to be protected from or fought against:

> I have to avoid getting things like colds and pneumonia or anything like that, because that's when it really, really attacks you. While I was still working, I fought against it without realizing that I was fighting against lung problems.

These metaphors reveal perspectives of our society with regard to illness and disease. We speak of *the war* on AIDS and cancer, medications that *combat* symptoms. War and fighting are associated with physical and technological resources. Possibly there is tension, worry of injury, or fatigue with war on the body. For persons with asthma, there may be some respite from the battle. They may try to protect themselves from attacks to some extent. Perhaps adopting a defensive position. Avoiding triggers. Being attentive:

> Frequently I'm on guard. Frequently I'm aware. Breathing is my worst symptom, so that's what I'm aware of. I'm frequently cautious of scenarios. So I'm planning. I'm thinking. I'm on my guard.

Others find that being on guard may not be sufficient. The occurrence and severity of asthma attacks were often unpredictable, perhaps even initiated by minimal exertion:

> Getting upset emotional, or crying, talking, laughing – anything that forces my air triggers it. I'm frequently cautious of scenarios. So I'm planning, I'm thinking, I'm on my guard. And sometimes I'm lucky. If I figure out what it is and I get away from it, then I'm okay. Now my asthma is bad, I can't avoid it. I can't identify the trigger. I would look until I was blue in the face, it didn't matter, I couldn't control it. That I find really hard.

These attacks are not something that one experiences silently nor in silence. An attack may be quiet or loud, mild or severe, but it cannot be ignored. The gasping effort, the incessant coughing, and the extensive wheezing are noted and remarked upon by self or an Other.

For those with moderate to severe COPD/emphysema, the fight for air may not completely cease, only ease or worsen. Persons with pulmonary illness perceive that they must defend themselves against infection, perhaps feeling vulnerable to types of attacks, as Jake describes: "being vulnerable and maybe my immune system has been lowered to the point where something can attack me." At times, the 'fight' might be nearly lost, and others may be called upon to help:

> I had a bad asthma attack, and unbeknownst to me, I had pneumonia. I thought I was going to die. I just could not catch my breath. I went into the bathroom. I came back and I went to lay down. And I couldn't. I had to sit up again. And I was fighting. I just kept fighting for breath. Fighting for breath. And fighting for breath. And finally, I just woke the wife up and I said, 'Call an ambulance now. I don't care what the hell it looks like. I need oxygen.'

The effort of living with pulmonary illness is not only the work of breathing that occurs with exertion or acute asthmatic attacks. There is an effort of partial or near-continual awareness and concern, which requires being "on guard" against infections and triggers.

Running Out

In both scientific and experiential language there are metaphors of energy demands with regard to breathing and exertion. Since the 1640's when breathing and combustion were linked (Miller, 1978, p. 150), we have conceptualized oxygen as a fuel for the cells, the body, and life. Exertion and energy demands are linked metaphorically and conceptually: "Prolonged muscular activity creates an enormous demand for energy: this can be provided only by the efficient metabolic degradation or burning of carbohydrate fuel; and oxygen plays an indispensable part in this degradation" (Miller, 1978, p. 170). Oxygen consumption is an indicator of cellular use and metabolism, calculated by differences between delivery and return.

In expressing experiences of pulmonary illness, numerous energy metaphors are used. One can run out of energy or not have enough. Energy is a precious resource, in demand by the body, and needing to be replenished. Karl needs to stop as "I'd just run out of steam." In asthma, oxygen is an actual or metaphorical form of energy:

> I'm out of breath. So it's the deep gasping thing. It's trying to think of saying, 'open you little alveoli' and there's pain. There's a feeling that I'm not getting enough oxygen that I need to get.

Within numerous contexts, the person may feel tired, perhaps running out of energy or expending a large amount of energy. The use of energy may be perceived day-to-day with emphysema, "I feel very, very tired and that I've run out of oxygen." Other times, it may be acute, such as after an infection "I feel tired out after I've expended out all that energy" or an asthmatic attack, "Because I've exerted so much energy, I was constantly tired, constantly tired." Oxygen is not just in demand because of exertion or strenuous exercise, the work of breathing increases oxygen demand. "Everything I do uses energy. Dr. X was talking to me the other day and he says, "For me to breathe and you to breathe, you use twice as much energy to breathe as I do."

We might 'run out' of various commodities, such as running out of space, out of room, out of time. In each of these metaphors, there is a notion of a precious resource, as there is when running out of 'air' or 'breath.' There is a sense of urgency when running out of breath. Not meeting the demand requires stopping the activity. Breath is going out, and not enough being replaced to meet the sense of need.' With any exertion, Jake describes that "I immediately expend my supply of oxygen." Feeling tired is understood within these metaphors of oxygen as a fuel and energy demands: "I was so tired. My metabolism has been running way more that it normally does. I've exerted more energy, that's for sure."

In philosophical perspectives of metaphor, emphasis is directed to the thought process, or the mental representation of metaphors. Metaphors are considered within semantic or semiotic approaches of language (Ricoeur, 1979; Lakoff & Johnson, 1980; 1999), or views of perceptual images and mental representations (Paivio & Walsh, 1993). Most often, physical or sensory aspects are unattended to or acknowledged. However, several metaphors of pulmonary illness evoke not only images, but body sensations. With interpretation and reflection, these types of visual and sensory images enable us to understand physical and sensory experiences of others. Metaphors may be 'mixed' and encompass various aspects of illness, as are these war and energy metaphors after an asthmatic attack:

> When it's bad I feel chronically tired. Chronically fatigued. I've exerted so much energy, I wake up and it feels like a tank has hit me. I'm always so surprised how much energy it takes. It's like running a mini-marathon all the time. The exertion. The energy. The calories. That's what I tell people.

Spatial-Temporal Expressions of Illness

The body inhabits and actively assumes space and time, providing significance and understanding through the body (Merleau-Ponty, 1962). In this manner of being-in-the-world, our body gives us a point of view and perspective of the world. We perceive and interpret sensations in relation to the body. As embodied subjects, words derive meaning from our experiences (Merleau-Ponty, 1962), thus language indicates and reflects body orientations. Thus, we may speak metaphorically of our spatial or temporal orientation (Lakoff & Johnson, 1980).

As upright adults, the spatial orientation of 'up' is given prominence and regard, whereas 'down' is given a lower status. Being 'up' is associated with our physical orientation and activities, and also reflects our emotions, success, or progress in life and society. It is as if spatial metaphors such as 'boost my spirits,' 'feeling low,' 'high-quality work,' 'things are looking up' reflect our erect posture as we move through the world.

Through orientational metaphors, our way of being-in-the-world is reflected in expressions of relationships between the body, space, and time. We may speak of having *high* points of our lives, and going *downhill* with age. Feeling 'up' is often connected with 'well' and 'down' with 'ill.' I may say of another, that he has *fallen* ill. Indeed, the word 'symptom' comes from the Greek word *symptoma,* to fall, perhaps in a sense that we are falling from our usual state (Kroenke & Harris, 2002). When we *fall* ill, we may notice our body more as object-subject. Perhaps feeling sensations that are distressful or uncomfortable, we focus inward, becoming distracted from the world. In illness, our body does not necessarily literally fall, yet our spatial orientation has changed into the metaphorical spaces of *low* and *down.* I feel a soreness in my throat, and say 'I might be coming *down* with something.' When Ed started to realize his limitations with emphysema, he had a period of being far down, no longer able to live at a higher level:

> I had gone into a very, very deep depression. And slowly I came out of that very black pit, (*coughs*) to the point where I could reassess those things that they were trying to tell me. And accept the fact that I cannot expect that life is going to be what it used to be. And I'm not going to be able to have the level of life that I used to have. I'm going to have to be content with the lesser things, and not want to do things that I intellectually know I can't do and stop moaning about it.

Our body gives significance to language; experiences of the body are described through and by language within the framework and in relation to the world (Merleau-Ponty, 1962). In this manner, "it is my body which gives significance not only to the natural object, but also to cultural objects like words" (Merleau-Ponty, 1962, p. 235). Through the relation of body and world, symptoms of illness are grasped and expressed corporeally; language embodying meanings and sensations. When we fall ill, we are no longer able to be upright and to move through the world with ease. We feel down. We sit down. We lie down. Effort and exertion in emphysema wears one down:

> Typically I have to force myself to go to the store. I know I'm going to have to lug stuff back. And I kind of dwell on that, that it's going to wear me down physically. There are certain times of the day when I am really dragged down. Mid-afternoon, between 2 and 4 o'clock where I start to kind of get worn out or tired. And I have to lie down.

Spatial senses of being *down* are revealed through descriptions of pulmonary illness, in day-to-day variations and the worsening of pulmonary illness over time. Illness is more than the body. Self and context may be expressed spatially: "Financial and mental stress drags my body down as well."

Down may describe acute or intermittent states within pulmonary illness. Jennifer limits her activities when she isn't "up to it." As the body is in the world, there are ups and downs of living with pulmonary illness. Ups and downs of good days and bad days. In the *downs* of *bad* days, the body may literally be down, the person spending most of the day sitting or laying down. Bill describes his asthma like the weather. Up and down. Good and bad. Perhaps like the weather, it also seems unpredictable? Uncontrollable? The body is situated in the world in which good and bad occur:

> It's the asthma that's causing most of the problem right now. But it's like the weather. It's up and down too. Some days it's bad and other days it eases off a bit. It's always there. I can hear it all the time when I'm breathing. Just like the weather, up and down! Some days not bad and other days not so good.

A few years ago, Jake had been able to "get up to a nice high point" but has been "down" for more than a year, with "periods of being knocked down with flu-like symptoms." For him, emphysema "really gets me down. And sometimes it gets me down to the point where I don't give a damn." Illness has knocked him down. He has fallen ill.

Living at a lower level, exercise is a possibility of moving up. Up to a lung transplant. Feeling up. Moving up may enable him to get ahead, rather than falling back.

> I would like to concentrate on the physical exercise program. Concentrate on that and get myself up to a certain level where I can either decide to get a lung transplant or take another step ahead from there. I want to get back up to a workable, physical level, instead of these ill feelings I'm getting all the time. I want to lead up to a lung transplant.

As chronic pulmonary illness worsens over time, a downward trend may be described. Jennifer's perception of her illness is within the phrase "I've been going down, down, down." It seems that it is more than the body that is going down. It is as her self is downward as well. Thus, language reflects the body space and the sense of self with illness. Karl describes "things just started going downhill" once he got emphysema. Valerie describes being in trouble with her asthma as "I've gone way down the line."

Ed also relays a sense of going downhill: "Once I got this, things just started going downhill. It's been getting progressively worse. *(Coughs).* It's getting progressively worse as time goes on." The worsening of lung disease is described as *progress* over time, the deterioration of the lungs and progression of the disease given honour over the body. The person's disease or symptoms *escalate*, leaving the body and self *behind.* No longer able is the body able to keep *up.* There may be a perceived inevitability to the 'progressive' deterioration:

> I have emphysema. In regards to the breathing it just gets to the point that I can't do anything. It runs in my family. I have uncles that have died from it. And now I'm following in the line.
>
> With anyone that's interested, I tell them I've got a genetic condition that is progressive and this will never get any better. And that's about where I end. There's no point in saying, here's how crappy I'm doing.

A temporal aspect may be described within the severity and inevitability of emphysema. It was described as "a slow but certain way to death," and several participants with emphysema expressed little expectation of the future:

> I don't have any big plans. I don't have a bright future or whatever.
>
> There is no promise; there is no hope as far as the emphysema is concerned.
>
> I don't see a lot of visible proof on either end of getting stable or getting better, I don't consider myself getting any better at this point in time.

Not unique to chronic pulmonary illness, falling behind or being down are experienced with other illnesses. Kate is a young woman recovering from an acute and severe pneumonia. With the effort, the trouble, and loss of energy, she is "falling further and further behind in the things that I've committed to do and planned to do. Totally lethargic. Just like it's too much trouble, too much effort even to cross the room to pick up the phone." I can 'see' the space and distance of falling behind another, such as when walking and not keeping up. But how can one fall behind in one's own activities? It is as if her body, in the world, is out of synchrony with part of her self. A high demand of energy is required to keep upright, to not fall behind. For those with severe chronic pulmonary illness, energy is limited as injury and inflammation impair gas exchange.

It is not only *feeling* down that is described within spatial orientation. At times the physical stance of the body must literally go from 'up' to 'down' because of breathing or fatigue. The person needs to sit or lie down. While visiting in the mountains, one person with emphysema noted that "in the middle of the main street in Banff I had to go down on one knee, and get my breath." Another describes a time that his breathing forced him to his knees:

> We went out fishing and even putting the boat in the lake I was having trouble. I was working hard to try and pull the boat up. And when I went to pull the boat out of the lake, I was to the point that I was just on my knees. I couldn't breathe. I just couldn't get enough air back into me. That was the first time I'd ever really come on to where it was actually putting me down.

The need to stop may be sudden, in a moment. Being able to stop and sit down is easier at home, as Gregory describes: "At home, If I'm doing something in the house and I get tired I just sit down for a minute. Two minutes. Get up and get at it again, as soon as I catch my breath." When away from home, there may be a bit of unease when feeling the need to catch one's breath. It is not only stopping that the body demands, but a change in space. Sitting down. Leaning over. No longer able to remain upright. When Peter starts to feel short of breath in public, he starts to get "antsy" and "I'm looking for a place to sit down." For Karl, his walker has relieved the panicky feeling when he needs to sit down. He is free to catch his breath:

> It's two blocks to the corner store. I used to be able to walk from here. But when I did that I'd have to stop about 5 times on the way over there. To catch my breath. And sometimes it gets to be a panicky thing. So that's why I got the walker. I can always, with the walker, I can always sit down. When I have the walker with me I'm not as panicky.

