Life's Changing Landscape - Exploring the Experiences of People with COPD: An analysis of public narratives.

by

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ABSTRACT

In this study, data and information publicly available on the Internet were analysed to examine the self-reported experiences of people with COPD.

Chronic Obstructive Pulmonary Disease (COPD) is a chronic progressive disease that may exist with and worsen many other conditions of ageing. The theoretical basis for analysis draws on the social model of disability that stresses the disabling aspects of the environment, as opposed to the individual's medical condition. This allows the voices and stories of people living life with COPD to be the focus of this research.

In this study, I found that people with COPD who post their stories to the Internet display a wide range of emotions and experiences of living with COPD. The people with COPD discuss, amongst other things, how COPD has affected their home life and activities of daily living, their work and finances, their spouse or carer, and especially appreciate the friendships and support found at pulmonary rehabilitation and through belonging to a support group. These people appear to be very open and authentic in their writings, wishing to reach out to others with the condition to offer hope, support and advice, in adapting to changing circumstances as the condition progresses. People expressed gratitude at being part of a community of fellow people with COPD.

This collection of stories shows that, despite having a disabling condition, people with COPD can demonstrate resilience and resourcefulness to successfully adjust the landscape of their lives, and the realities of living with a disability, to maintain a good quality of life for as long as possible.

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I extend my sincere thanks to my family and friends, too numerous to mention, who have provided me with endless support, incredible patience and kind understanding as I worked through the process of completing this degree.

My sincerest thanks and love to my late parents. My mother, Betty Helen Polak, and father, Dr Edward Jan Polak, who showed through their actions towards others, and through the way they lived their lives, a commitment to service, and the importance of a just and fair society, so that everyone could have a fair share of opportunities, each to reach their potential.

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This thesis also acknowledges the anonymous people, who by posting their stories to the Internet, thus unknowingly provided the data for my study. I trust that in my commentary I have done justice to their stories.

DEDICATION

This thesis is dedicated to my husband:

Dr William (Bill) Robert Scowcroft

10 December 1939 – 16 March 2009

Over many years, Bill taught me a lot about learning, living and loving.

In particular, he supported me in many different ways, however strange he sometimes thought my projects were. Bill always respected my choices and enabled me to fulfill my ambitions.

Bill especially showed that however hard life may be, every day lived was a blessing to be used to the full.

“*Carpe diem*”

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CHAPTER 1 INTRODUCTION

“When you can’t breathe … nothing else matters”™ is the Lung Foundation Australia motto; this is the sentiment and driving force of groups around the world whose focus is on people with different lung conditions.

My family has not had a tendency towards lung conditions. My husband had been a long-time smoker, starting with cigarettes in his mid-teens. He was also extremely athletic and was generally very “fit.” In May 1986 we went walking at altitude. About 20 minutes into the walk, I noticed that my husband was slowing down, and that his breathing was becoming more labored. He stopped, and said, “I can’t go on. I need to get back to the hotel room to rest.” Then we basically put the episode out of our minds.

My husband continued to smoke. In 1992, while on a holiday to Machu Picchu, located 2,430 metres above sea level, my husband experienced further bouts of breathlessness. When we left Colombia in 1994 he gave up smoking, ending his 40-year habit. However, the damage was done.

It was not until 1996 that my husband finally agreed to consult a respiratory specialist. On returning home, my husband said, “The specialist diagnosed bullous emphysema, but gave me no further information, nor did he suggest any medication or give me any advice or prognosis.”

Our marriage now consisted of me, my husband and Chronic Obstructive Pulmonary Disease (COPD). We lived life as usual, performing the usual activities of daily living. My husband continued to be a non-smoker; most of the time he was able to conserve his energy, control his breathing, and was no more breathless than to be expected as “one got older,” with a diagnosed “reduced lung capacity.”

In May 1999 my husband took up a position in Winnipeg. For me the move indirectly led to an interest in disability, patient-centred healthcare, health care advocacy, and a determination and passion for social and distributive justice.

In mid-summer of 2001 my husband was not feeling too well, “probably just tired,” he said. That was my husband’s last experience of being “normal,” as in not “disabled.” He needed medical attention, and we went to the hospital, where he was immediately triaged and admitted with pneumonia. Thus began perhaps the most difficult five months of our lives.

Two days after being admitted to hospital, my husband’s condition had worsened and he was transferred to the Intensive Care Unit (ICU), intubated and put into an induced coma on a ventilator. Six weeks later, at the end of August, my husband was still in isolation in ICU, on the ventilator, and attached to various monitoring machines. I was told many times that he was not expected to survive.

I was also assured that being in an induced coma my husband was not aware of anything that was happening.

After 70 days on the ventilator, they lifted him out of the coma, not really knowing how his body would respond to the requirement to breathe unassisted. He remained in isolation in ICU for a total of four months, and on a ward in isolation for a further month. During the period of hospitalisation he had lost 40 pounds and was very weak. He was discharged from hospital at the end of November, into the snow, and onto supplementary oxygen 24 hours a day.

Being a very determined person, he decided that if he was going to live, then he was going to live well, that “he would own this disease; it wouldn’t own him.” After some weeks of rehabilitation he returned to work part-time and after some months he was full-time, and continued to work in a senior position until past normal retirement age.

After he retired we returned to Australia. He “didn’t want to die in Canada or go into long-term care in Canada.” While in Canada we were active with the Manitoba Lung Foundation. When we returned to Canberra, we jointly decided to continue our advocacy by becoming involved with The Australian Lung Foundation (ALF), now renamed Lung Foundation Australia. We wished to devote our knowledge, enthusiasm, energy, time and resources to supporting the work of the ALF in increasing public awareness of lung conditions, to pushing local, state and federal governments for more resources, for including lung conditions as a significant issue in policy, and contributing to the literature on both COPD and patient-centred health care and health literacy.

We represented the voices of many who face barriers, and are silent because they are “shut-ins,” or severely impaired in their mobility by lack of access to supplementary oxygen, transportation, or other factors. For just over two years, we continued this commitment, with increasing periods of hospitalization and concomitant decreasing quality of life for my husband, and increasing need for caregiving responsibilities for me.

He died in Canberra on 16 March 2009.

Being a primary carer for a person with COPD, I experienced on a daily basis the barriers and the challenges that people with impairments or disabilities encounter in achieving a high quality of life.

Breathing is something that most of us just take for granted. In public places, if we see the rare sight of someone using supplementary oxygen, we often notice, and wonder what is “wrong” with them; children stare and ask questions. Supplementary oxygen, or oxygen therapy, is prescribed for many people with chronic lung disease who have low blood oxygen levels. Oxygen therapy is usually prescribed to prolong life and it may also improve the quality of life (Queensland Health and The Australian Lung Foundation, 2012, p. 60).

COPD is a long-term, progressive condition of the lungs that primarily causes shortness of breath due to over-inflation of the alveoli (air sacs in the lung). In people with COPD, the lung tissue involved in exchange of gases (oxygen and carbon dioxide) is impaired or destroyed. COPD is called an obstructive lung disease because airflow on exhalation is slowed or stopped because over-inflated alveoli do not exchange gases when a person breathes, due to little or no movement of gases out of the alveoli. This affects a person’s ability to breathe, but also the lack of oxygen in the body causes changes in the normal functioning of all body systems. COPD can also be referred to as chronic bronchitis, emphysema, chronic obstructive airway disease (COAD), airflow obstruction, and emphysema with various qualifiers (panacinar, distal, acinar, paraseptal) depending on the position within the lungs. The important point for my research is what effect it has on a person, and their quality of life, and the effect on their family and friends.

The World Health Organization (WHO) defines COPD as follows:

> Chronic obstructive pulmonary disease (COPD) is a lung disease characterized by chronic obstruction of lung airflow that interferes with normal breathing and is not fully reversible. The more familiar terms “chronic bronchitis” and “emphysema” are no longer used, but are now included within the COPD diagnosis. COPD is not simply a “smoker's cough” but an under-diagnosed, life-threatening lung disease.
>
> (WHO, 2012)

The various Lung Foundations also often include chronic asthma under the umbrella of COPD. The main cause of COPD, affecting over 600 million people worldwide, and 12 million in the United States alone, and causing one death every four minutes in the US, is known to be smoking, with some contribution from industrial pollution and jobs in high risk environments (American Lung Association, 2011). However, COPD is frequently under-diagnosed, misdiagnosed or undiagnosed, so the figures for the number of people with COPD could actually be double the reported statistics (Australian Lung Foundation, 2012; National Heart Lung and Blood Institute (NHBLI), 2012). Often it is not until a person has an acute episode of breathlessness requiring hospitalization that the diagnosis is made (Page, 2007).

COPD is currently the fourth leading cause of death after heart disease, cancer and stroke (American Lung Association, 2011). Raherison (2009) states that the projection for 2020 is that COPD will be the third leading cause of death worldwide (from sixth in 1990) and the fifth leading cause of years lost through early mortality or handicap (disability-adjusted life years (DALYs)) (12th in 1990). COPD is often referred to as the “silent killer” because there is no known cure, and because it is a progressive disease that develops slowly over time it is often mistakenly thought to be non-lethal (NHBLI, 2012).

According to the American Lung Association, people with COPD often say that one of the worst aspects of their illness is the feeling that they have lost control over their health (American Thoracic Society, 2012; Johns Hopkins, 2012).

After my husband's death I continued my interest in people living with COPD. Researchers have not examined the experiences coming *from* people with COPD, directly *from* them in their own words, that is, not in response to set questions as part of a research project. The authors of several studies have reported on the lives of COPD *patients* using a methodology of being interviewed or given questionnaires by medical professionals, such as physicians and nurses, usually in a hospital setting, when patients are having an exacerbation, or flare-up of their condition.

Therefore, these analyses are of *patients* as *objects of study*, rather than *people* as *participants*, using their own voices. The stories of everyday life experience of people with COPD, as told on social networking sites, online communities, blogs or tweets, has not been investigated in the academic context of disability studies.

This research study investigated individuals' experiences of COPD, with the disability created through interactions with a physical and social world designed for non-disabled living. In this case, an environment designed for those who can breathe "normally."

The aim of this research project was to explore, through an analysis of publicly available narratives found on the Internet, or other publicly available publications, the experiences, from their perspective, of everyday life for people living with COPD.

The research question for this study was, “What are the lived experiences and perspectives of people with COPD who post their stories on the Internet thus making these narratives publicly accessible?”

The data was collected from appropriate and publicly available Internet sites, which are blogs, online fora or YouTube, of people who contribute stories about their lived experience of COPD. A Google search of “copd blog” gives 3,630,000 results, of which the first four are: COPD Blogs and Websites – Health.com; COPD – IT’S NOT A DEATH SENTENCE; Headlines – COPD – About.com; and, COPD Info. A preliminary examination of these revealed that each of these leads to patients’ stories and information and links to reputable expert and reliable sites about COPD. There is overlap and cross-referencing between the sites, none of which require a password or account for access.

Prior to the process of formally collecting my data I systematically explored several websites looking for themes related to my interest in the lived experience of people with COPD. Only then was I able to choose the websites that provided a range of coverage and balanced approaches. There are also collections of stories on the Lung Foundation sites, or published by other groups interested in lung conditions. These latter may represent an ascertainment bias because they may have been solicited and moderated or edited before being placed on the website.

This research was of an iterative nature: viewing and reviewing the narratives as the data was collected, I explored perspectives that can be categorized as sub-questions, which arose during the course of the research. As Kozinets (2010) observes “The analysis of existing online community conversations and other Internet discourse combines options that are both naturalistic and unobtrusive – a powerful combination that sets netnography apart from [other] ethnographies" (p. 56).

The word netnography was first used by Professor Kozinets at York University, Toronto. His definition,

> Netnography: a type of online, or Internet, ethnography; netnography provides guidelines for the adaptation of participant-observation procedures - planning for fieldwork, making a cultural entrée, gathering cultural data, ensuring a high-quality ethnographic interpretation, and ensuring strict adherence to ethical standards - to the contingencies of online community and culture that manifest through computer-mediated communications (p. 191).

It is important to remember that "The … netnographic enterprise is about struggling to transcend our own illusory categories and to understand the categories of the community and culture we are focusing upon" (Kozinets, 2010, p. 167).

Kozinets (2010, p. 191) defines an online community as:

> A community manifest through any form of computer-mediated communications; a group of people who communicate and share social interaction and social ties through the Internet or other computer-mediated-communication, such as e-mail lists, forums, newsgroups, photo-sharing sites, blogs, virtual worlds, or social networking sites; levels of participation vary widely from largely passive subscribers to highly involved organizers.

I examined online fora, rather than information from online communities, as I did not interact as a participant with the people posting, nor was I able to observe their interactions with each other unless these were openly available to anyone who may search for them. Information did not come from any site that required membership or any form of login to access material.

According to Internet World Stats, on 30 June 2012 there were more than 2.4 billion Internet users (about 40% of the world's population). This number is up from 1.5 billion users in 2009 (Kozinets, 2010, p. 2). Kozinets states that, "these users are not passively consuming published content …. They are actively communicating with one another" (p. 2). I found that even though I did not interact directly with them to ask questions or prompt responses, there was rich data because people with COPD, in growing numbers, are providing their narratives openly and publicly.

I gained insight into questions such as: Which sites do people with COPD join/visit/contribute to, to learn more about their condition and to become participants and contributors online? What types of questions and concerns are people with COPD expressing online? What indications of barriers or frustrations in terms of aspects of daily living (space, place and time) are present in the narratives of people with COPD? As in all narrative or content analysis, I was careful in the analysis not to inflate the meaning in the posts.

It can be considered that there are two distinct and contrasting models or frameworks to describe disability: the medical model and the social model. However, while there is a distinct dichotomy in these approaches, within this dichotomy there are descriptors such as affirmative, individual, citizenship, and environmental, to describe the social model further; and for the medical model, charity, personal tragedy, worthy poor (Prince, 2009, p. 272).

According to the medical model, sometimes called the charity model or the personal tragedy model of disability, “disability” is a health condition dealt with by medical professionals (Carson, 2009). People with disability are thought to be “abnormal.” Disability is seen as a problem of the individual, a person with disability is seen as faulty and in need of being “fixed” or “cured.” This model sees disability as a tragedy, thus people with a disability are to be pitied and patronised. The medical or individual model of disability is about what a person *cannot do* and *cannot be*; this model has had, and continues to have, negative consequences for people with disabilities (Brisenden, 1986; Crow, 1996). “The medical model is often known as the personal tragedy model because it regards the difficulties that people with impairments experience as being caused by the ways that their bodies are shaped and experienced” (Swain *et al.*, 2003, p. 22).

The medical model of disability is one “rooted in an undue emphasis on clinical diagnosis,” leading to a “partial and inhibiting view of the disabled individual” (Brisenden, 1986). In order to understand disability as an “experience,” as a “lived thing,” Brisenden continues that we need much more than the medical “facts,” however necessary these are in determining medication. The problem comes when these facts determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person who happens to have disabilities.

Typical definitions based on this restricted medical model perception are those historically offered by the WHO (1980):

> Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function;

> Disability: any restriction or lack, resulting from an impairment, of ability to perform any activity in the manner or within the range considered normal for a human being;
>
> Handicap: a disadvantage for a given individual, resulting from an impairment or disability, that prevents the fulfillment of a role that is normal depending on age, sex, social and cultural factors for that individual (Carson, 2009, p. 8).

These definitions are somewhat contrary to the daily experiences of many disabled people, so it was inevitable that change had to be made.

The social model was created by disabled people themselves. It was primarily a result of society's response to people with disabilities, but also of these people's experience of the health and welfare system that made them feel socially isolated and oppressed (Carson, 2009, p. 10). Recent developments promote inclusion through anti-discrimination legislation, equal-opportunity policies and programmes of positive action, because it is now more widely (but not universally) recognised that disabled people are unnecessarily and unjustly restricted in, or prevented from, taking part in a whole range of social activities that non-disabled people access and take for granted.

The social model of disability rejects the idea that disability is caused by the functional limitations of a person's body; rather, it locates the cause of disability in a social failure rather than the individual's biology (Oliver, 1990). The social model posits that disability is the result of the interaction between people living with impairments (biological conditions) and barriers (social restrictions) in the environment, which may be physical, attitudinal, communication or social. It implies that these barriers must change to enable people living with impairments to participate on an equal basis in society (Shakespeare & Watson, 2001).

Later, these authors contribute to an exploration of the background to British academic and political debates over the social model, and argue that the time has come to move beyond this position. They consider three criticisms of the British social model, focusing on the issue of impairment, the impairment/disability dualism, and the issue of identity. They suggest that “an embodied ontology offers the best starting point for disability studies,” and suggest ways to develop a more adequate social theory of disability. By considering disability as a social construction, the social model of disability has become a political tool to advance the goal of full participation and equal citizenship for all people with disabilities (Oliver, 1990; Shakespeare & Watson, 2002).

Kitchin (2000, p. 7) explains that impairments are physical manifestations related to the biology of the individual while disability “is to be disadvantaged or restricted by a society which takes insufficient account of people who have physical, sensory or mental impairments and thus [are] … excluded from mainstream social activities.”

A social model perspective does not deny the reality of impairment or its effect on the individual. According to the social model of disability, disability is socially constructed. It challenges the environmental barriers to accommodate impairment as an expected part of human diversity. Proponents of the social model seek to change society in order to accommodate people living with impairment; it does not seek to change persons with impairment to accommodate societal barriers. The model supports the view that people with a disability have a right to be fully participating citizens on an equal basis with others.

The social model of disability is now the internationally recognised way to view and address disability. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) marks the official paradigm shift in attitudes towards people with disability and approaches to disability concerns (UN CRPD, 2006). Essentially, the convention asserts that people with disabilities should not be viewed as “objects” of charity, medical treatment and social protection, but as “subjects” with rights, who are capable of claiming those rights, can make decisions for their lives based on their free and informed consent and be active members of society.

It should be noted that many people are willing to adopt the social model and to make adjustments for people who have a *visible* disability. Most policy related to disability, however, still has the medical model underlying it, and people are not as accommodating towards people who have a hidden disability (such as diabetes or dyslexia), or a disability that is not clearly understood such as mental health issues. An important principle of the social model is that individuals are the experts on their requirements in a particular situation, and that this should be respected, regardless of whether the disability is obvious or not.

Analysis based on the social model of disability has as its premise that it is the environment, not the individual, which is disabling. “Every single instance of life can be regarded as tied to access – that is, to do anything is to have some form of access” (Titchkosky, 2011, p. 13).

