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Living with COPD through the eyes of veterans and their spouses residing in Ontario

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A thesis submitted in partial fulfillment of the requirements for the Master of Health Information Science degree in Health Information Science

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ABSTRACT

Chronic Obstructive Pulmonary Disease (COPD) is characterized by the progressive decline of lung function. Despite being twice more likely to develop COPD, very little focus has been placed on understanding the impact of this disease on veterans and/or their spouses who have it. The aim of this hermeneutical phenomenological study was to understand the lived experiences of Canadian veterans and/or their spouses with COPD. In addition to their knowledge and experience with the information and services provided to them. Thematic analysis of semi-structured interviews were used to reveal themes. The themes included: I don't feel so good; having to stop and rest; we're walking a marathon; they had good services; and ignorance is bliss when it comes to being informed. This study provides insight on the impact of COPD as well as the experience of the participants with information and healthcare services available. The implications for practice are also discussed.

Keywords: COPD, Canadian, veterans, spouses of veterans, services, information, hermeneutic phenomenology

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Falenderoj Zotin që më dha fuqinë e duhur për të mbaruar!

DEDICATION

To the best teachers anyone can hope for, my parents.

You are the strongest, most loving people I know.

Everything I am is because of you.

To my brother, who reminds me of the joys in life.

May your spark never die

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1. INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is a chronic, debilitating, progressive disease that affects lung function. Individuals who have COPD display symptoms such as coughing, wheezing, and shortness of breath (National Institutes of Health, 2013). Most cases of this disease are attributed to smoking (Criner et al., 2015). COPD often limits the health quality of life, daily functions, and activities of those who are diagnosed with it (Guthrie, Hill & Muers, 2001). As it mostly affects older persons, COPD is expected to become the third leading cause of death by 2020 (O'Donnell et al., 2008). The increase in medical and technological advancements, along with improvements in living conditions and public health have led to greater longevity worldwide (United Nations, 2015). This is resulting in an increase in the number of older persons (60 years of age and older) in the global population (United Nations, 2015).

Military veterans have a higher risk of developing COPD compared to the general population, in part due to their combat experiences and the uptake of risky personal health behaviours such as smoking (Murphy, Chaudhry, Almoose & Panos, 2011). There is little to no evidence in the literature focusing on the lived experiences of Canadian veterans with COPD. Additionally, little to no research explores the experiences of veterans' spouses with this disease. Veterans' spouses with COPD may have been exposed to second-hand smoke from, or, have adopted their partners' health behaviour. There is a large gap not only in knowledge but also lack of voice and representation for military veterans and/or their spouses with this disease. With the increase in the number of older persons in the population, it is important to understand and gain more insight into the experiences of individuals diagnosed with COPD, especially veterans and/or their spouses.

1.1 Background and Significance

COPD is often neglected by individuals until it has reached a critical state because it is commonly misconceived as non-life threatening (American Lung Association, 2008). The World Health Organization has estimated that approximately 80 million people around the world currently have been diagnosed with COPD (Godtfredsen et al., 2008). In 2013, the Centers for Disease Control and Prevention (CDC) reported that approximately 15.7 million adults in the

United States have been diagnosed with this disease (Wheaton, Cunningham, Ford & Croft, 2015, p.289). According to the CDC, the prevalence of COPD ranged from 2.6% among those aged 18-34 years to 12.3% among those aged 75 years and above (Wheaton et al., 2015, p.290). In the United States, the CDC found that women were 6.6% more likely to report having COPD than men (Wheaton et al., 2015, p.290). Only 5.4% of men in the United States reported having COPD (Wheaton et al., 2015, p 290). In the United Kingdom, COPD is the fifth leading cause of death and is responsible for approximately 30,000 deaths every year (National Institute for Clinical Excellence, 2004, pp. 24-25). According to the National Institute for Clinical Excellence (2004, p.24), 90% of the deaths that are caused by COPD occur in those who are over 65 years of age.