Slowing down has spatial-temporal connotations. Adam walks behind his wife: "She'll walk faster than when she's with me because basically, I can't keep up with her." Ed describes his life as a crawl compared to that before emphysema. His mobility through the world is at a lower level and slower speed. He perceives himself as crawling through life, not walking upright through the world. Timothy recalls coming home from the grocery store last winter: "It wasn't that cold, but it was cold enough that it was hard to breathe. And I went to Safeway, and this last block coming home, it was just like crawling on my hands and knees."

Indicators of disease may be measured and reported as *down* when they are less than or *lower* than reference or normal values. *Falling* oxygen saturations indicate worsened gas exchange or over exertion. Timothy's interpretation of his low oxygen determines his activities:

> My saturation is down as opposed to when I had a clear set of lungs. At the present moment I'm not doing any exercise because I went down so low that I think to do any at this time, right now, would be detrimental. So I'm going to wait until I've got my saturations at a level. When [the nurse] checked it the other day it went from 89-91. So it's gotta come up a little bit.

For Bill, when he has his oxygen on and is resting, his oxygen saturations are near normal. With severe pulmonary disease, any exertion causes them to drop: "As long as I don't do any physical activity I'm fine. My oxygen level stays very well. Around 95, 96. But the minute I start doing anything, they go to 90, or start going lower."

A decrease of drop in vital capacity may occur with worsened emphysema. The percentage reported as if it is a measurement and indicator of the state of being. At the onset of Jake's diagnosis with emphysema, "I was 55% capacity compared to a regular human being. Now I'm down to less than 30, 20's." When his vital capacity showed minimal improvement and the 'numbers' were *up*, he didn't *feel* up: "I feel like I don't have as much capacity to keep on going." Is there then a spatial and temporal sense of falling behind? Not able to keep going? Of progressively losing ground?

Not all indicators of pulmonary disease go down. Heart rate and respiratory rate may go up. Each may need to be “slowed down,” “calmed down,” “gotten down.” In this manner, down reflects a return to normal. Anxiety, chest tenseness, shortness of breath may come down when an acute asthmatic attack is resolving, as Valerie describes: “For me the shortness of breath is the last thing that drops. My respiratory rate would still be up, and the tightness may be eased, but I still have shortness of breath.”

The metaphors and expressions discussed in this chapter echo the themes interpreted within the previous chapters. The severity and distress of breathing in chronic pulmonary illness are heard in metaphors of drowning, suffocating, attacks, and battles. Substances of concrete and molasses, and energy metaphors impart the experiences of the body that works to breathe, slows down, does less, and, at times, stops.

Chapter Eight
Discussion

Science not only enriches knowledge, it "brings us to a renewed appreciation of the human condition" (Pagels, 1982, p. 348). Human science research contributes to a systematic and explicit body of knowledge through descriptions that facilitates understanding and appreciation of human experiences. Furthermore, insights from human science research are relevant for health care clinicians and professional practice.

In this chapter, I return to the research question 'What are experiences of adults with chronic pulmonary illness' and discuss interpretations and insights of the analysis. First, *dyspnea* is revisited. The diversity of experiential sensations is contrasted with scientific definitions of shortness of breath, uncomfortable breathing, and difficulty breathing. Second, sounds and sensations of pulmonary illness are discussed with regard to signs and symptoms, objectivity and subjectivity, assessment of breathing, outward indicators, and decisions for emergent treatment. Third, experiences of 'shortness of breath' are differentiated as normal, chronic, and acute. Fourth, the body and self are discussed in perceptions, interpretations, and meanings of scientific terms. Fifth, interpretation and appraisal of sense-experiences are discussed within the context of smoking. Lastly, strategies for living with pulmonary disease are considered, with comparison to coping and normalization literature.

Revisiting 'Dyspnea': Definitions and Meanings

In health care literature, "there is no consensus about a definition of dyspnea" and "no way to readily quantify dyspnea" (Govindaraj, 2002, p. 662). Not limited to the lungs or breathing, diverse sensations are described as shortness of breath. Shortness of breath in pulmonary illness is differentiated from that of health by the distress, frustration, and desperation that may be experienced. In addition, breathing may be perceived as difficult, requiring increased effort and work.

Diverse Sensations

Participants in this study provided numerous descriptions of both sensations and perceptions of breathing, affirming that dyspnea is a "composite of several sensations" (Simon, et al., 1990, p. 1012). Perceptions of shortness of breath included chest tightness, wheezing, and cough as reported by Janson-Bjerklie (1986). Additional descriptors were provided, including pressure, burning, breathing faster, working to get air, struggling to get air, or not getting in air. Furthermore, descriptions of shortness of breath extend beyond breathing sensations. Disruptions of body, self, and state-of-being-in-the-world were revealed in descriptions such as: "It's what I can't do," "It's the trouble coming up the stairs," and "It's making love and not having enough breath to finish." These phrases reveal perceptions of the body experienced within a time and space, and in relation to self and others (Merleau-Ponty, 1962; Sartre, 1956; van Manen, 1990). Thus, breathing symptoms, shortness of breath, and dyspnea extend beyond the lungs and body to the self in the world.

Kinsman and colleagues (1983) described dyspnea as a "rich tapestry of symptoms and experiences" and reported 89 individual symptoms associated with bronchitis and emphysema. When 33 % of their 68 participants with pulmonary illness described 'dyspnea' as pain and 45 % as fatigue, Janson-Bjerklie et al concluded that it was difficult to delineate the "exact sensations felt" during dyspnea (1986, p. 157) and the "inability" of persons to describe dyspnea was due to "the constancy of the symptom, lack of awareness of individual sensory response or denial of the symptom's intrusive presence" (p. 159). However, I would argue that the inability to describe these sensations is neither due to constancy or denial. The difficulty of describing is due in part to differences in meanings and experiences of shortness of breath in illness than health, and in part to the inadequacy or absence of language to relay sense-experiences. For example, words were insufficient for Mary to describe the sensations of wheezing that she does not *hear* but *feels* and *knows* in her body:

> It's that, that (*pause*) tightness in my chest. It's just a bit of a funny feeling. (*Pause*). Tightness might not be the absolutely the right word to describe the sensation but I can't think of another one! There's just a sensation in my chest that I know is associated with the onset of wheezing.

Several times during these interviews, specific words were insufficient for participants to directly express or describe their experiences of breathing and the body. Instead, sounds of breathing, such as gasping, wheezing, panting, and forced breathing, were substituted. Some persons used hand gestures that replaced or expanded verbal meanings, such as when a clenched fist was placed over the sternum to indicate a sensation of chest tightness. Descriptive metaphors, such as drowning, suffocating, battling, and fighting represented perceptions and sensations of feeling short of breath. Their use of sounds, gestures, and metaphors to describe sense-experiences does not indicate lack of awareness or denial, but instead demonstrates the insufficiency of words to express these sensations.

Descriptions in this present study indicate that in chronic pulmonary illness, a diverse range of experiences and sensations are perceived and labeled as shortness of breath. Descriptors include work/effort, suffocating/drowning, getting enough air, tightness/pressure/constriction, fatigue/tiredness, and breathing faster. These phrases are consistent with descriptions reported in the literature (e.g. Mahler et al., 1996; Simon et al., 1990). Instead of a single or precise definition, overt recognition of the diversity of experiences and meanings of both dyspnea and shortness of breath is essential.

Distress, Frustration, Desperation

With its component of distress, dyspnea is *more than* an unpleasant symptom (Gift, 1989a; Lenz, et al., 1997; Steele & Shaver, 1992), an "unpleasant or uncomfortable awareness of breathing or need to breathe" (Schwartzstein, et al., 1990, p. 185), or an unpleasant awareness of breathing (Elliott, et al., 1991; Miller, 1978). The terms dyspnea, short of breath, or breathlessness do not relay the distress, frustration, or desperation of being unable to breathe.

Defining dyspnea as "difficult, distressed breathing" (Zeppetella, 1998, p. 322) expands our awareness and understanding from that of uncomfortable or unpleasant. Yet, this definition is still insufficient to convey experiences of the body and the body-in-the-world. As it is not possible to encapsulate holistic experiences of the person's body and being-in-the-world into one phrase, term or definition, descriptions could be incorporated when novices are learning professional terms and phrases, such as provided by Zeppetella (1998, p. 322):

> I just can't get enough air into my lungs. Every breath I take is such an effort. It's as if I'm wearing a lead jacket. I'm so frightened that the next breath will be my last. My family can't bear to see me like this, they don't know what to say or do. I can't hold my new granddaughter I'm so weak.

Providing examples, narratives, and descriptions of lived-experience increase our understanding of what it might be like to be short of breath, such as that experienced as gasping for breath in the everyday exertion of having a shower. As Jake expressed, although "anyone can *say* emphysema," understanding of his illness was gained not by defining emphysema but by giving family and friends examples and descriptions of his illness.

In our day-to-day experiences and language, breathing is more than mechanics, muscle movement, and gas exchange. Breathing is connected with the world and our lived experiences. Inspiration and expiration are more than movements of air. The etiological roots of the verb to breathe are from Latin, *spirare* is from spire, with connotation of the immaterial part of man, the spirit or soul. The Greek word for breath, *pneuma*, is also indicative of spirit. Each of these reveals that to breathe and to have breath have aspects of life or spirit within the body. Indeed, inspiration is not only to breathe *in*. To *inspire* is to fill with thought, imagination, or action, whereas to *expire* is to breathe one's last breath and signifies endings. Amidst a technical and medically advanced health care system, it is the last breath that designates the cessation of life. Breathing and breathing *in* are not only physical movements of the body. Breathing *in* is associated with life and is a vital necessity, thus the sensation of not being able to get one's breath is *more than* feeling short of breath. It is feeling unable to get the next breath, as if one is suffocating or drowning.

The pre-Socratic philosopher Anaximenes recognized the significance of breathing as vital to life: "air, breath or pneuma was the sovereign element of the cosmos, the primal substance from which all others took their origin. By drawing breath, the living body was renewing its vitality from moment to moment, replenishing its existence and its spontaneity" (Miller, 1978, p. 144). Underlying meanings of life and living are essentially ignored in contemporary definitions and descriptions of dyspnea, and there is little recognition that breathing encompasses more than physical sensations. The location and control of breathing is conceptualized as discrete areas of the brain and brainstem (West, 2000), and breathing is most often compartmentalized to physical and mechanical aspects. Little recognition is given to emotional aspects of breathing, although it is acknowledged that "affective states such as rage and fear" can alter the rate and depth of breathing (West, 2000, p. 105). With chronic pulmonary disease, affective and physical states, such as laughing, arguing, crying, or talking, may initiate coughing, shortness of breath, or wheezing. However, emotional events and physical activities are not "different causes" of dyspnea as suggested by Bailey (2004). Instead, both emotions and activities are experiences that demand an increase in oxygen. Efforts to meet that demand may be insufficient, with subsequent air trapping, increased intrathoracic pressure, and perceptions of gasping for air.

In addition to extending our understanding of shortness of breath in chronic illness, these definitions and descriptions have possible implications for persons with acute pulmonary illness. Desperation and distress may be experienced in critical illness; mechanically ventilated patients reported feeling that they were choking and expressed terror as they perceived they were not getting enough air (Rotondi, et al., 2002). Misak described "the horrific drowning sensation when one can't breathe" (2004, p. 357). In both chronic and acute illness, intense distress, anxiety, and possibly alarm are perceived when they can't breathe, when life is threatened by the absence of breath.

Difficult Breathing

Definitions of dyspnea also include difficult breathing. Perception of mismatch between the inspiratory effort and subsequent ventilation has been postulated as a basis for feeling short of breath or having difficulty with breathing (Mahler, 2003; O'Donnell, 2000; Wasserman & Casaburi, 1988). When breathing occurs at the upper end of maximum inspiratory volume, total lung volumes are increased, compliance is decreased, and elastic work is increased. Even if tidal volumes are maintained, breathing may be perceived as being short or shallow, or insufficient to get enough air in.

Physiological relationships between work, perceived work, and impaired airflow have been reported in the literature. The decreased ratio between Vt and FVC demonstrated by Simon and colleagues (1990) supports the supposition of mismatch between volume and effort. Perceived work was correlated with less than 50 percent of the expected FEV_1 (Simon, et al., 1990), and decreases in Vt, VC, and FEV_1 correlated with increased diaphragm and inspiratory muscle work (Ferrari, et al., 1997).

Participant descriptions of effort, work, labour, struggle, and difficulty with breathing are consistent with reports from the literature of breathing work and effort with pulmonary disease (Brown, et al., 1986; Simon, et al., 1990). Effort and force are required to breathe in an asthma attack or upon any exertion with moderate to severe pulmonary disease. Effort and inhaled volume are interrelated sensations and experiences. *Work of breathing* was a major theme in this analysis. When extensive effort is required to breathe, the experience may be perceived and described as not getting enough air, as in *Gasping for Breath.* Several participants differentiated between the effort of breathing and sensations of airflow and volume, supporting that perception of 'dyspnea' may include multi-dimensional perceptions. Feeling *Out of Breath* but working hard to try and *Catch One's Breath.* Tiredness was associated with energy metaphors, particularly insufficient oxygen for energy. Feeling short of breath was defined by one person as "my whole body feeling tired and not getting enough oxygen." Another stated: "I feel very, very tired and that I've run out of oxygen."