A consequence of the aging of the population, which in the last 50 years has seen a tripling of the proportion of the elderly in most advanced countries, has been a rapid increase in the number of people with COPD (Gilmore, 2011).

Rainie (2012) claims that, “People are not hooked on gadgets – they are hooked on each other. When they go on the internet, they are not isolating themselves. They are conversing with others – be they emailers, bloggers, Facebookers, or Wikipedians” (p. 6). How can this power in the current environment be used to support people with disabilities, especially those with mobility issues? How much more difficult might it be for those who are isolated, or is technology more liberating for those people? Technology may be an enabler to break down isolation. Kaufert (1984), studying the implications of a disability, states, “any understanding of the implication of a disability must look at change not only as a consequence of disease processes, but also in terms of changes in the medical or social environments in which those changes occur.”

In my research I have explained how the geography of people’s lives, as reported by them on the Internet, changes with COPD, looking at real factors such as energy, speed, space, and time, and the simultaneous shrinkage of a person’s horizons with a chronic condition, but also the potential for counteracting this, and the opening up of those horizons by the use of technology.

Technology is also very important in the development of testing and monitoring equipment, the constant improvement in both home and portable oxygen systems, advances in new medications for symptom control, and recording physiological measurements to maximize the benefits of exercise and ensure that there are no harmful effects. These interesting aspects of technology are outside the scope of this research study, but are nonetheless worthy of noting.

These constantly developing technological tools allow data collection and analysis of how people with COPD describe themselves and how they live with the condition. People have access to new tools for communicating about their situations and lived experiences and these narratives are available to others in the public space of the Internet. Carpenter Negulescu (2012, p. 10) describes the Internet as “the world’s most vibrant cultural medium,” with “fundamental strengths of being distributed, ubiquitous, relatively inexpensive, not easily quelled or manipulated by any single actor.”

Turkle (2011) asserts that the use of modern technology leads to a version of self and living that is disembodied and distracted, but if a disability such as COPD causes a person to be physically limited, then perhaps the consequence of the use of technology can be one of liberation and participation. I am coming to regard the “virtual” as a “fifth dimension,” but have not come across this naming of the phenomenon in the literature.

I examined a “snapshot” in the lives of the people with COPD, using as a lens my own lived experience of changes in many aspects of everyday life, which will necessarily affect people’s capacity for achieving an optimum quality of life. My interpretations, observations and comments on the narratives are shaped by the social model of disability. With the rise of the consumer health and disability movements, there have been changes in the training of health professionals, as concerned researchers and educators seek means to break down previous barriers and communication gaps. Kaufert et al. (2010) report on different approaches to educate and inform first year medical students about issues involved with end-of-life ethics and disability.

The researchers "hope new knowledge may provide health care professionals with a greater understanding of the perspectives of patients with disabilities." Kaufert and Koch (2003) probes provocatively further in the discussion of the intersection of disability and end-of-life narratives, and different perceptions and interpretations of narratives by different people, depending essentially on "the life histories of the audience."

As Young states:

> We are at the dawn of a watershed change in the amount of data out there. It is created by us, about us. The stakes are high: will we use it for personal insight, and to build smarter, more sustainable communities, or will we use it for control, surveillance and profit? Only by understanding the revolution already underway can we debate where we want it to go.
>
> (Young, 2012, p. 6)

CHAPTER 2 LITERATURE REVIEW

The medical term for normal relaxed breathing is eupnea or eupnoea. The prefix “eu” means good, well, or true. The opposite of this is dyspnea or dyspnoea; in lay terms this is breathlessness or shortness of breath, the most obvious and distressing symptom of COPD. The effects of low oxygen levels on body systems are not so obvious, but certainly exist, and become more acute and of concern, as the condition progresses. See Barnes (2010) and Eisner (2007) for detailed discussions of this phenomenon.

People who practise yoga and other meditation techniques pay attention to their breathing, but this is a small segment of the population with studied breathing awareness. Nora Young (2012) makes the interesting observation that she has practiced yoga for more than twenty years, so has a heightened awareness of breathing, and was fascinated when Linda Stone describes the way our bodies respond when we are using digital technology. Stone coined the phrase “email apnea” (Young, 2012, p. 90), because as we interact with our devices, we either take shallow breaths, or temporarily stop breathing. Both sitting bent over a computer, and intense activity on the Internet, by people with COPD may contribute to episodes of breathlessness and anxiety (two major symptoms of COPD) (American Thoracic Society, 2012; National Heart Lung and Blood Institute, 2012; Nightingdale House, n.d., accessed 12 October 2012). Stone (Young, 2012, p. 90) believes this breathing or breath-holding over time is prompting a fight-or-flight stress response, where levels of stress hormones may build up. I did not find any literature reporting this, although the neuroscientist Stephen Porges has suggestions, such as physical exercises beyond slow breathing, to minimise the chronic fight-or-flight state to restore a feeling of safety and balance (Porges, 2008).

Disability awareness means a move away from the negative aspects of disability, which generate pity and charity, to a positive perspective with recognition of rights and equality. The medical model positions disability with the individual person, his or her "illness," or "problem," or "impairment," and seeks to "fix" the person to make them "normal." It would seem that the various Lung Foundations in many countries, because of their genesis in the medical system of the Thoracic Societies, predominantly take this perspective, although I have noticed that there has been a slow change as the patient-centred movement has become more powerful and vocal. For this historical reason, the majority of research on COPD has and continues to be, concerned with the medical, diagnostic and pharmaceutical aspects of the condition.

However, a recent publication (Expert Report on COPD, 2012, p. 4) stresses that "the latest thinking on COPD management represents a shifting paradigm to recognize risk reduction as being of equal and complementary importance to symptom control." This is a very welcome change from the previous approach: "As COPD historically has been perceived as an incurable, continuously progressive disease, it has been associated with a therapeutic nihilism amongst both patients and healthcare providers" (Expert Report on COPD, 2012, p. 19).

The more positive social model locates disability in a restricting environment. This is the perspective that underpins the "disability rights" movement (Stienstra, 2012) and intersects with the world-wide movement for patient-centred health care.

The experiences of disabled people are complex and varied. Much of the research in disability studies and the activities of people in the disability movement are aimed towards breaking down stereotypes. Although still perhaps primarily using a medical perspective, being in the early phase of disability studies, Morris (1992) suggested that the experiences of being ill and of physical and intellectual limitations are all part of "the experience of living and so there is a need to understand the subjective reality through research." Morris also suggested that "the individual and collective conditions of disabled people are not fixed, that the experience of disability demonstrates an emergent and temporal character." Thus, for people who have a progressive condition such as COPD, there is a need for constant changes to their response to their environment and conditions of living. This is especially so, because in the later stages of the condition, the person is likely to have increasing periods of hospitalization, referred to as "exacerbations" or "flare-ups." This means that as well as an almost constant adaptation to the home situation, there is also the periodic stress of reassimilating into the home, possibly with increasing support needs (Jowsey *et al*., 2011).

In a comprehensive search of the literature I found only one article that described COPD as a disability. Boyles, Bailey and Mossey (2011) reported on research using a focused ethnographic design to develop an understanding of the meaning of disability for individuals living with COPD in a Canadian community. In a sample of fifteen individuals interviewed, narrative analysis revealed 65 "dilemma" stories consisting of two structural components: the impairment, and the justification/explanation of the impairment. Participants told the stories to convey the meaning of COPD as a disability invisible to others, and at times, to themselves. As I also found in my literature search, Boyles *et al.* observe that to date, COPD research has been focused primarily on the pathophysiology of the disease process, the pharmacological management of symptoms, and the utility of rehabilitation strategies.

There has been substantive and ongoing research on the primary symptom of COPD that is dyspnea (breathlessness) and the management of acute flare-ups of COPD, much of which has been supported and funded by the Lung Foundations, Thoracic Societies, and pharmaceutical companies. In 1989 Williams suggested that “no research examining COPD as a disability existed because little could be done medically to help patients living with chronic respiratory illness.” While this may have been true in 1989 it is certainly no longer the case, providing people with COPD have access to the knowledge, medications and care that is currently available. Williams (1989) also noted that respiratory illnesses, constituting a less attractive area of inquiry than some others, were not on the cutting edge of research development. He also contended that COPD predominantly affected individuals later in life, and was a self-induced disease, the so-called “smoker’s disease.”

This “stigmatization” may still account for the reluctance of people to seek medical help for the primary symptoms of COPD, which are breathlessness, persistent cough and excess mucus production (American Lung Foundation 2011, other Lung Foundations, and medical sites on the Internet). These societal and research attitudes have slowly changed as smoking has been recognised as an addiction (eHealthMD, 2012). Previously, as Bailey, Montgomery, and Boyles (2009) suggest, it was considered a “less immediate medical, social, and moral concern.” Boyles (2011) observed that twenty years after Williams (1989), literature that examines COPD as a disability could still not be identified.

There is a substantial amount of literature that treats COPD as a disability in terms of claiming social service benefits; for example (Laurence, n.d., accessed 15 October 2012; MDGuidelines, 2012; Tinkelman, 2005), but this is using the term “disability” with a different meaning and within a different context.

There are also numerous books and research papers about COPD, some of which are included in this literature review, and some of which are used as a source of quotes in Chapter 4. This additional material ranges from collections of stories, to guides to living with COPD that include much medical as well as some psychosocial material, to strictly medical peer-reviewed research papers. Many of these, as well as my lived experience, have provided for me the background information, knowledge and understanding to enable me to choose what I consider are the best quotes to illustrate my approach to the analysis of the changing landscape of the lives of people with COPD; and to richly describe the everyday lives and strategies for maintaining quality of life which are seen in people with COPD as evidenced through access to their stories.

Disability geography and anthropology research perspectives: parallels with experiences of people with COPD

The literature search for information directly describing the lived experience of people with COPD from a social model perspective was limited. Therefore, I turned to literature on the experiences of people with other conditions, to seek to draw parallels with my research. A fruitful body of research was found in the recent writings of disability geographers. *Towards enabling geographies: "disabled" bodies and minds in society and space*, Chouinard *et al.* (2010), reflects a far more complex understanding of disability and impairment showing that human geography's interest in disability has broadened and deepened and that other bodies of difference have become included in the disability frame. This increased interest includes more detailed analysis of the bodily experiences of people with impairments, the increasing role of technology in disabled people's lives, and a growing desire to engage with policy debates that affect disabled people's lives. Each of these three aspects is of particular interest to my current research interests, although in my current research I shall primarily be concentrating on the first two of these aspects.

First, I shall explore the literature on the bodily experiences of people with impairments, particularly with respect to the place where they spend most of their time, the home. Imrie (2004, 2010) and Crooks (2010), and in a "morphed" workplace and discipline, Gold (2004; n.d., accessed 15 August 2012) and Robillard (1999) provide insights here.

Second, the role of technology for people with disabilities will be discussed in a later section.

The third aspect, of policy debates, is beyond the scope of my research project, so it will not be addressed here; nonetheless, it is important as the "third leg of the stool." As Chouinard (2010) observes, "the impacts of state policy and restructuring can lead to the marginalization of disabled people in society and space."

Imrie (2004) states that, "Empowerment is often found in the details of the mundane world. It comes from controlling access to personal space, from being able to alter one's environment and select one's daily routine, and from having personal space that reflects and upholds one's identity and interests" (Ridgway *et al.,* 1994). The impaired body is rarely imagined or drawn into domestic design, which is unsurprising given that representations of idealised domestic life revolve around what Hockey (1999, cited by Imrie 2004) refers to as "positively perceived values, such as companionship and freedom, but tend to exclude, even deny, other aspects of domestic life, such as disease, impairment and dying." Imrie (2004) states that, "It has been well established in housing studies that the home is one of the fundamental places that gives shape and meaning to people's everyday lives."

People with chronic conditions or disabilities, that impairs their mobility, may lead them to be largely confined to their homes. Many people with COPD are not only confined to their homes but often also "tethered" to an oxygen concentrator.

Chouinard (2010) sees an underlying positive current in much contemporary research. She states, "while geographers continue to examine and critique exclusionary (public) spaces and practices, there is a notable and welcome shift towards studying and promoting the means of creating more inclusionary and enabling social spaces for disabled people." This clearly includes the home, and can in some sense also include access to and embracing modern technology to break down barriers to inclusion in the wider world. Certainly, the results of developments in medical technology have caused a huge change in how people with disabilities or chronic conditions can live their lives. In Kaufert and Locker (1990), and Locker and Kaufert (1988) the researchers outline the "careers" of people with post-respiratory poliomyelitis and how developments in respiratory support technology and their adoption "made an enormous contribution to the quality of life of these people" whilst still stating "the problems it [post-respiratory poliomyelitis] created transformed both their experience of the illness and the character of their everyday existence" (1988, p. 23).

Crooks (2010) follows closely on Imrie's descriptions of the home, as a "central part of everyday life" and "houses are physical containers" that become homes when we make sense of them using our "personal meanings and associations" and they become "complex spaces of everyday life" because "we personally invest so much into making these places homes – through ascribing meanings, qualities, attributes, and associations." But, the home can take on new meanings in people's lives because of a "restructuring of daily routines after the onset of chronic illness." Crooks (2010, p. 46) describes the findings of research involving 55 women after the onset of fibromyalgia syndrome (FMS) with main symptoms of chronic pain and fatigue. Unsurprisingly, the onset of FMS led to altered lifeworlds, using Dyck's (1995) definition of "the taken-for-granted mundane experiences of daily life as carried out in particular spatio-temporal settings," for all the women. Crooks (p. 48) gives detailed information to contextualize and explain the women's reported experiences on disablement, embodiment, and coping, in the "home space."

Verbrugge and Jette (1994) state, "both personal factors and environmental factors can speed up or slow down how someone experiences the process of disablement after the onset of chronic illness" (p. 55). For my study, life in the home has both spatial and temporal aspects, as illustrated in the following research finding:

Time value: Tanisha Jowsey (researcher, edited personal communication of her experience visiting a Canberra Lung Life Support Group meeting, September 2012).

> I was planning to tell you some interesting statistics from our time use survey, like the median amount of time people with more than one chronic illness spend on health-related activity each month is 5-16 hours, but for people with COPD it is much higher. People with COPD who have five or more illnesses [comorbidities] spend about 109.5 hours per month or 3.5 hours per day on managing their health. On this day I began to understand on a new level the value of friendship and support, and in particular, support offered by this group. It is clearly highly valued by the group members, who brave the winter air and dedicate their time to attend. I have learned that as chronic conditions progress, time becomes increasingly accentuated as something that is limited and precious. This perception informs people's choices and behaviour. Health services have found ways to reduce unnecessary time spent on managing health. They have also found ways to increase the value of necessary time spent managing. The time with your group has illustrated to me the importance of this second dimension and I will now be putting my mind to finding more options for health services to contribute to increasing value in the programs and support they offer.

The intersection of anthropology and disability leads into consideration of the use of technology and mining social media, considered in the next section.

In *Rediscovering Place: Fieldwork by a Quadriplegic Anthropologist*, Gold (2004; n.d., accessed 15 August 2012) tells of his journey of transformation from being an able-bodied anthropologist doing research in the "real world," one of physicality and field trips, to becoming a "paraplegic anthropologist" undertaking "virtual disability." Gold (2004) discusses his experiences as a disabled anthropologist from the perspective of conventional fieldwork experiences, and then through the lens of fieldwork in virtual places and virtual communities. Gold states that "Fieldwork as a methodology is a craft of those able-bodied anthropologists who sustain long-term relationships with their informants and nurture an encyclopedic knowledge of spaces and places." He speaks of access to households, and relationships with cultural "others," through participant observation and other methods to deconstruct and analyse cultural experience. But, he admits that, access to the "field" is contingent on hidden factors such as the physical "wellness" of the researcher.

Neither Gold (n.d., accessed 15 August 2012) nor Robillard (1999) initially expected the disorientation of their own bodies to become a focus of their research and thinking. Through personal experience, Gold could identify with the challenge to rethink and redefine the accepted meaning of the “field.” He was forging a paradigm shift where previous discussions of “disability culture” did not include the considerations of physical “place” or of physical “space” characteristic of anthropology and geography. He is speaking of a different environment, but the parallels are clear with my research, when he reflects, “Recognizing invisible and marginal communities encouraged me to consider ‘places’ which are recognized by a subset of persons, in shared memory rather than in bounded spaces on a map.” He explains that these are places where you do not know you are “there” until you are able to read the cultural map that lets you know that “here is there.”

Parallels can be drawn with the experience of being part of a support group, where the members can be seen to be along a spectrum of different stages of a progressive chronic condition, and they and their carers exhibit quite diverse coping and management strategies.

Social media and virtual communities

There is considerable literature, both printed and online, on social media, although much of it is associated with selling products and marketing analysis.

Social media can be described as “interactive platforms via which individuals and communities create and share user-generated content” (Kietzmann *et al*., 2011). Effectively, social media is software that mediates human communication. When the technologies are in place, social media is ubiquitously accessible, so the detail of how communication is actually effected is not of concern here. No one, however, can have failed to notice the fact of the “ever-presentness of new technology.” According to the International Telecommunications Union, there were “six billion mobile phone subscriptions by the end of 2011; that’s 87 percent of the world’s population” (HIT, 2012). Turkle (2011) has extensively studied this phenomenon of the spread and use of technology.

Bennett (n.d., accessed 15 October 2012) is a wheelchair user and describes how immersion into virtual worlds can be more than mere escapism for people with disabilities. He relates the daily barriers in the physical world that many people, due to visual, cognitive, or mobility impairments, can’t negotiate. He states in a virtual world many disabilities can seem to disappear. He discusses “Second Life” and how people with various disabilities have formed online communities to meet and interact. He states that while support groups exist, both in the real world and in Internet chat rooms, the virtual environment adds another dimension. Bennett essentially is describing the virtual world as an assistive technology.

By the year 2012, social media became one of the most powerful sources for seeking and sharing information and connecting to one another, both to family, friends and online strangers, through Web 2.0 social networking sites. Facebook, Twitter, LinkedIn, MySpace and Google+ are the most popular social networking sites (SNSs) globally (Alexa, 2012). According to (Kietzmann *et al*., 2011) there are seven functional building blocks identifiable in the discourse on these platforms: identity, conversations, sharing, presence, relationships, reputation, and groups. These building blocks provide a possible structure for the analysis of interactions on sites contributed to by people with COPD.

