

Being-Breathless-In-The-World: A Heideggerian Hermeneutic Phenomenological
Interpretation of the Lived Experience of Advanced Chronic Obstructive Pulmonary
Disease (COPD)

by

Margaret Donahue

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for the degree of Master of Applied Health Services Research

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Supervisor: _____

Readers: _____

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AUTHOR: Margaret Donahue

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ABSTRACT

The purpose of this qualitative study is to explore how people living with advanced COPD experience their illness. The experiences of eight people were analyzed using Heideggerian hermeneutic phenomenology, an approach permitting consideration of the meaning participants ascribe to advanced COPD as it is experienced in their everyday lives. My research indicates that advanced COPD is integrated into all aspects of daily life. Ultimately, breathlessness, as the core experience of advanced COPD, caused suffering and existential angst that became interwoven into who participants now perceived themselves to be. These perceptions are reflected in the two main themes of *A Deflated Self* and *Navigating Contested Selves*. This suffering and angst was generally unaddressed by biomedical healthcare delivery system models. Despite this, participants learned over time to manage their fluctuating illness experiences, to engage their changing *selves*, and to remain engaged in the search to find meaning and pleasure in life.

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CHAPTER 1: INTRODUCTION

According to Heidegger, what makes a human being human is our capacity to reflect upon what it means to be a being-in-the-world. Breathing is something innate to human life, something most of us may not be consciously aware of throughout our busy daily lives; but nonetheless, something that upon reflection we would consider natural and essential to who and what we are as human beings. I have worked for over two years now analyzing the life stories of people for whom breathing is no longer something “natural”, but is still, obviously, essential to human life. I have worked as a qualitative data analyst on three research studies exploring the impact of low dose opioids for people experiencing advanced chronic obstructive pulmonary disease (COPD). This medical intervention is certainly important to study and assess, as it appears to offer some relief to those suffering with the breathlessness associated with advanced COPD. However, while listening to the stories of participants in these studies, I have become more and more aware of the “non-medical” influence of this disease.

When I refer to *disease* in this thesis, I will be referring to something fundamentally different from the experience of illness. Disease is a biomedical term denoting “only an alteration in biological structure or functioning” (Kleinman, 1988, p. 5-6). The work I have done in relation to the use of opioids to address the symptom of dyspnea in advanced COPD has been focused on testing a biomedical intervention to address a biomedical disease symptom. While working on these studies, I became more and more interested in the biopsychosocial experience of this illness, in how people who live with this disease in their everyday lives perceive and experience their *illness*. Illness is a biopsychosocial term that captures not only disease symptoms, but the “innately

human experience of symptoms and suffering” (Kleinman, 1988, p.3). Illnesses, as used in the context of this thesis, will refer to how the person, their loved ones, and their wider social network perceive, experience, and live with disease.

Illness includes judgements made by the person who is ill on how best to manage and address the practical day to day problems and possible restrictions created by their disease symptomology. In the biomedical model, a model that addresses dyspnea as a disease symptom to be “fixed” with a biomedical solution, the medical professional is considered the expert who manages disease symptoms, and the *patient* usually has little input into how the disease symptoms they are experiencing get addressed. In the studies I have been involved with noted above, the patient becomes the passive recipient of the opiate intervention. Level of dyspnea is evaluated by the health professional who then makes professional judgments concerning the amount and frequency with which the drug should be administered based solely upon how the symptom is assessed by them.

A very different understanding of how to approach disease and illness management is required in a biopsychosocial model. In this model, the person experiencing illness, of which disease symptoms are part, would be considered the expert of their own bodies and experiences. They, in fact, would be the person to guide their medical care and to judge what would be most helpful and life sustaining for them amidst the suffering and loss that inescapably accompanies chronic, debilitating illness. For example, people experiencing breathlessness may have their own ways to manage their breathing, ways that could, perhaps, be supplemented by pharmaceutical interventions such as opiates to further improve health and well-being. It is my belief that medical interventions are important and often reduce suffering; however it is also my belief that

more collaborative and respectful relationships are required between health professionals and people experiencing chronic illness to ensure optimal care for chronically ill people engaging with the healthcare delivery system. Disease impacts all aspects of persons and their lives. There is much that healthcare delivery systems could learn from people who are living with chronic illness and “managing” to remain engaged in daily living with or without formal medical assistance. Treating disease symptoms in isolation from the person experiencing them, as present healthcare delivery system models do, may be insufficient at best; perhaps unethical and immoral at worst.

There is limited research exploring the experiences of people living with chronic illnesses in general. This adds to challenges faced by healthcare delivery systems to adequately understand and address the health of populations impacted by such illnesses. Advanced chronic obstructive pulmonary disease (COPD) is one of many such illnesses. As one of the most common chronic illnesses worldwide, it is a major cause of disability and death. Presently, COPD is the fourth leading cause of death in Western societies (Bailey, 2001), and will be the third leading cause of death globally by the year 2020 (Rocker, Sinuff, Horton, & Hernandez, 2007).

COPD is a long term illness that is irreversible. People suffering with COPD will experience a gradual decline in lung function that will result in an increasing struggle to breathe and to live life as freely as they did before advanced COPD. As this disease advances, people suffering with it will experience progressively worsening impairments in their abilities to breathe normally, to socialize, to work, and even to walk or move around (Barnett, 2005; Guthrie, Hill, & Muers, 2001; Minkoff, 2005; L. Walke et al., 2007). Living with the loss of mobility and chronic suffering associated with COPD has

been described as painful, hard work, as a continuous fight taking all one's strength, and therefore exhausting (Barnett, 2005; Elofsson & Ohlen, 2004; Gysels, Bausewein, & Higginson, 2007; Jonsdottir, 1998; Nicholls, 2003).

Breathlessness, as the most troubling experience in advanced COPD has been well researched and studies have connected anxiety and depression to the breathless experience (Bailey, 2004; Giardino et al., 2010; Maurer et al., 2008). In the literature, anxiety and depression have been noted as the two most common emotional and psychological responses to illness in the COPD population. Nevertheless, the impact of these conditions on the overall health of people experiencing COPD remains unknown (Lewis et al., 2007; Maurer et al., 2008). Many unanswered questions remain as to whether or not anxiety and depression are actually a result of breathlessness or whether more complex illness factors contribute to their prevalence and severity.

Factors such as gender, social isolation and extensive comorbidities have been found to be important independent predictors of anxiety and depression in the COPD population (Lewis et al., 2007). COPD is often not diagnosed until it is moderately advanced. Many people experience COPD for some time before becoming consciously aware of the seriousness of their illness. This in itself may be, as of yet, an unexplored factor contributing to anxiety and depression. People living with advanced COPD may become unconsciously aware of its presence long before their experience of the illness is consciously confirmed. Prevalence and severity of anxiety and depression may be related to a yet to be defined existential angst, something in the unconsciousness alerted by the fact that breathing - that which is essential to our being - is now somehow threatened.

To date, limited research has been conducted exploring the experience of people living with COPD. In this thesis, I will explore how people experience advanced COPD from their own perspectives. For example, I examine what it means to have one's "abilities to breathe normally, to socialize, to work, and even to walk or move around" become increasingly limited in daily living. How do people negotiate and navigate through a chronic illness that will eventually lead to terminal illness and finally to death? In this research, I conduct a secondary analysis using existing data to explore what it is like to live with advanced COPD from patients' perspectives. The data I analyze was collected as part of a multi-site study exploring the impact of low dose opioids on dyspnea and quality of life for people living with advanced COPD. I analyze eight transcripts from the first set of interviews conducted with patients in Nova Scotia, Canada, prior to beginning the opioid intervention to try to understand what it is like to live with advanced COPD on a daily basis without the opioid intervention. I chose to explore what it is like to live with advanced COPD without the opioid intervention because this is not an intervention that is presently accessible to the majority of people living with this illness. I am interested to understand how people live daily with advanced COPD. I also consider the approach of the healthcare delivery system to advanced COPD and how people suffering with this illness may experience this approach. I use a qualitative social constructivist approach to the research, specifically employing Heideggerian hermeneutic phenomenology as a methodological approach to data analysis.

CHAPTER 2: LITERATURE REVIEW

COPD is a chronic, debilitating and eventually, in later advanced stages, a terminal illness. People living with advanced COPD are experiencing a chronic illness and chronic suffering. In what follows, I present a review of literature on chronic illness and chronic suffering before specifically focusing on an in-depth review of advanced COPD. I have chosen to order the literature review in this way to ground the experience of advanced COPD in the broader context of chronic disease to provide a deeper understanding of how advanced COPD is experienced. I wish to highlight the importance of chronic suffering and its various sources so that a richer context for interpreting and understanding the similarities and differences between the research and the experience of persons living with advanced COPD in my study can be identified. Breathlessness (dyspnea), as the predominant illness experience and source of suffering in advanced COPD, will receive particular attention in the final section.

2.1 Chronic Illness

Chronic illness is an umbrella term that incorporates a range of illnesses. Chronic illnesses are prolonged and rarely completely cured. The most common are various forms of arthritis, respiratory problems, diabetes, epilepsy and cardiovascular diseases. The patterning of chronic illnesses is fluid and often dependent upon demographic changes and the application of technology. For example, HIV/AIDS and some forms of cancer have now become chronic conditions in countries where effective treatments are available. There is also increasing interest in defining certain mental health conditions such as depression as chronic illnesses. Syndromes of uncertain aetiology such as chronic fatigue syndrome or fibromyalgia may also be classed as chronic due to their

long-standing and often debilitating effects (Dorwick, Dixon-Woods, Halsted, & Weinman, 2005).

In Western societies, chronic illnesses are the main reason why people seek healthcare and the major cause of death and disabilities. Chronic illnesses are the modern epidemic and there are many disease trajectories where therapeutic options have been exhausted and people pass from the chronic illness phase to a terminal stage. In 2002, 29 million deaths worldwide were caused by cardiovascular disease, cancer, chronic respiratory disease, and diabetes combined. It has recently been reported that in hospitals in Canada more than 70% of deaths occur from causes unrelated to malignant illnesses (Dorwick et al., 2005; Heyland et al., 2006). Yet, studies have shown that end-of-life care for patients with chronic illness is suboptimal and that research on the specific needs of these populations is limited (Edmonds, Karlsen, Khan, & Addington-Hall, 2001; Fitzsimons et al., 2007; Gore, Brophy, & Greenstone, 2000; Kutner, 2010; Shah et al., 2006).

2.1.1 Discriminating symptom burdens. Much of our understanding of symptom burden as people approach end of life is based on studies conducted with populations experiencing malignant illness. There has been little research conducted exploring the illness experience of non-malignant populations (Tranmer et al., 2003). The type and prevalence of physically limiting symptoms, and psychological responses to them, depends upon the particular disease processes of chronic or malignant illnesses. If appropriate care is to be provided, it is important that we further our understanding of differences and similarities between symptom burdens found in these respective populations. In a study measuring the symptom experience of cancer and non-cancer

patients, it was found that participants with cancer experienced a much higher prevalence of pain, nausea, unpleasant taste, constipation and vomiting than the non-cancer participants. Non-cancer participants experienced higher prevalence of cough and shortness of breath than the cancer participants. Even though distinct physical symptom burdens were presented, all participants experienced similar psychological responses to their illness. Both cancer and non-cancer participants experienced worry, sadness and anxiety (Tranmer et al., 2003). Other studies have shown that both populations also consider high quality medical care to include emotional support, effective and respectful communication, accessibility to necessary medical services and resources, and continuity of care within the healthcare delivery system (Curtis et al., 2002).

2.1.2 Chronic illness and the experience of loss. People who are chronically ill recognize that more is involved in the illness experience than physical pain and symptoms. Kleinman (1988) claims the central meaning of chronic illness is loss (p. 32). The loss of total bodily integrity and control over one's life are not "symptoms" that the medical narrative can tell. The loss of a pain-free existence, the inability to eat or sleep, the fears associated with waiting for prognosis and the fears often encountered after prognosis, the fear of painful treatment, and the limitations on movement and personal freedom associated with chronic illness are just some of the issues that contribute to suffering that are not easily addressed in the present medical model, and could potentially be silenced in the medical narrative (Frank, 1995, p. 6; Ohman, Soderberg, & Lundman, 2003). Participants in a study conducted by Ironside et al. (2003) began their narratives of chronic illness by describing the illness as the "breakdown in or loss of their habitual body" (p. 176). Life was now experienced differently and the nature of the lived or

habitual body was different. It required new understandings of living in a body that now had to incorporate chronic illness. This included suffering and loss as one was forced to let go of previously taken-for-granted aspects of daily life that now had become problematic. For example, one participant in this study who had sustained a brain injury lamented that she can no longer get down on the floor and play with her young children.

Due to the limitations of their illness, people living with chronic illness often cannot participate in family or social gatherings as they once did. Simple everyday events, such as the example above where it becomes difficult to engage with your children in play, impact and limit once valued roles. Some people experience the loss of full mobility and independence, sometimes leading to the loss of valued intrapersonal and interpersonal relationships. Work roles that once provided a sense of meaning and satisfaction may also be given up. This loss, accompanied with the resultant loss in income may further limit engagement in family and social activities (Sells et al., 2009) increasing isolation and a sense of powerlessness (Charmaz, 1983; Kleinman, 1988; Ohman et al., 2003). Many people suffering with chronic illness struggle daily to regain a sense of power and to stay connected as they are forced to learn to live a new kind of daily life (Delmar et al., 2005; Ohman et al., 2003). One way to assist those living with chronic illness to feel empowered and connected may be to provide an empathetic ear, to listen to their everyday stories and to pay attention to the details of the person's concrete experiences of daily life (Chesla, 2005; Clarke & Kissane, 2002; Frank, 1995; Kleinman, 1988). Yet, this aspect of patient care is not accessible to most people suffering with chronic illness (Chesla, 2005).

Experiencing chronic illness may result in people losing the thread that connected who they felt themselves to be in the past to who they perceive themselves to be in the present and to whom they envisioned themselves to become in the future. Self-concepts may shift and, at times, become elusive. The self in the present is somehow set adrift, somewhat disconnected from who one was prior to illness and from who one perceived one would become in future years. As Charmaz (1991) notes, when chronic illness occurs, how one views oneself is forever altered in “an irretrievable past, an unsettling present, and an irrevocably changed future” (p. 229). Diedrich (2007) claims that chronic illness triggers a dilemma in which a person’s sense of embodiment is destabilized, a dilemma that is often experienced by the person as a rupture (p. 116-117). People respond to this rupture in different ways, perhaps dependent upon the nature and extent of their illness experience. Frank (1996) discusses three types of illness narratives, not necessarily distinct from each other, that may capture for some the experience and struggle of chronic illness – narratives of restitution, chaos and quest. These narratives may offer some insight into the experience of chronic illness that some people may find helpful, but they do not capture the fullness and depth of illness as experienced by others, most especially those whose chronic illness experience slowly moves into a terminal phase. The narratives offered by Frank (1996) may be found inadequate in the face of unending suffering and impending death. As Diedrich (2007) notes, narratives eventually fail because they cannot possibly capture the unmaking of the self that occurs in many chronic and terminal illnesses. They may fail because there “is nothing in the experience of living to compare it to” (p. 75). The experience of increasing aloneness that occurs in many chronic and terminal illnesses evades explanation and cannot possibly be grasped

fully by those of us still living fully in this world, a world removed from the experience of those who can no longer fully and freely participate in it.

2.1.3 Self-management and chronic illness. Despite the impossibility of fully grasping the experiences of those living and dying with chronic illness, appropriate support can still be provided to people as they move through their illness experiences. A plethora of studies have been conducted exploring single dimensions of chronic illnesses, thereby studying aspects (compliance, social activities, physical pain) of the illness experience in isolation from the fabric of daily lives lived with chronic illness (Wright & Kirby, 1999). This focus on single dimensions has resulted in an understanding of “self-management”, as an activity people living with chronic illness engage in, rather than a holistic approach to integrating the effects of chronic illness into the lives of those experiencing it (Thorne, Paterson, & Russell, 2003). In a study conducted by Kralik et al. (2004), it was found that health professionals view self-management as a structured educational engagement, while patients view it as a process of bringing order into their lives. Dubouloz et al. (2010) found that this focus by health professionals often frustrated patients and left them feeling as if the health professional defined them only in terms of their disease, whereas they viewed themselves as people seeking to integrate an illness experience (Dubouloz et al., 2010).

Independence, self-efficacy, and taking responsibility for one’s life have been found, time and time again, to be of central importance as people work to integrate illness experiences. Self-management, the process of bringing order into one’s life, is key to this integration (Cardarelli, Vernon, Baumler, Tortolero, & Low, 2007; Delmar et al., 2006; Dubouloz et al., 2010; Kralik, Koch, Price, & Howard, 2004). The ability of people to

self-manage depends on both personal and social contexts. A personal sense of efficacy, that is the belief that one can master, control and shape one's life, may provide empowerment and encourage health-promoting behaviours; and, during times of illness, may contribute to improved quality of life (Cardarelli et al., 2007).