Defining dyspnea as "difficult breathing" (Gift, 1991, p. 196) contributes to awareness of the effort required, but it prohibits delineation of types of breathing, as well as the inclusion of a holistic range of sensations and experiences associated with not getting air (shortness of breath, gasping, shallow, can't breathe), breathing fast to attain air (panting), and feeling tired. Furthermore, difficult breathing may not only signify effort, its use was extended to diverse sensations, such as expressed by Karl who has severe emphysema: "My problem with the difficulty in breathing is the soreness in the chest and the phlegm or whatever it is."

Perception of difficulty with breathing is an area for further research. Decreased perception of difficulty has been associated with more hospitalizations and deaths in asthmatics (Magadle, et al., 2002). Other researchers have reported correlations between perceptions of difficulty in breathing with the severity of bronchoconstriction, FEV1/FVC ratio, and levels of Interleukin-5 and eosinophils in sputum (Jang & Choi, 2002; Janson-Bjerklier, Ferketich, Benner, & Becker, 1991). Further research is required to increase our understanding of perceptions and reports of breathing sensations, including exploring a broader diversity of descriptors in acute episodes of chronic illness and acute pulmonary illnesses, such as pneumonia.

To engage in dialogue, we must name an object or phenomena. Yet, "to name a thing is to tear oneself away from its individual and unique characteristics to see it as representative of a theme or a category" (Merleau-Ponty, 1962, p. 176). In the naming of *dyspnea* or *short of breath,* we simplify and reduce the multi-dimensional aspects of these sensations, not differentiating between shortness of breath in health and illness, nor recognizing that acute and severe sensations differ from everyday experiences.

In summary, descriptors of experiences by participants in this present study refute simplistic definitions of dyspnea as either 'shortness of breath' or 'difficult breathing.' Dyspnea does not "easily lend itself to precise definition" (Govindaraj, 1987, p. 63). Instead, it is a multi-faceted and complex phenomenon, in which shortness of breath and difficulty of breathing may be perceived, and diverse physical and emotional sensations may be experienced.

Sounds and Sensations; Signs and Symptoms

Signs and signals are used to communicate thoughts, emotions, and intentions. Signs provide meaning to others within a given context (Husserl, 1900/2001). Through traditions and conventional understandings, hand and body signals convey meanings to others in diverse social and recreational situations. We have road signs and car signals that indicate directions and planned actions to others. To grasp meanings of either signals or signs, we must attend to, or be attuned to, the means of conveying the signals, and have a shared understanding of the meanings being conveyed. We might even say we 'heard' the message when we notice and interpret the gesture or signal.

In pulmonary illness, sensations and sounds of the body are indicators to self and others. These sensations and sounds are interpreted and given meaning, which differs within various contexts and between individuals. Breathing sounds and body actions are interpreted by others, and may subsequently be regarded as signs of disease or distress.

Thus, sensations and sounds may be perceived and interpreted as both signs and symptoms of pulmonary disease and illness.

Sounds and Sensations

The body is described as calling, speaking, and announcing (Merleau-Ponty, 1962; Buytendijk, 1974; Bleeker & Mulderij, 1992. It expresses itself in vibrations, tones, and rhythms that may be heard as sounds or felt as sensations. We speak of a 'sound' body as healthy, yet sounds *of* the body may be signals of illness. Sounds of chronic pulmonary illness – wheezing, coughing, and noisy breathing – are sounds of injury or inflammation, not a sound body.

In both health and illness, there are notions of 'listening' or becoming 'attuned' to the body, that is, paying close attention to the body and heeding its message. Listening to the body is popularized in the vernacular with regard to pacing one's activities or managing stress. For example, listening to the body is the purposeful awareness when training to run long distances or starting a new exercise regime. Shawn has heart failure; he consciously tries to 'listen' to his body and pace himself accordingly, slowing down or even stopping the activity:

> I try and listen, as they say, listen to my body. Like the feeling of fatigue. Especially digging in the garden. I can go so, so far. I knew I was starting to breathe a bit heavier. And there were a couple of occasions where I got a bit light headed and I used to perspire quite profusely, so I would stop.

Persons with lung disease are encouraged to "listen to" their body, which will inform them "when you are pushing too hard" or indicate that "stressors are not being managed effectively" (Canadian Lung Association, 2004). None of the participants with pulmonary disease described listening to their body with this intentional awareness. In contrast, some *listened* to their breathing to determine the presence of wheezing; others noticed they were wheezing when they *heard* themselves.

There is a difference between listening to the body and hearing the audible lung sounds of breathing, coughing, and wheezing described in the themes *I Can Feel It* and *Much More Aware*. The onset of wheezing or noisy breathing may be sudden and abrupt. Once noticed, these lung sounds may be given more attention, such as determining if the wheezing is diminishing or increasing, or evaluated as indicators of allergens, bronchoconstriction, or infection.

Sounds of breathing are not necessarily noticed or interpreted with concern. The breathing of many participants was audible. Noisy and raspy breathing, coughing, and wheezing were heard, and at times use of accessory muscles was visible. This breathing was not remarked upon, and several participants commented that they were "nearly normal" or "fine" when sitting or resting. These sense-experiences seem to pass silently under conscious awareness, perhaps only noticed when they become louder or more intense, or when they occur within certain contexts such as in the theatre.

Reading the body is differentiated from listening to the body, and has been described to occur in illness, although not specifically pulmonary illness. Persons with chronic illness were described as "reading the body" for signals of crisis (Strauss et al., 1984, p. 18). In women having hysterectomies, Chasse (1991) describes learning to read the body as activities which are implemented to make sense of, cope, and come to terms with their health problem. These perspectives of *reading the body* have connotations of evaluating the significance of acute events and health concerns, which differ from *listening to the body* which is associated with pacing of one's self. Both differ from listening to or hearing the audible lung sounds of pulmonary disease.

Sense-experiences include sensations that are *felt* and sounds that are *heard.* Sounds and sensations of pulmonary disease may not be noticed or be purposefully ignored; the body is not listened to with attention and awareness. When sounds and sensations are abrupt and distressing, the body demands attention. The focus is on alleviating the sensation, such as halting activities, taking bronchodilators, increasing supplemental oxygen, and pursed-lip breathing.

Subjective-Objective

From the perspective of clinicians, signs and symptoms are differentiated according to subjective perceptions and objective indicators. Symptoms are defined as *subjective* sensations experienced by the person, whereas signs are *objective* findings. However, the dichotomy between subjective-symptom and objective-sign does not hold for numerous sensations, perceptions, and experiences of chronic pulmonary illness.

Sounds and sensations, such as loud or laboured breathing, wheezing, or coughing, may be both 'subjective' and 'objective' as they are not only felt, but also seen or heard. Furthermore, some sensations and sounds are interpreted by either the self or others as signs of illness. Indeed, *sensations* of shortness of breath, wheezing, or chest tightness are described as *signs* of asthma (Janson-Bjerklie, et al., 1991). Wheezes, cough, or noisy, laboured breathing may be both a symptom and a sign when perceived and interpreted by self, or act only as a sign when noticed and interpreted by an Other. The perception and experience of the sensation is subjective, whereas recognition and interpretation by self or an Other is both subjective and objective.

To be regarded as a symptom, the sensation requires interpretation as a signal of concern. As described in the themes *Never thought anything about it* and *Nothing the matter*, when the sensation is given other meanings, it is not deemed as *significant* with regard to health and illness and is not then interpreted as a symptom. We may then define symptoms to be sense-experiences of the body that are interpreted as signs of concern or experienced as illness.

This interplay between subjective and objective is evident not only in chronic pulmonary illness. It is also experienced in acute pulmonary illness as demonstrated in the following description by Kate, a participant who had had severe pneumonia and spent 8 days in Intensive Care. Her experience suggests that in acute illness there are also diverse perceptions of the body and interpretations of sensations. Kate came to Emergency with pain and tiredness. She does not perceive that she is short of breath, yet she is in severe respiratory distress and requires mechanical ventilation:

> I was just so tired, I felt just awful. And I had this chest pain and shoulder pain. When they were doing the X-ray, I remember saying "where do I hold on?" before I passed out. I blacked out all of a sudden, and was told that I had pneumonia. I've never had pneumonia before so this was like a new experience. And I didn't recognize having any problems breathing, although I came to understand after the fact that the nurse at the clinic picked up that my breathing was a little shallow and that I was very, very pale. I remember being in the ambulance, and the next thing I remember is being in intensive care, numerous people around me. And the doctor said to me, 'We may have to put in a ventilator.' And I said, 'No, no, no I'll be fine. I'll be alright.' And they asked me, 'Are you feeling short of breath?' And I said, 'No.' And I didn't feel short of breath. If they had asked, 'Are you tired?' I would have said, 'Yes I'm exhausted.' And they really thought I needed a ventilator but I didn't see why.

> Anyway, as the time went by, I came to recognize that I was breathing very, very quickly and I couldn't slow down. I just became cognitive about it. I heard it first. I was like (*mimics breathing fast*). And I tried consciously to slow down, and I couldn't. I wasn't able to. And I was breathing as though I had run several blocks and was very out of breath. I'm breathing too fast, I know I'm breathing too fast, I cannot slow it down. Because I couldn't slow it down, I recognized that this was a little bit scary, I can't slow down. And then I started to get anxious because I couldn't slow down my breathing at all. Obviously I was short of breath, I didn't recognize it, I didn't pick it up.

As she reflects back on this experience, Kate re-interprets the experience as "obviously" being short of breath, although at the time she did not feel short of breath nor interpret her fast rate as being short of breath. Interpretations were limited as she had never had an acute or chronic problem with her breathing; pneumonia was "a new experience." Initially, she did not perceive her rapid breathing rate to be significant or of concern. The sensation was similar to health; it was as if she had run several blocks and was very out of breath. Her concern was raised when she became aware that, unlike the context of running in health, she was lying in a hospital bed and her breathing wasn't slowing down nor could she slow it down.

With unpleasant or distressing sensations, such as thirst, nausea, and pain, the occurrence and perception of the sensation are considered to be equivocal. Thus, it is one and the same to have pain and know you have pain (Miller, 1978). Similar to sensations of nausea or pain, feeling short of breath or perceiving the effort of breathing occurs simultaneously within self and the body. However, breathing sensations differ from sensations such as nausea or pain, as they are not necessarily interpreted as 'symptoms' of illness, injury, or disease. Instead, these and other sense-experiences of chronic pulmonary illness have diverse meanings and individual interpretations. Furthermore, because alterations in breathing are both subjective and objective, it is not necessarily equivocal to having the experience and feeling the sensation. Some persons may require extensive work to breathe and, although they do not *perceive* the effort of breathing, it is evident to an external observer. Bronchoconstriction may be present without the person experiencing sensations of chest tightness or shortness of breath. Wheezes may not be noticed, felt, or heard by the self, yet heard with a stethoscope by a clinician. Thus, subjective aspects of sense-experiences may not be perceived in the presence of objective findings.

Miller describes disease as "making itself known" through findings, feelings, and failings; findings are "public features of illness" conspicuous and noticeable to others whereas feelings are private and "known only by the person who has them" (1978, p. 26). Comparable to the distinction between signs and symptoms, Miller differentiates findings and feelings by objective indicators and subjective experiences: "There are public *signs* of these states – groans, frowns, writhings, and so forth – but the actual pain and nausea and hunger and thirst are locked up in the unfortunate sufferer. The person with jaundice has only to exhibit it; someone with a pain has to announce it" (1978, p. 26). These distinctions between findings and feelings are as arbitrary as signs and symptoms. Sensations of the body, including pain and shortness of breath, are outwardly expressed by the body, not only verbally announced, and interpreted as an indicator of disease, disruption, or injury.

There is an overall consensus in health care literature that dyspnea is a subjective sensation experienced and interpreted by the person (DeVito, 1990; Gift, 1990; Mahler, 2003). That is, dyspnea is considered to be a "symptom and not a sign" (Zeppetella, 1998, p. 322). This distinction between symptom and sign does not hold in the context of the lived experience. Sense-experiences of the body, including shortness of breath, are signs to self and others, and may be interpreted as signals of concern. If dyspnea is deemed as the *sensation* of difficult breathing, then it may only be determined by the person experiencing that sensation. In contrast, the work and effort of difficult breathing may be perceived by an observer, and signals that the persons may be experiencing sensations of distress.

This differentiation between sensations and symptoms demonstrate the inaccuracy of labeling persons as poor perceivers of dyspnea (e.g. Bijl-Hofland, et al., 1999; in't Veen, et al., 1998; Kikuchi, et al., 1995; Magadle, Berar-Yanay, & Weiner, 2002; Turner, et al., 1998). If dyspnea is defined as a *symptom* or *sensation* experienced by the person, it is preposterous for a person to have "inadequate symptom perception," "overperception" or "underperception" of symptoms (Rietveld, 1998, p. 138). This type of language lends to trivializing or misunderstanding the diversity of experiences, and loss of the subtlety, complexity, and abruptness of breathing symptoms. Likewise, when there is decreased perception of difficulty in breathing against resistance, it is inaccurate to report this as "blunted perception of dyspnea" (Magadle, et al., 2002, p. 329). Rather than blaming or judging perceptions of others, it is important to recognize that there is a diversity of sensations and sensitivity to airway obstruction, and a variety of meanings and interpretations given to sense-experiences.

In summary, neither findings and feelings, nor signs and symptoms, are necessarily distinct in pulmonary disease. Wheezes are sensations which may be felt or heard by self, and evaluated as a sign of concern. Wheezes are not only private sensations or subjective symptoms. Audible wheezes may be interpreted by self or others as a sign of inflammation or bronchoconstriction. Moreover, findings and signs are not just the 'objective' criteria used by health care providers to diagnosis or assess. Family and friends may notice the person's laboured breathing and interpret it as a signal of concern: Are they 'well' or not? Are they short of breath? Do they need to rest? Should they use their ventolin? Thus, there are both subjective and objective aspects to the sensations and sounds of pulmonary illness.