Gold (2004) reinvented himself as a "virtual disability anthropologist" over a three year period, and, anxious to make contact with other persons with multiple sclerosis, he discovered "a rich source of daily interaction" in a Usenet group. "MSN" participants were people "with lengthy and relatively unrestrained narratives" or "tales" of multiple sclerosis. Although observing and participating in these conversations, he did not initially consider cyberspace networking as "field" research. Cyberspace was not a "place" in a conventional anthropological sense and he still considered his presence as experiential and reflexive. Without precise research plans, Gold (2004) approached cyberspace narrative with personal interest and saved thousands of messages, as insights into the culture of chronic illness and disability. Subsequently, these messages formed the basis of several papers, which illuminated, through an anthropological lens, the concepts of "virtual disability" and characteristics of virtual communities. Gold became a participant observer, with a similar sense of a damaged identity, but he used his new "space" and "place" to continue a very successful academic, research, and publication career.

Corroborating what Gold (2004) described, Tilley (2006) reported on a qualitative study that had developed a model, which also has implications for the wider community of people with disabilities, of a virtual community for people with long-term, significant physical or mobility disabilities. The methodology used qualitative techniques to determine the subjects' experiences and perception regarding virtual communities and the use of Information and Communications Technologies (ICT). The interviews explored in detail the elements, enablers, and barriers to the usage of ICT and/or assistive technology. The central theme to emerge from the narratives was that people with long-term disabilities regain a sense of control and independence in their lives, and that being online tended to break down people's isolation and potentially changed the work paradigm, giving people with disabilities access to work that was previously denied them. Tilley (2006) concludes that, "ICT and online communities offer ways to enhance every person's inclusion, participation and empowerment in society."

Tilley (2006) was able to actually initiate and control an online community in her study, and thus, was able to demonstrate and prove her hypotheses.

Data and social media

Literature exists on the use of social media for patients seeking medical information online, but these analyses are of a quantitative nature, as in "how many hits" a site received. On the Internet, there is an overwhelming abundance of access to medical information sites, general advice about healthy lifestyle choices and constant advertising of "products" to aid the consumer in these health matters. Many of these sites offer useful and seemingly dependable information, whilst others appear to be of questionable validity, and may indeed be harmful. More research is needed to develop guidelines to help health care consumers assess the validity and dependability of these sites.

There is a growing academic interest in the Health Informatics Technology (HIT) field, as discussed by Househ *et al.* (2012). The mHealth field focuses on the use of mobile technologies to support hospital care, healthy behaviour, patient monitoring, and educational awareness. Househ discusses the current state of, and the opportunities and challenges within, the mHealth field. They also introduce the term Mobile Social Networking Healthcare (MSN-Healthcare), which they define as follows: “The use of mobile health applications that incorporate social networking tools to promote healthy behaviors and awareness among patient groups and communities” and claim that this concept has not previously been introduced in the literature. Of interest is their discussion on opportunities for the implementation of mHealth in relation to chronic disease management, the education of health professionals, the needs of health professionals, and the decision-making process for patients and clinicians (Househ, 2012).

The pace of technological change has indeed been phenomenal in the last decade. Not only is the technology continuously evolving, but new concepts and terms are added to “everyday” language at an exponential rate.

Social media and health information technologies that support people with disabilities or chronic conditions

Borycki (2012) reports that her group is studying people with COPD from the perspective of using “M-health” technology to self-manage their disease. She comments that the Internet and mobile phones have revolutionized the ways in which those affected by chronic illnesses (not just COPD) obtain health information. She observes that, “Increasingly individuals affected by chronic illnesses are using social media (e.g., blogs, YouTube, Facebook, Twitter) to obtain information about their conditions. This rate is expected to grow with the increased use of the Internet, mobile phones, and mobile phone/social media software applications, or apps.” She continues by saying the future of COPD self-management is changing and will likely include the use of a blend of these three technologies. She also said that a literature review was being undertaken to determine the current state of the research at the intersection of COPD and the use of mobile devices and mobile social media applications in health care (Borycki, 2012).

Judy Gold (2011) reports that in recent years SNSs have grown rapidly in popularity. She states, “The popularity of these sites, along with their interactive functions, offers a novel environment in which to deliver health promotion messages.” Although the aim of Gold’s research was to examine the extent to which SNSs were used for sexual health promotion, useful methodological and analytical information justified this being included in the relevant literature for my research.

Moody (2005) is a proponent of health information technology and states that, “E-health delivers healthcare services and education, via a Web portal, to older persons with chronic conditions and their caregivers and enables the patient’s home to be the point of care.” She sees that “this growing industry is ripe for exploration by nurses who can empower the patient and caregiver to gain self-care and coping skills.” Moody (2005) gives a very comprehensive overview of various segments of the available health information technology, including discussions on E-Health, telehealth, telemedicine and web portals. In particular, she observed that “E-Health aims at the consumer or caregiver, applying a holistic view.” She continues, however, “the case for adopting E-health in the home setting is more compelling than ever, from a needs perspective rather than an economic or pragmatic perspective."

Moody (2005) expands on the various telemonitoring devices that may be used, for instance, via a Universal Serial Bus (USB) port on the user's computer, to download collected data for transmission to a health professional.

Chronic Obstructive Pulmonary Disease (COPD)

There is an immense amount of medical information regarding the diagnosis and treatment of COPD, which is a chronic progressive lung disease, and which may be comorbid with many other conditions. There is little mention of involving people with COPD as partners; this is an almost universal omission in the medical literature regarding any conditions, reinforcing the medicalisation of conditions and the lack of inclusion of the people who know the most about living with any particular condition.

The Australian Lung Foundation estimates that COPD affects one in seven Australians over the age of 40, and that half of those affected do not know it (Australian Lung Foundation, 2012). The numbers reported in Canada, the United Kingdom and the United States are similar (Najafzadeh *et al*. 2012; Health and Safety Executive (HCE), (2012); National Heart Lung and Blood Institute (NHBLI), 2012).

COPD as a disability for the person and macro considerations of the cost to society

Boyles (2011), as mentioned earlier, observed that twenty years after Williams (1989), literature that examines COPD as disability could still not be identified. While the approach in Williams was mainly medicalisation of COPD, with quantitative measures and medical model language such as “patients” and “suffering,” there was also discussion and concern for the social aspects of the condition. Essentially Williams was discussing the social determinants of health [a term not used at the time of his writing] that contributed to the disability felt by those with the condition and the disadvantaging effects that the family also experienced. Williams said, “COAD is linked in the public mind with smoking,” and that “the image of a wheezing, coughing, breathless (old) man is often greeted with little sympathy, adds to the potentially stigmatizing nature of the condition.” He concludes with a statement which is still remarkably true today: “As with many other chronic illness conditions much of the daily reality and experience of coping with chronic illness and disability, both for the sufferer and his or her family, goes on ‘behind closed doors’” (p. 609).

This behind closed doors aspect is part of my research focus, because I shall be reading the narratives of people with COPD who are writing about their own experiences with the condition. From a disability research social model perspective it is important to support everyone in the most appropriate ways, as defined by themselves, to allow optimal access to citizenship and provisions to break down barriers to full participation.

Perhaps one of the least openly considered aspects of living with a chronic condition is that of the emotions involved. Elisabeth Kübler-Ross (1969) outlines five distinct stages that are typical to the grieving process associated with a life-limiting illness: denial, anger, bargaining, depression, and acceptance. Other authors have expanded on this schema to the extent of describing nine stages of acceptance: grief, denial, rage, self-pity, depression, fear, frustration, resignation and acceptance, and finally choosing life over death (Carter *et al*., 2001).

Bestall *et al.* (1999) reported on research testing the Medical Research Council dyspnoea (breathlessness) scale as a measure of disability in patients with COPD. Their findings were "that the MRC dyspnoea scale was a simple and valid method of categorising patients with COPD in terms of their disability that could be used to complement FEV_1 [forced expiratory volume in one second] in the classification of COPD severity" (p. 581). Although they were using a "measure of disability" it was in fact used as an adjunct in a medical classification, rather than as a measure to contribute in any way to a patient's quality of life, thus being different in emphasis from my research.

French (2008) talks of the language used that leads to power imbalances in interactions between disabled people and "others." Thus, "on the one side" there are "patients, clients, customers, service users, carers, and so on, each term connoting a particular relationship between disabled people and service providers." On the other side, there is language such as "professional, service provider, care, cure, intervention," that connotes very much a medical model of service delivery and attitude towards disabled people.

There is a wide range of language usage, vocabulary and erudition, in the material I have read. Bennett (1986) states:

> Narrative is an extremely complex discourse phenomenon. Stories may be told for a variety of purposes … in order to play an active pragmatic part in human behaviour. Stories may be presented as illustrations, examples or case histories, and be valued for their usefulness as an information bearing resource (p. 394).

Thus, stories can be regarded as carrying very important information, in particular about the "lived experience" which is what I sought to investigate in my research. There are multiple approaches to analysis of important issues that exist in society. It is essential to apply the most appropriate quantitative, qualitative, or mixed methods, to the research question. Najafzadeh's (2012) research methodology highlights for me the approach and language of the standard epidemiological, big data, economic rationalist and medicalised approach to disability, in this case COPD. Najafzadeh declares that "COPD is a growing economic burden worldwide"; he continues that "it is important to explore potential interventions (screening tests, new drugs, predictive tests for flare-ups) on COPD burden because there is significant interest in developing population-based programs to address this global crisis." From their simulation the researchers concluded that the annual "burden" (cost, morbidity and mortality) in 2011 was Can$4.52 billion (B) which would reach Can$7.33B in 2035. They calculated that over the next 25 years, COPD would be responsible for approximately Can$147.5B in societal costs and 19.0 million Quality-adjusted life years (QALYs) lost.

As Johnson (2012), in "*There is more to life than avoiding death*," explains, when QALYs are calculated, the idea is to try to find some objective measure to make decisions about what health care should be provided. Johnson claims that the way this is done introduces serious bias and inaccuracies into the measure. The current QALY process asks people who are *not* ill to estimate what certain interventions would be worth to them in situations of increasing risk of death. It is done this way because people who are already sick are necessarily swayed in their opinions by that fact. He continues, the way QALY analysis is done essentially asks healthy people to imagine what the experience of disease is like, which is unrealistic. He concludes that using death (or avoiding it) as the principal determinant of value of life, skews things in other ways.

This is an important point when we are considering quality of life issues for people with a disability or chronic conditions, because it is important to listen to their voices, rather than the voices of “healthy people” imagining what it would be like to be unhealthy in some way.

Najafzadeh (2012) reported that the results suggested that the best strategy to reduce the financial burden of COPD is by reducing exacerbations (flare-ups). Smoking cessation, while it is the cornerstone of COPD prevention, has only a modest effect in attenuating the financial burden of COPD over the next 25 years in Western countries such as Canada. In conclusion, the researchers suggest “that any intervention that can reduce the number of exacerbations has a substantial impact on morbidity and costs of COPD and should be considered in conjunction with the ongoing efforts to reduce smoking rates.” This paper indicates an overall policy direction for a population-based approach, which one would hope would be translated into individual support for people with COPD and their families.

Use of social media by people with COPD

On the COPD International website (accessed 15 October 2012) there are a number of patients' stories, but while it is evident that the people who had submitted their stories used electronic means to do so, there was no mention of any other use of the Internet or other technology. Similarly, at COPD Support, Inc. there is a lot of useful information and patients' stories, but no immediate evidence of use of social media other than using technology to post to the site.

CHAPTER 3 METHODOLOGY

The gap I have identified in the literature is that researchers have not looked at the stories coming *from* people with COPD, directly *from* them in their own words, not in response to set questions. The authors of several studies (including Bestall *et al.*, 1999; Maurer *et al.*, 2008; Bailey *et al.*, 2009; Jowsey *et al.*, 2011; Boyles *et al.*, 2011) have reported on the lives of COPD patients using a methodology of being interviewed or given questionnaires by medical professionals, such as physicians and nurses, often in a hospital setting, when patients are having an exacerbation, or flare-up of their condition. Therefore, the analyses are of *"patients"* as *objects of study*, rather than people as *subjects*. However, the stories of everyday life experience of people with COPD, as told on the Internet, such as social networking sites, online communities, blogs or tweets, has not so far been investigated. The specific aim of this research project was to gain a better understanding of the experience, from their perspective, of everyday life for people with COPD, as told in publicly accessible narratives.

Specifically, the following sub-questions will be addressed: Where do people with COPD post their stories? Why do they seem to be motivated to make their stories available? What sorts of questions and concerns are these people with COPD expressing, and what sort of information are they seeking? What do the people with COPD say about their lived experiences and perspectives?

As Hahn (2008, p. 3) explains, "Qualitative research allows investigators to be dynamic and innovative. Qualitative methods evolve as new technologies and social forums emerge. For example, the Internet provides a good example of a qualitative methodology that would not have been possible in the early days of qualitative research – online research."

I used a qualitative approach to collect data about the experiences of people who use publicly accessible online locations to discuss their experiences with COPD.
The methodology is that of virtual ethnography. As Angrosino and Rosenberg (2011) say, "If they so choose, ethnographers can free themselves of 'place' by means of the Internet – the 'location' for so many of the most interesting communities on the contemporary scene." They continue, "Virtual communities are characterized not by geographic proximity or long-established ties of heritage, but by computer-mediated communications and online interaction. They are 'communities of interest' rather than communities of residence" (p. 473). I can access these narratives without concerns about issues of privacy and confidentiality.

Creswell (2007) discusses five methods of qualitative inquiry: narrative research, phenomenology, grounded theory, ethnography, and case studies. Creswell (p. 129) asserts that "New forms of qualitative data continually emerge in the literature" but in Figure 7.3 (p. 130) titled *A Compendium of Data Collection Approaches in Qualitative Research*, he does not include internet data usage. Creswell (p. 129) states, "Despite problems in innovative data collection ..… I encourage individuals designing qualitative projects to include new and creative data collection methods."

Initially, I investigated four public sites, chosen from blogs, online fora, YouTube or Lung Foundation sites, as well as some publications, to limit the scope of the research to a manageable level. I undertook this research at a distance from the University of Manitoba and thus my advisor and committee members, therefore it was-necessary to limit the amount of data collected, but to do a comprehensive and thorough analysis.

I searched for online information, specifically looking for the writing and postings of people with COPD. These stories give voice to the feelings and emotions of people with COPD. These extracts do not fully describe any one person's life, but when viewed together as a pastiche, snapshot, or amalgam, they provide a very interesting, and I believe realistic, view of how having a chronic condition such as COPD affects how a life is lived.

If a site is one where a person is required to subscribe (none of the data came from these sources, although I have followed these sites closely during the course of my research) to be able to interact with other members of the list, there is usually a warning ("Always consult your physician about any medical issues") and also posting guidelines. The warning of importance on many sites is a statement of this sort:
STATEMENTS/OPINIONS ARE NO SUBSTITUTE FOR YOUR DOCTOR'S ADVICE (accessed at EFFORTS (Emphysema Foundation For Our Right To Survive) Subscriber Information Page: http://www.emphysema.net/bbanner.html).
On these sites the purpose of the mailing list will be outlined along the lines of: for the exchange of information, ideas and support. For instance the EFFORTS list about Emphysema/COPD describes their purposes as "mutual education and support of patients, and activism/advocacy to increase awareness of our disease and obtain more research to end or substantially reduce it." The usual Internet etiquette applies, for instance any

opinions expressed are solely that of the person making the post, and contributors are asked to use common sense by keeping on topic, avoiding arguments, and keeping messages as short as reasonable.

Data collection and overview of information needed

What do people with COPD say about their everyday lives? How do they live in their homes, with their family members or carers or maybe alone? How do they get out and about physically, what barriers may there be to being part of society? I am particularly, but not exclusively, interested in observing how the computer and Internet technology is used to overcome some of the physical barriers that contribute to COPD as a disability.

My intention with this research is initially to search broadly across a range of publicly available Internet locations such as blogs, podcasts, Lung Foundations sites, open access help sites, or YouTube. The only data that I collected for narrative analysis was publicly available; that is, not requiring membership or logging or signing in to gain access to posted material. I searched for online information, specifically looking for the voices of people with COPD. It was necessary to narrow my breadth of interest so as to increase my depth, thus I chose the four websites that appeared to offer the richest information. I looked for people who indicated by virtue of their posting on the Internet, that they were already interested in what I was interested in researching.

When I chose these sites for my data collection, I delved further into observing and interpreting what is transpiring, to investigate the lived experience of people with COPD. Thomas (2007, p. 155) stresses the importance of including the lived experience in disability research, whilst also discussing how the approach of disability scholars and medical sociologists has differed and sometimes conflicted, although she also considers the possibilities for a unified sociology of disability. Of particular importance is to take care in the choice of language. Thomas, quoting Michael Oliver, a disability studies scholar (1996, p. 43), maintains that, "… the language used in much medical discourse including medical sociology is replete with words and meanings which many disabled people find offensive or feel distorts their experiences. In particular the term "chronic illness" is for many people an unnecessarily negative term, and discussions of suffering in many studies have the effect of casting disabled people in the role of victim."

In my research, "listening" to the voices of people with COPD, I focused on their use of language, as describing their own situations, as a theme of my analysis.

While describing the lived experience of people with COPD was the primary aim of the current research, I also compiled an extensive collection of relevant information. This included investigating resources that are useful in supporting people with COPD in their daily lives. I anticipate that in the future there will be opportunities to report my findings to the various Lung Foundations, Thoracic Societies and Departments of Health, to enable them to better serve their clients, thereby providing a strengthening of the voice of people with COPD, and consequently leading to an improved quality of life for the greatest number of people with COPD.

Research design and methods of data collection

The data was collected from publicly accessible information available on the Internet and the analysis was standard ethnography (in this case, netnography because of the means of data collection). Netnography is qualitative research using the computer/Internet/social media. Names for this research technique that are used in the literature are “netnography, e-ethnography, virtual ethnography, online ethnography, digital ethnography, and others” (Poynter, 2010, p. 246).