It is well documented that this personal sense of self-efficacy is socially embedded (Vassilev et al., 2010). Supportive social relationships contribute to positive adaptation to chronic illness through both emotional and practical assistance. Over the past quarter century, much research has convincingly documented the beneficial effects of social support on a variety of positive chronic illness outcomes, morbidity and mortality (Gallant, 2003). Social support reduces psychological distress and promotes psychological adjustment to chronic illness (Curtis, Groarke, Coughlan, & Gsel, 2004). Social support also contributes to medical adherence and more positive outcomes (Sells et al., 2009; Wells & Anderson, 2011).

Research has clearly shown that single aspects of self-efficacy and social support benefit the health and well-being of people living with chronic illness. Yet, very little research has been conducted exploring the *connections* between self-efficacy, social support, and chronic illness. A mixed method study on the challenges of patients' unmet palliative care needs in the final stages of chronic illness conducted by Fitzsimons et al. (2007) does shed some light on these connections. In this study, patients (n=18) with a diagnosis of end-stage heart failure, renal failure or respiratory disease and their significant others (n=17) completed questionnaires and were interviewed. Deteriorating health status was a central theme derived from the analysis. This deterioration, in turn, led to decreased independence, social isolation and increased caregiver or family burden,

in other words a diminished sense of self-efficacy. Accessing financial benefits and specialist appliances were found to be particularly challenging. For example, even the resources required to meet basic needs, such as a downstairs toilet or commode, were usually difficult to attain. Friends and family were identified as the main source of support in both physical and emotional care, and both patients and caregivers expressed the desire for greater social support from the community. This study highlights the cascading impact that loss of self-efficacy and lack of social support can have on people living with chronic illness and their caregivers. It also highlights the complexity of issues faced by many people living with chronic illness, even in meeting their most basic needs; and the need for a more holistic approach to the care of chronic populations. For participants in the Fitzsimons et al. (2007) study, the lack of a holistic approach left them feeling isolated, depressed, and either worrying about their futures or accepting the inevitability of imminent death without what they considered necessary supports in place to ensure a “good death”.

2.1.4 Summary. Even though chronic illnesses are the major cause of death and disability in Western societies, high quality medical care specific for persons with chronic illness in those societies is virtually non-existent. Due to this lack of high quality medical care, people living and dying with chronic illnesses also experience chronic suffering with little, if any, relief provided in the acute biomedical healthcare delivery systems of Western societies. As people experiencing chronic illnesses advance to a terminal phase, their palliative needs also remain largely unmet (Curtis et al., 2002; Delmar et al., 2005; Edmonds et al., 2001; Gore et al., 2000; Guthrie et al., 2001; Murray et al., 2002). There remains considerable uncertainty concerning what people

experiencing chronic illness need in order to attain and maintain optimal health and well-being in their varied circumstances as they strive to live with chronic illness and as they approach end-of-life (Curtis et al., 2002; Delmar et al., 2005; Edmonds et al., 2001; Ironside et al., 2003; Murray et al., 2002).

2.2 Chronic Suffering

Chronic illness is often enduring, progressive and permanent, involving an alteration in the lives of people suffering with it (Ohman et al., 2003). Chronic suffering, like that of chronic illness, is an umbrella term capturing how individuals experience and live with chronic illnesses, especially when the individual's life is transformed and is experienced as more difficult due to the chronic illness (Delmar et al., 2005). Illness stories or experiences share a common root in suffering. Suffering cuts across worlds of gender and race as well as all types of disease. Suffering is “an existential universal of human conditions”, experienced uniquely by each individual; yet, also an experience dependent upon the distinct socio-cultural worlds that individuals inhabit (Frank, 1995, p. 170). Individuals may tell uniquely personal illness stories, but individuals neither make up these stories by themselves nor tell these stories only to themselves. Individuals are always culturally and socially embedded; therefore suffering can only be experienced and understood in the individual's lived world; that is in their personal, social and cultural life contexts (Frank, 1995; Lethborg, Aranda, & Kissane, 2008).

Chronic suffering, the lived experience of illness - the experiences of loss of strength, energy and power to live – presents the human being with a sense of disorder. Chronically ill individuals often experience loss of control over their bodies and loss of self-perception. For many, to lose control over one's body is to lose control over oneself

and one's life. When chronic illness is experienced, the integrity of an individual's basic identity and social roles is challenged. Kleinman (1988) maintains that suffering occurs when a threat is perceived to the integrity of what he terms the "body-self", which is the self in its entirety encompassing all aspects of being for the person (p. 11). Suffering is not a static experience and can occur in any or all aspects of the person. It involves the perception of a threat to integrity of self and resistance to that perceived threat (Kleinman, 1988). At the core of this resistance lies the person's continuous struggle to learn to live with bodily limits and to create new understandings of what life now is, and will be, in a world of uncertainty with no stable "self" to rely upon (Ironsides et al., 2003).

2.2.1 Chronic illness as a social construct. According to Kleinman (1988), the struggle to create new understandings as people learn to live with chronic illness will be strongly influenced by our experience of chronic illness as it is socially constructed. Therefore, to understand illness, meaning and suffering, we need to understand how the body is normatively constructed in relation to the self and the world. Integral aspects of local culture and society instill in us ways to feel, perceive, and interpret bodily feelings and processes. According to Schatzki and Natter (1996), society is not a construct or system of rules that individuals adhere to; but rather, society is something embodied by individuals. By virtue of living in a society or culture, people are *eo ipso* drawn into the reproduction of that society or culture; and that society or culture in turn forms and informs the bodies of those who constitute it. Social order rests upon, or more precisely, within and among the bodies that inhabit societies (p. 1-9). We learn how to react to pain, label and communicate troubles of any kind through our lived environments. Hence, at the very core of our experience of chronic illness lies a tightly knit integration

of physiological, psychological, and social meaning. For Kleinman (1998), bodily processes can only be known and expressed through socially constructed categories (p.13-17). Similarly, in his book addressing body, illness and ethics, Frank (1991) maintains that our experiences of illness and suffering are articulated through social norms that have been internalized throughout our lives (p. 64-71). However, these experiences and articulations of personal suffering can become problematic in a society and culture where our personal experience of illness and suffering is taken over by technical expertise, where the story that trumps all others is the medical narrative.

2.2.2 Personal voices and socio-medical constructed narratives. The concession to have one's personal experience of illness transformed into a medical narrative is almost intrinsic in accessing necessary medical care in Western societies. Often, to attain the medical care we require, we not only agree to follow regimens as prescribed by medical systems, but also implicitly agree to interpret and tell our illness stories in medical terms. In these medicalized narratives lies the danger that our personal experiences will be reduced to pains and symptoms in a language not of our own making (Frank, 1995, p. 3-5). These narratives can potentially silence suffering associated with illness and rob individuals of the capacity to interpret and to voice their particular stories within their lived contexts. In the medical context, the story of "my" suffering often is transformed into the medical professional's story of "my" chronic disease and "their" struggle to manage symptoms. In a real sense, the objectifying language of the medical system camouflages how chronic illness is experienced (Ironsides et al., 2003). It can leave people who are suffering with a sense of being victimized by the very system that is designed to alleviate their suffering. Once illness is medicalized, the physician becomes

the spokesperson, and the ill person's story relies heavily on repeating what the physician has said (Frank, 1995, p. 6). This repetition very often involves only details of functional status and symptom control. In a study conducted by Ironside et al. (2003), participants suffering with chronic illness express that, although important, it is not their functional status or symptomology that is paramount. Rather, what is paramount is the meaning and impact of their functional status or symptoms in their lived worlds; that is, how their daily lives and activities are affected by their illness experience. For these participants, most suffering comes in working out the day-to-day living with chronic illness and the small everyday tensions that illness creates for them and their loved ones.

Some people suffering with chronic illness may feel that their illnesses are recognized, understood and addressed to some degree within acute care medical models. These people may engage the system, but may very well view the healthcare delivery system as a place only to access physical medical care, a place connected to, but remaining outside of their lived experience of illness (Frank, 1991). Other people, most especially in the case of environmental illness, struggle for recognition within acute care models. Many of these sufferers have, themselves, appropriated the symbols of biomedicine to construct biomedical accounts of their illness experiences. Rather than rejecting biomedicine entirely, people who struggle to have their illness diagnosed, or even recognized by the medical system, may separate biomedical knowledge from the "expert" medical system, and engage with this knowledge on their own terms in the construction and understanding of their illness experiences (Kroll-Smith & Floyd, 1997, p. 6-10).

2.2.3 Summary. Even though there is mounting evidence suggesting that people suffering with chronic illness may require palliative and supportive services, such as the psycho-social empathetic care mentioned above, few such services are available and chronically ill people are left to endure their suffering and inherent losses with little, if any, access to supportive services (Fitzsimons et al., 2007; Murray et al., 2002; Shah et al., 2006). All too often, the constructed social norms concerning illness serve to support present day healthcare system delivery models, and these models in turn support our illness constructs. Acute and terminal illnesses are understood to be “illnesses” and their symptomologies appropriately addressed to some extent in the present system; but chronic illnesses are far less understood and the symptomologies of chronic populations are rarely appropriately addressed. People experiencing chronic illness are mostly provided care in primary healthcare delivery systems that were originally and, despite the increased prevalence of most major chronic illnesses, are still primarily organized to react to acute illness (Dubouloz et al., 2010).

Even though the present acute model of care may provide some relief from physical suffering, in its present form it cannot possibly provide adequate care to those suffering with chronic illnesses, most especially those suffering with complex conditions difficult to diagnose, let alone treat. Reinke et al. (2008) noted that medical care in present day healthcare delivery systems is focused on transitions and timely transfer of patients from one level of care to another; very often transfer from acute or curative care to palliative care as end-of-life approaches. Present healthcare delivery system models accommodate acute or malignant populations but have little room for chronic disease

populations that require more than a “one-time” transition from one model of care to another.

2.3 Advanced COPD, healthcare provision, and personal experience

The transitional experiences of chronic illnesses such as COPD are marked by cyclical, overlapping and degenerative phases that can occur over a period of years (Dubouloz et al., 2010). These phases are accompanied by suffering and loss that often go unaddressed. As noted above, healthcare delivery systems in Western societies, as they currently function are challenged to adequately address the many complex and interwoven physical, emotional, social and existential issues contributing to suffering in chronic populations, leaving these populations to experience multiple symptoms that are poorly controlled for long periods, and diminished quality of life as they approach death (Curtis et al., 2002; Fitzsimons et al., 2007; Kite, Jones, & Tookman, 1999; Shah et al., 2006; Tranmer et al., 2003; L. M. Walke, Gallo, Tinetti, & Fried, 2004).

2.3.1 COPD and healthcare provision. COPD is an incurable and progressive respiratory disease in which health status and function declines slowly but inevitably, with end-of-life often bringing poorly controlled symptoms and diminished quality of life (Lynn et al., 2000). The term COPD should be understood to include all pathological health conditions related to smoking and inflammation-driven destruction of lung tissue, including chronic bronchitis and emphysema (Minkoff, 2005; Rocker et al., 2007). This disease is unique among the major non-malignant diseases in Western societies in that prevalence, illness burden and death rates due to COPD continue to rise (Mannino & Buist, 2007). COPD represents substantial and increasing economic and social burdens

in terms of morbidity and mortality (Bellamy & Smith, 2007). The WHO Global Burden of Disease Project estimated that COPD was the fifth leading cause of death worldwide in 2001 and is expected to be the third leading cause by 2020 (Buist et al., 2007). In the year 2000, COPD was the second leading cause of disability after heart disease (Minkoff, 2005). Of the six leading major causes of death in the USA, COPD is the only one to increase steadily over the last 30 years (Jemal, Ward, Hao, & Thun, 2005). COPD is presently the 4th leading cause of death in Canada and will cause more than 20,000 deaths a year by 2018 (Canadian Institute for Health Information, Canadian Lung Association, Health Canada, Statistic Canada, 2001; Lacasse, Brooks, & Goldstein, 1999). In Nova Scotia, a 70% increase in deaths due to COPD is projected to occur from 2004 to 2020 (Network for End of Life Studies Interdisciplinary Capacity Enhancement [NELS ICE], 2008). COPD is an increasing health issue globally, across Canada and within Nova Scotia.

COPD is often not diagnosed until it is moderately advanced (Bellamy & Smith, 2007). Two of the most prevalent reasons for the delay in diagnosis include the fact that many patients and caregivers fail to appreciate that COPD is a life threatening illness, and the highly unpredictable trajectory of COPD itself (Rocker et al., 2007). Many people experiencing COPD, therefore, receive inadequate or insufficient health care until they reach a moderately or severely advanced stage. Even after diagnosis, symptom burden is often not addressed sufficiently (Bellamy & Smith, 2007; Edmonds et al., 2001; L. Walke et al., 2007). There are no agreed upon criterion defining when COPD is considered to be in an “advanced” stage but common sense guidelines have been proposed to identify patients with “advanced” COPD who may benefit from hospice palliative care. These

guidelines include “patients who, despite an adequate trail of optimum and acceptable available treatment, have a chronic lung disease that has progressed to the point that the patient may die at any time because of an ordinary inter-current illness, such as bronchitis or pneumonia” (Rocker et al., 2007).

The final years before death for people experiencing advanced COPD are characterized by progressive functional decline, poor quality of life, and increasing dependency on informal (family) caregivers. Compared to patients with cancer, patients with COPD spend more time in hospital as their disease progresses (Au, Udris, Fihn, McDonell, & Curtis, 2006) and suffer from greater symptom burden (Gore et al., 2000; Solano, Gomes, & Higginson, 2006). As the predominant symptom, dyspnea is more likely to be poorly controlled (Claessens et al., 2000) and incapacitating (Bailey, 2004; Edmonds et al., 2001; Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005). Palliative care services and high quality symptom-focused interventional strategies are also less accessible to the COPD population than to malignant populations (Grbich et al., 2005; Luddington, Cox, Higginson, & Livesley, 2001; Solano et al., 2006). There have been several calls for greater involvement of palliative care services for patients with advanced COPD but this type of involvement has yet to be evaluated (Rocker et al., 2007). Even though a plethora of studies indicate a high level of symptom burden that is often poorly controlled in the COPD population, and even though the engagement of palliative services appears intuitive, little research has been conducted exploring how patients perceive and experience their illness process and the interventions they, themselves, may view as beneficial (Barnett, 2005; Elkington, White, Addington-Hall, Higgs, & Pettinari, 2004; Gore et al., 2000; Janssen, Wouters, Schols, & Spruit, 2008).

2.3.2 Dyspnea. The studies that have been done exploring aspects of patients' experiences of COPD have largely focused on dyspnea as the predominant symptom, and anxiety and depression as the two most common comorbidities. In its simplest definition, dyspnea can be understood as breathlessness, as some form of difficulty breathing (Bailey, 2004; Lynn et al., 2000). Dyspnea and breathlessness are terms that will be used interchangeably throughout this paper to indicate a subjective experience of breathlessness. I consider dyspnea to be more of a medical term; and breathlessness to be more of a lay descriptive term describing the experiences associated with *feeling* a lack or loss of breath. Dyspnea has been defined by the American Thoracic Society (ATS) as "the term generally applied to sensations experienced by individuals who complain of unpleasant or uncomfortable respiratory sensations" (American Thoracic Society, 1999, p. 322). The ATS consensus statement goes on to say that dyspnea arises "from interactions among multiple physiological, psychological, social, and environmental factors that may induce secondary psychological and behavioural responses" (p. 322). Dyspnea, therefore, is a complex and challenging phenomenon that appears to be interrelated with other morbidity and mortality risk factors. Nicholls (2000) states that dyspnea is "unique to the individual....bound up in his or her lived experience, hopes and aspirations, disappointments and frustrations" (p. 24). Studies conducted exploring the interrelations between dyspnea and life experiences have been inconclusive. Dyspnea has been associated with decreased quality of life, panic, fear and anxiety (Bailey, 2001; Bailey, 2004; Barnett, 2005; Godoy & Godoy, 2003; Maurer et al., 2008; Ries, 2006). Patients who survive a hospitalization after an acute exacerbation (severe loss of breath) of COPD often experience dyspnea for the rest of their lives (Lynn et al., 2000).