Currently the fourth leading cause of death in Canada, 4.4 % of the population aged 35 years and older have been diagnosed with COPD (O'Donnell et al., 2008; Public Health Agency of Canada, 2012). Consistent with international and national trends, COPD also affects the Ontarian population. In Ontario, between the years 2002-2011, a total of 722,494 individuals were diagnosed (Crighton, Ragetlie, Luo & Gershon, 2015, p.12). During the same time period approximately 31,842 Ontario residents died of COPD. For both men and women, the age group with the greatest prevalence are those 65 years of age and older. For this age group the prevalence rate was 249.1 per 1000 men and 202.2 per 1000 women (Crighton et al., 2015, p.14). It is predicted that by 2041 the number of Ontarians with COPD will grow to 1.2 million, which will account for 6.9 % of the population (The Lung Association Ontario, 2011, p.11).

COPD significantly affects the quality of life of the individuals who have it, often infringing on their lifestyle. Individuals diagnosed with this disease feel restricted in their recreational, professional, and daily activities (Kuprys- Lipinska & Kuna, 2014). The ability to continue working becomes increasingly difficult, and many are forced to discontinue their careers (Seamark, Blake, Seamark & Halpin, 2004; Hernandez, Balter, Bourbeau & Hodder, 2009). Feeling restricted, those with COPD often have no choice but to cease doing their favorite recreational activities such as sports, as it exerts them (Kuprys- Lipinska & Kuna, 2014). In addition, many individuals have reported being restricted in their ability to complete household chores resulting in becoming increasingly dependent on their spouse (Seamark et al., 2004; Guthrie et al., 2001).

The inability to contribute to the household, often leaves those with COPD experiencing feelings of being a nuisance, or the decrease of their role within the family (Kuprys- Lipinska & Kuna, 2014). Similarly, some individuals with COPD, do not feel as if they belong in, or are a part of, 'the world of the healthy' (Halding & Heggdal, 2011). This detachment often brings on feelings of isolation, loneliness, stigmatization, and rejection (Guthrie et al., 2001; Halding & Heggdal, 2011). Experiencing feelings of judgment, and fear of distressing others, many individuals do not participate in previously attended activities, and events such as family functions, or shopping, further isolating themselves from the world (Guthrie et al., 2001; Kuprys- Lipinska & Kuna, 2014)

One of the subpopulations affected most by COPD are veterans. Due to the lack of research reported on Canadian veterans, the researcher was unable to compare Canadian rates of COPD with those of Canadian veterans. Consequently, most of the information was acquired from American studies. Sharafkhaneh et al. (2010) found that an estimated 1 in 10 individuals in the Southeastern United States, utilizing the healthcare services provided by Veterans Affairs have COPD. The high prevalence of COPD found among veterans puts a substantial economic burden on the healthcare system. Sharafkhaneh et al. (2010) identified that compared to veterans who did not have COPD, veterans who did, had a significantly higher number of physician encounters, emergency room visits, acute inpatient discharges, and total bed days of care. The total healthcare costs due to respiratory-related problems were approximately 10 times higher in veterans with COPD compared to those without this disease (Sharafkhaneh et al., 2010). The total healthcare costs for veterans with COPD were estimated to be \$676.68 per individual, during the second year of utilization of the services. While the total healthcare costs for veterans without COPD were approximately \$68.50 per individual, during the second year of utilization of the services. (Sharafkhaneh et al., 2010).

Darnell, Dwivedi, Weng and Panos (2013) found similar results, as they examined the total healthcare costs for the 2008 fiscal year, of veterans using the services of the Cincinnati Veterans Affairs Medical Center (VAMC). The authors found that the total annual healthcare costs of COPD related care were \$6546 per individual. It was also found that hospitalizations accounted for 87% of the total COPD related costs, and were the greatest contributors to these costs (Darnell et al., 2013). Approximately, 3263 individuals were diagnosed with and received care

for COPD at the Cincinnati VAMC during the 2008 fiscal year. These individuals, had an estimated 10,032 clinic visits, 505 emergency department visits, and 1,332 hospitalizations (Darnell et al., 2013). The total COPD-related healthcare costs were approximately \$2.4 million for clinic visits, \$0.21 million for emergency department visits, and \$18.7 million for hospitalization (Darnell et al., 2013).