Hahn (2008) provides a comprehensive strategy for coding qualitative information using computer programs such as “Microsoft Office which is a suite of individual software programs – Word, Excel, Access, and Outlook – designed to share data and look similar” (p. 196), for keeping track of information and automating theme analysis. He also stresses that the use of a third party bibliographic reference software program, such as Reference Works (RefWorks), is essential to “automatically handle the tedious formatting that accompanies references and bibliographies” (p. 194). As Hahn (p. 15) remarks that, “Qualitative researchers collect relatively free-form data … It is not easy to organize these data, but orderliness is vital to the successful completion of the research project.” In a research project such as mine, with narrower scope, traditional methods for tracking, sorting and analysing the data were suitable. I performed a content analysis of a fairly limited amount of data. As defined by Berg (2007) content analysis is “a careful, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases and meanings” (p. 303).

For my research, I collected narratives from four sites, by reading and rereading the material onscreen, and chose the stories that I wished to print and further analyse. The printed stories were coded and then cut up into paragraphs or groups of paragraphs. I then categorised paragraphs by using colour coding and making piles of similar material, spread over all available horizontal surfaces, while also tracking themes and ideas on butcher's paper.

There are also many very sophisticated and powerful methods of gathering and analysing data, described using terms such as blog and buzz mining (Poynter, 2010, p. 221) and semiotic analysis of websites (Poynter, 2010, p. 317), web analytics (Reed, 2012, p. 19), and CAQDAS (Computer-Assisted Qualitative Data Analysis Software) (Kozinets, 2011, p. 126). These clearly were outside the scope needed for data analysis in the current project.

There are various reasons for using the Internet for the data collection. The intended research method was netnography, therefore by definition using the Internet was the only choice for data collection. Netnography and content analysis were feasible methodologies for the scope of this project.

A strength of this approach is that it is possible to collect data from many sources, including different countries, and I was not restricted to being in one physical location. The narratives were collected from publicly available sources and the data may initially be in different formats, for instance interviews, personal websites, contributions to special interest groups, blogs, discussions and videos. The content analysis unified contributions from these different sources and formats.

Because the posts were all publicly available, the writers would be aware that their stories could be accessed and may assume that their posts contribute in some way to providing support and information for other people with COPD.

Essentially, the data that I collected were opportunistic, that is, chosen from what was there. As Hahn (2008) argues, “qualitative researchers have a special challenge because of the nebulous nature of their raw data” (p. 1). Hahn continues, “The qualitative researcher discovers the quality and character of lived experiences by collecting data that are not bound by the constraints of quantitative methods.”

It is useful here also to refer to the concept of theoretical sensitivity. This refers to a personal quality of the researcher which may have been gained through professional experience,personal experience, or familiarity with the relevant literature. As Corbin and Strauss (2008, p. 41) observe: “It indicates an awareness of the subtleties of meaning of the data. It can be developed further during the research process.” They continue: “Theoretical sensitivity refers to the attribute of having insight, the abiliyt to give meaning to data, the capacity to understand.”

A similar approach to grounded theory and the part played by the researcher, is that of the French philosopher Pierre Nora, who names it “*ego histoire*” and says the aim is to “use refection on one’s personal experience to enhance our practice of collection, examination and analysis of stories, tales, voices and association" (Clark and Ashton, 2013, p. 56).

There is a significant amount of information on collecting and mining social media and many different ways of analyzing data. However, this appears to be mainly in the area of marketing. Also, many of the techniques are for quantitative analysis, referring to analysis of population data, or as it is called "big data," where results come out as "averages," or "trends," or "predictors," for policy-makers to compare and contrast and make decisions on a country or province/state/country-wide scale. My interest for qualitative analysis, is in the N = a small number, looking at a pastiche of information from individuals to build a representative picture of the experiences of people living with COPD.

Netnography as a method can reveal an understanding of important social issues without any confounding influence due to the researcher. This research approach cannot influence or harm the narrators while their writing is being read.

Online discussion groups are an emerging way for people to gain support and information with respect to their health and chronic conditions, so this research provided additional insight into how a random sample of people with COPD are using the new technologies.

Many of the techniques for collection and analysis of data on the Internet have their basis in market research. Nevertheless, many of the techniques are applicable in the case of social science research with concerns other than marketing.

Reed (2012, p. ix) states that "In today's attention economy … people spend more and more time online – especially on social networking sites." The nomenclature of "social media," and "social networking sites," seems at first not to be relevant to serious social research. However, the emphasis was on the "media" and "networking" aspects. Thus, Reed (2012, p. 239) defines "social media" as "the collection of tools people use to publish, converse, and share content online, including blogs, podcasts, videos, and social networks" and "social networking sites" as "places where users can create a profile for themselves, and socialize with their network of friends and contacts using a range of tools such as adding friends, posting messages, links and other content, importing blogs, and creating groups, pages and events."

Methods for data analysis and synthesis

Through stories we can understand our own experiences and those of others, providing some access, through interpretation admittedly, to inner thoughts and feelings.

> Storytelling has always been a powerful and basic human activity. In all civilisations and cultures, both the activity of storytelling and significant, individual stories have been passed down the generations. This is because, long before the printed word was available, story was the means by which people attempted to make sense of their experience of the world, to communicate that understanding and to achieve a collective wisdom through passing on accumulating knowledge and values in a memorable and accessible way. Stories both educate and entertain (Leicester, 2007, p. 8).

As Turner, Head of Policy, Diabetes UK (2012) contends:

> Stories can be very powerful if they are positioned in the right place at the right time to the right people and I truly believe it and that's why I think

> patient voices are really important about what's happened to them, their experiences of what they have gone through.

In their five-year plan, Diabetes UK are moving from an emphasis on the clinical aspects of the condition, and more towards awareness and patient inclusion in knowledge, self-management and quality of life issues.

This study continues this approach as it provides an analysis to understand the way in which the people with COPD, who are the authors, "view their social worlds" and produces a lens on how these views "fit into the larger frame of how the social sciences view these issues and interpretations" (Berg, 2007, p. 308).

The data for my research was from the Internet, and a small number of publications available electronically. I was guided in my methods, analysis and interpretation by literature in journals and other traditional forms.

Ethical considerations

Kozinets (2011, p. 142) states that:

> The Internet is not really a place or a text; it is not either public or private. It is not even one single type of interaction, but many types: chats, postings, comments on mass-trafficked blogs, … . The Internet is uniquely and only the Internet.

He continues:

> Usually, gaining the informed consent of research participants is a cornerstone of ethical research conduct, but in a major departure from traditional face-to-face methods like ethnography, … netnography uses cultural information that is not given specifically, in confidence, to the

> researcher. The uniquely unobtrusive nature of the approach is the source of much of netnography's attractiveness … . The analysis of archived messages does not, officially constitute human subjects social research.

Many other writers have debated aspects of ethics in the context of the Internet and online research (King, 1996; Sharf, 1999; Walther, 2002; Bruckman, 2006). The Association of Internet Researchers (AIR) (www.aoir.org/), of which I am a member, produced a working group report (AIR, 2002) setting out recommendations for ethics of online research.

Kozinets quotes Walther (2002, p. 207):

> It is important to recognize that any person who uses publicly – available communication systems on the Internet must be aware that these systems are, at their foundation and by definition, mechanisms for the storage, transmission, and retrieval of comments. While some participants have an expectation of privacy, it is extremely misplaced.

Kozinets continues:

> Analysing online community or culture communications or their archives is not human subjects research if the researcher does not record the identity of the communicators and if the researcher can legally and easily gain access to these communications or archives." Thus, content analysis and thematic analysis of online communications can be regarded as similar to the use of texts.

As Young (2012) points out

> We generate enormous amounts of online data about our habits: where we go, what we do, and how we feel. Some of that data is information we choose to record; some of it we leave behind in digital trails merely by going about our daily lives in an increasingly digital world.

As a result of extensive reading on the ethics of the type of research I conducted, I am confident that my research was carried out in an ethical way and that my online research did no harm to any person who had made their narratives publicly available.

Issues of trustworthiness

Authenticity, or trustworthiness, is the sense that something or someone is “real” and genuine. Blogs and podcasts enable people to publish content and engage in conversations that help them to develop an authentic voice online. Unlike activities such as Second Life, where participants take on a new persona, and define their own avatars, I see no reason to think that any of the people with COPD whose narratives were publicly available were anything but genuine, and that their online identity closely mirrored their actual “real life” identity. The more central the activity or interest is to the person’s sense of identity, and the more involved they become, then it seems reasonable to assume that the person will become more involved and pursue and value membership in a community online, just as we observe in real life engagement, and people will not seek to be other than what they are. Although I did not access formal online communities that required membership, the above sentiments apply to the people whose narratives I interpreted.

Limitations of the study

As the data are opportunistic, the theory followed the data, rather than being collected to prove a hypothesis as in quantitative analysis. In any research, there are both advantages and disadvantages to using particular methods of data collection and analysis. The method of content analysis or narrative analysis seemed the most appropriate for the sort of data I collected. As the research progressed, however, it became clear that a mixed methods approach was also appropriate and enriched the analysis of the data.

I am aware that my collection of narratives of people with COPD were from those people with current access to the new technology, and who were willing and able to use it for such purpose. As time passes, there will be increasing numbers of people (referred to as “digital natives,” whereas the current older generation are mostly digital “immigrants”) who are both familiar and comfortable with using social media for such interactions. As the number of people with COPD is going to increase for the foreseeable future, my collection of narratives, whilst in some ways showing ascertainment bias, can also be seen as being composed of the leaders and trendsetters. If “indeed” participation in social media supports people with COPD in having greater control over their lives, then it is imperative that more people with COPD have access to these technologies.

The demographic and historical data to which I had access was only that which was obvious from the specific narratives collected. As an extension of my work, however, I hope to join with a larger group of researchers, able to bring diverse skills and access to comprehensive records and statistical computational skills and capabilities, to effect a stronger influence on policy makers and health bureaucrats, to support people with COPD to lead an optimal quality of life.

In this section I have provided an explanation of how each component of my research methodology was developed, and was analysed to be presented in this thesis. Using the framework from Bloomberg (2008) I have shown how all of the components have combined to form a logical interconnected sequence to contribute to the overall methodological integrity of my study.

I have stated my research questions, how I underwent my data collection and what information I collected. The research design and methods of data collection, analysis and synthesis have been outlined. Issues of ethics, trustworthiness, and authenticity, have been discussed. Finally, some obvious limitations of my study have been described.

CHAPTER 4 LIFE'S CHANGING LANDSCAPE: EXPERIENCES OF PEOPLE WITH COPD

Introduction

Living with COPD, as with any chronic condition or disability, can be challenging, as these conditions can have a dramatic effect on everyday life. A diagnosis of COPD, however, does not need to be the end of people's dreams. There are lifestyle changes that can be made, and medications and surgery that may be indicated, which can greatly improve quality of life, and allow a person with COPD to continue to live life to the fullest. People with COPD do not have to be controlled by their disease but can take charge of their lives in a positive way with effective education and support. This point of view is stated in the COPD-INTERNATIONAL NEWSLETTER (accessed at http://www.COPD-International.com) and many other support publications.

The quotations presented in this section have remained true to the author's spelling and punctuation. In the analysis of the narratives I have been struck by the honesty and apparent strong self-knowledge of the people writing about their lives with COPD. In general, people use the act of writing or journaling both as a way for them to organize their own thoughts and feelings about life and to share these thoughts and feelings with others. This is the same for people living with a chronic condition such as COPD, where it is a way to reach out to other people with COPD, with the message "you are not alone."

At all times I was aware that I was working through the lens of the social model of disability, rather than the medical model. It is very important, however, to stress that the correct diagnosis, medication regime and management are crucial foundations for the person with COPD and their family, friends, and healthcare professionals to build on.

Lives as people live them are complicated, and certainly not static and unchanging. When a person is first diagnosed with a chronic condition, that will progress in severity, and is ultimately life-limiting, there are a number of emotions that must be managed, as well as the visible, external, or pragmatic factors such as the effect on work and finances; home life and activities of daily living; relationships with spouses, family, carers and health professionals; exercise capacity, breathlessness, and being on oxygen; pulmonary rehabilitation; smoking and quitting smoking; and death.

The emotional effect of COPD:
denial, anger, bargaining, depression, acceptance

The knowledge of the diagnosis can commonly cause reactions of disbelief, fear, anger and sadness**.** As mentioned earlier, Elisabeth Kübler-Ross (1969) outlines five distinct stages that are typical to the grieving process associated with a life-limiting illness: denial, anger, bargaining, depression, and acceptance. She points out that not all people go through the stages in order, and some do not necessarily experience all five. Other authors have expanded on this schema to the extent of describing nine stages of acceptance: grief, denial, rage, self-pity, depression, fear, frustration, resignation and acceptance, and finally you choose life over death (Carter *et al.*, 2001). There is continuing discussion and refinement of these categories in the literature, as various researchers find that within different cultures there is variation in the emotions which people report, and in some cases not all cultures exhibit all of these categories of emotion.

In considering the emotional aspects that may be dealt with by a person with COPD, I shall base my analysis on the categories of Kübler-Ross (1969), drawing on quotes from my searches to elaborate the issues. It may bbe argued that beginning with a list of already identified variables or categories may get in the way of discovery (Corbin, 2008, p. 49). However, because of the iterative nature of my data collection and the solid presence of these emotions being expressed, I feel confident that this starting point did not prevent me from discovering anything novel. If, however, further research were possible, I would limit my research question solely to emotions mentioned in the narratives and would approach the analysis not from a set list of categories, but would explain phenomena in light of the theoretical framework that evolved during the research.

1 **Denial** is a natural defense mechanism of conscious or unconscious refusal to accept facts, information, reality or diagnosis. Disbelief would seem to be a natural first reaction to any sort of terrible news, especially when it concerns one's own mortality. Common phrases may be "Not me!" or "This isn't happening to me," or "There must be some mistake."

> Quote 01. "At first I was in denial for several years until I was hospitalized a few times and then thought I had best find out more on the subject."

This person admits to being in denial for several years, which seems to be a common situation for people with COPD, who ignore their symptoms and do not seek diagnosis, as they attribute their increasing breathlessness and inability to exercise as natural consequences of the aging process, or of weight gain, or of ceasing to be as active as previously.

> Quote 02. I guess I'm in denial, I was dignosed (*sic*) 2 years ago with COPD and still feel that I will be ok. I worry that the meds may stop working at some point though. I'm not ready to deal with what may happen yet. I just hope my disease doesn't progress.

This quote appears to show a person in denial and perhaps some confusion. Possibly still hoping that maybe there has been an error, and that there won't be a progression of the disease. The person also exhibits worries ("the meds may stop working") but admits to being not ready to deal with the situation. This may be a very common observation about and from, anyone who has been diagnosed with a chronic condition.

2 **Anger** can manifest in many different ways. When dealing with emotional upset people can be angry with themselves, and/or those close to them. The seemingly inherent injustice of a life-limiting illness is a common reaction of someone who has received this news. Typical phrases may be "Why me?" or "Why is this happening to me?" These quotes are a small selection typically found in many stories.

> Quote 03. "I'm going back and forth between anger and acceptance myself."

This quote shows the writer being calm and analytical, working through the situation they find themselves in.

> Quote 04. I smoked for 40 years. Everyone did. They even smoked on TV then. Now, I am 59 and no longer smoke. I'm dying of COPD and getting no compassion at all. It's all my fault because I smoked. Well, too freaking bad. No one told me until many years later that smoking would ruin my lungs. Now I am 59 and on oxygen 24-7. I can't breathe, even with it. I have no life and hate the nose tubes so I don't go out. My family don't seem to care how close to dying I am. I really don't care either. I want to die. This COPD crap is sooo not me. Sometimes, I think it would be easier to just die and get this over with; this disease has left me isolated and alone. The only comfort I get is listening to music.

Quote 04, exhibits strong anger and exemplifies the complexity of feelings and emotions, along with the interactions with family, and the physical consequences of the COPD (“nose tubes”; “isolated and alone”).

The writer seems to be feeling a lack of compassion from her family and is certainly crying out for help.

> Quote 05. I rarely get depressed now. I am no longer angry about why I had to get emphysema and over the things I failed to do in taking better care of myself. To a large extent, I have accepted my disease. I know the word “acceptance” sounds scary, but I don’t want to waste my “breath” yelling and screaming inside myself.

Quote 05 is also analytical, and shows evidence of moving on to acceptance and a certain irony in the wasting breath comment.

3 **Bargaining** is traditionally a stage where people bargain or seek a compromise with whatever God the person believes in. It is natural that after the initial shock has settled, people start to reassess their lives and look towards the future for which they had hoped and planned. Focusing on specific events that are especially meaningful and normal, such as the graduation of a child or birth of a grandchild, can add to the overwhelming sense of loss, prompting the ill person to wish for enough time to be

present at a milestone event, and even motivating them to take more control of their lifestyle, such as quitting smoking or attending pulmonary rehabilitation, to achieve this aim. Phrases might include “But what if I ….?” Or “I promise I’ll be a better person if only …” And some people just have faith in God, and what will be will be.

> Quote 06. Proactive choices, preventative measures, positive attitude. I will again build up my walking endurance, concentrating on correct breathing techniques. I will eat more nutritious meals and snacks. I will listen to my body signals and not wait too long to take antibiotics. I will learn to pace myself and make the most of what I can still do. I will allow needed rest and relaxation. I will make responsible, yet realistic choices! I can and will control my COPD; COPD will NOT control me!

There is evidence of good knowledge about the condition and advice that is given to people by health professionals, such as about walking, breathing, eating, rest, and relaxation. This person is also showing determination and has probably been researching on the Internet, finding such mottos as in the final sentence.

> Quote 07. I have COPD and sometimes, I'm scared to go to bed at night because I feel like I'm smothering to death but I cant wake up. When I do wake up I can't tell if it is a dream or real. I'm afraid I just say what my mother always said: ‘God never makes mistakes’. My mother had it too; she lived to be 83 so to all of us with COPD I've always say God has our backs.

This writer seems scared, taking solace that she will be like her mother and live to quite a good age. Many of the stories I found referred to other family members who had COPD, and drew parallels with what would happen to themselves, as if there was an inevitability, seemingly unaware that the trajectory of illness can be modified by such factors as nutrition, exercise and medication.

4 **Depression** can also be referred to as grieving, and is often bracketed with anxiety. Kübler-Ross (1969) recognises that a combination of depression and sadness is a sort of natural precursor to acceptance. With the realization that the end of life is in sight, it is natural to feel overwhelming sadness and regret, fear and uncertainty. Maybe it shows that the person with the life-limiting condition has begun to accept the reality, but the magnitude of the anticipated loss can be extremely hard to accept. People will commonly say, “OK, it is me” and “I don’t care anymore.”