Assessment of Breathing

In nursing practice, respiratory assessment includes physical assessment of breath sounds, respiratory rate and depth, and accessory muscle use. Oxygenation is indirectly assessed through heart rate, level of consciousness, dizziness, fatigue, and oxygen saturation. In more acutely ill patients, further indicators of oxygenation may be evaluated, including comparison of arterial oxygen pressure with the amount and route of oxygen therapy. In critically ill patients, further calculations and indicators, such as oxygen consumption (VO2), venous oxygen saturation (SvO2), lactate levels, and acid-base balance, may be used to evaluate the balance between oxygen delivery (DO2) and demand. Despite use of advanced objective data, it remains difficult to ascertain if the cellular oxygen is sufficient for individual patients. Perceived sufficiency of oxygen is not formally evaluated in either acute or chronic illness. Several participants described an awareness of oxygen and energy, including the sensation of feeling "light-headed." It is unknown if these sense-perceptions are correlated with oxygenation, adoption of medical terminology, or expressive metaphors. Understanding moment-to-moment experiences of needing oxygen or feeling a lack of air eludes us.

As with pain, sensations of breathing cannot be determined by the clinician, and are only obtained by asking the patient. Although it is *appropriate* and *essential* to ask the person, further research is needed to provide insight as to *what* we ought to ask and *how* we might attain descriptions. Asking if the person is feeling 'short of breath' or to provide a numerical indicator of their shortness of breath is inadequate to capture the range of experiences, descriptors, and perceptions. This limitation is similar in the setting of cardiac ischemia when asking if the person is having chest pain. Exploring other descriptors, such as numbness, tingling, pressure, or discomfort, reveal the 'atypical' sensations of ischemia in persons who initially indicate they have no pain. In like manner, we need to increase our competency of assessing 'dyspnea' by using language that is meaningful to the patient. Potential descriptors for assessment were revealed in this study: tightness, pressure, coughing, drowning, suffocating, difficult, nausea, almost a panic, frustration, desperation, and very, very tired. In addition to descriptors of sensations, exploring descriptions of activities may reveal underlying disease that is not yet interpreted as illness, as described in the themes *Slowing Down* and *Doing Less.*

In episodes of acute and severe respiratory distress, it is challenging to assess sensations and symptoms. When the person has limited air to speak, instead of open-ended questions to obtain descriptions, it is recommended that questions should have a 'yes' or 'no' answer. Valerie portrayed her perspective:

> The shortness of breath is good. At least I think so. Another good word is relief. I'd like a nurse to say 'Are you feeling any relief yet? Any benefit of the medication?' When I'm that bad with the asthma, it's less energy and less air for me to talk.

To elicit what and how clinicians might ask about breathing during an acute event, I explored some phrases with one participant who had had numerous emergency visits and acute hospitalizations. He confirmed that it was beneficial to be asked questions to which he could give a 'yes' or 'no' answer, as a "bigger answer" requires a bigger breath and demands more air than he might have:

> C: How about if I asked you if you 'had trouble breathing?'
> G: Yes, I could answer that. Yes. That sounds good.
> C: And how about, 'Do you feel like you're getting enough air?'
> G: Yes, I could answer those, no problem. Those are very good. Nobody's ever asked me that before. So that's good. That way it sounds good. It means I can answer that. They say, 'How are you doing?' 'Well, I'm alright.' That's about all they get out of me. 'Not bad' or 'I'm okay.'
> C: How about if I asked you, 'How is your breathing?'
> G: 'How's your breathing?' Nah. That's going back to where all these other people are asking me, 'How are you doing?' 'How's your breathing?' It covers too much. I need a bigger answer for that one. Not just a 'yes' or 'no.' But the way you asked about trouble or enough air does a lot better. I mean, that makes me feel better. More at ease. I don't have to explain a lot of stuff. Just sort of a 'yes' and a 'no' and maybe a little bit added on in that.

Air and energy needs to be saved for the work of breathing, not used in the effort of speaking. Questions that participants in this study considered to be helpful were:

- Are you short of breath?
- Are you having difficulty breathing?
- Are you getting enough air?
- Are you having trouble breathing?
- Do you feel you're breathing too fast?

In addition to eliciting a broad range of descriptors and intensity of sensations when appropriate, a component of distress should be evaluated through self-report or close-observation and interpretation. Fear, anxiety, panic, frustration, anger, and worry may be experienced with the sensation of shortness of breath, extensive coughing, and wheezing (DeVito, 1990; Janson-Bjerklie, et al., 1986; Janson-Bjerklie, et al., 1992). Participants in this study described the cyclic effect of feeling anxious and gasping for air, which are described in the themes *Gulping Air, a Cat Chasing his Tail,* and *Almost a Panic.* Shortness of breath and anxiety are presumed to interrelate as air trapping, increased respiratory rate, and asynchrony of rhythm occur, increasing the cycle of demand for air and insufficient supply.

Both natural and human science perspectives are required to recognize and interpret signs of distress or concern experienced in pulmonary illness. For persons with acute exacerbations of chronic pulmonary disease or asthmatic attacks, it is essential not to minimize or misinterpret the intensity and distress by labelling it merely as 'short of breath.' It is more than shortness of breath, it feels like they *Can't Breathe,* which we would translate as apnea, not dyspnea. Appraisal of both breathing and emotional sensations may facilitate interruption of the cycle of distress, effort, and oxygen requirements.

Outward Indicators

Recognizing the importance of the person's experience and sensations does not exclude an outsider's interpretation of breathing distress. The "practiced eye" of clinicians recognizes and interprets concerns (Miller, 1978, p. 177). Janson-Bjerklie et al. (1986) reported that persons with pulmonary illness believed that others would notice that they were short of breath. Panting, wheezing, coughing, appearing immobilized, being very quiet, and being withdrawn were considered outward indicators that would be easily observed by others.

In this study, several participants remarked that others noticed their breathing, such as shortness of breath on the phone, coughing extensively, wheezing while coming down the hall, or leaning over a chair in the mall. "When I'm walking, I think people notice my breathing. When I stand and talk for too long they definitely do." Sounds of breathing were not only noticed by others, they *demanded attention* and acted as signals of concern.

Others may observe and recognize the distress of not being able to breathe. For example, Karl described that the nurses in Emergency "usually know. They look at me and know that I'm in distress. I guess that's another good word, 'breathing distress.' That's really when I can't get any air in at all." A compathetic response may occur with breathing distress, that is the clinician or family member has a physical response to the patient's distress (Morse & Mitcham, 1997). Family members have expressed difficulty watching an acute episode of COPD, feeling helpless, fear, and panic (Bailey, 2004); nurses have described that they felt out of breath "just watching patients having such difficult breathing" (Tarzian, 2000, p. 139).

When shortness of breath is so severe that the person cannot speak, they must then "rely on others to recognize" their "air hunger" (Tarzian, 2000). In acute events, patients may be diagnosed with 'respiratory distress' or 'respiratory failure,' both terms indicate the necessity and insufficiency of breathing and air exchange. When the person has insufficient air to speak and cannot communicate their concerns, the clinician needs to *interpret* their breathing effort or *infer* insufficiency of air. This is attained by 'objective' data such as accessory muscle use or respiratory rate, as well as signals of the body that are perceived and interpreted by others. In these instances, decisions for care are determined through the perceptions of others: family, friends, and health care providers. As one Emergency nurse described, the patient was "so anxious for air [he had] just that kind of wide-panicked look that people get when they can't breathe" (Tarzian, 2000, p. 139). Critical care nurses are reported to recognize patients' distress of difficult breathing: "When asked if she would tell [the nurses] when breathing was too difficult, a woman replied, 'Oh, I didn't have to tell them. They knew. They just took one look at me and knew'" (Logan & Jenny, 1997, p. 146).

Despite the necessity of inferred reports by others, there is scant and contradictory data in the literature with regard to evaluating breathing distress or discomfort. Shortness of breath in ventilated patients was considered to be under-recognized by Powers and Bennet (1999) who found that despite normal objective data and exclusion of unstable patients or those perceived in pain, half of the 28 patients reported moderate to severe shortness of breath; none reported no or slight shortness of breath. Likewise, Knebel and colleagues report that both shortness of breath and anxiety were higher than anticipated in ventilated patients (1994). However, there is uncertainty about the reliability of reports of others to determine breathing symptoms. After comparing elderly critically ill patient self-reports of pain and distress with nurse assessments, it was concluded that nurses tended to "overestimate patients' breathing problems" (Hall-Lord, Larsson, & Steen, 1998, p. 131). In terminally ill patients, some of whom had COPD, shortness of breath and anxiety had a greater variance between patient self-report and perceptions of family or close friends than other symptoms; it was postulated that nausea, pain, and tiredness were more "directly observable" (Nekolaichuk, Maguire, Suarez-Almazor, Rogers, & Bruera, 1999, p. 3627). It is evident that little is known with regard to how others recognize or interpret symptoms of difficult breathing or shortness of breath. This is an important area for further research as in acute events; persons with chronic pulmonary disease may depend upon rapid and accurate assessment of clinicians.

Emergent Treatment

Descriptions from participants indicate that there are numerous and complex considerations within decisions to use medications or seek emergency care. For some, ventolin was described as a "rescue" medication, its use to be delayed until wheezing and tightness were very severe. For example, one participant described "saving the puffer until I'm in real trouble." However, waiting may worsen the illness episode as relayed by Timothy: "This rescue pack is what I should have started, if had started this rescue pack on the 14th, I wouldn't have had to go to the hospital. But I didn't. I waited. And then I left it too late."

There are numerous aspects in deciding to seek treatment for severe or acute episodes of chronic pulmonary illness. As reported by Janson-Bjerklie and colleagues, medical care may be a "last resort" and delayed despite perceptions of danger and threat (1992, p. 271). There may be an uncertainty about the need for emergent treatment as expressed by this participant with severe emphysema: "I ended up two nights ago in Emerg despite the fact that I knew I was breathing, I knew I was moving air, I thought, 'Well yeah, but I can die moving air well, and I feel like I can't breathe.'" Several participants in this study delayed going to the Emergency Department, waiting to see if their sensations would subside, often they did not want "to bother" their family or staff in the Emergency. Others were aware of the need for urgent assistance and requested their family member to call an ambulance.

In an acute episode, the decision to seek treatment must be made while experiencing distress of not being able to breathe, severity of tightness and wheezing, or persistent coughing. Despite life-threatening circumstances and severity of sensations, the person with chronic pulmonary illness may not perceive the threat or seriousness of their breathing difficulty. Family members may then make the decision to call an ambulance or take the person to hospital. A critically ill patient's wife relayed to me why she had decided to call the ambulance: "He was gasping, fighting for air, really labouring, struggling to breathe – not just huffing and puffing." On arrival at the Emergency Department, his carbon dioxide was 112 mmHg (normal 35-45 mmHg), and the Registered Nurse charted "agonal respirations at 40" and "patient ++SOB [short of breath], dyspnea." His blood pressure dropped, he lost consciousness, and was immediately intubated and mechanically ventilated. The patient, who has COPD and is on 3L/min home oxygen, indicated that he did not recall being that ill and had not thought he needed to come into hospital.

The decision to go to hospital is complex and without clear or consistent indicators. One participant said they left it "too late" and ended up much more ill than they would have been. Another expressed not knowing when she would go as she did not have typical indicators of respiratory distress; perhaps she would wait until she could not speak. It is appealing to have objective indicators to decrease the uncertainty of this decision making process, and some participants obtained their own oxygen saturation to use as an indicator or *gauge of risk.* However, oxygen saturation has not demonstrated to be a reliable indicator of breathing status. Carbon dioxide levels are not necessarily correlated with oxygen; in persons with COPD, normal arterial oxygen and increased carbon dioxide have been reported with severe breathlessness (Ferrari, et al., 1997). No correlations were found between shortness of breath and oxygen at either rest or ambulation in persons with COPD (Gift & Narsavage, 1998). The use of an oximeter is also unreliable in that diaphragm fatigue may be occurring despite normal or near-normal oxygen saturations, or the person may have insufficient cardiac function. In critically ill patients, severe breathing distress was perceived in the presence of normal oxygen saturation (Jenny & Logan, 1996).

In contrast to an oximeter, a peak flow meter is considered to be a reliable and objective indicator that provides "early warning" and enables an early response for persons with asthma (Mayo Clinic Staff, 2003). None of the participants in this study indicated that they used a flow meter.

In acute episodes of respiratory distress, relationships of cardiac function and carbon dioxide levels bear investigation to the abrupt onset of panic, distress, and inability to breathe experienced in moderate to severe episodes of pulmonary disease. Further research is needed to understand the process of the decision to self-medicate or seek care, including use and reliability of peak flow meters and oximeters for oxygen saturation, and may elucidate perceptions between sensations of insufficient oxygen with arterial and venous indicators of oxygenation and ventilation.

Distinguishing Experiences of 'Shortness of Breath'

Persons with chronic pulmonary disease differentiated types, meanings, and perceptions of the sensation of being 'short of breath.' Distinguishing characteristics of these types of experiences are the amount and type of exertion that initiates the sensation, and dimensions of *distress* and *intensity*. In this section, I have differentiated and described the three distinct perceptions of shortness of breath as normal, chronic, and acute.