The increase in the number of older persons in the population puts pressure on the healthcare system, by demanding an increase for care and services to prevent and treat COPD (United Nations, 2015). COPD is a leading cause of healthcare utilization in Canada, contributing to the increase of economic costs (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015; Global Initiative for Chronic Obstructive Lung Disease, 2015). The annual direct costs related to COPD in Canada are \$1997.34 per individual (Chapman, Bourbeau & Rance, 2003, p. s28). Most of these costs are attributed to primary and secondary care visits, treatments, and diagnostic tests (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015). In the United States, the direct costs of providing health care for individuals diagnosed with COPD are estimated to be \$29.5 billion (Global Initiative for Chronic Obstructive Lung Disease, 2015, p.3). In 2000, the total annual cost of COPD to the UK National Health Service was approximately £492 million (National Institute for Clinical Excellence, 2004, p.27). In the European Union, the direct costs are estimated to be 38.6 billion Euros annually (Global Initiative for Chronic Obstructive Lung Disease, 2015, p.3).

The indirect cost of COPD, due to individuals not being able to work because of their disease, in Canada is approximately \$1198.18 per individual (Chapman et al., 2003), while in the US these costs are \$20.4 billion (Global Initiative for Chronic Obstructive Lung Disease, 2015, p.3). Additionally, the indirect costs to the UK National Health Service, for the year 2000 were £982 million (National Institute for Clinical Excellence, 2004, p.27).

The societal cost of COPD, which is the total cost of the disease to society, is calculated by combining the direct and indirect costs of COPD per individual (Pettinger, 2013). In Canada, these societal costs are approximated to be \$3195.52 per individual (Chapman et al., 2003, p. s27). In 2010, the total annual cost of COPD in the US was approximately \$50 billion (Guarascio, Ray, Finch, & Self, 2013).

Meeting similar trends, in 2011, the direct and indirect costs of COPD in Ontario were approximately \$3.9 billion (The Lung Association Ontario, 2011, p.5). It's predicted that by 2041, 1 in 11 workers in Ontario above the age of 55 will suffer from COPD. This in return will have an impact of \$138.4 billion, in indirect costs (The Lung Association Ontario, 2011, p.11). In the next 30 years the total expected economic burden of COPD in Ontario will be \$310.7 billion (The Lung Association Ontario, 2011, p.11). As the prevalence rate of COPD increases, the burden imposed on the healthcare system, as well as the economy, is predicted to undergo similar growth.

1.2 Study Purpose

The purpose of this study was to examine the lived experiences of Canadian veterans, and/or their spouses, who have been diagnosed with COPD. Specifically, the experiences of Canadian veterans, and/or their spouses who are 65+ years of age, current or former smokers, who reside in Ontario, will be studied. This study will also seek to gain a better understanding of the knowledge and experiences of the participants with the information, services, and strategies provided to them for coping with and managing their COPD. The research questions for this study are as follows:

- 1) What are the lived experiences of veterans and/or the spouses of veterans, residing in Ontario diagnosed with COPD?
- 2) What are the experiences of veterans and/or their spouses, residing in Ontario diagnosed with COPD regarding the information and services available to them?

1.3 Thesis Outline

Following this chapter this study will focus on: the current literature, methodology and methods, results and discussion. The literature review will explore the clinical aspects of COPD, the management strategies in place to help cope, the type of information provided to those with this disease, as well as the lived experiences of veterans and/or their spouses who are diagnosed with it. The methodology and methods chapter will present the philosophical underpinnings and theoretical framework used to guide this study, as well as the steps taken to conduct it. The

results convey the findings of this study. The discussion will focus on the contributions and limitations, in addition to providing recommendations for future research.