In a systematic review of dyspnea, Gysels et al. (2007) found that there is a paucity of literature on the meaning of symptom experience for these patients and their ability to manage. This systematic review claims that breathlessness is a complex, multifaceted and active process that is interwoven into the person's understanding of self. In actuality, breathlessness is something that can only be perceived and interpreted by the person her- or himself. There has been no definitive relationship established between breathlessness and physiological measures. Some people experience severe dyspnea with minimal physiological changes while others experience very little dyspnea with severe disease experience. It is, therefore, surprising that most of the research on dyspnea has been of a purely medical nature and has approached the symptom by quantifying it with objective measurement tools. The experience of dyspnea from the perspective of patients and caregivers in relation to personal perception and social influence has received little attention.

2.3.3 Dyspnea and related psycho-social illness factors. Research has explored the relationship between dyspnea and psychological factors such as depression and anxiety, but the precise relationship between dyspnea, anxiety, depression, and quality of life remains unknown. Many variables have been implicated in the dyspneic experience including physical disability, long-term oxygen therapy, living alone, low social class status and severe dyspnea (Maurer et al., 2008). Correlations have been found between dyspnea, anxiety, depression, and quality of life, with the relationship between dyspnea and anxiety receiving particular attention (Giardino et al., 2010; L. Walke et al., 2007). In a study conducted by Baily et al. (2004), a dynamic interaction between dyspnea and anxiety was reported by participants. Participants found anxiety to

be more of an indication of long standing or acute respiratory failure than an underlying cause of dyspnea. The presence of anxiety served as an indicator to them that they were actually breathless. In another study conducted by Mauer et al. (2008), it is suggested that anxiety may also be associated with such factors as pharmacologic effects of certain medications, high-dose corticosteroid therapy, and/or a concurrent depressive syndrome. There is consensus in the literature for the necessity of further research into the interrelationships between dyspnea, anxiety, depression, and quality of life in the COPD population (American Thoracic Society, 1999; Barnett, 2005; Cully et al., 2006; Elkington et al., 2004; Giardino et al., 2010; Gudmundsson et al., 2006; Guthrie et al., 2001; Lindqvist & Hallberg, 2010; Nicholls, 2003; Nicolson & Anderson, 2000).

Though the interrelationships between such health measures is not yet clear, a high prevalence of anxiety and depression in the COPD population has been noted. In a systemic review conducted by Solano et al. (2006), it was concluded that the prevalence of depression in the COPD population ranged from 37 to 71% and that of anxiety from 50 to 75%. It has been reported that two thirds of COPD patients with depression suffer from moderate to severe depression and that the prevalence of minor or subclinical depression may be even higher (Kim et al., 2000; Yolannes, Baldwin, & Connolly, 2000). Yolannes et al. (2003) found that approximately one-fourth of COPD patients had unrecognized subclinical depression. Studies have shown that 10 to 80% of the COPD population suffer from anxiety, exceeding that for patients with other chronic medical conditions, and a 3 to 10 fold increase compared to the general population. The two most commonly diagnosed anxiety disorders are generalized anxiety disorder and panic disorder which may occur in at least one third of COPD patients (Giardino et al., 2010;

Karajgi, Rifkin, Doddi, & Koli, 1990; Moore & Zebb, 1999; Yellowlees, Haynes, Potts, & Ruffin, 1988). Anxiety and depression are often undiagnosed, untreated or undertreated in this population (Cully et al., 2006; Lewis et al., 2007; Maurer et al., 2008).

2.3.4 Summary. To date, the disease-specific focus of most research conducted on COPD does not adequately reflect the full burden of symptoms, nor how people diagnosed with COPD experience their chronic illness based on their own perceptions. (Augusti, 2008; Barnett, 2005; Janssen et al., 2008; Lindqvist & Hallberg, 2010; Nicholls, 2000; Thorne et al., 2002; L. Walke et al., 2007). As is the case with many chronic diseases, and despite current knowledge concerning the impact of COPD on the lives of people who suffer with it, the symptoms, care needs, quality of life, end-of-life care treatment preferences and end-of-life care communication of patients with advanced COPD have been scarcely studied. Studies examining indicators of mortality and survival have been published but provide little insight into how patients experience their illness as they approach the end-of-life (Lynn et al., 2000). This research will explore how people living with advanced COPD experience their illness from their own perspectives.

CHAPTER 3: INTERPRETATIVE PARADIGM

Researchers are generally guided by principles that are derived from how the researcher views the nature of reality and what it means to be a human being (ontology), the relationship between the knower and what is known (epistemology), and how one knows the world or acquires knowledge of it (methodology). According to Denzin and Lincoln (2003), the researcher's ontology, epistemology, and methodology inform their approach to the research (p. 33). In what follows, I will present my worldview, theoretical perspective and strategy of inquiry (ontology, epistemology), methods and methodological approach (methodology).

The methodological approach I have chosen to guide my research process is Heideggerian hermeneutic phenomenology rather than Husserlian transcendental phenomenology. I have chosen Heideggerian hermeneutic phenomenology as a methodology because it fits with my ontological and epistemological framework of understanding. The underlying philosophical basis of Heideggerian hermeneutic phenomenology allows for an understanding of human beings as biopsychosocial organisms, as distinct individuals who are always in communion with, and influenced by, other distinct individuals (*Daseins*). It considers that knowledge is constructed in our inhabited contexts against a backdrop of historical, cultural and social experiences (*fore-structures*). Unlike Husserlian phenomenology, Heideggerian hermeneutic phenomenology seeks to understand human experience as it is interpreted within and through the worlds we inhabit. My particular research interest is to understand the everyday life experience of advanced COPD from patients' perspectives.

There is a great deal of confusion in the literature concerning similarities and differences found in Husserlian and Heideggerian phenomenology. I have included a summary of my understanding of Husserlian phenomenology in the section on *Methodological Approach* in order to clarify for the reader my understanding of that particular phenomenological approach and how it relates to the approach I have adopted for my research. Also, for clarity, I will present phenomenology, Husserlian transcendental phenomenology, hermeneutics, and Heideggerian hermeneutic phenomenology as separate sub-sections. All four concepts are distinct, yet interrelated. Both Husserl and Heidegger engaged in phenomenology to characterize the basic ways in which we encounter things. They differed significantly, however, in their understanding of, and approach to, phenomenological inquiry. Husserl's transcendental phenomenology is epistemological, focusing on the mystery of consciousness; while Heidegger's hermeneutic phenomenology is ontological, focusing on the mystery of being.

3.1 Worldview underpinning this research

I have been involved in health research for approximately eight years, working in various roles (interviewing, managing and coding data, data analysis). I have also worked for the past twelve years or so as a clinical chaplain with diverse populations. For the past two years, I have been involved in research with populations experiencing advanced COPD, their informal caregivers and their health care professionals. I have conducted interviews, coded and analyzed qualitative data on three studies relating to the use, and the impact, of low-dose opioids for relief of dyspnea. While working on these

studies, I have become increasingly interested in the quality of life experienced by people living with advanced COPD, and, in particular, how they experience their illness.

Through both my personal and professional experiences, I have come to view the lives we live and the stories that constitute these lives as narratives woven together within the broader social and cultural contexts that we inhabit. Ontologically (the nature and structure of being), I view humans as biopsychosocial spiritual organisms who continuously interact with their environments (Parse, 1996; Rawnsley, 1998). A positivist epistemology claims that truth and meaning are objective, measureable and verifiable; and when perceived by human senses can only be portrayed as knowledge once they have been processed by rationalistic, inductive and reductionist logic (Guba & Lincoln, 1998; Sarantakos, 1998). In contrast, I see truth and meaning as situated, embodied, and subjective in nature; and essentially the construction of individuals as they interact within their environments (Lincoln & Guba, 2003). In a social constructivist paradigm, all knowledge is sustained through a myriad of transactions that we have with other people, social institutions, and (constructed) natural and social worlds. (Bailey & Tilley, 2002; Williams & Collins, 2002). Truth, meaning and knowledge are not viewed as objective, measureable or verifiable. Truth, meaning and knowledge can, however, be trustfully interpreted and represented. Evaluation of whether research trustfully represents truth, meaning, and knowledge ultimately lies with the trustworthiness of the research and with the reader's assessment of that trustworthiness. This research will be guided by social constructivism, a worldview that endorses the existence of multiple constructed social realities, the mutual creation of knowledge by the knower and the known, and an

understanding of knowledge as individual and social constructions (Charmaz, 2000; Guba & Lincoln, 1998).

3.2 Strategy of Inquiry

A qualitative, social constructivist strategy of inquiry will be utilized to capture how people living with advanced COPD experience their illness. Utilizing a qualitative approach will be necessary to gain knowledge of participants' experiences, perspectives and understandings. Within qualitative research, subjectivity is appreciated and valued, and participants are recognized as the experts of their own experiences (Bailey & Tilley, 2002; Wuest, 1995). Social constructivism stresses the socially constructed nature of these experiences and the contexts in which they unfold. As stated earlier in this thesis, we constitute our social world as our social world constitutes us. All experience is constructed, understood and experienced within an individual's social world. Qualitative research seeks knowledge concerning how experience is created and given meaning in these social worlds (Denzin & Lincoln, 2003). Furthermore, qualitative methodologies are particularly well suited to guide research in which little is known about the phenomenon under study (J. Morse & Field, 1995). Qualitative researchers use qualitative data to formulate a picture of the phenomenon under study, as experienced by participants. For example, in this research I will discuss the experience of participants while providing vivid exemplars in which the participants themselves describe the experience in their own words. Knowledge development within qualitative research occurs as a result of an inductive approach to data analysis, "which means that categories, themes and patterns come from the data" (Janesick,

2003, p. 63). Exemplars that provide the “voice” of participants are key to understanding how they perceive their experience.

3.3 Methods

3.3.1 Secondary Analysis. My research involves a secondary analysis of existing data collected for the purposes of another study. The data that I will explore for secondary analysis are eight transcripts collected from qualitative interviews conducted in Nova Scotia in 2010. The purpose of my secondary analysis is distinct from the primary study for which these interviews were conducted (Heaton, 1998; Mason, 2007; Thompson, 2000). The primary study will be explained in more detail in the section below, but the initial qualitative component was designed to gain understanding of the experience of living with low dose opioids prescribed for severe dyspnea in advanced COPD; whereas the purpose of my secondary analysis is to explore what it is like to live with advanced COPD before the administration of low-dose opioid therapy. As the appended interview guide shows [Appendix A], the initial qualitative questionnaire included questions encouraging participants to discuss what it is like to live with advanced COPD before the opioid intervention begins. It is the data derived from these initial baseline interviews before the commencement of the opioid intervention, which formed the basis for my research.

Criteria for secondary qualitative data analysis continue to develop and evolve in response to the need to extend contexts in which labour-intensive and costly qualitative research data can be used (Williams & Collins, 2002). This approach can be used to generate new knowledge or support existing theories; can permit wider use of data from

rare or inaccessible participants; and, as is the case for this present study, it can reduce the burden placed on vulnerable participants by negating the need to re-interview or recruit further (Heaton, 1998).

My secondary analysis is utilized as a strategy for maximizing an existing data set by posing additional research questions beyond those for which the original data set was created (Hinds, Vogel, & Clarke-Steffen, 1997; Sandelowski, 1997; Thompson, 2000). The specific type of analysis that I will utilize is “retrospective interpretation,” that is the analysis of narrative data that was not fully examined in the primary study (Bailey, Montgomery, & McMillan Boyles, 2009; Sandelowski, 1997; Thorne, 1994).

3.3.2 Primary Study. The primary study was a multi-site research study recently conducted across three provinces in Canada. The principal objective of this larger study was to understand the experiences of patients and informal caregivers living with severe COPD following the addition of opioid therapy to conventional treatment; and to explore the effect of opioid therapy on dyspnea and on quality of life, anxiety, depression, and caregiver experiences to determine the proportion of patients finding opioids helpful at 6 months.

The methodological approach for the multi-site study was mixed methods (triangulation design with convergence model). To ensure data were rich enough to provide insight into patients’ and family members’ experiences of living with opioid therapy, sampling was purposeful to achieve a relatively homogeneous sample of participants (both patients and informal caregivers) who have experienced the phenomenon (exposure to low dose opioids). Thirty participants (15 patients and 15 caregivers) were recruited in each of the three provinces. The inclusion criteria included

a primary diagnosis of advanced COPD; eligibility for treatment with low-dose opioids on grounds of ongoing dyspnea despite optimal conventional treatment for advanced COPD according to 2008 Thoracic Society COPD guidelines; freedom from acute exacerbations for at least four months; and completion of a pulmonary rehabilitation program for at least 6 months. People were excluded if they had an overlap syndrome (COPD and sleep disordered breathing); were already taking opioids; had a documented adverse reaction to opioids; or where there were patient safety concerns during the conduct of the study; cognitive or other difficulties that would preclude questionnaire completion; inability to speak or understand English; patients considered to be dying or with an expected survival of less than 2 months.

Qualitative data collection involved three separate sets of qualitative semi-structured interviews with each participant: one at the onset of the study before the commencement of the opioid intervention; one at a two month interval after the commencement of the opioid intervention; and one at six months after the commencement of the opioid intervention, which concluded the data collection phase. Interpretive description, a grounded approach that facilitates enhanced clinical understanding of complex health-related experiences with the goal of informing clinical practice, is being used to analyze the qualitative data. Quantitative data collection occurred concurrently and included the completion of baseline questionnaires (The Chronic Respiratory Questionnaire (CRQ, for patients), The Hospital Anxiety and Depression Scale (HADS), the McGill Quality of life tool (for patients and caregivers), Caregiver Reaction Assessment (CRA, for caregivers), and demographics information.

3.4 Methodological Approach: Heideggerian Hermeneutic Phenomenology

Phenomenology can be understood as both a philosophy and a philosophically oriented research process that was originally developed as an alternative approach to the empirically based positivist paradigm (McConnell-Henry, Chapman, & Francis, 2009a). As a philosophical construct, phenomenology is complex and difficult to understand. Employed as a research method or methodology, it becomes even more complex and difficult, yet widely utilized in qualitative research. Some authors argue that phenomenology should not be utilized in qualitative research, and that, in fact, it is not a method at all (Clare & Hamilton, 2003; Crotty, 1996). They maintain that the concepts of method and sciences are insufficient to address the complexities of human living in general (Gadamer, 1975, p. 18). Others, myself included, situate ourselves in the grey area between these two polarizing positions. Many authors recognize phenomenology primarily as a philosophy, but also utilize this philosophical tradition to ground and guide methods employed in research processes (Cohen, 1987; Findlay; Houston & Mullan-Jensen, 2011; Larkin, Eatough, & Osborn, 2011; McConnell-Henry, Chapman, & Francis, 2009a; Norlyk & Harder, 2010; van Manen, 1997; Wojnar & Swanson, 2007). As with these authors, I understand phenomenology primarily as a philosophical tradition that can be employed to ground and guide a variety of research methods or methodologies (Dowling, 2007; Norlyk & Harder, 2010). In my research, I will utilize hermeneutic phenomenology as a methodological approach, drawing upon the philosophical concepts of the Heideggerian philosophical tradition.

3.4.1 Phenomenology. Etymologically, the word phenomenology is a transliteration of the ancient Greek word, *phainomenon*, which is a form of the verb,

phaino, meaning “to show”, “to bring to light” or “to shine or gleam” (Sembera, 2007, p. 53). According to Merleau-Ponty (1962, p. vii) phenomenology is “the study of essences”. Rather than an understanding of *essence* as some mysterious entity or some ultimate core of meaning, the term may be understood as a linguistic construct, a description of a phenomenon. The questioning of the essential nature of lived experience, of a certain way of being-in-the-world, is an appropriate topic for phenomenological inquiry. Phenomenology always asks what the nature of the phenomenon is as it is meaningfully experienced (van Manen, 1997, p. 39-40). Phenomenological inquiry, then, can concern itself with both the concreteness (ontic) and the essential nature (ontological) of lived experience. The task of phenomenological research is to “construct a possible interpretation of the nature of a certain human experience” (van Manen, 1997, p. 41).

3.4.1.1 Husserlian Transcendental Phenomenology. The term, “phenomenology”, was first used in the 18th century in a scientific context, most notably by Kant and later by Hegel (Cohen, 1987). As a philosophical tradition, phenomenology owes its origins to the work of the mathematician, Edmund Husserl (1859-1938) in the late 19th century. Husserl was inspired by Franz Brentano. Brentano’s ultimate aim was to develop a “universal science” that would restrict itself exclusively to empirically accessible phenomena and to adequately describe these phenomena. Husserl eventually moved away from Brentano’s philosophy and turning to Hume, Kant, and Descartes for inspiration, he developed a new philosophical approach which he later called *transcendental phenomenology* (Sembera, 2007). His purpose in doing so was epistemological, to find an indisputable basis for all human knowledge (Barkway, 2001).

Three notions dominant in this philosophical endeavour are *intentionality*, *phenomenological reduction*, and *bracketing* (Koch, 1999).