Normal Shortness of Breath

Shortness of breath that was perceived to be *normal* either occurred with severe exertion or was attributed to aging or smoking. Normal shortness of breath is revealed in the themes *Never thought anything about it, Nothing the matter, That kind of short of breath,* and *More or less normal.* With normal shortness of breath, there was no connotation of disease or illness and distress was absent or minimal. In contrast, shortness of breath that *Demanded attention* and could not be ignored was not perceived as normal. Participant descriptions in this study support other findings that intensity and distress are different dimensions of feeling shortness of breath (Desbiens, et al., 1997; Lenz, et al., 1997). As described in the literature, intensity, distress, and effort differ in health and pulmonary disease (Meek, Lareau, & Hu, 2003; Wilson & Jones, 1991a).

Burki differentiated between normal and abnormal shortness of breath, contending that shortness of breath in health is not a distressful sensation and thus distinct from the "unpleasant, distressing sensation of labored breathing" experienced in pulmonary illness (1980, p. 47). This assertion is supported by his finding that during exercise tests in health, although shortness of breath was at maximum *intensity*, minimal or no *distress* was perceived. Indeed, distress was rated between none to moderate on the first exercise test and from none to very slight on the second test.

Perceptions of intensity and distress differ significantly in pulmonary illness than those of health. Severe shortness of breath and distress may be experienced in the absence of maximum exertion. Differentiation between normal shortness of breath and that of "lung problems" by participants in this study is consistent with Burki's distinction of distress as a component. Ed contrasted normal breathlessness with lung problems:

> You would be breathless if you had been walking fast or running or something like that. And you know that you've been doing this physical exertion and you're not getting the breath the way you normally do. But that's got nothing to do with lung problems. That's got to do with the normal business of the body reacting to the exertions. All that means is you're trying to get the air in that you need. It's what the body can normally deal with and so you get breathless.

It is not only distress that differentiates shortness of breath as normal or not normal. In health, there seems to be an embodied knowledge that air is getting to the lungs, and an expectation that breathing will return to normal. In contrast, with pulmonary disease, the perception of not getting enough air differs from the normal or "usual" shortness of breath. This type of shortness of breath is contrasted with the usual shortness of breath with exertion or being out of shape and running or walking fast. Even with effort, the person does not feel that they are getting sufficient air, as described in *Gasping for Breath* and *Can't Breathe.*

Chronic Shortness of Breath

The second type of shortness of breath, *chronic* shortness of breath, is frequently experienced within the context of known pulmonary disease. This type of shortness of breath is not interpreted as normal because it is experienced with minimal exertion. There is minimal distress and it is expected to resolve with rest or pursed-lip breathing. *Chronic* shortness of breath may be ignored, tolerated, or avoided. Although chronic shortness of breath may occur frequently with minimal distress, it should not be dismissed as unimportant as it is very disruptive. The shortness of breath that occurs with minimal exertions is frustrating, restricting, and perhaps even embarrassing. As described in *Slowing down* and *Doing less,* the body and self are held back and limited from participating in life and activities. Unless consciously aware and attentive to their activities and movement, the person may experience shortness of breath with "little warning" and have to stop and rest, whether at home or in the middle of a store, as described in *Have to Stop.*

Acute Shortness of Breath

The third type of shortness of breath experienced in chronic pulmonary illness is *acute* shortness of breath. This type of breathing is not just that of difficult breathing, or having to stop and catch one's breath. In acute episodes, there is an increase in intensity. It is usually distressing and it may even be frightening. Acute shortness of breath is found in the themes *Gasping for breath, Can't get the air in, A terrible distress,* and *Almost a panic.*

Acute shortness of breath immobilizes, silences, and signals concern. No longer just 'short of breath,' the person may perceive that they *can't* breathe, they *can't* get air. Terrible distress, frustration, panic, anxiety, and desperation may be experienced with acute shortness of breath. Life-threatening metaphors of drowning and suffocating reveal the threat and intensity of acute shortness of breath. Indeed, the acute experience may be a life-threatening event and require medical intervention.

Chronic and Acute Experiences

Acute and chronic dyspnea have been conceptualized as different phenomena (Gift, 1987; DeVito, 1986; Hanneman, 1999; Janson-Bjerklier, et al., 1986; Horton-Deutsch, et al., 1992; McCarley, 1999), but are not well differentiated by research. Models of chronic dyspnea (Gift, 1990; McCarley, 1999) are helpful in explicating awareness of acute events within a chronic illness, and emphasizing the legitimacy, significance, and distress of either type of dyspnea. Shortcomings of these models include assertions of causal and simplistic relationships and the assumption that chronic dyspnea is continual. Neither of these is supported by this research or clinical observations.

McCarley proposed that in chronic dyspnea, there is "persistent shortness of breath which, although varying in intensity, is always present" (1999, p. 234). Descriptions of participants in this study refute this assumption. They described moments of awareness, episodes of shortness of breath, and intervals in which they were "fine" unless they attempted any exertion. Experiences of chronic and acute shortness of breath varied with individuals, the type and severity of the pulmonary disease etiology, and the use of oxygen therapy. For participants with severe pulmonary disease, shortness of breath was experienced with any exertion or activity that required an increase in oxygen demand. Even taking a few steps across a room caused the person to halt momentarily and take a breath.

The second set of assumptions regarding antecedents, experiences, and consequences of chronic shortness of breath require investigation to divulge additions and corrections to the models of chronic dyspnea. Other unpleasant symptoms, such as pain, fatigue, or anxiety were not perceived as 'causes' of dyspnea as postulated in the literature (Lynn et al., 1997; van der Molen, 1995; Gift & Pugh, 1993). Instead they were described as consequences or descriptors of shortness of breath. As well, in contrast to McCarley's (1999) model in which frustration is a 'cause' of shortness of breath, participant experiences in this study suggest that feelings of frustration are often a 'consequence' of the restrictions on the body and self. Living a *Static kind of life,* easily *Worn out,* and struggling to breathe, chronic pulmonary disease disrupts and frustrates the self in the world

Descriptions of the "usual and the worst dyspnea experienced" in pulmonary disease have elucidated differences between acute and chronic shortness of breath (Janson-Bjerklie, et al., 1986, p. 155). In their study, all but one of the 68 persons with COPD identified usual experiences of breathlessness precipitated by everyday physical activities, such as walking, housework, bending, hurrying, dressing, and bathing. Parshall (2002) also differentiated between chronic and acute shortness of breath through patient descriptions of their breathing sensations upon deciding to come to the Emergency Department. Of the 104 persons with COPD, 36 persons used phrases which indicated that they could not get air, whereas only 4 persons used the phrase 'short of breath' which was distinguished by its severity as in "Real short of breath" or the interval "Didn't know if my short-of-breath feeling would ever quit" (p. 337).

Although it remains unknown if acute exacerbations that occur in chronic illness are similar to acute illnesses (Morse & Johnson, 1991), it is apparent that in chronic pulmonary illness, shortness of breath that is experienced on a frequent basis differs from that of acute episodes. The latter are more severe and distressing, and described by war metaphors of attack and rescue, or life-threatening metaphors such as drowning and suffocating. With chronic shortness of breath, the person slows down or does less to alleviate the sensation, whereas with acute shortness of breath, breathing seems impossible and the body is unable to move. Severity and distress were also differentiated in the themes *Can't breathe* or *Have to stop.*

Persons with chronic pulmonary illness experience shortness of breath with mild exertion, such as walking. This *chronic* shortness of breath may be alleviated by resting or perhaps pursed-lip breathing. In contrast, *acute* shortness of breath is the perception of not being able to breathe, the experience of having to stop and nearly be unable to speak.

Differentiating Experiences and Sensations

Shortness of breath, difficult breathing, and unpleasant symptoms all represent aspects of dyspnea, which is "a medical translation of the patient's complaint of difficult breathing" (Fishman & Ledlie, 1979, p. 80). It remains unknown what sensations and perceptions are translated into this term by clinicians, or what meanings and understandings are held. However, the translation is significant to patient care. Eva and colleagues reported that when common terms such as shortness of breath were translated into medical terms, that the probability of accurate diagnosis by resident physicians was decreased, perhaps because the symptom that is reported in medical terminology is viewed as more "relevant" (2001, p. S13).

When clinicians and researchers do not differentiate 'shortness of breath' between that experienced in health and illness, or distress and severity in normal, chronic and acute shortness of breath, the sensation may be minimized and misunderstood. I recall walking home after an interview, determining that never again would I casually chart or report that my patient was "short of breath." When we no longer deliberate on the terms that we use, we may assume that we understand one another and our patients, perhaps perceiving that sensations in health are similar to those experienced in illness. One participant expressed this gap in understanding:

> I have trouble describing things to the medical profession. Through their training they have got their own terminologies and thoughts. The normal layman has something perhaps totally different. Having talked to quite a few doctors and nurses through my life, I often wonder whether they really understand what the layman is saying to them.

As clinicians, we describe patients' experiences as 'dyspnea' or 'shortness of breath,' whereas participants used phrases such as "gasping for air," "not getting air," and "can't breathe". Reports from the literature also describe the sensation as scary, hard to breathe, and can't breathe (Bailey, 2004; deSouza Caroci, Lareau, & Linda, 2004; DeVito, 1990). Severe distress and intensity are revealed in that 23 of 30 persons with COPD reported that they "experienced such severe breathing distress that they thought they would suffocate" (deSouza Caroci, et al., 2004, p. 106). Bailey (2004) describes dyspnea as scary *when* you can't breathe, not *if*. Heinzer and colleagues reported that with acute illness requiring hospitalization, participants expressed feelings of "fear, anxiety, panic, and helplessness" (2003, p. 96). The importance of not minimizing the experience of shortness of breath was expressed by DeVito (1990); patients emphasized the importance of having assistance with activities, not being rushed, and not being asked to talk when short of breath.

Despite the intensity of language, metaphors of attack, expressions of danger, fighting, and threat to life that is used by persons experiencing shortness of breath, clinicians speak of 'episodes' and 'dyspnea.' Is it a medical translation or purposeful attempt to understate the experience and decrease the emotional distress? Brookes (1994, p. 31-32) contrasts a physician's perception of asthma with his own, asserting that it is an attack, *not* an episode:

> The word "attack" is wrong, a prominent local allergist told me. Use *episode*, she says: asthma is a condition of chronic airway inflammation, so it's there all the time, whether you are wheezing or not. Once you understand this, you recognize the dormant phase, the build up with its drop in pulmonary function, and see the acute phase as merely the culmination, the manifestation, the world made flesh. This makes sense, I suppose, and it may help to avert some of the panic that clings to the word *attack*, but trust me: it feels like an attack. The most accurate word I can thing of, actually, is *crise*, the French for "attacke": it *is* a crisis, and the word's hissing exhalation, its vowel clamped down by a sibilant consonant, echoes the asthmatic's wheeze.

Through language we minimize experiences by converting attacks into episodes, translating gasping into dyspnea. Perhaps misunderstanding or interpreting shortness of breath as known in health, we do not recognize the distress or understand the physical limitations. Subsequently clinicians may try to rush patients, cajole them to do more than one task and not provide them sufficient time to 'catch their breath.'

In summary, in chronic pulmonary illness, there are multiple interactions and complex interrelationships that influence not only perception, but interpretation of sensations, and subsequently the illness experience. Feeling 'short of breath' in everyday activities was distressing and frustrating for many participants, and differentiated from that of health. Acute exacerbations or infections were unpredictable and sudden; signs were interpreted by both self and others to determine whether to self-medicate or seek medical interventions.

Awareness of breathing with pulmonary illness is not the same as in health. In health, we might notice that our breathing is a little loud or quick or deep when respiratory rate and depth immediately increase to meet oxygen demands. In health, there are minimal or no sensations of tightness or sounds of wheezes; no perceptions of threat, concern, puzzlement, or frustration; no immediate distress or prolonged tiredness. The sounds and sensations of breathing quickly return into silent unawareness.

Perceptions, Interpretations, and Meanings of Pulmonary Illness

For this study, I chose the clinical population of persons with chronic pulmonary illness. Part of my research process was reflection on definitions and assumptions embedded within the language of this phrase, attained in part through comparison to the experiential aspects. Chronic pulmonary illness and chronic pulmonary disease are technical terms that convey biological, social, and health science perspectives. *Disease* and *illness* have been differentiated in health care literature; disease defined as pathophysiological changes that occur to cells or tissue, and illness as sensations and experiences of the person (Jennings, 1986; Kleinman, 1988). Disease may be present in the body without being detected or experienced by self. For instance, cardiac damage which occurs without the person's awareness is described as a 'silent' myocardial infarction. Pulmonary disease may be silent and invisible as alveoli, airway, and vasculature damage may occur without any awareness of the self. In this manner, the disease is 'silent' even though wheezing, coughing, or fatigue may be experienced, for they are not interpreted as illness. Thus, the presence of pulmonary disease is not equivalent to the experience of pulmonary illness, which is the focus of this dissertation.

Chronic, Pulmonary, Illness

The terms *chronic* and *pulmonary* express biological, social, and health science perspectives of time and anatomical structure. Chronic depicts a continuous and ongoing process, and pulmonary indicates the lungs as the anatomical location. Thus, the term *chronic pulmonary disease* depicts a process of lung damage and injury that occurs over an extended period of time. In contrast, acute pulmonary disease, such as pneumonia, is of sudden onset and expected to resolve within a short period of time. Although situated in the lungs and described as continuous over time, chronic pulmonary illness is experienced within the body and self, and is dynamic state within and over moments of time. The term *chronic* does not relay the episodic and unpredictable characteristics of experiences with acute attacks of asthma and intervals of wellness, acute exacerbations of emphysema, suddenness of the moments that the body halts, unable to breathe, or infections that may occur with any of the various etiologies. Nor does it convey periods of time when the persons feels "fine," not noticing or able to ignore their raspy, laboured breathing, clearing of secretions, or wheezy respirations.