2. LITERATURE REVIEW

This chapter will review the literature on the causes, symptoms, and diagnosis of COPD, the various strategies recommended to manage this condition, as well as the information available to individuals diagnosed with this disease. In addition, this section will also review published phenomenological studies on lived experiences of individuals with chronic conditions, including COPD.

2.1 Disease definition

COPD is defined as “a respiratory disorder characterized by progressive, partially reversible airflow obstruction and lung hyperinflation, systematic manifestation and increasing frequency and severity of exacerbations” (O'Donnell et al., 2008, p. 2 Global Initiative for Chronic Obstructive Lung Disease, 2015). COPD is an umbrella term that encompasses many conditions including chronic bronchitis and emphysema (National Institute for Clinical Excellence, 2004).

Chronic bronchitis and emphysema both interfere with normal breathing by causing obstruction to the airflow (American Lung Association, 2008). Airflow obstruction is defined as a FEV1/FVC ratio less than 0.7 (70%). “FEV1 is Forced Expiratory Volume in 1 second and FVC is Forced Vital Capacity” (National Institute for Clinical Excellence, 2004, p.22). Obstruction of airflow occurs due to the collapse of the bronchial tubes during exhalation, preventing the lungs from expelling the air (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015).

Chronic bronchitis is the presence of a cough and the production of mucus for a minimum of three months during two consecutive years (International Association of Fire Fighters, 2010). Due to the inflammation of the airways of those with chronic bronchitis, the production of extra mucus occurs (International Association of Fire Fighters, 2010). Airway obstruction occurs in chronic bronchitis because the extra mucus and the inflammation cause the breathing tubes to narrow (International Association of Fire Fighters, 2010). This prevents the air from reaching the air alveoli and the lungs to fully empty (O'Donnell et al., 2008).

Emphysema is defined by the permanent enlargement of the air sacs at the end of the branching airways and the destruction of their walls. Healthy lungs are elastic and have an

inherent stretchiness and springiness (Global Initiative for Chronic Obstructive Lung Disease, 2015). In emphysema, the lungs lose their elasticity and as a result, it becomes harder to empty the air out of them. This results in them containing more air than usual and producing hyperinflation or ‘air trapping’ (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015; Qaseem et al., 2007; International Association of Fire Fighters, 2010). In contrast to chronic bronchitis, individuals with emphysema can experience airflow limitation without experiencing coughing or mucus production (International Association of Fire Fighters, 2010).

Exacerbations are acute events that occur during the natural course of the disease where there is an increase in the individual’s coughing, dyspnea (labored breathing), and/or sputum that is beyond the normal day-to-day variation for the individual (Rodriguez-Roisin, 2000). The severity of exacerbations is dependent on the outcome that it produces. Mild exacerbations are defined as the presence of clinical symptoms with no change in treatment (Criner et al., 2015). Moderate exacerbations are defined as a change in clinical symptoms that results in a change in medical treatments, while severe exacerbations result in hospitalization (Jones & Higenbottam, 2007). Exacerbations are responsible for frequent hospitalization, relapses, and hospital readmissions (Matkovic et al., 2012). Exacerbations account for the majority of the morbidity and mortality costs associated with COPD (Miravittles, Garcia-Polo, Domenech, Villegas, Conget & de la Roza, 2013). Regardless of the impact of exacerbations, not much is understood about their cause, prevention and treatment (Criner et al., 2015).

2.2 Causes of COPD

Exposure to indoor and outdoor air pollutants have been linked to increasing the risk of developing COPD (Global Initiative for Chronic Obstructive Lung Disease, 2015). In urban areas, outdoor air pollution has been found to be a major public health problem. This is primarily due to the large amounts of emissions from motor vehicles and industrial plants (Ko & Hui, 2012). Schikowski et al. (2005) investigated the influence of long term exposure to air pollutants on respiratory symptoms and pulmonary function amongst women 55 years of age. The authors found that women who lived near a major road and were exposed to nitrogen dioxide (NO₂) and particle matter 10 (PM₁₀) due to motor vehicle emissions, were at an increased risk of developing COPD (Schikowski et al., 2005).