> Quote 08. Am I coping with my condition? No, I am not. The once confident person has disappeared, gone, completely gone. There are times when I am alone at night that I stay awake for as long as my eyes can stand looking at the TV screen.

Many of the stories I read were heart-rending. Quote 8 is part of the story of an older person whose spouse had recently died. They had taken care of each other, each with a different chronic condition (actually several chronic conditions each). The story showed a sadness and almost unbearable loss for the surviving spouse.

> Quote 09. Depression can best be described as a feeling of hopelessness, that nothing is worthwhile, no one wants you and there is nothing that you can do about it. This is all pretty well nonsense since there are many things you can do, but first you must recognize the symptoms.

This is a quote that seems to show a bridging from depression, and the recognition of the symptoms, to acceptance. Many stories showed an amazing strength of character, where people were literally not going to give in until their “last breath.”

5 **Acceptance** is a stage that varies very much according to the person's situation. Not all people diagnosed with a life-limiting illness are able to make peace with the notion of dying, but the sense that someone has accepted their fate can result in a greater sense of calm for the patient and those who are closest. When they are first diagnosed, many people are determined to fight and win out over their illness. Once a person is comfortable that they have done all that they could in hopes of regaining their health, however, accepting the inevitable can help people to make the most of the time they have left, focusing on the quality, rather than quantity, of their remaining time. Sometimes people dying (or learning to live with their disability) can enter this stage long before the people around them, who also must necessarily go through their own individual stages of dealing with grief. Perhaps they are grieving for the person with COPD (who may have comorbid conditions) as well as grieving about chronic conditions of their own and worried about their own mortality, especially if they are a primary carer for the person with COPD.

> Quote 10. "I think it's important to get to the acceptance stage in order to move on and to be at peace with self. It's truly not about quantity but quality of life."

This quote shows acceptance, and thoughtfulness in the wish for quality, rather than quantity of life. Many people in the stories I read were insistent on this aspect, preparing advanced care directives that included such phrases as "no heroics" and "no resuscitation."

> Quote 11. Acceptance is a difficult thing to get your head wrapped around when you're looking at your own mortality. In another fellowship I belong to I learned an important lesson. That life isn't

> about the destination – it's about the journey. The Serenity Prayer helped me a lot then – and does today. It reminds me of where I fit in His will …

Many people, as exemplified in this quote, are both carefully introspective and showing good self-knowledge, but also wanting to reach out with their personal discoveries and hard-won wisdom, to help other people.

> Quote 12. [I was depressed] until my emphysema diagnosis. Now I live for today and enjoy it. Even if I feel bad that day, I will look over the day before I sleep and think of the good parts of it. I still have my moments when I get scared but I think that's natural.

This quote is an example of many others expressing hope and optimism in the stories. Many people had a conversational and light "tone" to their postings, and many showed warm home-spun philosophy and humour.

> Quote 13. Wait! Remember the little engine that could? *Puff! Puff! I think I can! I think I can!* Yes, I WILL again conquer this hill. My life does NOT have to be a steady road to final defeat. It CAN be a string of small victories. I have choices.

This very optimistic quote displays a sense of humour and recalls good things past.

> Quote 14. In an open letter to family members from your COPD person: Our lives may never be quite the same, A.D. (after diagnosis). In a perfect world, I wouldn't have COPD. But we can both try to seek more joy, derive more pleasure, from what we are fortunate enough to have … one another. Let's make the most of our time.

> Quote 15. "'Never give up! Never!' This was the best promise I offered to myself [when I was diagnosed with COPD]. However, my promise does need reminders and prompts from me."

> Quote 16. How do I feel having COPD? I don’t like it one bit but life goes on and I appreciate the time I have. I am still smiling. Right now, “how wonderful it is to breathe”!!!! Have a good day and keep smiling.

These Quotes 14, 15, and 16 continue to show the theme of giving, sharing and acceptance, facing up to what is, and then getting on with life. These emotions and expressions of reaching out, which were so prevalent in the stories were representative of how people, even in the face of a debilitating disease, want to reach out and be part of society, to still contribute and be included.

Kübler-Ross (1969) believed that all people would experience at least two of these stages. The same stages may also be experienced by those who are close to the person. Sometimes people regress to earlier stages of the process as other events take place in their lives. This is shown in the following quotes, referring to the schema of Kübler-Ross (1969).

> Quote 17. We can actually go through the stages more than once also. You may work through one step and move to another and then find yourself going through the first again. Example, start off in denial, progress to acceptance, and revert to denial again. At least that has happened for me.

> Quote 18. I seem to go through all these steps, and then perhaps something will happen, or change, and boom, I’m back to square one. Sometimes it’s all about finding my new normal, and becoming comfortable with that. I try not to dwell on what used to be, but sometimes it can’t be avoided. When that happens I just have to allow myself a good cry.

> Quote 19. “I think we do go thru these stages more than once, as our symptoms change or our disease progresses.”

In an attempt to quantify and assess the stages of the grieving process in COPD, researchers in the Netherlands (Boer, 2013) have validated the Acceptance of Disease and

Impairments Questionnaire (ADIQ) and describe four distinct stages of grief in people with COPD: denial, resistance, sorrow, and acceptance. Thus, their findings are very similar to the five stages of Kübler-Ross (1969). Theoretically, this leads the authors to say that, “Measuring the stages of grieving is important for disease management: addressing patients with a specific therapeutic approach for the stage they are in could help to motivate patients to engage in self-management and change their lifestyle.”

This is also seen in the new approach articulated in the *Expert Report on Chronic Obstructive Pulmonary Disease and its Management* (Takeda, 2012)**,** where the previous nihilistic approach of assuming a steady decline in lung function leading to increased exacerbations and eventually premature death has been replaced by a more positive and proactive person-centred approach.

A common story among people with COPD is that for years they were unaware of [or denied] their slowly deteriorating health.

> Quote 20. A person in her early 40s diagnosed with COPD said: Over the years I went to different Doctors about other health issues but never really about any of these COPD symptoms, mostly because none of the symptoms I was feeling connected in my head as being anything to be worried about – like not being able to walk up one flight of stairs, (just thought I was tired) or falling asleep anytime, (again thinking I was pushing too hard and just worn-out).

It is important for a person to be very aware of their body, and any changes, so that they can discuss matters fully with their GPs and other health professionals.

> Quote 21. Diagnosed at 58 years of age, stated: I wonder what the benefit of diagnosis may have been at age 45. My quality of life,

> though diminished has been much better than my father's; I have the absolute view that the earlier you can diagnose COPD and implement common sense strategies, the sooner your quality of life will improve.

This quote is an example of a person realizing that an earlier diagnosis would have been helpful to improve their current quality of life~~.~~

> Quote 22. This person who is now 80 years old, said: Having been diagnosed as having chronic asthma at age 60, I did wonder why it was I was not having any "good days." I moved to the country and saw an advertisement for a breathing support group in the local paper, then I started to learn about COPD which I had not previously heard of. I asked my GP for lung function tests and was diagnosed with COPD.

This is a common story of someone being diagnosed with, and treated for, asthma, a restrictive condition (in contrast to COPD which is an obstructive condition). Many people refer to the "good" days and the "bad" days. This person may indeed have asthma, a condition that, if properly managed, should be asymptomatic most of the time. This person realized that they were not experiencing any good days, and looked into the matter further. Quite serendipitously, the person found a support group, and was then able to start learning about their [newly diagnosed] COPD, and taking measures to improve their health through the suggestions and knowledge gained from the support group. It is interesting to note here that increasingly chronic asthma is actually being included under the umbrella term COPD. Also, a recent study, reported by Collins (2011), showed that one in three people in their study, who were "diagnosed" with COPD, were actually misdiagnosed, because GPs relied too much on symptoms-based diagnosis, which the researchers labeled as "unreliable," and the GPs failed to confirm diagnosis by using spirometry testing, which is the "gold standard" for diagnosing COPD.

Thus, not only is there a need for early diagnosis of COPD, but also correct diagnosis, to avoid exposing people to potentially adverse medication effects, and to reduce unnecessary healthcare expenditure. There is a great need for education and awareness, not only amongst the general public, but also among the medical and health professionals. Many people report that they have started to learn more about their lung conditions through consultation and education sessions with their pharmacist, than through their GP.

While smoking is considered to be overwhelmingly the primary cause of COPD, it is now being recognized that many environmental factors may also contribute to the development of COPD, even in those who have never smoked.

The topics of "secondhand" or "thirdhand" smoke will not be addressed here. However, COPD can rarely be caused by a genetic condition as in quotes 27 and 28.

Here is a story about working in agriculture as well as smoking:

> Quote 23. I drove bulldozers during the summer and fire seasons, my work involved rolling for clover burr for weeks on end, always best on the hottest days and continually working in very heavy dust [without any protection]. On both jobs on a very "dirty" day you would clean the air filter on the tractor twice a day. At the end of a 12-14 hour day you would have a white ring around the eyes and lips and you would be spitting out wet dust for days … and of course the continual fags (hand rolled).

A story about environmental factors involving combustion and chemical fumes, as well as smoking:

> Quote 24. I am 84 years old. I spent most of my adult life fighting fires, a little over five years ago I was diagnosed with COPD. Years of exposure to smoke and chemicals from burning homes, businesses and factories, in addition to more than 60 years of smoking, left me with COPD.

Environmental factors can cause COPD in those who have never smoked:

> Quote 25. I experienced my first asthma attack whilst under anaesthetic to have my tonsils removed at age 16. I was prescribed preventatives and different relievers as they came onto the market, and often had the course of antibiotics and cortisone. My condition was managed quite well over the following years. Until I was diagnosed with a severe dust mite infection, caused from having cleaned out the unit of my aged aunt. Although I took all the preventative steps, I still became a victim [of COPD].

It is also recognized that working/environmental conditions can cause a worsening of symptoms as seen in quote 26:

> Quote 26. This person, who was diagnosed with COPD at the age of 45, stands for 8.5 hours each day, inspecting clothing in a sewing factory. The story continues: What has started happening is that since there is no air conditioning [in the summer] and it’s an enclosed factory, I am always inhaling dust from the sewing machines. A couple times I’ve had to leave work and go to the doctor because I’ve had a breathing fit. Some days I can get through, some days I can’t. It depends on the weather. When it’s hot and humid, I struggle badly and have to use my rescue inhaler a lot. Most days I can get through, but by the time I get home I have to rest and relax before doing anything else.

Many individuals with COPD have similar frustrating stories related to a work environment that has a negative effect on their condition. Many employers are completely unaware of, or choose to ignore, the difficulties that the work environment can cause people with lung conditions. Not only does COPD create problems for workers, but it is also costly for businesses and employers.

As an example of person-driven action, a phenomenal achievement is that outlined in Quote 27:

> Quote 27. Seeing a need to fill the void in research and awareness, this is an example of a patient taking the lead in founding and building a support organization for people with Alpha 1 Anti-Trypsin Deficiency (A-1ATD). John W. Walsh is the Co-founder and President of the COPD Foundation. He was diagnosed with A-1ATD [included in the definition of COPD] in 1989, and upon learning there was no organized effort to promote research and find a cure for the disorder, he decided to dedicate his life's work to this end, and has done so with incredible enthusiasm and effectiveness. The COPD Foundation's vision is to encourage, empower, and engage individuals with COPD in order to improve the qualities of life of all those who are affected by the disease.

> Quote 28. A father spoke of his daughter's experience with A-1ATD: Our daughter's childhood and youth were uneventful with no evidence of any respiratory difficulty. Around the age of 15 years, like so many other young people she started smoking. There had been no experience of smoking in her home, peer pressure was the motivator, her family gave her considerable encouragement to quit, but to no avail. She worked in a dusty environment, married, had a couple of kids, but sadly the smoking continued. Both she and her husband occasionally showed symptoms of asthma, causing overnight admission to hospital with breathing difficulties. On one occasion a newly arrived registrar was of the opinion that there was something different going on, and ordered the simple blood test to measure Alpha 1 Anti-Trypsin, he discovered the deficiency and ordered a genome test to confirm the hereditary condition. Eventually the COPD caused by the A-1ATD developed to the stage of a lung transplant being considered. Unfortunately, before this could happen, she was hospitalised with a severe lung infection. It was discovered that she had a hole in her lung, which caused a pneumothorax, which in turn led to cardiac arrest, which caused her death.

The above two examples exhibit the complexity of living with COPD and how it can change a person's life, and the life of those around them.

People with COPD talk about work and finances

The epidemiology of COPD has been changing over the last few decades. No longer is it seen exclusively as a "smoker's disease" or an "old man's disease. " More than half of people newly diagnosed with COPD are women and about 70% percent of the 24 million Americans with COPD are still under the age of retirement, that is 65 years old, meaning that many are still in the workforce (Fletcher, 2011, p. 9). This disease has a tremendous effect, not only on the individual but also on the productivity of the workforce, the cost to the health care systems, and the loss to economies.

Work loss for employees with COPD is associated with many factors, not just COPD, because many people with COPD have other significant health issues, or so-called comorbidities. These other health issues can significantly add to the problems already caused by the COPD.

In the quotes I found the response of employers to employees with COPD varied from being extremely understanding to very harsh.

As mentioned in Chapter 1, my husband returned to work after a period of five months in hospital and two months of rehabilitation. His employer had an excellent return to work program and was very understanding of various legal requirements for accommodation of employees with a disability. By each side being open and honest about their needs and expectations, accommodations such as oxygen cylinder delivery to the workplace and provision of a parking space as close as possible to the building, were accomplished. These were not major concessions, and could be achieved at no cost, but they certainly made a significant difference to the ease with which my husband could continue to work, and were much appreciated.

A selection of other stories demonstrating workplace situations follows:

> Quote 29. This person described how the job has made accommodations: I found out I had COPD. I quit smoking 10 years before. Now I am on oxygen. Working 3 days a week in retail. My bosses are great and have helped me by changing some of my duties enough to make it possible for me to continue to work. I live by myself and pretty much take care of myself. I stay active and try not to dwell on tomorrow. The people I work with, my church group and my family and close friends help keep my spirits up. It can be hard at times, but you can do it.

Clearly the person quoted has a very positive attitude, that is reflected in the way he has been treated in the workforce. No doubt accommodations have been made in both directions through a certain amount of redeployment and a lot of understanding.

> Quote 30. I have a very energetic job at a insurance company. It involves a lot of running around, and I just found out I have COPD. Ok, it got me down a little but I am on the 2nd week of sickness from work and am hoping to go back to work so my boss can put me on lighter duties, he is very understanding.

In this quote, the person is anticipating that things with the job will be alright. At the time of writing, the person had to be off work, but was anticipating lighter duties. The employer would appear to be a good one, and it is to be hoped that the negotiations were mutually satisfactory.

Similarly, in the following quote 31, the writer explains that he misses a lot [of work] but the employer is understanding. He also describes how difficult it is to actually get up and go, and the things put in place, such as the air purifier, to try to make life easier.

> Quote 31. I am newly diagnosed. I missed a lot of work and my year of service, had two hospital stays also. I have summers off so I work my butt off to stay active. My boss is understanding so far. But, when I was so sick those other months, it was so difficult to get up and go, got breathless just dressing. I keep an air purifier in my room now, wash & disinfect. I fear those who are sick. I don't like to do breathing treatments at work, but will if I have to. I plan to work till I can't any longer or they let me go!

In quote 32 the writer is still able to work, but finding it more and more difficult. It seems that this person is looking for ways to stay in the workforce, even to the extent of considering asking for supplementary oxygen for use during the workday to improve conditions. This is a radical shift in attitude from previous widespread prejudices and aversions to using oxygen in public.

> Quote 32. I am a business person. I was diagnosed with severe COPD a year ago. I am still able to work, but, it is getting more and more difficult. I am going to talk to my doctor about using oxygen during my workday to see if that makes things better.

Another person who reports that things are going well in terms of work:

> Quote 33. I am nearly 55 years old, with a wife and two teenage children, I was diagnosed with COPD four years ago. Fortunately I am still in reasonably good health which enables me to work full time in a purchasing position.

Some people have not been so fortunate and needed to leave work:

> Quote 34. It was impossible for me to work at my job in the auto parts industry as although I am only in my 50s, COPD and asthma mean that I have two to three trips to the hospital each year. Fortunately, I am now doing pulmonary rehabilitation and may be able to return to work.

This person also mentions some financial issues as well as retirement, but is somewhat optimistic and "making it":

> Quote 35. This person in their early 60s, had to take early retirement: When diagnosed I was an over-the-road truck driver. The stress of the job and the varied hours made me feel that I was unsafe to continue working. My Social Security took a hit and $ is tight but I am making it.

Now for the other end of the spectrum: two stories of people for whom the diagnosis of COPD meant the end of their jobs. Finality is demonstrated in the use of “fired” and “COPD killed my job.”

> Quote 36. “I got fired for being sick – so I have had a negative response. I haven’t had a long term job since. I also haven’t been officially diagnosed yet. It’s been 12 years since I lost my job.”

> Quote 37. I lost my job. My performance and mental thinking slowed done and I lost my 10+ year job because my boss thought I was loafing. I got short of breath a lot and wasn’t aware that my speech and thinking was slower. My boss thought I wasn’t reliable any longer. 17 mos after my job ended I ended up in the hospital and then was told I had severe emphysema and chronic bronchitis, it progressed so slowly I didn’t realize it. The week I spent in the hospital the nurses kept asking my (sic) what kind of oxygen concentrator I had at home and how many liters did I use. No one acted like they believed me when I told them I didn’t know I had lung disease and did not have oxygen at home. A mediator filed for my Social Security Disability before I left the hospital and I was awarded my disability 5 & 1/2 months later. I miss my job and my life before this disease. My last cigarette was the day before I was admitted to hospital. Wish I had been smarter about the respiratory system.

In this instance, the person whose COPD killed his job was unaware of his condition until he was admitted to hospital. This may seem like an extreme case, but it is frighteningly common. The need for public awareness about lung conditions, more effective education campaigns about the dangers of smoking, and the probable efficacy of mass screening programs, or at least automatic spirometry of smokers aged over 40, would seem to be indicated. That person was “lucky” in being able to claim and be awarded “disability.”

However, the person in the next quote has been unable to get disability, and has been told that they should be able to work. Note: this quote is exactly as it was posted.

> Quote 38. i have c.o.p.d i have it quit bad my doctor said i should not be woking i have tryed to get incapacity benifet but the e.s.a said i am capable of going to work and i dont think i am what can i do

Information about finances was often implied or included as part of longer stories, but undoubtedly, those with COPD, especially people on oxygen, would be financially disadvantaged, as is true for the majority of people with any type of disability.