The names of the disease seemed to hold little significance for most participants with COPD or emphysema, who described themselves as "listed as emphysema or COPD or whatever" or "named as emphysema." The diagnostic labels of asthma, emphysema, and COPD do not portray the dynamic and complex nature of pulmonary disease and illness. Although these diagnoses connote a 'chronic' disease to clinicians, the person may not perceive pulmonary illness as chronic or constant. Asthma was perceived as discontinuous for some participants who described intervals as "when I have asthma" or the "first sign" of asthma. In contrast, others used expressions that suggested that they perceived asthma was continuous in presence but not intensity, such as "when it's bad I can hardly climb a flight of stairs." Another with severe asthma described that it was "always there" but varied in intensity. For DeSalvo (1997, p. 73), asthma is continuous, not a possession that can be set aside:

> I can't tell her I have asthma. That sounds like I hold/possess/own/contain a thing, separate from myself, called 'asthma.' That my asthma is something I can take up or put down, whenever I choose. I haven't chosen asthma—far from it—though asthma has surely chosen me.

It is not only asthma that is intermittent in severity and occurrence. The experiences of persons with COPD/emphysema varied with days, seasons, and weather: "I got emphysema and COPD. I have my good days and my bad days." Regardless of the etiology of disease, numerous phrases were used by participants that revealed the abruptness of sensations, such as being fine one moment and not the next. For example, asthma has a suddenness for Adam, "A shortness of breath comes on first. I don't have a particular tightness in the chest or anything. It's just that I'm breathing heavier and *the next thing I know* I'm starting to wheeze a bit." In this manner, illness and symptoms are not chronic, but intermittent and sudden, occurring in the next moment.

These moments of disruption of self, body, and activities differ from that of health in which there is a sense of being "'in tune' with self, other and the environment" (Jensen & Allen, 1994, p. 352). With severe emphysema there may be few moments of being in tune with self, any exertion may cause the lungs "to protest" and the body to halt. One participant described that near-normal was experienced through the use of steroid and antibiotic therapy: "I'm almost semi-normal for awhile, where I can breathe, where my lungs are wide open, the rest of my body feels in tune with me."

Differentiating between disease and health, or wellness and illness, is neither tidy nor discrete (Jensen & Allen, 1994). It is the clinician that perceives *chronic* pulmonary disease as ongoing. In contrast, the person who experiences pulmonary illness may perceive illness as acute episodes within short and longer intervals of time. Pulmonary illness is not experienced as a continuum of sensations and awareness, but in moments of exertion, attacks by allergens or bacteria, or with good days and bad days. Asthma is considered to be a pulmonary disease that is considered to be more episodic and predictable, that is, sensations, sounds, and signs are experienced in response to various stimuli. Yet this was not experienced by these participants, as the cause-effect response was not predictable in either occurrence or severity. Thus, categorizations between episodes or severity may not be distinct, particularly for persons with more severe episodes or multiple triggers of asthma.

Lungs, Body, and Self

The use of the anatomical terms of either pulmonary or lung to delineate chronic pulmonary illness and disease are both descriptive and deceptive. The disease process is not confined to the lungs or breathing, nor is breathing the only experience or focus of chronic pulmonary illness. Instead, the self and the body experience the injury that has occurred to the lungs.

As embodied-subjects, we are *in* our body and we *are* our body (Merleau-Ponty, 1962). The ease of moving through the world is disrupted with pulmonary disease. With moderate to severe lung damage, the ability to live simultaneously and spontaneously is disrupted, and ways of being in the world are impaired. Exertions, speech, and actions are no longer immediate and of the moment; the body cannot follow the intent of self. When the *body* slows down or is halted, *self* is out of tempo or synchrony with their world and others. In that the body is "our medium for having a world" (Merleau-Ponty, 1964, p. 147), the body-in-the-world becomes limited by the lungs and breathing. The themes of *Doing Less, Slowing Down,* and *Have to Stop* reveal the constraints of chronic pulmonary disease on the body and self. When persons with severe pulmonary disease forget or don't think about breathing, and start to move quickly, they are slowed down or stopped by the incapacity of their lungs.

Participant descriptions and metaphors revealed the body as a vehicle which requires energy to move through the world. Participants described that they "run out of gas" or have to "conserve their breath." Breathing no longer only supplies oxygen and energy, breathing becomes work that requires more energy. With severe disease, energy and oxygen are limited resources which need to be saved or conserved, "I have to conserve my energy and I only use physical energy when it is essential that I do so."

Tiredness and fatigue are reported to be prevalent with lung disease (Gift & Pugh, 1993; Janson-Bjerklie, et al., 1986; Small & Lamb, 1999). Many participants experienced fatigue and tiredness which most often, but not always, were attributed to breathing or lung "problems." With more severe lung disease, even the ordinary activity is altered: "I really (*pause*) get very short of breath. Not doing much and I get very tired. Too much talking, I get tired." Tiredness occurred with minimal exertion, such as drying dishes or making the bed: "If I'm doing something in the house and I get tired I sit down for a minute. Two minutes. Get up and get at it again, as soon as I catch my breath." Participants with moderately-severe or severe disease were no longer able to do activities or work they had formerly enjoyed. It is not that activities are "no longer of interest to the patient (e.g. sports)" (Lareau, et al., 1999, p. 72). Instead persons with pulmonary disease *have to stop* in the midst of everyday activities such as showering and are *unable* to do many activities they would like to do, including sports and hobbies. Golfing, traveling, socializing were some of the many activities that had to be discontinued when breathing itself was *A Chore*.

Participant experiences in this study are consistent with findings that many persons with COPD have "frequent symptoms of breathlessness, coughing , and wheezing that limited their ability to carry out everyday activities" (Chapman, Bourbeau, & Rance, 2003, p. S24). When the physical body is limited by breathing, it is no longer continuous with self. Self *in the body* becomes aware of the body and of breathing; body and self *in the world* is constrained by breathing. Still themselves, and yet not quite the same self, some felt held back and constrained by their breathing and their body.

Obstruction, Restriction, and Work of Breathing

Chronic pulmonary diseases include obstructive, restrictive, and vascular etiologies (West, 2003). The hallmark of COPD is persistent and non-reversible obstruction of airways, whereas asthma is typified by reversible bronchoconstriction and an ongoing inflammatory process from irritants and allergens. Categorization by reversibility of obstruction is not discrete. Mixed etiologies such as bronchitis and asthma occur, and persons with asthma are at increased risk for COPD (Silva, Sherrill, Guerra & Barbee, 2002).

Pulmonary disease is determined by the individual's history, risk factors (primarily family history and smoking), sounds of breathing (crackles, cough, and wheezes), chest X-Ray, and Pulmonary Function Tests (PFTs). In PFTs, the person's volumes of air and diffusion of gases are calculated and compared to the values expected for that individual's age, sex, and body type. Diffusion and uptake of oxygen is decreased with fibrosis, increased dead space, acute inflammation, and carbon monoxide displacement, particularly from smoking. Various inspiratory, expiratory, and lung volumes are determined, including vital capacity (VC), the volume which is exhaled after a full inspiration and maximum expiration, total lung capacity (TLC), and residual volume (West, 2000). In both obstructive and restrictive etiologies, vital capacity is decreased, whereas total lung capacity is decreased in restrictive disease and increased in obstructive disease.

Inspiratory and expiratory reserve volumes are the amount of air respectively inhaled or exhaled after a breath that is not forced. After taking a relaxed breath in, the inspiratory reserve volume is the amount of air that can be inhaled with effort. Conversely, after breathing out, expiratory reserve volume is the volume of air that can be forced out of the lungs. In both types of chronic pulmonary disease categories, inspiratory and expiratory reserve volumes are decreased and work of breathing is increased. Expiratory airflow and airway diameter are evaluated by forceful exhalation: peak expiratory flow, forced vital capacity, and forced exhaled volume in one second (FEV_1). Exhalation of full lung volume at maximum force (FVC) increases positive lung pressure, resulting in airway collapse and closure.

With obstructive pulmonary disease or acute bronchoconstriction in asthma, airways close early and exhaled volume is decreased. Decreases in FVC, PEF, or FEV_1 indicate narrowed airway diameters, early closure of airways, or both (West, 2003). With extensive disease or severe airway response, minimal increases in either exertion or airway resistance will result in forced, laboured breathing. Increased airway resistance from bronchoconstriction or mucous production may result from inflammatory or immune responses to allergens or irritants, such as cold air, smoke or perfume.

In this study, several scientific terms of lung function and disease were used by participants, although they do not seem to be adopted as reported by Janson-Bjerklie and colleagues (1986). Instead, their use of these terms was used with different connotations or definitions. For example, one participant used "congested" to describe an asthma attack. When asked to expand on the term, he related, "It's just a heaviness in my chest and then that feeling that I've got to start working harder at breathing." This perspective of congested differs from the scientific definition of excess fluid which is attributed to physiological principles of inflammation and altered permeability. Yet, phenomenological and physiological meanings of congestion are entwined. The increase in lung water and exudate in asthma is experienced as the chest *feeling* heavier and the person *working* harder to breathe.

Work of breathing was a term used by many participants through a variety of expressions. The experience of working to breathe is far more than the physiological factors of elastic work required to expand the chest and friction work of airway resistance. Work of breathing is not only the perceived exertion required to breathe. It is the effort needed and felt, and the inability to maintain paid work. With the effort required by breathing, everyday activities become *A Chore*, and the person may feel *Worn Out*.

The terms obstruct and restrict were used to describe experiences of living with pulmonary disease, with regard to sensations and actions of the body in the world. Persons with asthma are *restricted* in choices or actions, such as eating certain foods or attending certain venues; those with COPD/emphysema are *obstructed* from activities, such as golfing or walking with family members. Capacity and reserve also held different meanings than the technical terms of PFTs. They were used to describe body sensations and abilities, not measured volumes of air. Thus, required capacity is more than the air required for breathing. Insufficient air determines the capacity for exertions and activities.

I recommend that when we discuss pulmonary disease and illness in nursing education, we incorporate both technical and experiential meanings of terms such as capacity, work of breathing, obstruction, and restriction. In this manner, the abnormal air flow or volumes that define the disease would reveal the illness experience:

> Not being able to breathe and do the things you want to do is hell. Ah, it restricts. My capacity is compromised. And I can't do a lot of things 'cause I don't have volume. Can't stretch the vital capacity I don't have (*Long pause*).

In summary, chronic pulmonary disease is described by obstruction or restriction of air flow, and increased work of breathing. These and other scientific terms may be used by persons with pulmonary disease, but from a phenomenological or lived-experience perspective. Each reveals an aspect of the frustration and effort of living with pulmonary disease, particularly in acute events or severe lung injury.

Interpretation and Appraisal of Sense-Experiences

As described above, disease and illness are not equivalent, and pulmonary disease may be present without being experienced as illness. Pulmonary illness is perceived *in* the body with sounds and sensations, and *through* the body actions and movement in the world. Aronowitz (2001) asked, 'When do symptoms become a disease?' Descriptions and analysis in this dissertation prompted me to ask, 'When do sensations become *symptoms*? When does a person *become* ill?'

Chronic pulmonary disease is described as *progressive*, with ongoing inflammation and lung injury. The 'progress' of disease is experienced as the person with emphysema as "getting progressively worse as time goes on." Due to this gradual and slow process of injury, sense-experiences may be noticed for months or years, although they may not be attributed to disease or perceived as illness.

Mild to severe alterations in the lungs may occur before they are noticed by self and the disease is diagnosed. As one person described, prior to his diagnosis of emphysema, "I felt that I was walking through molasses all the time. I was still doing things, but I really had to work at it to get it done." These experiences may vary between etiologies. Asthma may have either a gradual or more abrupt onset, whereas the division between health and illness is less recognized as a point in time with COPD/emphysema.

The experience of illness requires perceiving sense-experiences as *symptoms*, that is, when sounds and sensations are interpreted as possibilities of disease, injury, or infection. Although lung disease may be present, one is not ill when shortness of breath is not thought about, able to be ignored, or considered to be normal. Illness is not perceived when cough is attributed to smoking or tiredness to aging, and therefore these sensations were interpreted as normal.

In acute illness, symptoms force the body into the foreground and are evaluated as to whether they are normal or not (Morse, et al., 1995). In contrast, although awareness of the body moves into the foreground, when sensations are interpreted as normal, the body is not perceived as dis-eased. Thus, shortness of breath, cough, intolerance to exercise, or fatigue are *sensations* of the body but not necessarily interpreted as *symptoms* of illness.

Unlike a silent myocardial infarction or other acute diseases which are deceiving due to the absence of symptoms (Morse, et al., 1995), pulmonary disease is deceiving to the body and self in its silence and invisibility, and in the presence of sensations which are interpreted as normal or able to be ignored. COPD or asthma may go unnoticed, undiagnosed, and untreated until sensations are no longer perceived as normal. Furthermore, sensations of pulmonary disease are subtle, indistinct, obscure, and may not demand attention. When sensations are not interpreted as symptoms, illness may be perceived as “sudden,” such as this person who was diagnosed with severe emphysema: “Before I even knew that I had a respiratory problem, I just passed right out. Just bang, ended up in the hospital.”