Husserl adopted the concept of *intentionality* from Brentano as a core concept in his development of transcendental phenomenology. Intentionality in this context has little to do with the everyday meanings associated with the term as it is employed today. Husserl used this term to indicate the essential relatedness of consciousness to objects. Husserl believed that every thought is a thought of something. Every desire is a desire for something, and every judgment is an acceptance or rejection of something. In other words, for Husserl, *intentionality* indicates the existence of a binding union between subject and object (Crotty, 1996). It speaks to our relationship with the world and how as conscious, embodied, and situated persons our experience is always of something as it appears in the world. An intentional act is comprised of a relationship between that which is experienced, and how it is experienced by human consciousness (Larkin et al., 2011). Intentionality, therefore, refers to the internal experience of being conscious of something (Dowling, 2007).

For Husserl, the purpose of phenomenology was to arrive at an essential understanding of human consciousness and experience through an unbiased study of things as they appear. A key epistemological strategy proposed by Husserl was *phenomenological reduction*. Husserl's aim was to understand human experience in the life-world (*Lebenswelt*). He believed that to effectively accomplish this understanding one has to purify one's consciousness of its natural attitude by suspending one's belief in the actual existence of the objects of experience (Crotty, 1996). In other words, one attempts to meet the phenomenon as free and unbiased as possible so that the

phenomenon presents itself as free and unbiased as possible. In this way, the phenomenon can be precisely understood and described as free as possible from its social and cultural context (Dowling, 2007).

To accomplish phenomenological reduction, Husserl advocated the neutralizing of the ontic residue of consciousness (McConnell-Henry, Chapman, & Francis, 2009a). In other words, one must “bracket” or suspend implicit judgments that they have always made in advance concerning how things have to be and how they should show up, so as to see them as they actually do show up. Husserl utilized the concept of *epoche* to describe this process. *Epoche* is a Greek word meaning to “refrain from judgement or to stay away from the everyday, commonplace way of perceiving things” (Dowling, 2007, p. 132). We do not simply discard attitudes and accompanying assumptions, however, but we continually work against them in an increasingly radical series of “reductions” that “bracket” or suspend them. In this way, we eventually shift ourselves into a radically different attitude that is free to see things as they appear (Greaves, 2010, p. 9) so as to see them as they actually are.

In summary, transcendental phenomenology is a descriptive phenomenology that has a complex philosophical history. Husserl, although acknowledging that the natural sciences could not adequately explain lived experience, nonetheless remained a positivist. He was not interested in everyday life, individuals, or in existing things. His primary interest was in concepts, in “the things themselves” as they appear in consciousness before we attempt to grasp them in a changeable external world. He believed that a characteristic of our “natural attitude”, the way we go about daily living, constituted a naive belief in existence; that is a belief in external objects in an external world. Husserl

believed that through exercising the *epoche* we could disable belief in an external world. This belief is referred to by Husserl as the general thesis of the natural attitude. By disabling this belief, he maintained that we would completely eliminate the changeable external world as a source of error and enter a realm in which complete certainty is possible because this realm would be the transcendental foundation of all further experience (Sembera, 2007, p. 18-19). Therefore, transcendental phenomenology calls for investigators to set aside all preconceptions through the procedures of bracketing and to define the phenomenon under investigation in universal descriptive terms. The ultimate test of quality of this description would be testimony from the participants themselves that the investigator's universal description of the phenomenon has captured their personal experiences (Wojnar & Swanson, 2007).

3.4.2 Hermeneutics. Etymologically, hermeneutics is a Latinized version of the Greek word, *hermeneuein*. Hermeneutics means to “interpret” or to “understand”. In folk etymology there is an obvious link to Hermes, who functioned as a messenger of the gods, translating divine knowledge and understandings to humans concerning the decisions of the gods. Hermeneutics as a disciplined approach to texts can be traced back to the ancient Greeks studying literature and biblical exegesis in the Judeo-Christian tradition. Texts were taken as a whole. Therefore, grammar and style were expected to be consistent in any particular text. On this basis, principles of grammar and style were developed and used to identify the logic found in particular authors and schools. Hermeneutics has a long and complex history, but it was Martin Heidegger (1927) who fully transformed this understanding of hermeneutics. For Heidegger, hermeneutics was not a body of principles or rules for interpreting texts. He saw hermeneutics as

ontological understanding, as concerned with the most fundamental conditions of humans' being in the world (Reinhart, 2011).

3.4.3 Heideggerian Hermeneutic Phenomenology. While Husserl was fascinated with the mystery of consciousness, Heidegger spent his life-time focused on the mystery of being. Both Husserl and Heidegger engaged phenomenology to characterize the basic ways in which we encounter things. Husserl, however, maintained that consciousness is always directed toward something that it *intends* and that phenomenology is primarily interested in describing how this directing ourselves towards things brings about their appearance. His focus was epistemological (Greaves, 2010). Heidegger, on the other hand, sought to understand or interpret lived experience in cultural, social and historical contexts of everyday life. He maintained that the primary concern of phenomenology was the meaning of *being*, of our presence in the world. Unlike Husserl, Heidegger believed that human beings are hermeneutic or interpretative beings who cannot encounter things in isolation from their lived worlds. Meaning always exists, but to discover meaning one needs to find the meaning of being in the context of that being. Heidegger's focus was ontological. He viewed phenomenology as an academic discipline to address the being of entities – ontology. His name for this systematic pursuit is hermeneutic phenomenology (Dowling, 2007; Sembera, 2007, p. 55-57; Wojnar & Swanson, 2007). Three key concepts of Heidegger's phenomenological philosophy that were drawn upon to guide this research are discussed below.

3.4.3.1 *Dasein*. Heidegger used the concept of *Dasein* to emphasize that individuals cannot abstract themselves from the various contexts that influence their choices and give meanings to their lived experience (Wojnar & Swanson, 2007). *Dasein*

is a German word that, in everyday terms, means “existence”. Etymologically, *Dasein* is a compound of the adverb *da* (there) and the infinitive *sein* (being). Heidegger uses the term in its strict sense, denoting “being-in-the-world,” or the constitutive unity of the world, the self, and the world-self relation. At times, however, he also uses the term as a synonym for the self alone. Heidegger maintains that there are many separate selves or individuals, but that all of these individuals share and constitute a common world (Sembera, 2007, p. 47).

3.4.3.2 Hermeneutic Circle. From a Heideggerian phenomenologic view, temporality is constitutive of being in that neither knowledge nor experience is gained statically. Heidegger did not see time as linear, chronological time. He maintained that time was fluid and that attempting to explain human experience in an atemporal fashion, as Husserl attempted, was nonsense. Past experiences influence both present and future interactions. Humans are at all times immersed in their world and that world strongly influences both existence and experience. Therefore, every interpretation begins with some preliminary frame of reference, some preliminary understanding of the thing in question. Heidegger termed the basis for this preunderstanding the “forestructure of understanding”. This forestructure is an existential aspect of the *Dasein* itself. The forestructure is threefold consisting of fore-having, fore-sight, and fore-conception. Fore-having indicates the practical familiarity or background practices that individuals come to a situation with from their own world. Fore-sight indicates the socio-cultural background that provides a point of view from which interpretation is made. Fore-conception indicates the socio-cultural background that provides a basis for anticipation of what might be found in an investigation. Together, these three concepts are called the

hermeneutic situation, and they determine the way in which things are interpreted. In carrying out an act of interpretation, we begin from a particular hermeneutic situation (our forestructure) and move towards a particular understanding of the phenomena or situation we seek to understand (Sembera, 2007, p. 90; Wojnar & Swanson, 2007).

It is our forestructure that opens the door to the hermeneutic circle in the “proper” way. Traditionally, the hermeneutic circle signifies a methodological process of understanding, namely that of coming to understand the meaning of the whole of a text; and coming to understand that its parts are interdependent activities of the whole. One can only make sense of the whole by grasping the meaning of its parts and grasping the meaning of the parts depends on having some sense of the whole. For Heidegger, this circularity of understanding is not only a methodological process of understanding, but belongs to the structure of meaning itself, and the structure of meaning is rooted in the existential constitution of *Dasein*. By virtue of being a being-in-the-world, we are always and inescapably in the hermeneutic circle. All interpretation and understanding takes place in our lived contexts and there is no special experience or meaning that can be interpreted or understood outside of those contexts. In other words, we can only be properly understood as a function of our various involvements in the world, and the world in turn can only be properly disclosed and understood by us as a function of our involvements with it. Unlike Husserl, Heidegger maintained that understanding is a subjective experience based upon our socio-cultural backgrounds and experiences and the meanings we attribute to them. The proper way to enter or interpret the circle is to continually examine our forestructures and their impact upon our understanding and interpretation (Kinsella, 2006; Ormiston & Schrifft, 1990).

3.4.3.3 *The role of Moods in Understanding.* For Heidegger, moods hold a particular position in the process of understanding. *Dasein* is relative to the world in which it exists and is, therefore, never devoid of mood or disposition. The mood in which experience is lived is always the starting point of understanding, regardless of the phenomenon. For Heidegger, moods are something that happen to us. They can come over us, at times feeling overwhelming, sometimes feeling as if they are not our own but yet affecting us. According to Heidegger, there is no position in which one can absolutely control or manipulate one's mood. Moods are created in many different ways and for many different reasons. We are at all times engaged in dealing with moods and never free of them. The only way to "master" a mood is by way of a counter-mood. Moods have a double structure. They grip us and in so gripping us reveal to us ourselves and our way of being-in-the-world. Heidegger creates a new term, *existentiale*, to designate this being-in-the-world by way of being in a mood. Moods belong to us as beings that are always in the world and these moods dispose us toward things in a certain way. In Heideggerian thought, moods and the emotions they create are the conditions for intelligence and understanding. Understanding *always* has a mood. Our circumstances affect our mood and our mood, in turn, helps us to understand our circumstances. There is a mutual and continuous reciprocity of mood and circumstance (Greaves, 2010, p. 64-66; McConnell-Henry, Chapman, & Francis, 2009b).

3.4.3.4 *Summary.* Heideggerian hermeneutic phenomenology aims to elucidate the subjective, humanistic meaning of experience, the nature of phenomena as humanly experienced. The goal of hermeneutic research is to enter the world of the person and to interpret the meaning they assign to their experiences (McConnell-Henry, Chapman, &

Francis, 2009a). The concept of *Dasein* is central to the interpretive process. Fundamentally, it denotes a human being with the capacity to ask what “being-in-the-world” means. The meaning each person experiences or understands is subject to the context of their being-in-the-world, and the moods through which they interpret or understand their life experiences at any given point in time. This methodological approach is especially suited for exploring the experiences of health and illness. In the absence of unexpected demands upon our bodies, we often do not notice our bodies in our involvement in the world. But, when illness, such as advanced COPD, places unexpected demands and/or restrictions upon our bodies and how we interact with the world, we become very aware of ourselves as *Daseins*, as beings-in-the-world. Our interpretations of illness experiences in these situations are often filtered through troubling and disturbing moods brought about by unfamiliar and challenging bodily sensations (Larkin et al., 2011).

According to Heidegger, humans cannot abstract themselves from these moods or from the world we experience through them. As we are being constructed by our world, we in turn are constructing this world from our own experiences and background. In a real sense, by virtue of being born into the world we enter the hermeneutic circle and the socio-cultural biases and prejudices we inherit are forces that enter into all of our understanding (McConnell-Henry, Chapman, & Francis, 2009b; Schwandt, 2003). Individuals are situated in ever-changing and varied life contexts and those contexts influence our choices and shape the meanings we attribute to our lived experiences. Therefore, Heideggerian hermeneutic phenomenology seeks to address the situatedness of the individual’s *Dasein* in relation to broader social, political and cultural contexts in

which *Dasein* exists. Hermeneutic phenomenology is rooted in the belief that researchers and participants come to the research with forestructures of understanding shaped by their respective backgrounds and contexts (Wojnar & Swanson, 2007). As already elucidated, these forestructures cannot be forgotten, ignored, or “bracketed”. It is imperative, therefore, that the researcher makes explicit her forestructure and its probable influence upon the research process. In Heideggerian hermeneutic phenomenology, researchers participate in making data precisely due the incapacity to eliminate forestructure. The hermeneutic circle cannot be avoided and, therefore, co-constructed data must be contextualized not only with the participants’ lived context, but also with the researchers’ perspectives.

3.5 Participant Selection

Twenty-eight participants took part in the original study. For the purpose of secondary analysis, I selected eight individuals who most openly explored and vividly described events and emotions concerning their experience of advanced COPD and the impact it has had upon their daily lives; in other words, those who provided the thickest description of their experiences. Thick description refers to the detail participants provide in their interviews as they explain, understand, and meaningfully interpret their life circumstances. Contextual and experiential understandings of attitudes and actions that render an event meaningful are taken into account (Geertz, 1973).

My interest in this study was exploring the experience of advanced COPD from the perspective of people experiencing the illness. What drew me most to these select participants was their ability to verbalize in rich description their daily challenges, the

struggles with their symptoms, and their responses to the restrictions placed upon their daily living. They not only provided descriptions of their immediate experiences, but placed those experiences into the broader context of their present lives and life histories, attaching social and historical significance to their illness experiences. For example, when asked how daily life has changed through the course of the illness, some participants responded with short non-descriptive accounts such as *“hasn’t changed much. I’m always a mess.”* The participants I have chosen spoke of the changes they’ve encountered and of the emotional struggles associated with those changes, responding to the same question with more elaborate comments such as:

“I can’t go outside and walk very far. I can’t go shopping, I can’t do my housework. I can hardly even dress or undress myself. I’m restricted in everything, in what I do around the house or going out. I get frustrated and disgusted.” [NS 001, F, 89 yrs]

3.6 Data Analysis

Consistent with social constructivism and with Heideggerian hermeneutic phenomenology, I began this research with the understanding that my own interests and experiences would contribute to the construction of the data. Because the hermeneutic circle cannot be avoided, Heideggerian hermeneutic phenomenology affirms the position of the researcher in the hermeneutic circle. It was therefore essential for me as the researcher to critically reflect each step of the way by keeping a personal journal. Getting into the hermeneutic circle “properly” requires maintaining a reflective journal (Caelli, 2000; Koch, 1994; Koch, 1996). My journal was used to systematically evaluate and interpret my own experiences and how those experiences were impacting my understanding of the data as I moved through the research process. For example, before

even reading the transcripts, I reflected extensively and wrote in my journal concerning my own ideas and experiences of illness. This enabled me to identify my own “forestructures” of understanding and to enter the hermeneutic circle “properly” so as to engage in coming to understand the experience of others.

The principle of the hermeneutic circle is that both the parts and the whole are important in understanding. Therefore, to function at both levels, to give an adequate account of the entire text and to build this account through identifying discrete units of meaning, I began the analysis process by first developing a sense of the whole of the text (Chang & Horrocks, 2008). I iteratively read and reread the transcripts and the field notes that were available to me. I engaged with the text through reflective reading, by making marginal notes comprised of questions that arose for me as I read, and by writing comments on particular words or phrases that stood out for me. To better understand the participant’s stories of their illness experience, I then wrote a narrative rendition of each transcript. This rendition summarized my understanding of how participants described their life experiences and the impact of their illness on life as they now lived it. To illustrate how these renditions were constructed consider the following excerpt for Transcript 001 – pseudo name of Wendy.

Wendy spoke of her life as “having no joy” anymore. She described feeling that COPD prevents her from doing the things she wants to do – everyday activities such as walking, shopping and housework. She says she has no social life because she can’t go anywhere without getting out of breath.

Following the reading and rereading of the transcripts and the construction of narrative renditions of each transcript, I moved from “the whole to the parts”. Eight transcripts were imported into a QSR Nvivo version 7 software data management program. Once imported into N7, the data were broken down into basic units of meaning

or 'categories'. Categories are bits of data that present intelligible and coherent points which in some sense are self-sufficient. This systematic categorisation of the data involved two interrelated processes: the construction of a node list by identifying categories or codes within the text; and, line-by-line coding of the entire data set to the created nodes. This process was iterative, moving back and forth between texts and marginal notes, reading and rereading individual transcripts while coding discrete units of meaning across transcripts, and creating or re-defining nodes as the coding proceeded. For example, data that contributed to the narrative excerpt above would have originally been coded under the category of "Life changes", subcategories of "Daily adjustments" and "Social life". Further along in the coding process this same data was coded under the category of "Impact of advanced COPD upon emotional well-being".

Once the coding process was exhausted, that is all data were coded and re-coded until no new codes could be constructed, categories of similar meaning were grouped into clusters of categories to form themes. For example, keeping with the excerpt above, I explored the implications of what it means for participants not to be able to live life on a daily basis as they would desire to live. I examined the words they used, the moods I felt projected, and the phrases they repeatedly utilized when discussing how they felt. Phrases such as "*not much you can do about it*" or "*you have to learn to live with it, I guess*" and about being "*restricted in everything*" were common. I explored the categories and subcategories I had constructed and read and reread the transcripts and my notes as I struggled to grasp the complexities of their illness experiences and possible meanings of such phrases as "*not much you can do about it*".