However, in less developed areas, indoor air pollution is a more important risk factor. The use of wood, animal dung, coal, crop residues that are burned in open fires or poorly functioning stoves may lead to very high levels of indoor air pollutants (Global Initiative for Chronic Obstructive Lung Disease, 2015). Globally, approximately 3 billion people use biomass fuels and coal as their main source of energy (World Health Organization, 2016). In these less developed communities, indoor air pollution is the biggest risk factor for developing COPD, bypassing smoking and outdoor air pollution. The high prevalence of COPD in non-smoking women in parts of the Middle East, Africa and Asia, is due to the usage of biomass fuels for cooking (World Health Organization, 2016).

More than 1.1 billion people are smokers and the use of tobacco products is increasing worldwide (World Health Organization, 2015). Smoking has been identified as the cause of the majority of the COPD cases, making it the greatest risk factor (National Institute for Clinical Excellence, 2004). Cigarette smoking is thought to be responsible for approximately 85%-90% of the diagnosed COPD cases (Doherty et al., 2006). Smokers have a higher chance of experiencing respiratory symptoms and abnormalities in lung function, greater decreased rate of FEV1 and a greater COPD mortality rate. Smokers are 12 to 13 times more likely to die of COPD than non-smokers (American Lung Association, 2008). The risk for developing COPD among smokers depends on the total number of packs smoked, the age the individual started smoking, and current smoking status (Godtfredsen et al., 2008; O'Donnell, 2008). Lundbäck et al. (2003) identified that 50% of smokers eventually develop COPD.

Exposure to second-hand smoke is also an important risk factor to consider for developing COPD (Eisner, 2009). Second-hand smoke greatly affects the lungs. According to Eisner (2009) an hour of exposure can cause an acute decline in lung function. Although, second-hand smoke causes lung damage to non-smokers, it is unclear as to whether second-hand smoke can cause further lung damage to those who already have COPD (International Association of Fire Fighters, 2010). As smoking is the predominant factor for developing COPD, this study is focusing on smokers and former smokers.

Occupational exposures to organic and inorganic dust and chemical fumes are also known risks for developing COPD (Centers for Disease Control and Prevention, 2012). Exposures to organic and inorganic dust and chemical fumes are seen in miners of coal and hard rock, tunnel

workers, and workers manufacturing concrete (Wise & Tashkin, 2007; Centers for Disease Control and Prevention, 2012). Individuals who work in industries such as rubber, plastics, and leather manufacturing; utilities; building services; textile manufacturing; and construction are also at a higher risk of developing COPD due to the organic and inorganic matter that they are exposed to while working. Additionally, firefighters have an increased risk of developing this disease because of their occupation (International Association of Fire Fighters, 2010). For firefighters, exposure to dust and chemical fumes occurs during fire suppression, as well as during overhaul when the self-contained breathing apparatus (SCBA) is less likely to be used. During overhauls, firefighters open up walls, ceilings, voids, and partitions to check for fire extensions in order to reduce the damage caused by the fire (Sheridan, 2011). Approximately, 10-20 % of individuals in the United States have developed COPD due to their occupation (International Association of Fire Fighters, 2010).