Smoking and Interpretation of Illness

There is a strong correlation of smoking with COPD, emphysema, and chronic bronchitis. It is estimated that between fifteen and fifty percent of smokers acquire COPD (Chapman, et al., 2003; Lundback, et al., 2003). In the “Confronting COPD” national survey, 99.5% of the patients with COPD were current or former smokers. With regard to coughing, smoking is considered to be the leading ‘cause’ of chronic cough which is directly related to the number of cigarettes smoked daily (Ludviksdottir, Bjornsson, Janson, & Boman, 1996).

Recent evidence supports that there is a relationship between smoking and asthma (Chalmers, et al., 2002; Chaudhuri, et al., 2003; James, et al., 2004; Thomson, Chaudhuri, & Livingston, 2004). Smoking is considered to be a possible risk factor for the development of asthma (Sandstrom & Lundback, 2004; Ulrik & Lange, 2001), and in persons with asthma, it has been demonstrated that steroid therapy is less effective for smokers than non-smokers (Chalmers, et al., 2002; Chaudhuri, et al., 2000). Both smoking and aging are risk factors for asthmatics to develop COPD (Silva, et al., 2002).

The prevalence of COPD is considered to be underestimated, and as many as 50 % of smokers may have undiagnosed COPD (Lundback, et al., 2003; Chapman, et al., 2003). It is asserted that persons “with early symptoms” of COPD do not seek contact with health care professionals (Chapman, et al., 2003, p. S23). In a recent telephone survey (American Lung Association, 2004), smokers were asked if they experienced one or more of the following, regarded by the Lung Association as "primary symptoms" of COPD: chronic cough, shortness of breath, a greater effort to breathe, increased mucous production, or frequent clearing of the throat. Although 55 percent of those surveyed experienced one or more of these per week, 64 percent were not concerned about developing COPD. The survey results were reported as "alarming" and interpreted that "a majority of smokers who could have COPD are ignoring the signs."

Contrary to their conclusions, this present study reveals that these "signs" may not be purposefully unreported or ignored. Instead, these sensations are not perceived as indicators of disease nor interpreted as symptoms of illness. As described in *Noticing Breathing and the Body* and *Revealing the Invisible,* some participants interpreted their sensations as normal. A 'smoker's cough' was not perceived with concern. Feeling short of breath was interpreted as normal and attributed to being "out of shape" or due to smoking or aging: "I noticed I was short of breath. But I didn't attribute it to anything because I smoked then." In discussing this study with a young woman who has mild asthma, she remarked, "Sure, when I was smoking, I thought it was normal to be out of breath after walking up one flight of stairs. I only realized it wasn't normal when I quit." Cough or shortness of breath may have been noticed and remarked upon, but in the context of smoking was not regarded as a signal for concern. Consequently, the interpretation of these sense-experiences as normal mitigates against diagnosis of COPD.

With smoking, breathing 'difficulties' and 'problems' may occur for many years, without being interpreted as disease or experienced as illness. Reflecting back on these experiences, some participants described that they "misinterpreted" these sensations, and reinterpreted them as indicators or illness. These perceptions of perceived normality are important to target public education for early diagnosis and intervention, including smoking cessation. Canadian recommendations include that "patients who report progressive activity-related shortness of breath" be evaluated for COPD (2003, p. 14A). Wheezing, shortness of breath, and cough are reported as more prevalent among smokers than non-smokers with COPD (Abramson, Matheson, Wharton, Sim, & Walters, 2002). Non-diagnosis of COPD is postulated to be due to its "slowly progressive nature" which is undetected for years (Lundback, et al., 2003, p. 116). Descriptions of participants' sense-experiences and interpretations in this study elucidates this supposition in that shortness of breath, cough and sputum, and fatigue may be perceived as normal and expected with smoking. Thus, the initiative for earlier diagnosis and intervention lies with clinicians to inquire not about sensations of breathing and level of activities.

A decrease in mortality has been demonstrated with smoking cessation in persons with "asymptomatic airway obstruction" (Anthonisen, et al., 2005, p. 233). Questions for further research include the effects of smoking cessation on decrease of symptoms and restrictions of illness, decrease in emergency visits and hospitalizations, prevention of critical care admissions, decrease in the progression of disease, and alleviation of symptoms, including cough, shortness of breath, and fatigue. Perceptions of these effects with persons with lung disease are also relevant. Only a few participants in this study were completely successful in their attempts to stop smoking. Others continued to smoke, some perceiving that "the damage was already done." Two participants who stopped smoking perceived that there were physical improvements. One person who had a long history of smoking indicated that she used less oxygen after quitting and stated that "I definitely think my breathing certainly improved. Yes, most certainly. My health is better, I felt better after quitting."

Perceptions of smoking and sensations of breathing and the body are significant for public health and education. COPD and emphysema severely affect life abilities and health costs. In 1997, nearly 60,000 patients with COPD were admitted to hospitals in Canada (Chapman, et al., 2002). It is time that smoking is regarded as significant a health hazard as coal dust is in 'miner's lung' and grain dust in 'farmer's lung' disease. Smoking cessation has shown to increase with advice from physicians, interventions from nurses, and nicotine replacement therapy (Anthonisen, et al., 2005; Lancaster, Stead, Silagy, & Sowden, 2000). Acute episodes and hospitalization create opportunities for Registered Nurses to promote smoking cessation. Described as teachable moments (Canadian Nurses Association, 2000), it is not known if these times provide an incentive or create an awareness of readiness to stop smoking.

Areas for further research with smoking cessation include perceptions, experiences, and physiological changes. Are there improvements to oxygen delivery evidenced by diffusion of gases and tolerance for exertion? Areas to explore are the frequency and severity of wheezing, cough, and shortness of breath, which may correlate with inflammation, mucous production, and bronchoconstriction.

Living with Pulmonary Disease

Although COPD and asthma are prevalent throughout Canada and the world, I found few studies that addressed living with chronic pulmonary illness. Various perspectives of living with other types of chronic illnesses include coping strategies, minimizing symptoms, normalizing life, transforming self and meanings, and gaining mastery. Conventional coping strategies were not used by participants in this study, nor was normalization perceived in comparison to others or their previous selves. Primarily physical strategies were used to minimize sensations.

'Coping' with Chronic Pulmonary Illness

Coping is described as emotional or problem focused, with use of cognitive-behavioural processes to manage the psychological stress of a perceived threat (Folkman & Lazarus, 1980; Folkman & Lazarus, 1985; Lazarus & Folkman, 1984; McCrae, 1984). Primarily, coping mechanisms are developed and utilized to attain a feeling of mastery and control (Fife, 1994). There is extensive discussion in the literature on coping with the threat of serious illness, which is understood to disrupt everyday life and force meanings to be redefined with regard to the significance of the event. Less is known with regard to coping with chronic illness, and no specific literature was found with regard to coping with chronic pulmonary illness.

A significant aspect of coping involves regaining a feeling of mastery over one's life, either by minimizing the significance of the stressor or preventing its reoccurrence (Fife, 1994). Sharoff asserts that "symptoms develop not so much from the disease or treatment for [the disease] but by the patient's inability to cope with the disease or treatment for it" whereas "appropriate coping skills enable medical patients to regain or retain control of their life" (2004, p. 4 and 5).

Living with pulmonary disease requires strategies that address physical aspects of the body and breathing, not cognitive-behavioural strategies. Physical strategies were directed to avoiding or alleviating acute sensations through minimizing activities, avoiding irritants and triggers, alleviating tiredness, and focusing on breathing. Some strategies were deliberate when shortness of breath or coughing could be anticipated, such as: "I no longer run for buses in cold weather;" "I even bought terry towel robes, so that I don't have to fuss so much drying off I can just climb into the terry towel robes and be dry;" "I'm no longer buying shoes with laces. I buy slip on shoes and I buy those nice long shoe horns so that I don't have to bend over to put my shoes on because bending over and standing up, I gotta take five minutes after that to catch my breath again."

Neither mastery, predictability, nor control were evident within these participants' experiences of pulmonary illness. For some participants, symptoms of exercise-induced asthma were minimized rather than controlled with use of a bronchodilator and avoidance of some activities. These strategies do not indicate mastery or control. Sensations of shortness of breath, tightness in the chest, and not getting enough air were unpredictable, and only attained through restriction of activities. Thus, the disease directs personal activities and choices:

> The Ventolin fixed me up right away. I would consider it mild, exercise induced, and very controllable using Ventolin. It's more a matter of it restricts some things that I would like to do.

Asthma was not intermittent or 'episodic' for all participants. Those whose asthma was triggered by multiple allergens, known or unknown, had experiences that were more comparable with emphysema and COPD. As described in metaphors of attack and battles, asthma could not always be controlled or predicted:

> It's bad control, despite all the efforts. I'm frequently cautious of scenarios. So I'm planning, I'm thinking, I'm on my guard. And sometimes I'm lucky. If I figure out what it is and I get away from it, then I'm okay. Now my asthma is bad, I can't avoid it. I can't identify the trigger. I would look until I was blue in the face, it didn't matter, I couldn't control it.

For persons with moderate to severe pulmonary disease, not even an extremely sedentary lifestyle prevents the reoccurrence of distress. Any exertion, allergen, or trigger may have the person feel short of breath, cough until exhausted, or have to suddenly stop and try to breathe. COPD and emphysema were not portrayed as something that could be controlled, predicted, or fixed. Slowing down or doing less was not a choice but a necessity. Not perceiving to achieve mastery and control, severe pulmonary disease directs the person's activities, plans, and expectations. In contrast to transformation of meanings through coping with serious illness (Fife, 1994) or reformulation of self with suffering (Kralik, 2002; Morse & Carter, 1996; Ohman, Soderberg, & Lundman, 2003), there were no descriptions of new meanings or perceptions of a new self within this context of pulmonary illness. Regardless of etiology, participants described being frustrated as their body and breathing restricted *them* or when others tried to rush them and they were unable to do so.

Breathing In

Most participant descriptions of breathing, regardless of disease etiology, focused on breathing *in*. Even when they were informed otherwise and thus intellectually understood that the problem was breathing out, they knew and felt with their body the compelling need to breathe in. The underlying pathophysiology of COPD, emphysema, and asthma is described as alterations with *expiration* due to bronchoconstriction, early airway collapse, surrounding pressures, and mucous production. In contrast to these physical changes, the experiential perspective focuses on *inspiration*, with sensations of not getting enough air, feeling short of breath, or wheezing and coughing which impede breathing in. Thus, it is perceived that inspiration is difficult and insufficient air obtained, although physiologically it is expiration that is decreased. Interestingly, clinicians also focus assessment on inspiration, with questions such as 'Are you short of breath?' 'Are you getting enough air?'

Attending to the sensation on inspiration reveals possibilities for this apparent paradox between perception and definition. Obstructive airflow limitations in COPD, emphysema, or asthma result in hyperinflation and the intake of tidal lung volumes at higher total volumes, which subsequently increases elastic work and decreases muscle efficiency on *inspiration* (Anonymous, 1999). When the lungs are overinflated, less airflow and volumes may be attained despite the increased effort and difficulty to breathe in. Thus, dynamic hyperinflation is considered to be an independent contributor to the sensation of dyspnea in COPD (Thoman, Stoker, & Ross, 1966).

Strategies to minimize perceptions and difficulty of breathing are targeted to both inspiration and expiration, most commonly positioning and pursed-lip breathing. Forward learning positions are considered to improve diaphragm and intercostal muscle function, and were used by some participants with COPD or emphysema: "When I get going too fast then I'm out of breath and I'll have to lean against something to catch my breath." Prone positioning has demonstrated to be effective in patients with severe bronchitis or obstructive disease (Mentzelopoulos, Zakynthinos, Roussos, Tzoufi, & Michalopoulos, 2003; Mentzelopoulos, Roussos, & Zakynthinos, 2005). None of these participants used this strategy; this type of positioning could be further explored with this clinical population.

Pursed-lip breathing may interrupt or ameliorate the effects of dynamic hyperinflation and airway compression, although the mechanisms are poorly understood. It is effective for some persons to slow their respiratory rate, increase exhalation and alveolar ventilation, and decrease dynamic compression and work of breathing. Additional benefits of pursed-lip breathing include a decrease in respiratory rate, beneficial change in muscle patterns, increased expiratory time, and increased tidal volumes, however, although symptoms may decrease, gas exchange or minute ventilation are not necessarily improved (Anonymous, 1999; Grosselink, 2003; Thoman, et al., 1966). It is not reported in the literature as an effective strategy in asthma, however, based on its potential benefit to increase airflow, the use of pursed-lip breathing bears investigation with this clinical population.

Further studies are required to explore the relationship of dynamic hyperinflation with actual and perceived work, airflow in inspiration, and tidal volumes, and effects of breathing patterns and body positions. In addition, elucidating phenomenological experiences and physiological underpinnings may determine interventions that alleviate work of breathing and shortness of breath. There are numerous questions for further research with regard to alleviating the distress and difficulty of breathing, such as: Does hyperinflation contribute to anxiety related to airflow, abnormal gas exchange, and/or chest expansion in asthma, emphysema, or COPD? Does pursed-lip breathing alleviate hyperinflation and decrease elastic and friction work of breathing? Is dynamic hyperinflation present in acute asthma attacks and does it contribute to sensations of breathing effort, insufficient air, or chest tightness? Does obstruction of *inspiratory* airflow contribute to sensations and achieved tidal volume in chronic obstructive disease?

Other strategies may be considered to alleviate the distress or sensation of shortness of breath. For example, it is reported that the sensation of shortness of breath may be alleviated with movement of air over the face, such as the use of a fan or open window (Anonymous, 1999; Gift, 1990). These strategies may be considered to determine if individuals find a breeze or fresh air to be as beneficial.