Once constructed, the themes were further analyzed from the Heideggerian perspectives to illuminate the ontological meanings of the lived experiences of the participants. During the writing process, I continued to utilize Heideggerian perspectives as I moved back and forth between the analyzed data (themes), the transcripts, constructed narratives, and field notes to obtain a perspective of the emerging structures of the participants' experiences in the context in which they were experienced (Chang & Horrocks, 2008). Two major themes of "A deflated self" and "Navigating contested selves" arose in my understanding as to what participants were trying to convey. Both these themes are rooted in the participants' search to discover what it means to be a being-in-the-world amidst the daily struggles they encounter in their now destabilized and unpredictable worlds. From immersing myself in the data, it appeared to me participants were communicating that they could no longer be who they wanted to be and that they were in a continuous process of adjustment to a life they felt was no longer theirs to own. They spoke of how difficult it was to no longer be able to be who they wanted to be, of the anger and frustration they struggle with as they seek to understand and define their *selves* in this new reality they are encountering due to their illness. Quotes such as the one presented below exemplify the ontological struggle I felt that participants engaged with as they sought to live daily life amidst the many unknowns of their illness experience:

She [Mother] used to tell me, I'm like a young woman stuck in an old woman's body because her mind was so good. She wanted to do all these things and her body wouldn't let her. And I said, you know, that's the same with me. There's so many things I want to do, but I don't feel good. I'm lying in bed and I'm thinking 'Oh, I feel great. Tomorrow when I get up I'm going to do this and I'm going to do that', and stuff like this here; and I get up the next morning and I'm just, seems like you're shot right down cause, and you know that does

make you angry when you really think about it, really angry. [NS 008, F, 68 yrs]

3.7 Trustworthiness

The central feature of trustworthiness of data is to confirm that the findings, as accurately as possible, authentically represent the experiences and viewpoints of participants, rather than solely the perceptions of the researcher (Fossey, Harvey, McDermott, & Davidson, 2002; Polit & Beck, 2008). For trustworthiness to occur, most especially in secondary analysis, it is imperative that thick description occurs. Thick description is “an ongoing process of interpretation intended to achieve a level of insight into nuances and complexities of human actions that are always open to further interpretation (Dawson, 2010; Geertz, 1973). As well as taking into account the immediate behaviours in which people engage, thick description takes into account the contextual and experiential understandings of those behaviours that render an event or action meaningful. For the purposes of this research, I chose the eight transcripts from the primary study that provided the thickest description of participants’ experiences. For example, those participants who discussed in more detail not only their immediate life situations, but included experiential, historical, and contextual information as well. These transcripts stood in contrast to others that provided only thin description; that is only a glimpse of the impact of the illness within their lives with little, if any, experiential, historical or contextual information. Thin description has the potential to limit analytical processes by missing peculiarities and hidden complexities. At best, findings can only be tentative and in need of further investigation (Dawson, 2010; Morse, 2010). Thick description, on the other hand, illuminates the characteristics and

particularities of the phenomenon by emphasising contextual details, relational dynamics, and unspoken communications (innuendos, body language). The aim of thick description is not to provide a definitive account. It is impossible to provide any definitive account of the “whole story” of any phenomenon as there is always more happening than can be contained in any one interpretation. Thick description does make it possible, however, to put forth ideas regarding the many possibilities intrinsic in the stories we interpret (Dawson, 2010).

Thick description is one important component in the establishment of trustworthiness in hermeneutic phenomenological research. Because hermeneutic phenomenology views understanding as a basic structure of being human, continuously engaging in self-reflexivity is also essential (Crotty, 1996; Greaves, 2010; Schwandt, 2003; Sembera, 2007; Whitehead, 2004). I continuously engaged in self-reflexivity throughout the entire research process, reflecting before I engaged the data by exploring my own background, context, presuppositions, and experiences of illness and health. Throughout the research process, I held conversations with my thesis committee members exploring my own thoughts and presuppositions and how they may be impacting my analysis. I reflectively read and re-read the texts, making marginal notes and exploring how my own thoughts and feelings shifted as I read and reread the transcripts. For example, while engaging with Transcript 010, I felt a strong connection to how the participant approached her illness experience. As I explored this ‘connection’ I realized that from a very young age I had been taught to approach illness as this participant was approaching it, to internalize my illness experiences and to just keep going ‘despite it all’. I reflected on what this way of being meant not only in my own

life, but to my way of understanding the experiences of this participant, as well as all other participants. As I read through the stories of other participants, I became more aware and more open to the many ways there are to experience chronic illness and of the similarities and differences in how we, as distinct individuals, respond to similar illness experiences.

Trustworthiness also encompasses different dimensions of credibility. According to Beck (1993), credibility lies in how vivid and faithful the description is to the lived experience. Hermeneutically, there is no set method or measure to ascertain the correctness or incorrectness of any interpretation. Rather, argumentation is used as one reasons, doubts, re-reasons, re-doubts and re-reasons again in an iterative cycle as one seeks to understand and to describe as faithfully as possible the experiences conveyed by participants. The goal of hermeneutic phenomenological inquiry is to “understand”. The purpose of hermeneutic inquiry is “not to validate our shared understandings, but rather to help build trust in our interpretative capabilities as we work through our own understanding to open ourselves to the ideas of others and to continue to search for ways to invite the topic to say what it has not yet said about itself” (Freeman, 2011, p. 550). The intent of credibility is to demonstrate that the inquiry was conducted in a manner that ensures the topic is as accurately identified and described as is possible within the context in which the research was conducted (Lincoln & Guba, 1985). When this is done, the insight is self-validating and others will see the text as representative of the experience itself (Laverty, 2003). I have engaged in critical reflexivity throughout the entire research process and I provide in-depth descriptions accompanied by exemplars of the complexities involved with living with advanced COPD. I present here one

understanding of how people living with advanced COPD experience their illness in their particular contexts at a particular time in their lives, in the hope that this research will bring increased understanding to others.

3.8 Ethical Considerations

3.8.1 Informed consent. Certain ethical issues are of particular concern when involved in secondary analysis of data. Consent given for the original study may not explicitly cover the question posed for secondary analysis. The process for gaining consent for secondary use of data is similar to gaining consent for primary research, i.e., studies in which the research question is known in advance. The issue, then, is not whether the analysis is primary or secondary, but specificity of research purposes known in advance (Bishop, 2007). Ethical secondary research, therefore, requires a defensible judgement as to the scope of the original consent as well as an analysis of the specific conditions under which secondary analysis is appropriate (Thorne, 1998). In the present study, the scope of the original consent covers the secondary analysis that will be undertaken. Even though the primary purpose of the original study is to explore how people with advanced COPD respond to low dose opioid therapy for dyspnea, the original consent does stipulate that the data will be explored to help broaden our knowledge base and “better understand the experiences of people living with advanced COPD.” The primary intent of the secondary analysis being undertaken is to explore what it is like to live with advanced COPD without opioid intervention.

3.8.2 Confidentiality. Primary researchers may sensitize themselves to delicate issues within communities or cultures that may not be accessible to secondary analysts.

They may often mask individual responses with the awareness that certain informants may be more easily recognizable than others. Contextualizing research within a cultural and social frame can guide the researcher's decisions about when and how to report them. Secondary analysts have a special obligation to familiarize themselves with the actual or potential privacy needs of both individuals and populations represented in the data they employ (Thorne, 1998). As a member of the team who conducted the original research, I am familiar with the cultural and social environments of the primary research. However, to ensure confidentiality, I only received transcripts for which all identification information had been removed. The data that was analyzed for the secondary analysis remained anonymous to me, further ensuring confidentiality of participants.

3.8.3 Nonmaleficence. A researcher's ethical obligation includes doing no harm, referred to as nonmaleficence. It is widely accepted that research participants be treated as an end in and of themselves rather than a means to an end. Harm may take the form of violations to privacy or arise from an attitude of neo-colonialism in which the researcher believes she understands what is best for a population better than they understand it themselves. These issues warrant particular attention in secondary analysis because the researcher has not established any personal relationship with the person or communities involved in the research. Researchers have also, however, identified potential benefits to secondary analysis of health research. In contrast to more theoretical disciplines, health professional researchers always assume that findings may have an impact on health practice, whether these findings are portrayed as generalizable or not. When working through ethical considerations inherent in secondary analysis it may be beneficial to consider this larger social responsibility underlying health research. As

Thompson (2000) and Bishop (2007) have shown, it may be less “nonmaleficent” and more socially responsible to enhance understanding and increase knowledge through secondary analysis than not to re-engage primary data. Furthermore, the temporal distance imposed by secondary analysis may also offer some advantages that are not accessible to the primary researcher. A historical consciousness toward the data may actually clarify prejudices and enhance possibility of understanding (Fielding, 2000; Thorne, 1998).

3.8.4 Fidelity. Fidelity is best characterized by the obligation of truth telling. In secondary qualitative analysis, the distance between the original data source and the analyst can pose threats to fidelity in the interpretation of findings. When engaged in the interviewing process, one assumes they will be corrected if misunderstanding occurs or that respectful relationships built with participants through data construction activities create some natural impediments to misinterpretation. Due to the lack of face-to-face interaction with participants in secondary analysis, there is risk that analysts may find what they seek rather than learning from what is in the data (Thorne, 1998). Researchers have also pointed out, however, that with the increasing evolution of multi-disciplinary and collaborative research, primary researchers themselves do not always conduct interviews nor build personal relationships with participants. It may be one member of the team who actually interacts directly with participants or a research assistant hired by principal researchers to conduct interviews (Broom, Cheshire, & Emmison, 2009). Bishop (2007) also maintains that the process of “constructing” data encompasses not only the interview, but also the reading of background literature, the creation of a sample, the reading of a transcript, or the composition of field notes and analytical memos.

Therefore, even though a face-to-face relational approach to data collection is preferable in qualitative research, the case for fidelity does not necessarily rest upon that one component in the data construction process.

3.9 Ethics Approval

Ethics approval was obtained prior to commencement of this research project from the Research Ethics Board (REB) of the Capital District Health Authority, Halifax, Nova Scotia, the REB who approved the primary research project. The Research Ethics Boards of Capital District Health Authority and Dalhousie University have a reciprocal agreement, and a copy of the ethics approval has been placed on file at Dalhousie University.

CHAPTER FOUR: FINDINGS

Breath is something that, as humans, we automatically do without thought or even, in most instances, conscious awareness. It is something that we take for granted as we go about our daily activities. As one breath leaves our bodies, another breath enters bringing with it life and vitality. As a bearer of life, breathing is more than a physical bodily function. It is something that is deeply and intimately connected to our understanding of what it is to be a living human being. Since ancient times, breath has been intimately connected to life and spirit. For example, the ancient Hebrew word for breath, *ruah*, and the ancient Greek word *pneuma*, encapsulate not only our physical breath, but also the underlying spiritual and existential experience of what it means to have life. Breathing has for centuries, throughout many cultures, been linked to whatever one considers the source and sustenance of life. It is the silent initiator of all that we do, and all that we are. For participants in this study, breathing was no longer something automatic and no longer something to be taken for granted. Due to advancing COPD, breathing had been transformed into something that now required struggle and continuous monitoring. Breathing, or more accurately the lack thereof, appeared to consume the conscious everyday lives of participants. Rather than a bearer of life, breathing had now become a bearer of continual loss and grief as participants struggled to find some sense of coherence with the *selves* they had been prior to becoming chronically breathless and the *selves* they were now becoming living with and within breathless bodies.

Participants in this study had an average age of 72 years, were retired, and resided in Halifax Regional Municipality. One participant completed Grade 8, three participants

had some high school, two completed high school, one had some university and one completed a university degree. Five participants were female and three were male. All eight participants were Caucasian. The study participants appeared to be in a similar stage of advanced COPD and seemed to experience similar life contexts. No “Activities of Daily Living Scale” (ADLS - a scale measuring abilities or inabilities to perform every day activities, i.e. housework, personal hygiene) was administered; and no socio-economic data were collected. However, it was apparent from the interview discussions that participants were mostly housebound or close to it, and restricted in similar ways in relation to their daily activities and social interactions. They commented on their busy lives prior to their illness, speaking of regular travel and social events, indicating somewhat similar socio-economic backgrounds. All participants expressed regret that, since becoming ill, they could no longer participate in those activities as much as they would prefer. Being treated well and cared for by family and health professionals was also expressed as a common experience.

I present below my analysis of the themes of “a deflated self”, and “navigating contested selves”. These two themes capture my understanding of the struggle participants engage in as they work to establish a sense of a stable self amidst the changing landscape of their illness experiences, most especially their underlying experience of being-breathless-in-the-world.

In the midst of navigating through the illness process, participants appeared to experience themselves as *deflated*, as selves they no longer recognized nor wanted to be. I have separated the theme of “a deflated self” into the two major sub-themes of intrapersonal and interpersonal ruminations. By doing so, I do not maintain that

intrapersonal and interpersonal aspects of self are, in any way, separate or disconnected. I would agree with Heidegger that in the hermeneutic circle, a circle in which all understanding occurs, that one can only make sense of the whole by grasping the meaning of its parts and can only grasp the meaning of the parts by having some sense of the whole. In this sense, I maintain that intrapersonal and interpersonal aspects of a ‘whole self’ are interdependent and continuously forming, informing, and co-constructing each other. I have divided them into separate sub-themes here only to provide clarity and to enhance understanding of how participants perceive and manoeuvre their illness experiences.

It is in the lived world, in the intrapersonal and interpersonal contexts of daily living, that *Dasein* must struggle to find meaning and understanding. As Heidegger claims, *Dasein* cannot abstract itself from its life context. As advanced COPD progressed, increasing limits on daily living were experienced. Participants struggled to find meaning and understanding as these increasing limits prevented them from engaging with life as they had prior to illness. On good days, participants appeared to feel somewhat like their pre-illness selves, but on not so good days, they seemed to feel like selves yet unknown or undefined. In the midst of their fluctuating daily experiences of self, participants described an incessant process of *navigating contested selves*. Most of these selves were perceived as foreign and unwelcome. Navigating these selves entailed attempts to live a day at a time while nurturing a positive attitude. It also entailed connecting with a deeper sense of self as participants drew upon past life experiences to inform and strengthen their resolve to live each day as fully as possible.

4.1 A Deflated Self

4.1.1 Intrapersonal ruminations. As advanced COPD progresses, daily activities become more and more restricted, resulting in unstable and shifting understandings of self. Being unable to engage in everyday life in a manner that is of one's own choosing, a manner that is familiar and secure, can create dissonance between the self we perceive ourselves to be and a self we now may feel forced into being or becoming due to illness. This dissonance can create fear, confusion and frustration as one struggles to move through an unending grey zone of identity with little, if any, sense of a stable self. Participants found themselves in this grey zone. They gradually became more and more aware of the impact of their illness. As they began to grieve a self that was no more they searched for some sense of a stable and secure identity amid an array of everyday illness-related losses and challenges. In my analysis, I found that advanced COPD moves beyond the respiratory system to create existential distress, to actually cause a deflation of the self in its entirety. Participants appeared to experience 'loss of breath' in every aspect of their being as they searched for some sense of continuity with their former self-understandings.

4.1.1.1 *A self that is no more.* All participants lamented the loss of who they had been prior to their illness experience, and continuously searched for who they could become in light of their emerging illness. Their *forestructure* was no longer a solid basis for guidance or security. Existential distress had disrupted a once stabilized forestructure. Understandings of who they now were and aspirations for whom they may possibly grow to become were now, to some degree, uprooted from their previous understandings of self. The self they were becoming appeared still connected to the self they were before

illness, but this pre-illness self could no longer provide any secure knowing of who they now were or who they may now become. The future envisioned in a pre-illness forestructure was no longer possible. Restrictions now placed upon daily living due to illness were continually changing participants' self-understandings. These restrictions appeared to be experienced as personal failures and served as constant reminders to participants that the person they once were is no more. The dwindling away of one's ability to engage in activities that contribute to a positive self-image and a sense of well-being left participants feeling distressed and often speaking in terms of self-negation. In describing themselves and their lives, they used such words as "old and useless", "inadequate" and "disgusted". It appeared the loss of the ability to perform, what most of us may consider the most mundane tasks and chores of daily living – washing dishes, cleaning the house, mowing the lawn – was most significant to participants.