Veteran Affairs in the United States provides care for approximately 500,000 veterans with COPD on a yearly basis, making this disease the cause for the most discharge among military personnel (Sharafkhaneh et al., 2010). A study conducted at Boise Veterans Affairs Medical Center found that males who were over the age of 65 with a history of smoking had the highest prevalence of COPD (Thompson & St-Hilaire, 2010). Matthews, Abraham, Zacher & Morris (2014) found that there was no evidence of increased rates of COPD diagnoses post-deployment. These results were supported by the Gulf War study conducted by Karlinsky and colleagues (2004). The authors evaluated whether deployment resulted in long-term adverse respiratory effects for veterans of the Gulf War. They found that deployment did not result in an increased prevalence of pulmonary abnormalities 10 years later (Karlinsky et al., 2004). However, due to COPD being one of the most common and costly chronic conditions among veterans (Sherman, Lanton, Nield & Yano, 2003), it is important to conduct further studies examining this subpopulation, and in particular Canadian veterans with COPD.

Other causes include having a childhood history of respiratory infections, and hereditary Alpha-1- antitrypsin deficiency (Alpha-1) (Global Initiative for Chronic Obstructive Lung Disease, 2015). Alpha-1 is a genetic defect of the protein alpha -1 antitrypsin (AAT) or alpha-1 protease inhibitor (American Lung Association, 2008, National Institutes of Health, 2016). AAT is responsible for repairing the lungs from injury caused by other destructive proteins and

enzymes such as the neutrophil elastase (National Institutes of Health, 2016). Neutrophil elastase fights infection, however, if it is not controlled by the AAT it will damage normal lung tissue (National Institutes of Health, 2016). When AAT is missing, an imbalance between injury and repair occurs in the lungs (American Lung Association, 2008). The absence of AAT, which is produced by the liver and dubbed the “lung protector”, greatly increases the risk of developing emphysema (American Lung Association, 2008). Symptoms for emphysema may never develop for some individuals, especially those who are non-smokers. For smokers however, symptoms usually develop between the ages of 32 and 41 (American Lung Association, 2008).

2.3 Symptoms and progression

There are various stages of COPD: mild, moderate, severe and very severe (Qaseem, 2007). Mild COPD is classified as having an FEV1 \geq 80% predicted, moderate as having an FEV1 50% to <79% predicted, severe as having an FEV1 30% to 49% predicted and very severe as having a FEV1 < 30% or FEV1 < 50% predicted plus chronic respiratory failure (Global Initiative for Chronic Obstructive Lung Disease, 2015; Wise & Tashkin, 2007; Qaseem et al., 2007, O’Donnell, 2008).

COPD is a diverse disease often affecting individuals in different ways. In the early stages of the disease, very few symptoms such as chronic cough and sputum production may be present (National Institute for Clinical Excellence, 2004). The most common symptoms of mild COPD include dyspnea, and/or chronic cough with or without sputum production. However, during this stage of the disease, individuals with COPD are often unaware that there is something wrong with their lung function (Chee & Sin, 2008). Those who suffer from moderate COPD usually experience shortness of breath, mild exacerbation, coughing, and sputum production. It is usually during this stage that individuals seek medical help (International Association of Fire Fighters, 2010). The defining clinical symptom for severe COPD is difficult and labored breathing, known as dyspnea; fatigue; weight loss; malnutrition; reduced exercise capacity; and frequent exacerbations (Niewoehner, 2010; Kessler et al., 2011). Individuals who have been diagnosed with very severe COPD often experience chronic respiratory failure (International Association of Fire Fighters, 2010). Respiratory failure is defined by hypoxia, which is a low level of oxygen in the lungs. Aside from the aforementioned symptoms, individuals who have COPD may also

develop swollen ankles; cyanotic or bluish discoloration of the lips and nails; wheezing or high pitched noises; and rhonchi or lower raspy noises (National Institute for Clinical Excellence, 2004; National Institutes of Health, 2013; Kessler et al., 2011).