> Quote 39. From the widow of a person with COPD: Towards the end, my husband was on very high levels of oxygen. The cost was neither covered by insurance nor any other sort of plan, the oxygen was costing more than $1200/month. Because my husband also wanted to continue as “normal” a social life as possible, we also purchased a portable concentrator for over $6000, and had modifications made to our home to enable wheelchair access (of course we had to purchase the wheelchair). These expenses, along with medication expenses and extra heating, were certainly a drain on our savings. I guess we were lucky to have savings.

Similar stories of additional expenses, whether it be for oxygen, portable oxygen, power, heating, medications, transportation, dental and medical bills, special foods, extra help with personal tasks such as showering and dressing, and house cleaning and gardening, all add to a diagnosis of COPD being a very expensive exercise.

Part of one such story:

> Quote 40. I am now on oxygen 17 hours a day. I hire oxygen at $90 a month and the power bill is astronomical. I even had to spend $5000 on a portable oxygen unit as I cannot go out without it.

The quotes in this section show just some of the consequences of COPD on active, productive individuals aged from 40-65 years, who are at the peak of their earning power. COPD places a huge burden on healthcare resources, and is also associated with a range of indirect costs such as absenteeism, lost productivity, and a reduced quality of life for individuals and their families. There is clearly, in aggregate, an enormous and wide-ranging economic impact on individuals of working age, their families, and communities. The considerable scale of the economic, social, physical, and emotional effect of COPD underlines the fact that this is becoming one of the world's most serious health issues, affecting millions of people world-wide.

How COPD has affected people's home life and activities of daily living

In the following quotes it seems that people with COPD are working hard to make their home life, and their activities of daily living, as "normal" as possible. That is, they are trying to retain the situation as it was before their diagnosis for as long as possible. These people are not in denial. In fact, they show a great deal of acceptance, leading mostly to a "can do" attitude.

In this first quote, the writer regrets that he can't do the things he used to do, showing some incredulity at the fact that he's a hard worker, never smoked, is young, and yet has COPD.

> Quote 41**.** “I'm a hard worker and have COPD now. It's hard as I can't do the things I used to do and i never smoked. I'm 52.”

The next quote shows that the writer values, and works towards, control over his life. It was mentioned previously that the American Thoracic Society said that people with COPD often say that one of the worst aspects of their illness is the feeling that they have lost control over their health. In this case, the writer is working at controlling their health, in order to control their life, and remain as active as possible.

> Quote 42. As I developed more understanding of the disease and available treatment, I began to feel I had some control over how I spent my day. Even on a bad day, I get to choose. I realize it’s my choice: I could spend the day being sick and complaining or focus on trying to get better. I like to choose the latter. On a bad day, I spend most of my time on regulating my breathing, doing light stretching and lots of relaxation exercises to get some relief from symptoms.

The person in the next quote is fortunate to have a devoted carer. Often, when people have a carer, they don’t realize just how much the carer does, and what a stress it is for the carer (Jowsey, 2013, p. 9). Sometimes as the disease progresses there can be a change in attitude, or even personality, of the person with the chronic condition, which makes it even more stressful for the carer to cope and remain calm (Felner and Schneider, 2008, p. 69).

> Quote 43. The effect on my life has been great, with shortness of breath curbing activity in the home and garden. Most people with COPD will find restrictions in what they can do, but if you have a wonderful carer like I have, it makes life all right.

> Quote 44. One widow reported that: Towards the end of his life, it took all of his and my energy and resources to keep him alive. It was

> exhausting for both of us. It took me years to re-establish my own health, and a sense of who I was, after being a carer for so long.

Unfortunately, unless people can afford to pay for personal support services, there is little help available for people to assist them in their homes, and thus to stay in their homes as their condition progresses. As seen in the next quote, people are very grateful for the little help they receive.

> Quote 45. I have help for almost 2 hours per fortnight to clean my home. I try to find the best way to do whatever else I need to do with helpful tips from speakers at our self-help group. I also have a Safety Link alarm which has given me added confidence around my home in case of a fall. My GP assists me in every way and also does an extensive health assessment every two years. I also attend regular exercise classes so necessary for continuing good health.

A major frustration for people with declining physical health, especially if they have led very active lives, is precisely their declining physical health. However, some people can still remain optimistic and also have a social conscience about advocacy and awareness-raising about lung conditions as shown in the following quote. They are making the most of life, despite the existence of a chronic condition.

> Quote 46. “I am still very [mentally] active, and enjoy computing, reading, playing cards etc and actively pursue projects to help others not yet diagnosed with COPD – for example educating 35-40 year olds to have bi-annual lung tests.”

Similarly, when commenting on self-awareness and control, the following speaker is intent on structuring their activities so as to find a balance, between actually doing what they want to, and the problem of breathlessness which comes with having COPD.

> Quote 47. When I pace my breathing I can perform an activity longer. I exert according to how strong or weak I feel at the time. I call it my "exertion strategy." While performing an activity, exercising, walking or engaging in any other type of exertion and effort, I modulate my speed and breathing so I don't make myself breathless but still work at a moderately challenging level.

Of course, many people have lived with lung conditions for many years, and are therefore very much the "experts," especially when it comes to their own health, and crafting the environment for their own needs. In the following the writer explains how she recreated hospital rooms as "home" and even "office."

> Quote 48. Now in my mid-50s, my journey with asthma, and over these last few years with COPD, has been life-long, as I suffered my fist attack of asthma at 14 months of age and my first respiratory arrest at age 12 years. I have had several more respiratory arrests in the intervening years. As well I suffered from Type II diabetes, high cholesterol and borderline hypertension. Difficulties with breathing are my earliest memories with the attendant rushed visits to emergency departments and frequent admissions to hospital. Until the last two years, I spent several months each year in hospital – my hospital room was my second home and on many occasions over the years my office.

In this quote we can see how the writer is coming to terms with increasing disability by "pacing" outings and limiting those to daytime. The stress of talking at the same time as breathing is also becoming evident because of the amount of energy required.

> Quote 49. My circumstances have deteriorated and I am now finding any movement is becoming very difficult. I can only "do" one outing every second day and can no longer manage night outings. It is

> becoming very difficult to converse (talk) as I find the energy required is at times, too much of an effort.

This writer tells of restrictions of movement within the home. Regretting not being diagnosed earlier, maybe treatment and rehabilitation would have delayed development of the condition, which would have delayed dependence for activities of daily living.

> Quote 50. This writer was now 75, on oxygen 24/7, diagnosed at 53, but in hindsight admits symptoms were present from his late 30s: If I had been diagnosed earlier, treatment and rehabilitation might have slowed the progression of my disease down and I might still be able to walk from one room to another without a rest in the middle. I require help with washing and getting dressed. My father had smoked and passed away with the same disease and I also had two elderly aunts, who had never smoked but who were both also diagnosed with the disease. My sister also has COPD, however she is a smoker.

There are many similar stories giving voice to people who have COPD. A final selection shows that despite pulmonary rehab and close collaboration with the GP, most “daily tasks are extremely difficult.” Grocery shopping is the writer’s “last normal task,” leading to a high anxiety about what will happen “at the end.” In my opinion, this shows that the management of COPD for this person, and many like them, is through the lens of the medical model, not the social model.

> Quote 51. I was diagnosed 7 years ago and am 66. I have been able to stay out of the hospital for over a year but doing pulmonary rehab and wirking (*sic*) with my Doctor on drug theray (*sic*). My concern now is that I am at 4 on the BODE scale (very severe COPD), I am able to do very little Most daily tasks are extremely difficult. most debilatating symptom (*sic*) is restricted airways. Sometimes they are so tight and restricted. I produce a lot of mucous and it makes breathing difficult. I'm concerned about the ongoing use of prednisone (20mg) day as I cana (*sic*) not reduce it without almost becoming immobile. Grocery

> shopping is my last normal task and it is becomming (*sic*) very difficult every time. I'm worried about what will actually happen at the very end. Will I just sit and struggle and slowly choke to death? It's frightening as no one talks about it (guess they can't).

The selection of quotes is representative of those found on the four websites, and in the publications I accessed. A person with COPD is at the very least moderately restricted in what they can do at home, and the activities of daily living, and these restrictions will increase as the condition progresses.

COPD and the relationship with a spouse

A diagnosis of COPD does not affect just the person with the condition. Family members are also affected, as are employers and coworkers if the person is still in the workforce. The progression of the disease particularly affects a spouse, as the average life expectancy after diagnosis is about five years, depending on the severity of the COPD and other health factors (Felner and Schneider, 2008, p. 9). There can also be grave financial consequences for the surviving spouse as expenses of the illness have depleted savings.

Many of the stories and comments I collected included references to the spouse of a person with COPD, or were written by the spouse of a person with COPD. Overwhelmingly the reports were of love and affection and caring, but also sometimes of a feeling of guilt at somehow letting the spouse down or being a “burden” as the progression of the condition caused the person to become more dependent for even seemingly simple things like washing and dressing.

> Quote 52. The most frightening for me is being unable to take care of myself. I've been married to a wonderful man for eight years. I told him of the disease before we started dating, but when you are “young” and in love, nothing matters. Every year I do less and less. I live with

> guilt. He now does the laundry because it's downstairs. When I'm sick with a cold I can barely take care of my own personal hygine (*sic*). I will not have my husband doing for me. It's not fair to him. He retires this year. I want him to enjoy his life.

In this quote, the person also said that there was a fear of letting go. The words “frightening,” and “guilt,” and “not fair” are in contrast to “wonderful” and “in love,” and the writer’s desire for her husband to “enjoy his life” in retirement. Certainly a rich mixture of emotions is shown here.

> Quote 53. “I live with my husband who also has the beginnings of emphysema. I now have to ask him for help and I find that hard to do being such an independent person.”

Again, in this quote the concern about losing independence and becoming dependent is shown. Also perhaps the realization that her husband is on the same disease trajectory and concerned with what the future will bring.

> Quote 54. It was me who created the problem. It was up to me to help myself. With my wife’s assistance we started running. Initially I couldn’t run a few hundred metres without stopping, but in the past 3 years (with practice and effort) have competed in many “fun runs” with my wife, including a half marathon (21kms). I’m not saying that I find these events easy, as I know that will never be the case. However I also realized that with the support of a good partner, it was easier than doing it alone.

This person is accepting responsibility for his condition, and then becoming pro-active about managing it as well as possible. He has worked hard at this, and admits that it is not easy, but also realizes that without the support of his wife, it would have been even harder.

> Quote 55. My sweet husband, age 64, died 2 months ago from COPD. I wish there was more research as this is a leading cause of death world-wide. Take a page from AIDS activists: ACT UP! COPD is a major killer but no one knows anything about it. All the drug company commercials make it sound like mild asthma. When he died I filled up a large zip bag with his pills for proper disposal. Thousands of pills. He tried to live and we tried with him. But I keep coming back to the fact that this is such a hidden disease when it should be front and center.

This man was young when he “died.” “He tried to live and we tried with him.” Being a carer for a person with a life-threatening condition becomes a lifestyle.

People with COPD discuss spirituality

Many of the stories of people with COPD talked about a relationship with their God. Clearly people drew tremendous support, solace, and strength from this. Quote 56 offers a “dedication” or message through the article to express her feelings. Quote 57 writes of making a “blessings list.” Although in quote 58 there is also a reference to anger, this segues to “counting one’s blessings.”

> Quote 56. I will dedicate this article to my God Who still offers hope and in Whom all things are possible; to my loving husband, children, and grandchildren who give endless support; and to the pulmonary rehab therapists who love their jobs, care so much, and have taught me to rise and conquer.

> Quote 57. I have been down myself the past couple of days, feeling like what I do doesn’t matter. Then I make another blessings list and have a chat with my inner self. God had not yet tired of man and He has not yet tired of me. We are here for a reason.

> Quote 58. Some people’s attitude to emphysema I find unbelievable when they say we who have emphysema deserve it because we were smokers. No one deserves to suffer so much and we were not all smokers. Shall I stay angry at God for not taking this illness away and

> fret about why I even have this when I never smoked in my life. Shall I hibernate in despair over what the future may bring, or shall I live in the sunshine of blessings I have today?

COPD, the ability to exercise, and being breathless

Again, there was a multitude of quotes to choose from in this area. The first example deals with someone who has no doubt about the effectiveness and necessity of pulmonary rehabilitation (discussed in a later section) and exercise.

> Quote 59. "Pulmonary rehabilitation along with an approved exercise program should be essential for all patients as soon as possible after confirmed diagnosis – it was and continues to be a great assistance for me almost 20yrs after diagnosis."

In this quote the effect of emotions, in particular anxiety, is mentioned as a cause of difficulty breathing. Physiologically a cycle sets in, and it is undeniably very important that a person with COPD learns how to control their emotions as much as possible to be able to break this cycle of breathlessness.

> Quote 60. I have come to realize how much my emotions affect my breathing. I am learning to regulate my emotions. It's a constant work. I am an anxious person by temperament, but by doing muscular relaxation, breath relaxation and mental relaxation, I don't let the anxiety get out of hand. Breath related anxiety has lessened quite a bit.

The following quote talks about depression and advises that exercise is a way to overcome it.

> Quote 61. Now one thing that can do away with 90% of depression is EXERCISE. Walking, swimming, weight lifting, biking, anything that puts a physical demand on your body will help you build up your strength, allow you to use oxygen more economically and make you feel good. The fitter you can get, the more confidence you gain, and the more your outlook improves.

Many stories also spoke of the time element when doing exercise. In the following the writer already puts in a lot of time on exercise, but also qualifies this with, "I spend as much time as it might require." Clearly, not everyone can do this, through lack of time, or other resources such as access to a gym or transportation. However, it is very possible to build "incidental" exercise into the normal activities of daily living, so this becomes an awareness issue of alerting people to that possibility.

> Quote 62. I have to put in a lot of time and effort in keeping better health. I spend about 3 to 4 hours every day on different self-help tools such as walking, breathing exercises, flexibility and strength training, weights and meditation. However, when my symptoms worsen, I spend as much time as it might require.

Here is the story of a young person who was always very fit, then suddenly needs to come to terms with having COPD and describes how she is self-managing her condition.

> Quote 63. Diagnosed in her early 40s. Because I have always been very fit and I have been a long-time member of my Gym (going at least 4 times a week and being an average jogger) it was winter [a colder climate having recently moved from a place with a milder climate] that was the turning point for me. I went from being able to fairly easily complete a cardio class (even if getting puffed) or run/jog/walk 5 ks fairly easy to not even being able to go 300 metres. I do think that the amount of time between having my symptoms noticed/tested will impact on the treatment or what will eventually become the outcome – because even though I waited, I am very lucky in that my diagnosis is very early in the disease compared to others. As such, I have a much better chance of stabilizing the condition. I am conscious of keeping up with my exercising and at the same time conscious of resting when my body needs it.

An older person tells her story of walking and exercising that has helped her condition.

> Quote 64. I am not sure when I was diagnosed with COPD, but it would be several years ago. With the walking and exercising I am starting to feel much better and still playing lawn bowls, but realize my limitations when climbing stairs or walking up [a] slight incline.

Of course, breathlessness was a topic many of the writers included, as breathlessness is one of the primary symptoms of COPD. In quote 65 the writer talks about how breathlessness is terrifying and urges people to give up smoking. This is a topic that will be covered in a later section, as many of the stories mentioned smoking and its effect on them and their families. In Quote 66 a respiratory therapist recounts what her patients report when they regain the ability to breath and presumably have a relative lack of breathlessness.

> Quote 65. The breathlessness is terrifying and I am scared of it killing me. While I am only 55, I can't enjoy what I used to and I miss that so much. I can't chase my grandchildren for fun, or even laugh too hard, please everyone who smokes give up NOW for your own, and families sake, this illness is exausting (*sic*)and scary.

> Quote 66. Pulmonary patients have often described to me the amazing, liberating experience, sometimes following treatment, medication, or even surgery, of being able to take in that wonderful, full, deep breath. They say, I felt myself taking a big deep breath like I hadn’t been able to in such a long time, long time. It was an incredible feeling! You know, people who don’t have breathing problems just don’t have *any idea* what it is like. They can’t possibly understand how good it feels. They take their breathing for granted.

People with COPD discuss pulmonary rehabilitation

Pulmonary rehabilitation (PR) is part of the standard of care for people with moderate to very severe COPD. Many of these people are older, and would not perhaps normally take a course or seek further academic education, but their need for education and self-management about their health condition is considerable. Courses in PR, however, are hugely successful and well-attended, due to the skill of the health professionals and the care with which the curriculum is devised and presented.

> Quote 67. My wife suggested I enroll in a pulmonary rehabilitation program. I was skeptical because I was having such a hard time breathing with any exertion. But I've always been interested in a lot of things and have always kept myself busy. I was always doing something. Now I couldn't do anything – so I figured I might as well go to the rehab.

> Quote 68. GPs and Specialists are generally running against the clock, therefore having little time to fully educate each patient. That is where rehabilitation programs so ably fill the void. Pulmonary rehabilitation programs are the pathways to conveying information – which is the key to ongoing wellness and quality and quantity of life as well as limiting frequent hospitalisations.

> Quote 69. The program was exclusively for lung ailments, and as a patient, I found this most beneficial and successful in developing confidence for all patients within the group. The need to exercise was very evident to all and everyone walked to their own level not competing with others, or feeling inadequate because you could only move slowly in comparison to others. I would highly recommend pulmonary rehabilitation programs to others.

> Quote 70. I found the Pulmonary Rehab Program interesting, full of information and practical knowledge to help me understand the many uncertainties I felt since diagnosis with COPD. For instance explanations were given for the medications, the anxiety, exercising effectively and the mechanics of breathing, also what causes our breathlessness and how to self manage and monitor one's day-to-day health.

> Quote 71. At a pulmonary rehabilitation course and a self-help group, I acquired skills to cope with my condition. Knowledge is the key to being able to live with this disease, for it is frightening (especially at night, alone) not being able to breath.

> Quote 72. This person was 84 years old. They started me off very slowly and by the end of 12 weeks I was much better. I learned how to breath better, eat better, and take control of my health. I learned that I can't overdo it. If I do, I'm just going to undo everything I've gained. I learned to pace myself, and a year after I started rehab I was able to tend my home gardens again. The pulmonary rehab manager asked me to help with the flower gardens at rehab and I work on that before going in for exercise. I plan to continue rehab as long as I'm able, and to help with the garden. The staff have given so much to me, this is a way for me to give something back to them.