I can't sweep the floors. I can't cook a meal. I can't do the dishes. I shake so bad that if I get doing something and it's anything sharp, like a knife or something, 'Get out of there. Don't touch it,' cause they're scared I'm going to cut myself. And then, that makes me mad. I get really nasty when they want me to do something and I can't, nasty. [NS 019, F, 61 yrs]

This participant, Jane (pseudo-name), lives with her partner and children.

Previous to her illness, Jane was a very active homemaker, and took great pride in her abilities to care for her home and family. Her family now appears to want to care for her by "doing" for her. Jane is quite limited in what she can do, and struggles greatly with who she is now that she can't be the person she has always known herself to be, the one who cooks, house-cleans and takes care of her family home. Anger and frustration rise to the surface when her family won't permit her to cook or clean, even though she admits to being incapable of doing either. Through the above quote, Jane captures something of

the deep hurt and confusion she appears to be experiencing at the loss of ability to physically participate in her life and the life of her family as she has always done. For Jane, the anger expressed toward her family members is but one more consequence of the unremitting knowing that the self she has “known” is no more.

4.1.1.2 Disharmonious Existence. Much of what we do in our daily lives contributes to our self- understanding, our understanding of who we are in our lived contexts. Being restricted in everyday activities necessarily causes one to question this self-understanding. Possessing bodies incapable of engaging in our chosen activities and future plans creates a discord between body and self-identity. Heidegger would maintain that this discord is created in our being-in-the-world, that the constitutive unity of the world, the self, and the world-self relation is somehow ruptured. Participants found the discord created in, and by, their now restricted bodies to be both disturbing and frightening. As illustrated in the quote above, living in a body incapable of supporting one’s dreams and aspirations caused emotional ruptures for participants. These ruptures appeared to eventually lead to a sense of weariness as life became consumed with finding some sense of stability and security amidst an uncertain and ever-changing disease trajectory.

I dread it and I hate it. I hate every day because I don’t know what’s going, I don’t know one day to the next, and you should look forward each day you know. My dad used to say live that day for itself you know and live it all you can, but this isn’t living. This is just existing as far as I’m concerned anyway. [NS 010, F, 68 yrs]

Existing implied living everyday with fear and dismay as the illness progressed, placing increasing restrictions on daily activities. Managing these increasing restrictions became part of a daily regime as participants struggled to maintain some sense of their

personal self. One participant was especially poignant in his description of life before illness in contrast to how he experiences it today:

Before I had this, I'd go down the road 20 hours a day. I'd go driving or go deer hunting, go walk 12 hours a day, go deer hunting or whatever in the woods. I never stopped, like I was in the last five years. I used to be able to go seven days a week, even if I just walked. I seen myself walk up the road seven or eight times a day, or fishing, or deer hunting in the winter time. [Now] If I was here alone, I know I couldn't do nothing. So, you think about that. This is killing me. [NS 014, M, 61 yrs]

4.1.1.3 Search for meaning. Being incapable of participating in daily activities diminished available resources for managing emotional disruptions. This resulted in a lessening of quality of life. A strong sense of frustration was expressed with the lack of ability to live life as participants would wish to live, and a search for meaning and understanding in what life was now becoming became a constant. This search was not a linear process, and meaning and understanding were sometimes elusive. At times, confusion, expressed as the grey zone, became overwhelming. Disorientation seeped in as participants struggled to understand this new life context and what it meant for their self-understanding. During these periods of disorientation, participants appeared to be aware, and to feel disheartened, that the answers they sought may not be easy to find, nor indeed may never be found.

Quality of life, well things I used to do, I used to like working on my old cars. I can't do that anymore. I can't work outside very much because I've got no breath to do anything. I miss all that. You know, everything I do, it's too hard to do. And there's not really much you can do but worry about your health I guess. So, I learned to live with that and that's all I can do. You know just try to make a life with what I got. I got to learn to live with I guess, hey? [NS 025, M, 70]

4.1.1.4 The Battle for Breath. As stated in the introduction to this chapter, to breathe is something that most people do without a thought, something our bodies seem to do automatically for us. Breathing is deeply connected to who and what we are as

human beings. For participants, an unremitting fear and anxiety concerning loss of breath lay beneath all efforts to adjust to worsening health status. As COPD progresses, breathing becomes more and more difficult. All participants spoke about breathing with trepidation. Panic and fear were words most frequently used to describe feelings about breathing. Struggling to breathe appeared to disturb not only physical bodily processes for participants. Implicit in the fears expressed was a sense of complete and total loss of the self as a living, breathing human being.

Well, I guess what bothers me most right now is perhaps the mental effect of COPD and the interaction fear about you get short of breath and you get a little bit fearful, and the fearful kicks into your noggin. You know, your last breath and it kicks in. [NS 011, M, 78 yrs]

Loss of self as a living, breathing human being – death – was explicitly spoken of by three participants. It was not death itself that was spoken of with fear, but as one participant states, it's "the nature of my dying" [NS 004, F, 82 yrs] that is feared. This fear was connected to the medical system. Concern was expressed that the medical system may fail to adequately address worsening pain and discomfort, thus resulting in increased suffering. Fear was also expressed concerning the power of the medical system to take control of the dying process, providing unwanted treatment or artificial breath sustaining measures. The employment of artificial breath sustaining measures was a particular concern, perhaps representing an ultimate loss of self control, control over how one may choose to live and to die.

[What worries you most?] Being put in hospital and having to stay there. I like to be home if anything happens to me. I'm always scared if they intubate me I won't come out of it. You know what I mean? I'm scared I'm going to have to be intubated again. That's my main worry. I don't think I'd want to be left on a ventilator. You're just a vegetable. That's it. It's not yourself. [NS 010, F, 68 yrs]

4.1.1.5 Summary. For participants, the self that was familiar and known was gradually being lost amidst the illness process. Grief was also gradually settling in as participants came to the slow realization that the self they were becoming was unfamiliar and unwelcome. This new self was someone who no longer possessed control of daily life, nor of who s/he was becoming. This loss of control, and the power of the illness experience to take control of one's very self, was met with fear, anger and frustration. Implicit in the participants' stories was an underlying feeling of being somehow entrapped in a body that no longer would function as they may wish, or will it to; a body no longer in harmony with one's personal identity. One participant captures this sense of entrapment when she states that she feels like "a young woman *stuck* in an old woman's body" [NS 008, F, 68 yrs]. The desire to engage more fully in life was strong, but the body was no longer capable of supporting that engagement.

4.1.2 Interpersonal ruminations. The impact of illness-related losses not only affected how participants experienced and viewed themselves as "self", but also their abilities to interact in social environments. As the struggle to breathe increased, both physical and emotional barriers made it increasingly difficult to engage in social interaction.

4.1.2.1 Physically challenging. Physically, it became more and more challenging to visit with friends or to gather in social locations. For some participants, a simple walk to their vehicle took all the energy and breath they had. The structure of houses and public buildings made it challenging, sometimes impossible, to physically manoeuvre. The physical exertion required to walk up a walkway and up steps to enter houses or buildings was too challenging for most participants. So, for the most part, they

“just don’t bother going out no more” [NS 014, M, 61 yrs]. When they did attend social engagements, participants were always conscious of their breathing and attentive to bodily signs that it may be time to leave in order to prevent an exacerbation from occurring.

We had our 50th anniversary over to my daughter’s. She put a big thing on for us, just close friends and family and I stayed. I was having a good day because the wind was blowing a little bit, and all of the sudden the wind died down. So, it started getting hot and muggy and my breathing started, frigged up on me. So, I said I better go home. [NS 008, F, 68 yrs]

4.1.2.2 Emotionally unsettling. Coupled with the physical challenges of social engagement was emotional unrest. As Heidegger claims, *Dasein* is never devoid of moods, and these moods dispose us toward things in a certain way. Our moods inform our understanding of our life contexts, inclusive of the personal and social worlds we inhabit. Moods very much influenced the self-understanding of participants and their level of engagement within their social contexts. Participants were very aware of how their breathlessness may be perceived in social settings and experienced some level of anxiousness when spending time in the presence of others. Some participants expressed concern for the impact an exacerbation may have on others in their presence. They appeared to view themselves as a danger to those around them, to feel as though they were somehow now a source of fear and distress to be hidden from public view. One participant expressed uneasiness with spending time with his grandchildren. He states that if he lost his breath in their presence, they would “get scared to death” [NS 025, M, 70 yrs]. Another participant describes an occasion when she was in a public environment and experienced an exacerbation, causing fear for both herself and her companion:

My greatest fear is that I will get out somewheres and panic that I can't breathe cause that happened to me once. I scared myself, plus I scared my sister-in-law. It was terrifying for her. [NS 019, F, 61 yrs].

Participants felt embarrassed when breathlessness was experienced in public. Breathlessness draws attention. The idea that people were watching, that your breathlessness was being seen, appeared to be particularly disturbing. Perhaps inner fears and discomfort with an inability to breathe are raised to a more conscious level when witnessed by others. Personal identity, an already fragile and confusing process due to the illness experience, may be threatened when others *see* your struggle for breath. Misapprehension by others of who you perceive yourself to be may mirror deep seated fears within oneself of the person you are becoming, fears you may find easier to manage if not mirrored directly back to you.

"I get so out of breath walking from the parking lot, walking just from there into a store. It tires me out and I feel embarrassed cause I get into the store and I'm going [gasping] - like this here, and people look at me and I don't like that." [NS 008, F, 68 yrs]

4.1.2.3 Summary. Socializing, sharing life with friends and family, can have positive health benefits and increase well-being. Feeling as if one is "not part of something" [NS 001, F, 89 yrs], becoming more and more distant from friends and family, negatively impacted emotional well-being for participants. The inability to socialize was, in part, due to the inability to engage in daily activities. Physical limitations caused by the illness were the primary cause of decreasing social activity. These limitations also, however, created emotional mayhem when contemplating or engaging in social interactions. Being housebound, having little social involvement with the outside world, appeared to increase feelings of aloneness, depression and frustration

for participants. These feelings, in turn, appeared to limit interest in, and ability to, socially engage.

4.2 Navigating Contested Selves

All participants had resigned themselves to the fact that they had advanced COPD, that it would place increasing restrictions upon daily living, and that they would never recover to live life as they had prior to advanced COPD. As they were confronted with increasing illness-related restrictions on how they could choose to live and define themselves, participants appeared to be in a continuous state of flux, with no fixed self-identity. They had become *Daseins* who unremittingly sought answers to what being-in-the-world now means. The ebb and flow of their illness experiences entailed a continuing search for new understandings of self. These understandings were always shifting and being modified dependent upon health status. I heard existential grief expressed at the loss of a self-concept, but also a determination to engage with the selves that was now emerging through the illness experience. To navigate the uncharted waters of this emergence, participants strived to maintain a positive attitude, attempted to live each day as fully as possible, and drew upon their life histories/stories for guidance and support.

4.2.1 Staying positive. All participants spoke of the importance of a positive approach to learning to live with advanced COPD. Staying positive was sometimes viewed as challenging, but always seen as a necessary element in continuing to live as fully as possible within the confines of the illness experience. A positive attitude was not something static or objective to be obtained. It was something that participants appeared

to continually engage and work toward amidst daily demands and frustrations experienced due to advancing illness.

Cope with it as best you can and never give up. Things will probably improve with medication or with psychological acceptance. In other words, you might surprise yourself by taking a positive approach. Certainly a negative approach, which basically is what I've gone through a little bit, does not help. It exacerbates the problem. So, I really am trying to think positive and I would submit that the same thing to other COPD patients. Just give it your best shot. [NS 011, M, 78 yrs]

A positive attitude didn't come without effort for any of the participants. As the quote above illustrates, there were moments when a positive attitude could not be generated. Participants seemed to inherently sense an importance in maintaining a positive attitude, but often grappled with attaining it amid daily frustrations and hardships. There appeared to be a movement between moments of feeling despair and disheartened to feeling positive and hopeful, always returning to the importance of remaining positive and hopeful but with consciousness of its fragility.

I don't let it get to me if I can, you know what I mean. Sometimes it gets to me. I get very depressed easy now, never did before. I just get down and have myself a good cry and I get over it. I have hope. As long as you have breath in you, I think you've got hope. [NS 010, F, 68 yrs]

4.2.2 Living today for today. As exemplified in the themes above, participants were very aware of their diagnosis and illness trajectory. As COPD advances, breathing becomes more and more of a challenge, placing more and more restrictions upon active living. This, in turn, may intensify isolation, amplify loss of independence, and increase fears concerning the nature of one's death. One way that participants appeared to quell thoughts of the implications of their advancing illness was to consciously work to "just go with the flow" [NS 019, F, 61yrs] of everyday life.

I don't really make plans nowadays, just go day by day. That's how we do it, nice weekend, just go for a drive. I just go day by day. [NS 014, M, 61 yrs]

Intentional efforts were made to live each day as fully as possible and not to look forward to what may occur as a result of worsening health status. It appeared that to simply live today for today and to deal with the challenges and losses inherent in advanced COPD on a daily basis helped participants to move through their days with manageable stress levels. Participants viewed looking to the future as destructive and self-defeating. The resistance to look beyond today appeared to provide some measure of self-protection against fears and concerns that may not be manageable if allowed to dominate daily life.

I haven't had time to think about the shortness of my life. Either that, I haven't time or I put it aside because I believe it's the present. It's the here and now, in other words. What's that old phrase or prayer, Lord please let me cope with the things that I can't change, and change those things which I can change. So I would say if you're thinking too far ahead in a negative fashion you just dig a bigger hole leading to full-blown depression. [NS 011, M, 78 yrs]

Even though participants did not look too far into the future in relation to their disease trajectories, some did employ their hopes for the future as a support to continue living as fully as possible. An apparent discord existed between avoiding looking to the future for fear of what it may bring and looking to the future as a means of perseverance. Family ties were one important component of future hopes that intensified the will to thrive:

I can survive anything. I have to be here to make sure my grandchildren are raised up and I'm a great grandma. I have to be here for them because it's just we're so close. I have to be here for them. [NS 008, F, 68 yrs]

The future that was looked forward to was always one in which disease symptoms were manageable and daily life and activities were improved from what was presently being experienced. There were no illusions that the disease would not advance, but hope

was expressed that their health status would remain stable or become improved with the help of medical interventions. A future hope expressed by all participants, explicitly stated by one, was that medical interventions could work to provide “at least some life” [NS 008, F, 68 yrs] in future years as the illness progressed.

4.2.3 Life histories. Participants not only looked to the future but also to their past life experiences for support and sustenance. Situating their COPD illness experience in the context of other challenging life experiences appeared to normalize it. Reviewing other stressful life events that had been successfully charted seemed to bolster self-confidence and resolve. Perhaps, tapping into a part of oneself that had previously existed served to bind the person you knew yourself to be before the illness to the person you were now becoming. A common thread weaving through all of one’s life may provide vital support during times of turmoil and instability. One thread appeared to be a tenacity that had been developed through time while overcoming other troublesome and demanding past life events.

I had a heart attack ten days ago. I broke my hip almost eight months ago. I went six weeks with a broken hip. Something broken but they couldn’t find it. I was in agony. I didn’t give up. I still kept going on. Oh, I’m a scrapper, I am. I’m tough. I don’t give up easy. [NS 010, F, 68 yrs]

Another thread was self-reflection on how this illness experience resembles other past life experiences. This self-reflection may have served, in part, to weave a continuous uninterrupted story of life events by integrating COPD illness experiences into enduring understandings of self. Reflecting on the events of one’s life in light of new experiences serves to connect threads between past and present that one may not apprehend without such reflection. These connections, again, may serve to maintain a perception of a stable and evolving self throughout all life experiences. New experiences may shed new light

on old experiences, while old experiences may inform and provide guidance and comfort while moving through the uncharted waters of new experiences.

I don't know how many people with lung disease who have to sit a lot tend to think a lot and observe a lot and do pattern recognition. You know, one of them is that the pressure's off us. You know, I think of all the ways in my life that I've said to myself, "I can't breathe", and it was purely psychological, purely environmental. Yah, this whole situation I'm presented with is suffocating, like work and jobs. It's nice to let go of that stuff. [NS 004, F, 82 yrs]

4.2.4 Summary. All participants appeared to possess a strong will to remain actively engaged in daily life. Despite the sometimes dire challenges faced on a daily basis, all participants agreed on the importance of maintaining a positive attitude while continuing to work toward improving their health status. They struggled to live each day as it came without looking too far ahead into what the illness may hold for their futures. In another sense, however, they did look to the future when they felt it would be beneficial and supportive of their efforts to continue the struggle. They engaged with their life histories and contextualized this illness experience in a manner that was manageable and that permitted them to live their daily lives as fully as possible.