Given that COPD develops in long-time smokers in older age, individuals often have a variety of other diseases that are related to either smoking or aging (Sarkar, Bhardwaj, Madabhavi & Khatana, 2015). Related comorbidities of COPD include coronary heart disease, lung cancer, diabetes, depression and anxiety, and osteoporosis (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015; O'Donnell, 2008; Sarkar et al., 2015). A strong epidemiological link exists between COPD and coronary heart disease, as they both share the same main risk factor of smoking (Schneider, Bothner, Jisck & Meier, 2010; Cazzola, Bettoncelli, Sessa, Cricelli & Biscione, 2010). Schneider et al. (2010) found that cardiovascular diseases were more prevalent among COPD individuals. Symptoms of chronic bronchitis increase the risk of death due to a coronary event by 50%. It has also been found that for every 10% decrease in FEV1, the frequency of coronary events increases by 20% (Cavaillès et al., 2013).

Several studies have found a strong link between lung cancer and COPD. Those who have COPD have a higher risk of developing lung cancer (Raviv, Hawksins, Decamp & Kalhan, 2011). The prevalence of COPD ranges between 40% and 70% among lung cancer patients (Cavaillès et al., 2013). Individuals who suffer from both COPD and lung cancer have been found to have a very poor prognosis (Raviv et al., 2011). The 3- year survival rate in individuals who have COPD and lung cancer is 15%, while for those who only have lung cancer without COPD is 26% (Cavaillès et al., 2013). Similarly, Papi et al. (2004) found that COPD increased the risk of squamous cell carcinoma of the lungs in individuals with surgically removed non-small cell lung cancers.

Another common comorbidity of COPD is type 2 diabetes. The presence of COPD has been shown to increase the risk of developing diabetes. The prevalence of diabetes in COPD individuals varies between 2- 37 % (Rogliani, Luca & Lauro, 2015). In a study conducted by Cazzola et al. (2010) reported an increase in diabetes among those who had COPD. Suggesting, that the inflammation of the airways somehow contributes to the pathophysiology of diabetes.

Anxiety and depression are two common disorders among individuals who have this disease. A strong link exists between anxiety and dyspnea, and depression is more frequent in individuals with COPD than in any other chronic diseases (Cavaillès et al., 2013). The first hospital admission due to COPD occurs sooner in those individuals who suffer from anxiety and/or depression, compared to those who do not have anxiety and/or depression. One suggested reason for this is because it is believed that dyspnea is experienced more intensely and earlier in those who have anxiety or depression. It is estimated that depression affects approximately 20% to 60% of individuals with COPD (Cavaillès et al., 2013).

As the number of older persons increases, the prevalence of bone disorders such as osteoporosis also increases. Osteoporosis is a bone disorder that leads to bone fragility and an increase risk of bone fracture (Sarkar et al., 2015). Individuals with COPD find doing physical activity increasingly difficult as their disease progresses, and as a result become inactive. Consequently, there is an increase in the risk of vertebral fractures (Cavaillès et al., 2013). As the number of vertebral fractures increases, the total lung capacity of the individual becomes progressively reduced (Cavaillès et al., 2013) further exacerbating their COPD. Cazzola et al. (2010) found that women with COPD were most at risk of developing osteoporosis in comparison to men, or women without it. Similarly, Sarkar et al. (2015) reported on osteoporosis being a significant comorbidity for individuals with COPD.

2.4 Diagnosis

Individuals who have COPD are typically not diagnosed until they are in their fifties (National Institute for Clinical Excellence, 2004). However, a diagnosis of COPD could be appropriate for individuals over 35 years of age, with the presence of a risk factor (generally smoking), and signs of breathlessness, chronic cough, regular sputum production, frequent winter "bronchitis", or wheezing (National Institute for Clinical Excellence, 2004). It is important to note, that occasionally, individuals may be asymptomatic making diagnosis difficult (Chee & Sin, 2008; O'Donnell et al., 2008).

Airflow obstruction is a key indicator of COPD. Spirometry is currently the only method that can accurately measure airflow obstruction (Zieliński, Bednarek & Know the Age of Your Lung Study Group, 2001; Collins, Feemster, Rinne & Au, 2015). Spirometry operates by recording the

amount and rate of air that is inhaled and exhaled by the individual over a specified period of time (American Lung Association, 2008). Although the test can be used to determine diagnosis, it is unable to differentiate asthma from COPD or predict the quality of life and disability in patients with COPD (National Institute for Clinical Excellence, 2004).