As the following quote shows, pulmonary rehabilitation is much more than just exercise. Here we see evidence of spirituality, as well as inspiration, support, and appreciation of other people as friends and supporters.

> Quote 73. I was reminded one recent Sunday morning that I should try to be thankful for adversity and challenges in life. [He then goes on to describe the fellow members of the pulmonary rehabilitation group and the richness they add to his life at each session] For all the others in the class who inspire me by their determination, and for the staff members who help me, I am thankful. So now, because of my breathing problem, my life has become enriched. I have found joy and contentment in the midst of adversity. I am thankful for my pulmonary struggle. And I am thankful for the richness it brings.

The person in quote 74, with saying, "I don't know where I would have been now" is certainly a supporter of PR.

> Quote 74. This person was asked what he might say to others who are wondering if PR would help them: For me, I tried the program and it's helped me a lot. I don't know where I would have been now if I hadn't taken the program. I was nervous on the first day of PR, but I put trust in the instructors and their advice, put forth my best physical effort, kept a positive attitude – and stuck with it. Now I can exercise for 60 minutes, twice a week.

To show that PR is not all just serious stuff and education, the following quote shows just how supportive the patients, health professionals, and hospitals are.

> Quote 75. A person with COPD was recently crowned the "Queen of Pulmonary Rehabilitation" at her local hospital, because she has faithfully attended pulmonary rehabilitation for 20 years. Her story: After being sick for five years and ending up in the ED, she got a new pulmonary doctor who recommended PR. Her husband had to take her in a wheelchair. Two therapists – one on either side – had to hold her on a bike just to ride for 5 minutes. After several months she could walk in by herself. Her most recent illness lasted 5 months, but she still returned to PR when able. Her advice to other patients with lung disease "Keep on going – never give up." She and her husband also attend a monthly Breathers Club to lend support to other lung patients.

Through tenacity and willpower, and with a supportive husband and family, this person has been able to maintain an improvement in all her program goals – reduce symptoms, increase functional performance, and improve quality of life. As well, she supports other patients with lung conditions. This is a very admirable achievement, but by no means unique.

Being on oxygen with COPD

One of the most feared aspects of their disease for a person with COPD is the thought of needing supplementary oxygen, and thereby being tethered to a concentrator and becoming a "shut in." The many Lung Foundations, patient groups, respiratory therapists, and pulmonologists are available to help people when they get to this stage, providing many handouts, booklets, and personal advice. The oxygen suppliers are often very helpful too. There is also a huge amount of information on the Internet.

Here are some stories from people on home oxygen, also referred to as Long Term Oxygen Therapy (LTOT). In quote 76 the person talked about the progression of his condition: hospitalization, discharge on oxygen, elimination of the oxygen with some weight loss, and then, as his condition progressed, needing to resume LTOT.

> Quote 76. I spent many days in intensive care with surgical emphysema. Since then I have been hospitalized many times. Through decisive action on my part I lost 23 kgs. Over time I was on oxygen for 3 years, but due to the weight loss I was able to live a "normal" life and get off oxygen. However, after a couple of years, my condition deteriorated despite my best efforts, and I again required oxygen, and now use it 24/7. Attached to an oxygen machine all day every day isn't quite the retirement I "expected." But that's what COPD will do to you. But every day, I am thankful for "another day in paradise."

Here in quote 77 is a person who is continuing in the workforce while using LTOT. This is clearly a difficult thing to do, and may not be sustainable long term. I am not sure what she means by "I haven't been totally diagnosed with COPD," as chronic bronchitis comes under the definition of COPD. This is an example of confusion with diagnosis and nomenclature that sometimes interferes with a person receiving the correct medications and self-management instructions.

> Quote 77. While I haven't been totally diagnosed with COPD, its leaning that way. I found out I have chronic bronchitis and we're still trying to fix that before the last breathing tests. I am a business person and now on oxygen 24/7. It absolutely wears me out. I find I can only work a few hours and have to take a nap. I sleep hard at night (with O2), and am waiting to be put on a V-Pap [for sleep apnoea]. Insurance is taking its time. I feel I will have to retire from this job that I love. But just don't have the energy anymore.

Another quote showing the difficulty of living with COPD, and how, with much reduced lung function, this person needs to use the supplementary oxygen constantly, even when showering.

> Quote 78. I've suffered with COPD for 3 years. I was diagnosed as extreme COPD and only have 10% of lung functionality left. My breathing is so bad, that I have to keep my oxygen on even when I shower; my apartment does not have a tub.

The following quotes show the “warrior” attitude that people can develop as they live with COPD.

> Quote 79. We are living, walking, BREATHING examples of how courage, strength, perseverance “look” and “feel” to the world. We walk around with plastic prongs in our noses and sometimes people look at us funny but, know what? WE are still standing. We are still walking. We are strong. We make a difference in this world and perhaps, in some way, even because of COPD.

> Quote 80. I made the decision to gain control of my condition. I decided to “live with COPD, rather than die from it”. I continue to be very active, despite being on permanent oxygen therapy. I exercise 1-2 hours per day, eat nutritionally, enjoy gardening, play in competitive game tournaments, write about COPD and my scientific interests. My motto for living with COPD is “*Carpe diem*” – seize the day.

Oxygen therapy can be very beneficial if lung capacity is diminished due to COPD. When breathing is impaired, the body may not get enough oxygen, which can affect how people feel and how much activity they can perform. Supplemental oxygen therapy can improve lung function and increase the ability to exercise and be active.

Support groups and information for people with COPD

Support groups can be an essential part of life for people with COPD. A patient support group is a group of people who have common interests and needs. Many Lung Foundations around the world, as well as other institutions, facilitate networks of support groups for people who have lung conditions and their carers and families, so that patients may benefit from activities, ranging from social outings to special seminars and education days, to online support chat rooms.

Here are some comments about support groups:

> Quote 81. I have volunteered for many years now and COPD has been the main focus and all those elements that do make an enormous difference to the quality and quantity of life. By joining a group it encourages ongoing incentive to continue the program [referring here to PR] and a certain amount of social contact. Maintaining physical exercise has become a regular part of my routine, both walking and in a group situation at a nearby gym, to work under the supervision of a qualified instructor.

Support groups are for carers too:

> Quote 82. Through my association with a support group I have learned much which has helped me as carer for my husband, a sufferer of COPD for many years. This knowledge, gained from my 5 or 6 years of association, has been invaluable in helping me with my carers duties and responsibilities. I have also made new friends amongst the other carers who support me, because they know what it is like to be caring 24/7 for someone who can’t breath.

There is not always support when people go looking for it. They can either forget about it, or become more proactive and actually find their own information and then, as in this case, support others:

> Quote 83. As I didn't know anything about COPD I decided to contact organisations in the hope of receiving help. To be honest I found out that as I wasn't "sick enough" there was little that anyone could do to assist. As I was still in reasonable health and it was me who had created the problem, then it was up to me to help myself. I now am very active in a group which provides support to people who are perhaps a bit more advanced with their disease than I am at the moment. But I know my time will come, and then I will be very needy of support.

A message that this member of a support group likes to share is of her life with COPD and what she has learned. Knowledge of the condition is a first step to managing it:

> Quote 84. Diagnosed with COPD many years after first symptoms appeared. I was asked recently what questions a Doctor can ask to a patient to trigger the thought processes of looking for this disease. There are a few but I think it comes down more to the patient telling the doctor the right information. Building a rapport with your doctor is vital, so they know that they can rely on what you're telling them. The key to all that for the patient may well be simply knowing that there is such a disease in the first place.

Using the Internet for information and contact with others with COPD

The following two quotes are typical of how people, especially younger people, approach seeking information once they are diagnosed with COPD. As the technology becomes more widespread, familiar, and accessible, this trend is likely to increase. Also, the amount of information on the Internet is expanding exponentially, so people have access to the latest information on scientific research, medications, and sources of support. Often older people will ask their children or grandchildren for help seeking out information, which will encourage the whole family to find out more about the condition and be more involved in the caring process. In quote 85 the writer talks of being on the road to self-empowerment.

> Quote 85. There was no pulmonary rehabilitation program near where I lived, so I read everything regarding lung rehabilitation and exercises from libraries, Internet and patient associations. I studied extensively to understand my disease, medication and treatment options. Coping with the disease is a process of learning. When I was told I had emphysema, I knew nothing about it. I had heard the name and thought it was a disease suffered by elderly people in nursing homes.

This quote illustrates a not uncommon phenomenon where someone goes from not knowing anything about the condition, to running a support group and being an enthusiastic co-owner of a virtual support group.

> Quote 86. I went to the internet and found a lady who directed me to a support group only five minutes away from me and I never knew it. So I went along and I read a lot and asked a lot and learnt a lot and now I run the support group. I now also am co-owner and moderator of an Internet Support Group for people with lung disease and their carers.

> Quote 87. There is a wealth of reading about patient stories on the site, covering a wide range of lung diseases. …. These lists are very helpful and enlightening in terms of talking to other patients and learning even more about your disease and options. I completely got over my fears and reservations via the knowledge and real life stories. My experience of COPD … some days misery flows and ebbs hour to hour, no matter what you do and other days feeling decent, good, even great holds steady; again, no matter what you do …

Quote 88, whilst not from a person with COPD, is a short but very heartfelt example of someone who is scared for her dear friend, and feels helpless, but is there as support, a hugely important role.

> Quote 88. I have a very dear friend who has just been told he has COPD. It hurts to see him struggle to breath sometimes and I am so scared for him. He tries to cope and make light of things but I know he struggles with the situation and the uncertainty of when the next bad turn is coming. I only wish it wasn't such an unpredictable illness. I can only be there for support and will be although seeing him struggle for breath makes me scared as i feel so useless.

Quote 89 is a synopsis of a very much longer story that had a great effect on me because of its clarity, comprehension, completeness, and compassion. The writer, who coincidentally also has COPD, talks about her friend and describes so much about the sequence of events, the ups and downs, and the ultimate consequences of having COPD.

> Quote 89 My friend, a longtime smoker, was fiercely independent. Developing a thick cough in her mid-seventies, she loved smoking and could not stop, although we talked about it. For years I accompanied her to medical appointments, always walking, but I noticed that it became an increasingly slower journey. Her GP diagnosed early stage emphysema and constantly reinforced that she would feel better if she stopped smoking. Usually compliant with her doctor’s orders, she tried quitting numerous times. She was referred to a respiratory specialist who said, “This lady has very advanced COPD.” My friend was hospitalized shortly after and died. The best I can do for my friend now is to become active in awareness-raising about COPD.

The story in quote 90 is quite remarkable. This young man is facing up to mortality with a strength and humour much to be admired. The story exemplifies how dependent a person with COPD can become on their family. The only thing worse than having COPD, is to have it alone.

> Quote 90. I am 19 and act as a carer for my elderly grandfather. In my experience of being a carer over the last 15 months I have seen my grandfather’s health in constant fluctuation, ranging from general breathlessness to a near complete state of collapse, where he constantly shakes, and can’t find the strength to stand. Even with these ups and down he still finds it within himself to keep some form of independence and clings to that independence like the stubborn old goat that he is. Most days I spend doing chores around the house – cooking, cleaning, washing, and driving. But my biggest task as my grandfather’s carer is to watch over him. He has been suffering from depression and anxiety more and more. Some days it is very hard to be his carer. I love my grandfather and intend to stay by his side until I am no longer needed.

In quote 91 we see the poignant story of an elderly gentleman talking about the loss of his wife and his family dynamics.

> Quote 91. I am 80 years old and recently bereaved. My late wife looked after me well but I still had the whole family constantly worried. When my wife was first diagnosed with cancer she did not pity herself. She cried and said, “Sorry, I will not be able to look after you as I used to do now.”

A diagnosis of COPD can be a catastrophic happening for both the person diagnosed and the family. There are many heart-wrenching stories, but there are also stories that show that the diagnosis of the life-limiting condition have helped to strengthen relationships and lead to new understandings and solutions, new friends and pastimes, and an awareness of how precious our lives and our loved ones are to us.

Smoking, quitting, and never smoking

Smoking is the single most important factor in people developing COPD. As many as nine out of ten COPD cases are attributed to smoking. Physically, smoking affects every part of the body, not just the lungs. Quitting smoking cannot reverse lung damage, but it does slow down the progress of COPD.

The following quotes are representative of what people with COPD say about their smoking history, their attempts and successes at quitting, and their reactions to having acquired COPD when they have never even smoked.

As seen in quotes 92 to 97, these people took up the habit while still very young, and continued for many years, if not decades. What is insidious about COPD is that it takes many years of abuse for the lungs to finally show signs of declining function to the point of incapacity in breathing. Healthy lungs have a lot of excess capacity. It is when this is depleted that people start to be affected by lung disease, and by this time, it is too late, because unlike many other organs in the body, the lungs once damaged do not regenerate.

Specifically, quote 92 also mentions that smoking was the “done thing.” The person in quote 93 was advised by their doctor to smoke. In quote 94 the person who was working like a man, therefore doing the “manly” thing and smoking, was also advised by his football coach to “Have a fag … it helps to clean your lungs out!!!” The woman in quote 95 gave up during her pregnancies, but took up the habit again. In quote 96 the person details the many different techniques used to try to quit. Finally in this group of quotes, in quote 97 we find that the person was actually provided with free cigarettes as a “benefit” of his job.

> Quote 92. I started smoking at boarding school when I was 11, because it was considered the “done thing,” totally different from today’s attitude. I have always been involved in sport and continued to play in “Golden Oldies” rugby and softball teams. As a male and “bullet proof,” it wasn’t until I was about 50 and during a game of softball, that the game had to be stopped because I couldn’t run two bases and I realized I may have a problem. A short time later I “woke up to myself” and visited a specialist, and was diagnosed with COPD. When I was diagnosed I was “pissed off,” but realized there was only one person to blame. Within six weeks of the diagnosis my wife and I gave up smoking.

> Quote 93. I feel regret that I ever had that first cigarette when I was 12 years-old and continued to smoke for 43 years. The doctor who first told me to smoke because it was good for the nerves better than medication for me, died of lung cancer. He also did not know the dangers of smoking back then and I do not blame him at all even though I forced myself to smoke because he said it was good for me. If only we knew then it was so bad.

> Quote 94. I started smoking when I was only 14 as I was a dairy farmer and doing the work of a man. I played football and always looked forward to having a smoke at half time, as our coach would say "Have a fag … it helps to clean your lungs out!!!" We had Government developed tobacco farms in the area so smoking helped the Federal and State governments with taxpayers subsidizing the industry. I did 3 months National Service and was provided with cigarettes … it would be interesting to examine this policy now.

> Quote 95. I'm 80 years old now. I was a smoker of 20 cigarettes say from age of 15 to 50 when I gave the habit up. I did not smoke during my two pregnancies; four years for the first and one year for the second.

> Quote 96. I smoked lightly for approximately 20 years from the age of 16, tried all types of stop smoking devices, did courses, and finally gave up smoking with the help of hypnotism. My health was badly affected of course, now I'm facing the consequences of my habit.

> Quote 97. John. Now 69 years old. Unfortunately I did smoke cigarettes from about age 17 to 29, and it didn't help that my first full time job starting as an office boy at [a tobacco company] (for six years) included free cigarettes any time from the company. I am not blaming them as I was the fool who did the smoking, they didn't force me! I contracted pneumonia at age 29 and the doctor said you cannot smoke for 3 weeks so I didn't restart.

In quote 98 we see denial, which continued for many years, and then deep regret, after ignoring medical advice and developing severe COPD. In quote 99 the compounding effect of environmental factors, from both living and working conditions [fortunately, many countries have enacted health and safety legislation to improve workplace condition] and smoking are described. Quote 100 is another example of the workplace condoning, indeed even encouraging, the habit of smoking. It has been standard practice for military personnel to have cigarettes or tobacco issued as part of their rations. Many people stated, as seen in the quotes, that they started smoking when in the services.

> Quote 98. Recently bereaved and 80 years old, describing how he finally came to cope with this debilitating condition. I was diagnosed with emphysema a long time ago. The doctor told me if I valued my health I should stop smoking straight away. I am too fit, this is not going to happen too me. How stupid and wrong I was! I finally stopped smoking at the age of 69. I was still coaching kids' soccer but while running the breathing was labored. In a few words it was too late.

> Quote 99. Yes I did smoke on and off for 18-20 years, stopped finally for good about 7 years before diagnosis. But I was also raised on a rural property in an environment of extreme dust, from stock yards to wheat dust. I also worked in night-clubs for 10 years with heavy exposure to passive smoking, over a shift which could be as long as 8 hours.

> Quote 100. I started smoking when I was in the British Army in Germany. My time spent in the Army was the start of my going downhill with emphysema. After the war cigarettes and tobacco were very cheap in Germany. They were almost like currency, especially as far as the girls were concerned.

Many people spoke of their attempts to quit smoking. As quitting an addiction is so inordinately difficult, doctors, researchers, and therapists have come up with many different approaches to quitting. The success rates, defined as being smoke-free a year or more after quitting, vary widely for different people and different techniques. There is no single technique that is guaranteed to completely extinguish an addiction.

In quotes 101 and 102 the expression "cold turkey," meaning quitting without nicotine replacements or other stop-smoking aids, is used. This is a method that some ex-smokers, and even some experts, think is the only effective way to quit. Withdrawal symptoms can be intense, but only last a few days. Physiologically, the health benefits of quitting kick in as early as 20 minutes after smoking a cigarette, which is of course why smokers feel the urge to light up every 20 minutes or so. However, without reinforcing the nicotine in the body, the health benefits get better the longer a person is smoke-free.

> Quote 101. I have COPD and a minor asthma content – yes – I smoked for about 33 years after taking up the habit soon after I joined the Navy mid 1945 using all forms of tobacco products along the way – and kicked the habit immediately following medical advice. I chose to quit "cold turkey" and successfully on the first attempt.

> Quote 102. I was still putting in extremely long hours due to the demands of my very responsible public service job … I started to put on weight, was doing little exercise and still smoking 60 – 80 cigarettes a day. My father died from Emphysema, and 5 days later I stopped smoking COLD TURKEY.

Quote 103 exemplifies the many stories of using many different methods to try to quit. It is so hard to quit because it is a physical, mental, emotional, and behavioural battle with addiction, and even though the majority of smokers express a desire to quit, it often takes many attempts to achieve success.