CHAPTER 5: DISCUSSION

The discussion is divided into three sections. I have placed the three overriding concerns expressed by participants in this study in conversation with extant literature on those concerns. The first section addresses chronic illness, suffering and self-identity and discusses the struggle to continually find oneself anew amidst the ebb and flow of chronic illness. The second section is more focused on advanced COPD and what participants found to be the most disturbing and limiting experience of living with the illness, breathlessness. This section is sub-divided into the two areas of the illness experience that participants found most challenging to live with: existential angst and social isolation. The final section discusses self-management, and explores how the medical system understands and engages the concept in contrast to how participants in this study understood and engaged the concept. After the discussion, I present what I perceive to be the strengths and limitations of the research.

5.1 Chronic illness, suffering, and self-identity

There is an abundance of literature on the medical experience of COPD, its symptomologies, and how to best address disease progression. Most of these studies are disease specific and do not address the nature and extent of suffering that inextricably accompanies severe illness (Claessens et al., 2000; Edmonds et al., 2001; Elkington et al., 2004; Elkington et al., 2005; Harris, Smith, & Veale, 2008; Lynn et al., 2000; Maurer et al., 2008; Maurer et al., 2008; Ries, 2006; L. M. Walke et al., 2004; Yohannes, Baldwin, & Connolly, 2003). Frank (2002) maintains that “critical illness leaves no aspect of life untouched” (p. 6). When a person’s body breaks down, when it does not, or cannot,

support the life one chooses to live, not only the body, but the life “lived in that body” is also broken; that is, it is changed forever from what it was prior to disease (Frank, 1991, p. 8). Participants in this study were concerned with the physical symptoms of their disease and with the pain and discomfort they felt, but they also expressed deep concern about the impact that COPD symptoms were having in limiting their abilities to engage in daily activities. The inability to live and participate in daily activities as they had done prior to their illness led participants to a deeper existential questioning of issues of identity, and purpose and meaning in life. Participants spoke of suffering with physical pain and discomfort, but they also spoke of suffering in the broader context of their lives. They spoke at length of suffering due to the intrapersonal and interpersonal losses they had endured as part of their illness experience. These experiences of suffering caused participants to engage with questions concerning who they were in their innermost selves as human beings; in Heideggerian terminology, existential questions as to what it means to be a being-in-the-world. To be more precise, for participants, what it means to be *this* being-in-the-world. For example, George [pseudo name – *NS 014, 61 years*] was a very active and outgoing person before his illness. Now, he experiences limited mobility and is restricted to his house most of the time. George is actively searching for ways to understand himself and his now limited existence. He says that it is “killing me...not being able to do nothing”; and indeed, in many ways his experience of advanced COPD is “killing” the person he knew himself to be before his illness. George, as other participants in this study, is struggling to figure out what it means to be a being-in-his-world with a body that can no longer accommodate the life he chooses to live.

Suffering requires a rejection of the historical dualism of mind and body that is so ubiquitous in Western culture. Kleinman (1988) claims that the person who suffers is a *body-self*; that is, a body in which emotions and cognitions are integrated, a body that is an “organic part of a sacred, sociocentric world, a communication system involving exchanges with others (including the divine)” (p. 11). This understanding of self is implicit in the accounts participants relayed of their experience of living with chronic illness. Participants did not speak of their disease symptoms as an adjunct to their bodies, but as deeply and intimately integrated into their evolving self-identities. On some days, when symptoms were manageable participants felt like their “old selves”, while at other times when the symptom burden was great, they were thrown back into a space where identity became an enigma, a puzzle without all of the pieces.

Kralik (2002) notes that shifts in self-identity, involving ongoing negotiation between the self and the illness experience, are part of the process of chronic illness. As noted in this thesis, self-identity is a fluid concept for people experiencing advanced COPD and the *selves* that are experienced are, to a large degree, dependent upon the experience of illness at any given time. For participants in this study, it appears that different experiences of self emerge influenced by past and present life experiences as the illness unfolds. In a Heideggerian hermeneutic phenomenological framework, one would see these different experiences of self as informed by forestructures: by fore-having - practical background practices; fore-sight - socio-cultural situatedness; and fore-conception - the ability to anticipate what might be found in future engagement with life (Kinsella, 2006). Chronic illness shifts how a person views themselves and the way in which their changing bodies are experienced. Due to disease, participants in this study

could no longer engage in life as the self they had been prior to disease. Mundane, everyday tasks and chores – cooking a meal, washing dishes, mowing the lawn - held significant identity-meaning for participants. To a large extent, these daily activities defined participants' self-understandings as connected and contributing to family and social life, as individuals capable of caring for, and sharing life with, others. Due to the nature of their changing bodies, participants could no longer provide the care they once had, nor share life with their loved ones as they would choose to do. The self emerging from the illness experience became a self who was moving further and further from its historical grounding. Participants continually sought to understand and define this emerging shifting self in the context of the everyday familial and social worlds they now inhabited, worlds in which their active engagement was becoming increasingly limited as their bodies increasingly diminished in their functional capacities.

Viewed phenomenologically, bodies become habitual while living daily life. They function in capable and non-reflective ways. Bodies are experienced as extensions of interests and activities that are embedded in meanings and significances. When bodies can no longer function in their habitual way, they are experienced differently (Ironside et al., 2003). For participants, changes in their habitual bodies resulted in changes in their lived-world contexts, which resulted in changes in their self-understandings. As the disease progressed, the disease, and themselves as diseased persons, became more and more the focus of their daily lives. Daily interests and activities waned as the ability to engage in them became less and less a possibility. The search for meanings and significances in daily life without those interests and activities became a constant source of angst. Participants knew that their disease would continue to progress and their bodies

and lives would continue to change in ways not of their own choosing (Charmaz, 1983; Frank, 1991, p. 38-39).

Charmaz (1983) contends that the nature of suffering is, at its core, the *loss of self*. For participants, this loss of self was an ever-changing life process. Participants in this study did acknowledge and lament their experiences of the loss of the stable self they knew themselves to be prior to illness. However, in this thesis, I use the term ‘contested selves’ because it appeared to me that while participants acknowledged the loss of their prior selves, they also were very much engaged in understanding their experiences of the various, not so stable, selves emerging from their fluctuating illness experiences. At times, they appeared to feel like a self they did not know nor want to be, a self they feared but, yet, still struggled to understand. For participants in this study, *loss of self* appeared to be an iterative process of coming to know emerging selves in light of lost past and future self-concepts.

Although participants did suffer physically, the main concerns expressed by them in this study were not of a physical nature. Their main concerns lay with the gradual process of losing their *self*; as noted above, of constantly engaging and struggling to understand the selves emerging due to their illness. Their bodies were increasingly becoming incapable of supporting the selves they knew and wanted to be and the selves they were becoming due to their bodily disintegration were unknown and feared entities. Participants constantly struggled to find identity and meaning in their daily lives as illness continuously restricted their involvement in relationships and activities, relationships and activities that, to this point in their lives, had formed and defined their understanding of who and what they were as beings-in-the-world.

5.2 The breathless self

5.2.1 Breathlessness experienced as existential angst. The most pronounced and debilitating, and therefore most restrictive, experience for participants was their struggle to breathe. Numerous studies report that dyspnea is the most debilitating and isolating symptom of advanced COPD (Elkington et al., 2004; Gullick & Stainton, 2008; Gysels & Higgnson, 2009). The physical aspects of breathlessness and its relationship to comorbidities, especially anxiety and depression, have received much attention (American Thoracic Society, 1999; Bailey, 2004; Claessens et al., 2000; Gudmundsson et al., 2006; Guthrie et al., 2001; M. Gysels et al., 2007). Yet, the unique nature of breathlessness has received little attention in the literature (Nicholls, 2000). We know little, for example, of the *meaning* of breathlessness, of the unique nature of the experience for people living with advanced COPD (Barnett, 2005; Lindqvist & Hallberg, 2010; Nicholls, 2000). For example, we know nothing of what it *feels* like to live each moment knowing that your breathing, that which gives and sustains life has now, in actuality, become a bearer of death. Participants lived each moment with the conscious awareness that they had to fight for breath, and that at any moment this breath may not come. Participants experienced existential angst as they lived each day with awareness that death was always looming close by. Heidegger (1988) claims that with death, we stand before our ultimate possibility for non-relation, with knowledge of our *being* towards our end. As humans, in our everydayness, we hide from ourselves the reality that we are in fact, through every moment of living, dying. Heidegger maintains that as human beings we know about the certainty of death, and yet we are not authentically certain of our own. This evasion causes human beings to engage life with a certain

amount of underlying angst that is unavoidable until one reaches their demise (Heidegger, 1962, p.294-303). All participants in this study knew that their breathlessness could at any time lead to their demise. In their continual struggle to breathe, and in the moments when they could not, death moved close and made the knowledge of its reality inescapable. This knowledge, knowledge that most of us keep hidden from our selves, lay beneath a heightened existential angst that participants were left no choice but to experience and to engage.

Perhaps due to this enforced engagement, in contrast to the predominant understanding present in the healthcare delivery system, participants did not speak of dyspnea as another symptom of disease. They spoke of their experience of breathlessness as something more, as an integral part of who and what they were, or were becoming, as living and dying human beings. Rather than understanding dyspnea as another symptom to endure, as a single entity to be experienced or controlled, participants spoke of their breathlessness as a complex core phenomenon that was interwoven into their very existence. According to Ek et al. (2008), breathlessness robs a person of physical strength and emotional equilibrium. For participants in this study, it also robbed them of their basic trust in life. They could no longer take breathing for granted, and because they couldn't they lived with a deepened awareness of the fragility of life and, as noted above, the certainty of death. Although much of the literature speaks of the similarities of chronic breathlessness with other chronic illness symptoms, unlike these other symptoms breathlessness is deeply and intimately connected to who and what we are as living beings. Breathlessness separates advanced COPD from many other chronic diseases because breathlessness can never be just another symptom of disease. It cannot be so

because, unlike most other disease symptoms, if we do not breathe we do not live. Breathing is vital to living. To live without knowing when breathlessness will exacerbate, and when it does whether the breath you struggle for will be your last is unique to the experience of breathlessness alone. Acute exacerbations of arthritis can be extremely painful and debilitating, but acute exacerbations in advanced COPD can, and sometimes do, lead to a frightening and sudden death (Nicholls, 2003).

5.2.2 Breathlessness experienced as social isolation. For participants in this study, the fear of losing their breath, of the ultimate loss of self, was a constant and nagging companion. This constant companion not only caused existential angst, but also impacted upon all aspects of daily living. Kleinman (1988) maintains that all illness meanings are shared and negotiated in familial and social contexts. Nicholls (2003) states that breathlessness can only be correctly understood in relation to a person's "experiences, beliefs, values, emotions, influences and social relations" (p. 124); in other words in relation to who and what we are in our everyday lived contexts.

Illness is inseparable from the structures and processes that constitute the individual's lived-world. This world is a social world and all understandings and experiences of illness are deeply embedded in it (Kleinman, 1988, p. 186). Social visibility of obvious suffering can cause friends and acquaintances discomfort since this obvious suffering tears away the previously known sociable presentation of the self, thereby making social interaction problematic (Berger, Kapella, & Larson, 2011; Charmaz, 1983). For participants, breathing was no longer inconspicuous and automatic. The struggle to breathe made it difficult to continue to handle even limited social encounters.

Participants expressed worry that they may *frighten* others or *shame* themselves if an

exacerbation should occur at a social gathering, no matter how closely knit the relationship may have been to those they gathered with. As their condition worsened and their breathlessness became more pronounced, social isolation continued to intensify. Increasing breathlessness made it more and more physically difficult to socially engage; and experiences of social exclusion due to perceived reactions to their breathlessness made social engagement more and more emotionally disturbing and undesirable.

Social support has been shown to buffer the impacts of debilitating illness and to aid in more positive adaptation to changing self-identities as illness progresses. Simply the presence and/or availability of caring others, through family assistance in practical day to day chores or emotional comforting in times of stress and disappointment, can help create and maintain a more positive self-concept (Sells et al., 2009). For all participants in this study, family and/or social support had noticeably diminished. Those participants with some support spoke of it as essential to their health and well-being. For participants who had some level of family and/or social support (n=5), it increased their sense of self-worth and was a key factor in their determination to engage in daily life and to work to remain as healthy as they could for as long as they could. The absence of social support has been shown to foster loss of self, to lead to emotional isolation and existential distress (Charmaz, 1983). For participants who experienced less family and/or social support (n=3), daily life was experienced as more challenging. It was difficult to attain the practical (e.g., rides to appointments) and emotional (e.g., empathy) supports that appeared to bolster the determination of other participants to engage in daily life. For one participant in particular, being socially isolated intensified feelings of fear and

anxiety concerning his breathlessness, and left him feeling intensely alone and vulnerable.

5.3 Self-management and the healthcare delivery system

Even though illness heavily impacted daily living, participants did not permit their illness to dominate their entire lives. Studies have shown that adjusting to chronic illness is largely dependent upon inner strength, life history, and social circumstances (Lindqvist & Hallberg, 2010). Heidegger would perhaps maintain that these resources are drawn from ones' forestructures. Participants drew on their inner strength, their personal histories and circumstances including their limited social supports to aid them in their daily struggles. It is interesting to note that none of the participants discussed their interactions with the medical system as supportive of their efforts to engage with these resources. When asked about their experience of the medical system, participants spoke positively of their person-to-person interactions with health professionals, but for the most part, spoke with a sense of trepidation when speaking about the healthcare delivery system itself. For people experiencing advanced COPD, engagement in the healthcare delivery system normally entails trying to negotiate appropriate chronic care in an acute healthcare system, a system designed to cure or control symptoms. This acute biomedical healthcare system is technologically driven, a system that places value on the scientifically "hard" facts of disease, but devalues and often disregards the "soft" psychosocial concerns and meanings that are a natural part of chronic illness. As this study demonstrates, and as many other studies support, these "soft" psychosocial concerns are a significant cause of suffering for people living with chronic illness (Frank,

1991; Frank, 1995; Gysels et al., 2007; M. Gysels & Higgnson, 2009; Heyland et al., 2006; Ironside et al., 2003; Kleinman, 1988; Koch, Jenkin, & Kralik, 2004). In the end, because the present biomedical model of care found in acute healthcare delivery systems does not adequately address, or even at times acknowledge these concerns, it immobilizes health professionals and robs those who live with chronic illness of enhanced services that could better address their needs (Kleinman, 1988, p. 9).

An increasingly popular response of the biomedical model to chronic disease is to *teach* patients to self-manage their disease. Many medical self-management models have been developed in recent years to address the control of chronic symptomology in COPD. Bourbeau (2004) defines self-management as “any formalised patient education program aimed at teaching skills needed to carry out medical regimens specific to disease and guide health behaviour change for patients to control their disease and improve their well-being” (p. 271). In the case of COPD, these management models seek to reduce risk factors, assess and monitor disease, and manage COPD symptoms including exacerbations (van Schayck et al., 2007). The successes of medical self-management on clinical and functional outcomes are determined by behavioural change believed to be brought about as a result of formal education aimed at enhancing knowledge, developing more positive psychosocial beliefs and strengthening self-efficacy.

Most of our understanding of self-management comes to us from the perspective of health professionals. The medical prescriptive approach to self-management is widespread and emphasizes adherence to treatment procedures and processes as defined by health professionals. Although this approach appears to result in some positive improvement in certain aspects of patient health outcomes, the extent of health benefits

gained from it are much debated (Disler, Gallagher, & Davidson, 2012; Gysels & Higginson, 2009; Hernandez, Balter, Bourbeau, & Hodder, 2009; Koch et al., 2004; Koch et al., 2004; Kralik et al., 2004). In this medical prescriptive approach, patients are expected to be compliant with medical directions given to them by health professionals. There is little room for reciprocity of knowledge or appreciation for the importance of the contextual experience of living with advanced COPD on a daily basis (Koch et al., 2004). Participants in this study were very appreciative of the medical care they received, but this care was most often divorced from their everyday existential and social experiences of illness, and it was those existential and social experiences that largely determined how they integrated illness into their evolving selves and life contexts.

Not surprisingly, participants viewed medical care as only physical care aimed at controlling their disease symptomologies. The importance of controlling physical symptomologies, most especially breathlessness in advanced COPD, cannot be overstated. However, even though the possible effectiveness of medical self-management programs is widely accepted, there are some concerns that they are too focused on symptom control, failing to adequately address existential and psychosocial issues such as those expressed by participants in this study (Hernandez et al., 2009; Kralik et al., 2004; Lemmens, Nieboer, & Huijsman, 2008). According to participants, breathlessness encompassed much more than physical suffering. Breathlessness was the core experience underlying their physical, existential, and psychosocial suffering. Participants experienced pronounced existential angst as the realization sunk in that they were now, in actuality, living in the shadow of death. The accompanying experience of psychosocial isolation brought on by changing and contested experiences of self were

equally troublesome. Even though these existential and psychosocial experiences were of primary concern for participants, and even though they had a significant negative impact on health and well-being, these concerns remained unaddressed in the medical care received in the healthcare delivery system.