Distraction, Relaxation, and Breathing Exercises

Strategies such as deep breathing, progressive muscle relaxation, guided imagery, and meditation are recommended to alleviate stress of chronic illness. Sharoff asserts that these strategies "ought to be employed when anxiety and autonomic arousal are too high" (2004, p. 101). However, although both anxiety and the stress response are elevated, these strategies are neither effective nor appropriate in severe shortness of breath. The psychological and emotional distress of feeling unable to breathe or get the next breath occurs with the physiological threat of insufficient respiration. Not just a 'stressor,' insufficient alveolar ventilation and gas exchange threatens the person's air, life, and well-being. For the person with severe shortness of breath, the distress, difficulty, and insufficient air is not a *psychological* stressor but a *physiological* threat (Rotondi, et al., 2002).

It is important to not minimize these sensations of insufficient air, for fear and panic may be important warning mechanisms to seek assistance such as medications or emergent care (Janson-Bjerklie et al., 1992). Reduction of distress, anxiety, and catecholamines need to be attained by regaining sufficient air, such as through pursed-lip breathing, use of ventolin, or increase in inspired oxygen. In contrast to relaxation or breathing exercises, pursed-lip breathing is a physical strategy to reverse the cyclic effects of shallow breaths at high inspiratory volumes.

When shortness of breath is severe, attempts to control breathing with distraction or through pursed-lip breathing may increase frustration, anxiety, or distress (DeVito, 1990; Grosselink, 2003; Logan & Jenny, 1997). Participants in this study identified their inability to "relax" or breathe "properly" to interrupt this cycle of gasping for air. To regain their breath, they need to remove themselves from the irritant or allergen, stop all exertion, and perhaps use a bronchodilator. Participant descriptions in *Demanding Attention* reveal that breathing must be focused on, not ignored or distracted from.

Participants in this and other studies (DeVito, 1986; Bailey, 2004) suggest that distraction, another strategy in the coping literature, is ineffective in acute moments of being unable to breathe. Instead of distracting themselves from breathing sensations, breathing is focused on. As described in *Can't Breathe,* the person with acute distress may isolate themselves or withdraw from others to focus on their breathing and try to interrupt the cycle not getting air in. Instead of distraction, family members or health care providers need to enable the person's focus on breathing, perhaps breathing *with* the person to audibly hear and slow down each expiration. The presence and reassurance of another may enable the person to move breathing to the conscious, voluntary level and interrupt the downward spiral of the anxiety felt with being unable to breathe. Ed describes a time when in an airplane, his wife and a physician passenger enabled him to slow down and regain his breath:

> We were on an airplane coming home from visiting friends in Vancouver or Victoria Island. And suddenly on the plane, I couldn't get my breath. I know I had some kind of a struggle in the washroom on the plane, and by the time I got back to my seat I was quite desperate. But my wife just says, 'Relax.' And I said, 'I can't bloody relax.' (*Forcefully, through clenched teeth*). She says, 'You can. You've got to relax. Don't tighten your muscles like that. Loosen your muscles and start to breathe as slowly as you can.' Thank god on the plane there was a doctor, because once I knew there was a medical specialist there I think that my psychology said, 'That's ok, (*Coughs*) he can deal with it, because I know I can't.' If I get into that state when I'm on my own, I don't know what I would do, quite frankly. But when it has happened in the past my wife has invariably been with me. And if I get into that kind of panic if I'm on my own I don't know what the hell would happen, I'm sure.

Understanding the cyclic nature of the distress of breathing *in* is of particular importance for the nurse to intervene, reassure, and support the person to alleviate the escalation of distress, not minimize the severity of their experience. Regardless of etiology, not being able to breathe is both a physical and psychological stressor, a threat to life, and not alleviated by cognitive-behavioural strategies. When severe, oxygen, ventilatory assistance, and sedation may be required.

Normalization

Normalization is the process of adopting actions and behaviours to manage an illness and lead 'normal' lives (Deatrick, Knafl, & Murphy-Moore, 1999; Robinson, 1993; Morse, Wilson, & Penrod, 2000). Unlike descriptions of parents attempting to normalize aspects of their children's lives, participants in this study reflected upon and contrasted their sensations and activities with normal. Descriptions from or about activities demonstrated no construction of the story of "normal persons leading normal family lives" (Robinson, 1993). **There was no suggestion that a "normalcy lens" (Deatrick, et al., 1999, p. 210) was adopted by persons with moderate to severe COPD/emphysema. Life events were not interpreted as normal nor were strategies described to live a more normalized life. The interpretation of fatigue, noisy breathing and cough as normal is an indication of the normalization of sensations expected with smoking or aging, not normalization of pulmonary illness. The person with severe pulmonary disease is compelled to become aware of the abnormal, exertions or triggers force the body into the foreground. Sounds and sensations must be monitored for possible infection or response to allergens. Even that which is usual or typical is not perceived to be normal. Although it may be normal to *hear* breathing sounds or wheezing, these sounds are not interpreted to *be* normal.

The invisibility of pulmonary illness may create a false layer of normality to others. When mobility is altered, triggers avoided, and activities limited, the disruption of the body is more outwardly apparent to others, but not necessarily noticed or understood as illness. Some participants were disturbed when they perceived others considered them to be normal, perhaps wondering why they parked in a handicapped zone, or why they didn't assist with lifting or opening doors. Although some participants described themselves as "nearly normal" or "back to normal" it was within a context of limited activities and their self in illness, not in comparison with others or health.

Minimizing Symptoms

In contrast to the above strategies for managing chronic illness, participants in this study used various strategies to minimize their symptoms. In COPD, non-significant findings between the severity of pulmonary disease and the intensity of dyspnea are postulated to be due to the reduction of exertion to minimize symptoms (Anonymous, 1999). Persons with pulmonary disease are perceived to "easily avoid the sensory experience and minimize symptoms" (p. 326) by reducing work of the lungs, such as in taking the elevator instead of walking the stairs. However, descriptions from participants in this study reveal that, although distressful sensations are reduced through *Doing Less* and *Slowing Down*, 'symptoms' are not "easily" and completely avoided.

Pulmonary disease prohibits the use of pushing and pacing to conceal illness. Unlike *pushing* self or *pacing* one's activities to conceal illness as reported with multiple sclerosis (Robinson, 1993) and rheumatoid arthritis (Weiner, 1975), the person with moderate to severe disease cannot conceal their illness by maintaining activities. Participants were unable to push themselves to do more or at a faster speed to create a sense of normal; their limits are imposed by breathing and the body. Although encouraged to move faster, to keep up, or to hurry up, the person is unable to do so as the effort and demand of breathing limits their speed and movement. The person *must* slow down and do less, thus falls behind instead of keeping up.

It is important for nurses and other health care providers to recognize that exertion is severely limited in asthma attacks or with exacerbations of COPD or emphysema. They require a slower pace and intervals of rest to recover their breath. Several participants with severe emphysema, two of whom were on supplemental oxygen, remarked upon the amount of time required to recover their breath. Gregory needs to take a minute or two to catch his breath after minimal activity such as making his bed: "If I'm doing something in the house and I get tired I sit down for a minute. Two minutes. Get up and get at it again, as soon as I catch my breath." After he showered, Karl ends up "just standing there. Drip drying for about five minutes or so." Jim takes "five minutes to catch my breath again" after bending to tie his shoes. It is unknown how much time is needed to recover their breath, or if their minute or two is objective or subjective time. What is known that we cannot rush our patients, even if they have supplement oxygen and 'normal' oxygen saturation.

Persons with severe shortness of breath must move slowly and may need assistance with basic activities such as bathing or sitting up. Unlike other distressing sensations experienced with illness, such as nausea or pain, the body cannot continue its activities when the person is unable to breathe. With exertion or severe bronchoconstriction, the body demands the person to slow down or even stop. *Unable to breathe,* the person must do less, slow down, or come to a stop. The person *must* stop and visibly labour to breathe, perhaps leaning or sitting, and the sounds of wheezing and coughing further disclose the illness. In these moments pulmonary illness is revealed, no longer concealed by its invisibility.

In summary, illness is a state of being, within a context and time. Although defined by health professionals as chronic and delineated as pulmonary, pulmonary illness may be experienced as acute and life-threatening, and is experienced by the body and self. When chronic pulmonary disease is present, distressing sensations are at times unpredictable and sudden; other times they are anticipated and alleviated. With asthma, there may be a sense of predictability when triggers can be avoided or bronchoconstriction alleviated with medications, yet the unexpected may occur at any time, such as a reaction to an appetizer or a candle. With severe COPD or pulmonary fibrosis, actions and plans are disrupted, control is not attained. Physical restrictions of the body and breathing limit possibilities to 'adapt' or 'cope' with this type of illness.

There are numerous questions for research with regard to living with pulmonary disease. Is deconditioning due to a reduction in activities or pathology of skeletal muscle and oxygen utilization? Does reassurance interrupt cyclic effects of increased distress and anxiety when perceiving the need and inability to breathe?

Conclusion

Through the lived-experiences of participant descriptions, I have attained a glimpse of the hidden, invisible, and nearly indescribable experiences of breathing, body, and self, and an understanding of the limitations and frustrations, distress and desperation, effort and work experienced in chronic pulmonary illness. The disruption of the phenomenological and physical body is apparent through the descriptions of lived-experiences and the explication of the themes. With chronic pulmonary illness, perhaps gradually or suddenly, the *self in the body* becomes aware of the body and of breathing. These sense-experiences are not only noticed by the self in the body, but also the *self in* *the world* when mobility is altered, triggers must be avoided, pace is slowed, and activities are limited. When experiencing 'shortness of breath' in chronic pulmonary illness, there are diverse perspectives of attention, interpretations, and meanings. More than just noticed, breathing may demand attention and impede the body. With moderate to severe illness, or in acute episodes of asthma, actions and intentions of self are no longer done with ease. Even activities that require minimal exertion may be difficult.

With pulmonary disease, the body metaphorically and literally loses its silence, and calls attention to itself with noisy breathing, chest tightness or pressure, coughing, or wheezing. At times, breathing demands attention and cannot be ignored. Feeling short of breath is differentiated from the 'normal' or usual shortness of breath in health or upon minimal exertion. Instead, feeling short of breath with pulmonary disease is not being able to get enough air in, despite extensive effort, and feelings of panic, distress, and desperation were experienced when the person was unable to get air. Metaphors of attacks, drowning, and suffocating, and focus on breathing *in* further reveal the threat of severe pulmonary disease.

The focus of this dissertation was experiences of persons with chronic pulmonary illness. In my proposal, I indicated that I would initiate the conversational interview with "Tell me about your breathing ..." Early in the interviews I realized that living with asthma, emphysema, or COPD was far more than breathing. Sensations and limitations of chronic pulmonary illness extend to the body and the body-in-the-world. Delineated as *pulmonary* or *lung* disease, sensations of illness are not limited to the lungs or pulmonary system. For some, it is the body-in-the-world which reveals pulmonary disease. Tempo and actions are altered; the person has to slow down, do less, and at times even has to stop. Several participants were frustrated with their change in pace and activities, as if held back by the body. No longer lived in the now, in the moment-to-moment of life, breathing constrains and limits body and person.

There were diverse descriptions of shortness of breath, including coughing, wheezing, breathing faster, tiredness, and struggling to get air. Language was limited in some descriptions, at times replaced by breathing sounds; other times acknowledged that there weren't words to describe their sensations. Subjective-symptoms and objective-signs are not discrete categories between patient and health provider. Sensations were experienced as symptoms and interpreted as signs for concern; sounds were indicators of illness. This study is significant in understanding the delay for diagnosis of pulmonary disease, particularly but not exclusively emphysema and COPD. Sense-experiences are not ignored or unreported; for many they were attributed to smoking or aging and interpreted as normal.

The intent of this study was description, not comparison. Nevertheless, these descriptions and their analysis have revealed embryonic understandings of differences in sensations and "types of dyspneic states" (Govindaraj, 2002). It is apparent that effort, sensations, and emotional aspects of shortness of breath differ between experiences in health, in day-to-day exertions with chronic disease, and in acute exacerbations of pulmonary illness. The prevalent and distressing difficulties with breathing in pulmonary illness have been extended through these descriptions and analysis. The decrease in mobility that occurs with shortness of breath, wheezing, or coughing has immediate relevance to rehabilitation and exercise programs. For these participants, a sedentary lifestyle was necessitated by the body, not adopted or chosen. Participants with all types of pulmonary etiologies reported avoiding triggers, including cold weather and irritants. For persons with more severe disease, energy was conserved by doing less and resting for minutes between activities.

Although "we are still a long way from understanding fully the subjective symptoms of dyspnea" (Govindaraj, 2002, p. 662), our current understanding with regard to perceptions, meanings and interpretations of experiences with chronic pulmonary illness has been extended through this research. It is apparent that dyspnea is not equivalent to individual perceptions of shortness of breath, difficult breathing, coughing, wheezing, or rapid breathing, although one or more of these sensations may be experienced. Nor is shortness of breath perceived to be limited to breathing and the lungs as participant descriptions extended beyond the lungs to body sensations and physical limitations. We need to differentiate these nuances, instead of continuing to translate patient experiences into the language of health care providers, with our assumptions and understandings.

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Appendix 1

Demographical Data

Pulmonary Etiology / Diagnosis	Gender		Paid Employment		History of Smoking	
	F	M	Y	N	Y	N
Exercise asthma	1	1	2		1	1
Asthma	2	2	4		1	3
Emphysema	2	4		6	6	
Asthma and COPD/Emphysema	1	1		2	2	
Asthma and fibrosis		1		1		1
COPD and bronchiectasis		1		1		1
TOTAL	6	10	6	10	10	6