> Quote 103. At 84, after 60 years of smoking. It came on slowly at first, then I became more short of breath and eventually found that I was doing less and less. Then one day my doctor told me I had just four years to live. I'm not a quitter. I had to do something! I knew it was mainly from my smoking, so I tried the patch, the gum, hypnosis … nothing worked. Then I found a seven-step program where I started by setting a target date to quit and went from there. I slipped back a couple times, but I didn't give up and finally I quit.

Quote 104 talks about smoking being the "normal" thing to do. In quote 105 the writer describes that she is drowning with shortness of breath as there is always an atmosphere of smoking in her home, which makes it very hard for her to succeed in quitting. It is known that smoking rates are highest amongst those reared in a smoking household. This is so even when people are aware of the effect smoking has had on their parents or other older relatives. Quote 106 shows the difficulties experienced by someone who doesn’t smoke, but is surrounded by smokers. She reveals that there are days when breathing is “near impossible.”

> Quote 104. Doc just told me i have COPD. I'm 53 and have to be on oxygen 24/7. I wish I had listened to my kids when they used to tell me to stop smoking. But I was brought up in a family where my parents smoked, so it seemed to be the “normal” thing to do.

> Quote 105. I've had COPD for 4 years now, along with other conditions and constant pain. I know I should quit smoking but I'm finding it extremely hard. With 2 in this household who smoke and 2 grandchildren who smoke, it is very difficult. How do I quit smoking, when it is all around me?

> Quote 106. I have had asthma all of my life (almost 70 years). I have never smoked, but have lived with hard core smokers all of my life. In fact, my parents, and my older brother died with lung complications, emphysema and lung cancer. About 7 years ago I was diagnosed with COPD. I now take medicine for both asthma and COPD. I am very independant and hate that there are days when breathing is near impossible. How do I convince people that their smoking is killing me, albeit slowly it is no less painful.

People with COPD talking about their own death

Some people spoke about their own death quite unemotionally and matter of factly, some were emotional, some were accepting, and some were angry and fighting all the way. The small collection of quotes below shows some of these aspects.

The person in the first quote is very clear that when she can no longer get out of bed, that’s when she wants to die.

> Quote 107. I quit smoking in 2004. My COPD wasn't that bad. I am not on oxygen, my O2 level is fine. My lung function is very low, I have severe COPD. I have been very active all my life, but now it's

> hard for me to do anything. I told my primary care doctor that I prayed to die. She put me on antidepressants. I still dread getting out of bed. As long as I lie down I am fine; it's when I am up & moving. My pulmonary doctor has put me on a nebulizer 4 times a day, it helps for a couple of hours. I get my inhalers from Canada; $59.00 plus tax compared to $275.00 which is terrible here in the states. I asked my doctor about lung volume surgery & he said there's a 10% death rate. Do you call this living? My fear is that there will come a day I can no longer get out of bed, that's when I want to die.

This young student is showing concern for both himself and his parents, in a very emotional way. Of course, the student should seek a second opinion and make lifestyle decisions to arrest the development of his COPD.

> Quote 108. I am just an 18 year old student, started smoking 3 years back, and I don’t want to give up, it is too hard. Recently I visited my doctor and he told me that I am suffering from COPD. Till today I didn't know this was such a dreaded disease but now that I know, I am just scared. I have my whole life ahead of me. What if I die ? My parents would die along with me as I am their only son. Some one help please. I really don't want to die.

The first quote below typifies the feeling of loss of what this person “loves,” she is frightened at leaving her family. She has also had exacerbations, and experienced her mother’s death from COPD, so she is aware of what her future might hold. In quote 110 there is a similar situation with a son having experienced his father’s passing from COPD.

> Quote 109. I have had COPD for about 5 years. My mum passed with it. I am on oxygen 15 hours a day, most of which is during the night. I've had 2 really bad attacks where I nearly lost my life twice in 18 months. The most frightening thing is leaving my 4 grandsons, sisters, brothers and my 3 lovely grown-up kids.

> Quote 110. “I am afraid of dying with this. I watched my dad pass away with this. They said I was in the early stages, but I still have a hard time catching my breath a lot.”

This person in quote 111 also fears dying, but is going to make the most of being here until then. He has a very comprehensive knowledge of self-management and is determined to follow his plan:

> Quote 111. I'm 62 and I've had severe COPD for around 10 years now. As much as I fear dying from this I've learned to focus on each day, hour, minute or moment as necessary to gain some control over this. I've lost a lot of weight because I didn't have an appetite. I lost muscle mass which only aggravated my COPD flare ups. I've decided enough of this!! I'm now eating more and better than when I was 20. I'm forcing myself to do some exercise each day to rebuild my muscle mass. I make an effort to keep in contact with people and get out and about and get involved to improve my mental health. I'm tired of worrying about the what ifs of this disease. I want to make the best out of this situation and pray for my family and friends while I'm at it. While we are dwelling on our COPD they may die from something a lot less predictable at any time. At least we should know better to enjoy the time we have left! I refuse to die a death of a thousand cuts with negative thinking for the time I have left.

I finish this section with an unemotional statement of fact, which in a literal sense is not true: the writer *will* die *with* emphysema, but maybe he means not *from*:

> Quote 112. **“**The specialist explained to me that I won’t die with emphysema, more likely with a heart attack or pneumonia.”

Messages of hope and support

There are also many messages of hope and support, that speak out strongly as people report on what has worked for them: having a relationship with fellow members of a support group, exercising, the friendships made at pulmonary rehabilitation, and speaking out to help others and to show someone cares.

Quotes 113 and 114 illustrate this with respect to a support group:

> Quote 113. The writer is welcoming a new member: “Welcome to the group. There are a lot of great people, all trying to learn from one another and to help each other out.”
>
> Quote 114. “[A particular support group] has been so helpful in allowing me to move through my stages [of grieving], as I need to, and offer support in such a wonderful way. I’m so grateful.”

These writers comment on how exercise has helped them:

> Quote 115. “Exercising has enabled me to remain active in the community, helping others both physically as well as by serving on various committees to establish pathways for consumers to regain fitness in the best possible way.”
>
> Quote 116. This person took up running after being diagnosed and is being very modest about his achievements. Please don’t think I’m bragging, more so realising how fortunate I was to stop smoking when I did, before the damage I had done was more serious. Every year, on World COPD Day I walk the corridors of the local hospital to remind myself of exactly how lucky I am and to understand that many others did not get a first chance, let alone a second one in several cases – through no fault of their own. When I reflect on the past 4 years I can see many positives. My wife and I have stopped smoking, and with her support, we have commenced running and continue to participate in sport. As we regularly run around out neighbourhood we are often asked why we do it. This gives me the opportunity to reply “to keep alive,” as I honestly believe the longer I run, the longer I live.

Commentary on the loss of support group members is shown in quote 117, but even while acknowledging loss, the writer expresses hope, and exhorts that, “in spite of COPD, we can have a really good life.”

> Quote 117. Sadly we recently lost two of our COPD support group members. They passed away on the same day. Okay, I know it’s no fun living with obstructive lung disease. But we still [most of us] have our vision, allowing us to see the beautiful things – and people – around

> us. Sometimes it takes the loss of a friend to make us realize that, in spite of COPD, we can have a really good life.

Speakers who are motivating others, and through this probably motivating themselves to be stronger when faced with the adversities of living with a chronic condition, are shown in the next three quotes.

> Quote 118. Someone said it so beautifully, "What is, is! Now it's up to me!"

> Quote 119. "About the future? I try hard to remain positive and surround myself with like-minded people. COPD cannot be reversed, but with help, we can maximize our quality of life."

> Quote 120. Dear friends, do your best to seek joy in every day. Find it, take note of it, cherish it, celebrate it! Life with pulmonary disease is about opening the doors of ourselves to invite joy to enter, to stay awhile, to live within us as much as possible – and ultimately to help carry us through the dull gray sky days of life.

Advocacy for COPD awareness

Many people commented on how COPD had changed their lives emotionally, physically, and socially, many times for the worse as the progression of their condition made everyday living increasingly difficult. There were, however, many comments about how the disease had caused positive changes in their attitudes, and how they wanted to make a contribution to help other people avert the same problems.

This is shown in the following quotes:

> Quote 121. Rather than the retirement full of golf that many of my peers might be enjoying, I have committed all my time to raising awareness about lung health, the importance of lung function testing and taking action to prevent or fight lung disease.

> Quote 122. “I feel it is very important to elevate the profile of lung disease including COPD to the community and to have young people at risk identified early.”
>
> Quote 123. “Surely with the public being bombarded on the need for early examination leading to early diagnosis, early intervention, early detection for cancer, diabetes, heart conditions, etc …….. WHY NOT LUNG DISEASE?”

I have analysed how people with COPD adapted to, and reported on, life living with COPD. The quotes show how people can take measures, such as attendance at pulmonary rehabilitation, where they can learn the skills to reclaim much of their independence and improve their quality of life by incorporating relatively simple new techniques into their everyday lives.

For anyone recently diagnosed with COPD, the details definitely can be confusing. As the disease progresses, physical activity or social interactions may prove increasingly difficult. Many of the people quoted reiterate the need to learn as much as possible about the condition and to comply with medications, exercise routines and other treatments, that have been shown to help people live better with COPD, to help control their symptoms and to improve their quality of life. A person with COPD needs to develop techniques to manage their breathing as they go about their daily lives. The Internet can provide a much needed sense of community, understanding and experience in a virtual landscape they may be far more flexible and adaptable than the physical landscape they may have been far more accustomed to prior to diagnosis.

As exemplified in the quotes, a diagnosis of COPD often causes severe disability, and can lead initially to feelings of denial, and anger. As a person adapts to their new reality, they may feel depression and anxiety. Acceptance and rising to the challenge of living with COPD is the overwhelmingly positive message shared by contributors.

CHAPTER 5 CONCLUSION

The research question for this study was, “What are the lived experiences and perspectives of people with COPD who post their stories on the Internet thus making these narratives publicly accessible?” This question was important to pursue because I identified a gap in the literature: researchers have not collected and analysed the stories coming *from* people with COPD, directly *from* them in their own words.

I searched for online information with a specific focus on the writing and postings of people with COPD. These stories gave voice to the feelings and emotions of people with COPD and allowed me to collect information about their lived experiences and perspectives. These extracts do not fully describe any one person’s life, but when viewed together as a compilation of information, they provide an interesting, and I believe authentic, view of how having a chronic condition such as COPD can have an impact on performing activities of daily living.

The data was collected from publicly accessible information available on the Internet. There were various reasons for using the Internet for the data collection. The method of analysis used was standard ethnography. In this case, the qualitative technique is referred to as netnography because of the means of data collection. Netnography is qualitative research using the computer/Internet/social media. The research method is netnography, therefore by definition using the Internet is the only choice for data collection. Netnography and narrative content analysis were feasible methodologies for the scope of this project.

Netnography as a method can reveal an understanding of important social issues without any confounding influence due to the researcher. This research approach cannot influence or harm the narrators while their writing is being read and analysed.

Whilst there have been some doubts cast upon the use of evidence, which is anonymous, and as all “chat” is, lacking context, the users’ veracity is verified by their very access and use of such sites, which are designed for the sharing of the lived experience of those with COPD, and their carers and supporters. These authentic voices speak for themselves, and in the context of the nature of COPD, they are very eloquent. In the researcher’s role as an active member of various lung condition support groups, for over a decade, the comments are cogent with my broader experience of personal contact through phone conversations, meetings, conferences, outings and other activities, in the real world.

As could be expected, on all of the sites I chose to investigate, there were people at different stages of the condition, people in different countries, and people of different ages and personal circumstances. Unsurprisingly, people with COPD reflect the demography and diversity of the world’s population.

Systematic searches of the sites I had chosen as the richest sources of data yielded a mass of information. This actually presented some methodological difficulties for choosing the most appropriate quotes as examples to illustrate my salient points.

During the data collection I chose quotes that most clearly exemplified the key issues I had identified. These quotes, which are grouped and collated under various headings or themes as a context, spoke about the experience of living with COPD, as related to each particular theme.

The research was of an iterative nature: first the collection of a large number of stories, then the searching and sorting for themes, then revisiting the stories and searching for more on a particular theme, and finally choosing the best exemplar quotes for inclusion, and making my commentary to draw the quotes within a theme together to form a cohesive presentation.

Many of the stories showed how people now typically use the Internet to conduct their own investigations on health issues. This was especially so for apparently younger people who seek information once they are diagnosed with COPD. As the technology becomes more widespread, familiar, and accessible, this trend in Internet use is likely to increase. The amount of information on the Internet is expanding exponentially, so people have access to the latest information on scientific research, medications, and sources of support. Often older people will ask their children or grandchildren for help seeking out information, which will encourage the whole family to find out more about the condition and be more involved in the caring process.

With so much information available via the Internet it was surprising how many people with COPD frequently declared a lack of knowledge of the condition. People with the condition admitted to the gap, but they also reported that often their GPs, the first point of contact for primary health care, failed to recognize the symptoms of COPD, and thus neglected to order confirmatory tests, in particular spirometry.

The changing landscape for a person with COPD has been examined using the schema developed by Elisabeth Kübler-Ross (1969). Other authors, including Carter *et al*. (2001) and Martin (2010), who have expanded on this schema, include descriptors such as grief, rage, self-pity, fear, frustration, and resignation. These words were used frequently in the included stories and reveal a strong sense of authenticity, and consistently portray natural emotions. People wrote openly about their lives with the condition, their everyday experiences, and how they managed to overcome barriers which arose because of being a person with COPD.

There were also many stories of hope, love, support, appreciation, and contentment, of choosing life over death, and making the most of the situation. People expressed gratitude for being a part of a community of fellow people with COPD, particularly when reporting the outcomes of attending pulmonary rehabilitation and having a close relationship with members of a support group. Even after the death of the person with COPD, people reported that continuing to attend support group meetings and activities gave them solace in their grief.

There was much peer advice from people with COPD to others on such matters as adapting to the shrinkage of a person’s horizons through lack of access to previous spaces, coping with a decrease in energy, coping with the panic which accompanies breathlessness, accepting a slowing down of the pace of life, and realising some of the inevitable restriction as activities of daily living become more difficult and more time-consuming. It was clear that not everyone wants to be acknowledged for helping others. They just want to do it, and this is enabled by modern technology to an extent not previously possible.

In addition to describing the emotional aspects of living with COPD, describing relationships with spouses and others, and providing much advice in that respect, there were also stories about the more visible, external, or pragmatic facets of living with COPD. These latter stories included the effect on work and finances, the modifications needed to the home environment, and sharing experiences about smoking and quitting. In particular, because breathlessness is a primary symptom of COPD, there were many stories about the ability to exercise, the necessity for exercise, and the effect exercise had on quality of life.

A common theme among the very diverse people with COPD was the aspect of stigma, because the public tend to believe that people have brought on the condition themselves through smoking. For people for whom smoking was not the cause (for instance those who had the genetic form or who had been exposed to environmental pollution or secondhand smoking), this was particularly distressing, and they seemed to draw solace from being able to know that they were “not alone.” This understanding had a cathartic effect on their well-being.

The use of netnography as the means for data collection was extremely successful. I used the technology of the Internet to access the stories of people with COPD. This was an essential technology for this study; without the technology I would not have had access to the stories, and without the technology the people with COPD would not have been able to post their stories. The power of Internet communication breaks down geographical barriers and allows for asynchronous communication. The Internet is also a powerful repository of knowledge and an aid to education, allowing people with COPD to find answers to their questions other than through doctors and other health professionals, who are sometimes not as knowledgeable about the condition as the patients themselves.

From the number of stories accessible on the Internet, it is clear that the technology has been of great utility to this sample of people with COPD. They are motivated to post their stories for a number of reasons, amongst which are the wish to reach out to other people with COPD to share experiences, and to break down isolation. Given the number of people with COPD, there are likely to be many more who do not have access to the Internet or are not aware of the sites, and thus are unable to reap the benefits which have been described. Therefore, a recommendation of this study would be to encourage authorities to alert patients to the availability of these and other sites, to provide Internet access where it is lacking, and encourage Internet use, particularly amongst people with COPD who are older, or immobile, and thus isolated in their homes.

When people post stories to the Internet, or report on the sorts of information, questions, and concerns they are seeking to address, the topics cover all aspects of daily life, not just issues about their COPD or other conditions. In the chat rooms and message lists much of the information and material discussed concerns visits to medical and health professionals, issues about different medications including cost and availability, hints and pitfalls of travel with supplementary oxygen, and personal experiences of various surgical procedures. Many people do not make frequent postings, but will occasionally send a message to say that they are very grateful for all the information which other people provide, and reporting that they visit the site frequently.

Many people wrote about how they adapted their activities of daily living to remain functioning successfully in their homes. People also spoke about the support received from their spouses and other family members or unrelated carers. People who live alone spoke of the issues of living without a carer, particularly in terms of self-care such as preparing meals, and doing laundry and other household chores, especially referring to the need to pace themselves to conserve energy. Concern was shown by many people at their increasing dependence on others, in particular for such things as driving and activities outside the home, such as shopping and attending social occasions.

In a sense, because of the method of data collection, there may be questions about fragmentation of the data, with no possibility of recourse to reengage the authors to clarify issues of meaning or context. However, it must be remembered that the number of quotes which I was able to include was limited by the length of the thesis, and for each quote included, there were many more from different authors which satisfactorily corroborated the sentiments, and the conclusions drawn, of these decontextualised single quotes. Additionally, in each quote where it was possible to do so, I have indicated an age, or gender, or other additional information, to supply some demographic information to allow the reader at least some minimal context for a particular quote, and to allow some inferred comparison between quotes.

This collection of stories indicates that, despite having a disabling condition, people with COPD can demonstrate successful actions which adjust the landscape of their living, and the realities of living with a disability, to maintain a good quality of life and to be as resilient and resourceful for as long as possible.

I anticipate that in the future there will be opportunities to report my findings to the various Lung Foundations, Thoracic Societies and Departments of Health, to enable them to better serve their clients, thereby providing a strengthening of the voice of people with COPD, and consequently leading to an improved quality of life for the greatest number of people with COPD. I believe that through being a health activist and reaching out to people offering them support and access to education and other resources, thus making a difference one person at a time, changes can be made which have a multiplier effect in increasing activism and mobilizing new social movements to the benefit of all in society.

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