Despite the proliferation of literature on ‘patient-centered’ care and the insistence of placing the patient at the center of care, medical management of disease still persists, with little, if any, consideration given to the broader experience of illness (Frank, 1991; Frank, 1995; Koch et al., 2004). For self-management approaches to be effective, a collaborative, patient-centered system of care is required. The present acute care model cannot adequately address the complex and interrelated physical, existential and psychosocial needs of people living with advanced COPD. To effectively address the needs of people living with advanced COPD, self-management requires a healthcare delivery system designed to provide consistent, long term chronic care. Improving knowledge, as the current approach does, is necessary but insufficient. Providing tools and skills to be utilized in daily life is also necessary, but insufficient. With chronic illness, the person who is the patient cannot fit into a predetermined biomedical acute care plan of care. They cannot because, in such a plan, their embodied knowledge and experience is not, and cannot be, included. They may experience acute episodes, but their illness experience is not a one-time fix. It is a continual and gradual decline in overall health status that requires something different than an acute episode of ill health requires (Bourbeau & Nault, 2007; Koch et al., 2004; Kralik et al., 2004).

Thorne and Paterson (2001) have disputed the biomedical prescriptive approach to self-management. They maintain that such “textbook” interventions are ineffective

and problematic because they do not recognize, nor incorporate, the experience of patients who are already self-managing their own illness. The understanding of self-management that guides the healthcare delivery system appears to be at odds with how people suffering with chronic illness understand and engage in self-management. Frank (1991) captures what appears to be a chasm existing between how people living with chronic illness learn to “manage” their illness and how the healthcare delivery system “manages” their disease. Frank (1991) describes his interactions within the healthcare delivery system following a heart attack. After suffering a heart attack at a young age, he describes being ‘communicated to’ as if he were a computer in need of repairs with health professionals describing the mechanics of what happened to his heart, simply a problem in need of repair. Frank (1991) then goes on to explore his dismay at the expectations he felt placed upon him by the healthcare delivery system to also treat his heart attack as if it were simply a breakdown in need of repair, as if the fear and frustration he experienced were not part of this breakdown experience. He described feeling pressured by the healthcare delivery system to think and feel as though something was wrong with him for experiencing fear and frustration as part of his illness experience. Health professionals spoke of the seriousness of his heart attack, but only in terms of how *they* could still “manage” it if *he* would agree to follow the prescribed medical regime. In the present medical model, Frank (1991), like many people experiencing chronic illnesses, are viewed and treated as though they are machines that have parts that have broken down that need to be addressed and placed under the management of the medical system; much to the neglect of the whole person who is living that breakdown (p. 10-12).

For participants in this study, their illness experiences were not something simply to be medically managed, but to be lived through in their everyday lives. Participants did not understand or experience their illness purely as a breakdown of their lungs. They experienced their illness as part of who they now were and were becoming as beings-in-the-world. Participants sought to “manage” their illness experiences by living each moment as fully as they could amidst the ebb and flow of everyday life. According to Kralik, et al. (2004), people living with advanced COPD engage in self-management from the moment they discover they are living with a chronic disease. They are inherently self-efficacious, learning through daily living with the disease how to self-manage, that is how to create a sense of order and coherence amidst the changing conditions of everyday life. Participants in this study were very much guided by their embodied knowledge. They had learned through time, and trial and error, to monitor and manage their illness. Kralik (2008) maintains that creating a sense of order and coherence amidst the changing conditions of chronic illness entails four key tasks. Participants in this study engaged these four tasks. They understood and respected the imposed limitations of their disease; utilized the personal and social resources available to them; engaged with their changing identities; and planned, paced and prioritized their activities dependent upon their physical and emotional resources on any given day.

For Kralik (2008) self-efficacy, that is a person’s belief in their ability to execute necessary actions in response to specific situations, is a particularly important factor in the management of COPD. Self-efficacy can influence actions that individuals choose to engage in and the effort they invest in those actions (Bourbeau & Nault, 2007; Bourbeau, 2008; Lemmens et al., 2008). Enhancing self-efficacy receives particular attention in

medical self-management models. What the medical self-management approach fails to recognize, however, is that self-efficacy is not something simply to be learned through formal education. Harris, et al. (2008) remarks that the failure of the medical system to address the person in their life context may assist in improving disease outcomes, but will fall short of effectively supporting self-efficacy unless other health determinants are also addressed. Self-efficacy, then, is something inherent in individuals as they engage the process of daily living, something that can most effectively be supported and strengthened through engaging with individuals in their lived environments. Participants in this study displayed high levels of self-efficacy. They made decisions on a daily basis in relation to medication, diet, rest and activity. They participated in daily activities dependent upon the status of their health, drawing upon their forestructures and listening to their bodies to guide the level and intensity of their participation. As Cassell (1982) notes, suffering is “experienced by persons, not merely by bodies” (p. 639). For participants, advanced COPD was experienced in every aspect of their being. The self in self-efficacy included family and social relationships shared in the context of their everyday lives. Participants considered medical professionals to be a valuable asset and gratefully acknowledged their expertise and advice, but they equally valued the advice and support of their family and loved ones when interpreting the meaning of new symptoms and/or making decisions concerning their health.

A medical approach that does not engage the resources people suffering with illness draw upon in their daily living and that does not collaborate with them and listen to their lived experience of illness is doomed to be ineffective at best. In some ways, a medical self-management approach may, perhaps, have been more burdensome than

helpful to the participants in this study. By not effectively communicating with patients and by imposing prescribed procedures and processes, the medical approach to self-management holds the potential, as it did for Frank (1991), to cause further distress. One of the key findings in a study exploring the factors influencing self-management in COPD was the need that people living with COPD felt to balance disease specific recommendations from medical management approaches to their care with everyday life (Disler et al., 2012). For the participants in the Disler, et al. (2012) study, self-management was perceived as disruptive and burdensome. Due to high symptom burden and fatigue, they found it difficult to balance prescribed self-management tasks with daily activities that they enjoyed and that gave them pleasure. The inability of present medical self-management models to *listen* to people living with chronic illness and to integrate everyday living left these participants feeling that they had to survive COPD in their daily lives and maintain some quality of life *despite* self-management. For people living with advanced COPD, and as the Disler, et al. (2012) study as well as the present study supports, self-management is not a linear, prescribed process. It is grounded in the personal and social contexts of everyday lives. If self-management approaches are to be successful, they must incorporate an active role for people experiencing chronic illness and utilize a holistic approach, inclusive of biomedical understandings, but not focused on bio-medical outcomes and disease symptoms to the neglect of personal illness experience.

5.4 Strengths and Limitations

5.4.1 Strengths. This research supports other literature in highlighting the highly contextual nature of the ways in which people integrate illness experiences into their lives (Koch et al., 2004; Kralik et al., 2004). In particular, it moves beyond an understanding of breathlessness as a symptom. It supports an understanding of breathlessness as a core phenomenon in the experience of advanced COPD. Even though this understanding may be implicit in limited literature (Disler et al., 2012; Nicholls, 2000; Nicholls, 2003), this research is novel in that it explicitly discusses breathlessness in this manner and explores the implications of such.

A homogenous sample was purposively chosen in order to elicit detailed and rich accounts of perceptions and experiences of advanced COPD. This approach may have deepened the analysis and my understanding of the phenomenon of living with advanced COPD. Use of Heideggerian hermeneutic phenomenology allowed for in-depth analysis of existential issues and their impact in every day lived contexts. I was conscious of my preunderstanding throughout the entire research process, kept a reflexive journal, discussed emerging ideas and themes with my thesis committee members, and tried to interpret the text as open-mindedly as possible.

I have ensured that there is a “fit” between the purpose of the analysis and the nature and quality of the original data. I was an analyst on the original project and, therefore, had access to the original data, including tapes and field notes, and access to the team members who collected and analyzed the original data. In the methodology section of this thesis, I provided a detailed report on the original study and secondary data

analysis. Finally, I considered the ethical issues involved in the original study as well as the use of the data from that study for secondary analysis.

5.4.2 Limitations. Due to the small sample size (n=8), findings from this study are not generalizable. According to Heideggerian hermeneutic phenomenology, there are many ways to experience and interpret life experiences. I present here one interpretation of the experience of eight individuals living with advanced COPD that could be transferable if people experiencing similar situations can recognize the interpretations and experiences as their own. The study took place in an urban setting and may not be applicable to more rural contexts. Perhaps the greatest limitation to this study is the use of secondary analysis. This means that I was not the person to interview participants and, in fact, they remained anonymous to me. As noted earlier in this thesis, there is much debate concerning the utility of secondary analysis and the debates continue as to the benefits and pitfalls of developing face-to-face relationships with participants. I have considered and addressed the four key issues relating to the use of secondary analysis as highlighted in the literature: informed consent, confidentiality, nonmaleficence, and fidelity (Heaton, 1998; Hinds et al., 1997; Thorne, 1994).

CHAPTER 6: CONCLUSION

My overall intent in this study was to increase the level of understanding of how people live with advanced chronic obstructive pulmonary disease (COPD) from their own perspectives. I purposely included participants whose expressions of their illness experience contained details regarding the impact of their illness upon their daily living in hopes of capturing a rich and informative description of their lived experience. It was through these descriptions that a deeper and more coherent understanding occurred.

This research provided insight into the complex practical and emotional struggles that participants engage on a daily basis. These struggles involved negotiating the physical restrictions being experienced due to advancing disease, as well as the impact these restrictions placed upon daily living. Participants could no longer, and indeed will never again, live their daily lives as they had done prior to their illness. As this new reality seeped into their conscious awareness, it caused grievous suffering and left participants in a constant state of flux as they strived to establish some sense of a stable self-identity amidst the ever changing nature of their illness experience.

As noted in extant literature, dyspnea is a particularly debilitating symptom of advanced COPD. However, in this research, participants spoke of breathlessness as something more than a symptom. They spoke of *their* breathlessness as an integral aspect of their evolving self-identities, as a personal attribute now underlying their physical, existential, spiritual, and social experiences of life. Breathlessness controlled not only physical aspects of being, but also how, and to what extent, participants engaged life. Ultimately, breathlessness was the core experience of advanced COPD contributing to how participants now defined their *selves* as beings-in-their-worlds. Given the global

impact of breathlessness on health and well-being noted in this study, the experience warrants further research.

Present models of care that address only the physical impact of dyspnea fall far short of adequately addressing the suffering inherent in the experience of breathlessness. Participants in this study engaged with the medical system to address their physical and psychological symptoms, but did not appear to consider the healthcare delivery system to be concerned with their overall experience of illness. Over time, participants learned through trial and error to self-manage their fluctuating illness experiences. They worked to reconstruct their lives and redefine themselves by continually engaging their changing body-selves on a daily basis dependent upon the ebb and flow of their illness experiences, most especially their experience of breathlessness. Despite the limitations placed upon them, participants continually engaged their changing lives and their contested selves in the search to find meaning and pleasure in life. Their 'self-management' included medical interventions when necessary, but appeared more focused on engaging their forestructures to address their existential angst and to continually define and re-define their *selves* in light of shifting illness experiences. This was a difficult and challenging struggle but, strangely, acknowledging the inevitable loss of their pre-illness *self* appeared to strengthen the resolve of participants to negotiate their emerging *contested selves* in order to live each day as fully as possible for as long as they could.

It is my belief if the healthcare delivery system would approach self-management from a broad contextual perspective integrating the daily experiences of people living with advanced COPD, listening to them, being guided by their stories and providing medical care according to their knowledge and experience of *their* illness that an

effective and appropriate level of care could be provided. Participants in this study engaged their unpredictable illness experiences daily and found ways to not only survive, but to live. These lives could be enhanced by a medical self-management model that would incorporate *their* illness experiences and the knowledge gained from them. In turn, self-management models that would incorporate such knowledge would be enhanced and provide more effective support for people living with advanced COPD, supporting them in their struggle to understand and live with their fluctuating identities as beings-in-their-worlds.

6.1 Future Directions: Health Services and Policy Implications

In a world where acute care models of health care delivery dominate, one may ask what this focus on the psychosocial experience of chronic illness has to offer. It is my belief that it has much to offer. This research provides evidence of the need for development and implementation of health system policies and programs to address the needs of chronic illness populations, most especially advanced COPD.

Chronic illnesses are the most common cause of disease burden and the number one cause of death worldwide. This research offers insights from patients themselves on how they experience such illnesses, in particular advanced COPD; and on the health concerns they, themselves, feel need to be addressed. Physical pain and discomfort cause suffering and, in many cases, these physical symptoms are addressed by present health care delivery systems in Western societies. However, as this research demonstrates, a considerable cause of suffering for people with chronic illness is also psychosocial in

nature. Present acute care delivery models of health care found in most Western societies fail to address such suffering.

With rates of chronic illness continuing to rise worldwide, alternate models of health care that seek to address psychosocial as well as physical suffering in chronic populations are beginning to evolve. One such model is presently being piloted at Capital District Health Authority here in Halifax, Nova Scotia. From my perspective, these “chronic care” models are in infancy stages of development and appear to struggle to integrate into dominant acute care models. In order for this integration to occur, policy addressing patient-centered care would need to more clearly outline how programs in acute care could be further enhanced to incorporate a broader range of health needs specific to chronic populations. For the COPD population in particular, generating guidelines to address the existential and social suffering unique to the experience of breathlessness could be one way to draw attention to these psychosocial aspects of care. Of course, changing well-established patterns of care is, and will continue to be, challenging. I see greater integration of psychosocial aspects of care as a long term goal, one which will involve fundamentally addressing the limitations in the models of care that currently exist - models that will need to shift in order to care well for those with chronic illness. Research, such as I have described in this thesis that challenges us to look at breathlessness from a new perspective, demonstrates the limitations of our current understandings and approaches and can help to open the door to health services and policy change within health care delivery systems.

To inform the development of more effective policies and programs, and to better understand the experiences and needs of people living with advanced COPD, more

research is required. We cannot adequately address the needs of this population when we know so little about their needs. As the present research indicates, psychosocial suffering is a major cause of worsening health status and deep distress for people living with advanced COPD. Further research is needed to explore the specific psychosocial factors contributing to this worsening health status and distress, and possible connections that may exist between these factors. Further research is also required to explore how people living with advanced COPD already engage their illness experiences, most especially breathlessness. Breathlessness may be experienced differently as COPD progresses. To develop programs that effectively address this core experience, it would be important to gain understanding of how disease progression influences the psychosocial suffering associated with increasing breathlessness and the contested selves emerging due to this suffering. It would also be important to explore the relationships of these contested selves within the context of daily living. Although this research did not investigate relationships with caregivers, it does suggest that these relationships are impacted by disease progression and interwoven into patients' illness experiences.

Ultimately, as contended above, self-management programs delivered by health care delivery systems are presently inadequate, and will continue to be inadequate, if they do not incorporate the experience and knowledge of patients who are already "self" managing their illness. This self- management could further be enhanced and supported by health care delivery systems. This research provides evidence of the key role psychosocial suffering plays in how individuals live their daily lives with advanced COPD, and supports the need for health care delivery system research, policies and programs to address this suffering.

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APPENDIX A

Pre-Opioid Patient Interview Guide

Thank you for participating in this study. The purpose of this interview is to gain an understanding of your experiences with this illness. The questions are meant as a guide to help understand your experiences. Please be assured there are no wrong answers. I have a few questions that will help to generate discussion about your experiences. Do you have any questions or comments before we begin?

1. How would you say that your life has changed over the course of this illness?
 - Were there things you could no longer do? Why/what stopped you? What was most difficult for you about this?
 - Do you think this illness has affected your relationships in anyway (e.g., with spouse, family members, friend) If so, how?
 - Other ways this illness has affected your life or relationships?
2. What are some of your fears when you think about this illness? Your life in general?
 - If I were to ask you what your greatest fear or fears are? (What do you fear most? (exacerbations; getting help; burden to loved ones)
 - What about your greatest hopes? (What do you hope for?)
3. What about formal care—how have these experiences been for you? (doctors, nurses, respiratory therapists, clinic visits, hospitals, home support)
4. What bothers you most right now? What would you most like to change if you could?
 - Quality of life factors mentioned in #1; breathing; relationships formal care; other things; fears; hopes
5. What were your thoughts when your doctor first talked to you about starting morphine? (fears, concerns, hopes, understandings)
 - Did you talk about any of these things with your doctor, then or since? (Why not?)
 - How did your doctor explain it to you? (what did s/he say)
 - Have your thoughts changed since being on the morphine?
6. Is there anything else you think might be helpful for other COPD patients or families to know about this illness? Doctors or other formal caregivers?

Is there anything else you'd like to say...anything we may have missed that you think important?