Additional tests and measurements that could be used to support a diagnosis of COPD include bronchodilator reversibility testing, chest X-ray, arterial blood gas measurement and alpha-1-antitrypsin deficiency screening (American Lung Association, 2008). Chest X-ray testing is usually used to exclude any other respiratory disease/disorder such as pulmonary fibrosis, bronchiectasis, pleural diseases, tuberculosis, and diffuse pan bronchiolitis (National Health Services, 2016; Global Initiative for Chronic Obstructive Lung Disease, 2015). Arterial blood gas measurement is used to measure the levels of oxygen and carbon dioxide in the blood (Verma & Roach, 2010). Alpha-1- antitrypsin deficiency screening is used to test for the genetic disorder AAT. This screening is usually administered when individuals who are younger than 45 years of age present signs of COPD and emphysema (American Lung Association, 2008). Alpha-1- antitrypsin deficiency screening is also administered to those individuals who have a family history of COPD and AAT, and have never smoked but have signs of this disease (American Lung Association, 2008). Bronchodilator reversibility testing is used to differentiate between asthma and mild COPD (Calverley, Burge, Spencer, Anderson & Jones, 2003). An absent bronchodilator response is also used to determine the stage of COPD and the appropriate treatment (Calverley et al., 2003).

If COPD is diagnosed in the early stages of the disease, it can be partially reversible (Doherty et al., 2006). However, most individuals overlook the early signs and symptoms and consequently, COPD often goes underdiagnosed (Doherty et al., 2006; Health Quality Ontario & Ministry of Health and Long- Term Care, 2015). Individuals often do not seek medical care until they suffer from dyspnea or labored breathing (Doherty et al., 2006). Despite multiple interventions such as spirometry, COPD under-diagnosis still remains a big problem in many areas of the world (Lamprecht et al., 2015). To prevent further damage to their lungs, it is essential that individuals in the early stages of the disease be evaluated using spirometry so that the initiation of effective treatment can occur (Doherty et al., 2006).

Although rare, inappropriate diagnosing of COPD has occurred due to a diagnosis being made solely based on an individual's medical history and physical examination that is not confirmed by spirometry (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015; Lamprecht et al., 2015).

2.5 Management

2.5.1 *Pharmaceutical Treatments*

Given that COPD is incurable, numerous treatments and management strategies are recommended by both the national *Canadian Thoracic Society Clinical Practice Guidelines* and the international guideline, *Global Initiative for Chronic Obstructive Lung Disease (GOLD)*, to aid individuals in coping and managing COPD. Several pharmacological measures are used as a method to help reduce symptoms, improve health status, and reduce the severity and frequency of exacerbations (American Lung Association, 2008). The administration of each pharmacological measure has to be individual specific, as people present different symptoms, exacerbation severity, and airflow limitation (Global Initiative for Chronic Obstructive Lung Disease, 2015).

Smoking is the number one risk factor for COPD. Therefore, treatments for smoking cessation are essential for slowing down the progression of this disease (Godtfredsen et al., 2008). Nicotine replacement products such as varenicline, bupropion, and nortriptyline increase the long term rate of smoking cessation and should be used as an element in a supportive intervention program (Cahill, Stevens, Perera & Lancaster, 2013). Other recommended strategies that have shown to be effective in helping smoking cessation include intervention programs as well as counseling delivered by either physicians or other healthcare professionals (Global Initiative for Chronic Obstructive Lung Disease, 2015). For a smoking cessation intervention program to be successful it has to contain the behavioral, physiological, and psychological consequences of smoking; recognize prior unsuccessful attempts at quitting; and target high-risk smokers (Criner et al., 2015).

Bronchodilators are pharmaceutical interventions that help reduce symptoms and increase FEV1 by opening the airways in the lungs (Criner et al., 2015; Doherty et al., 2006; American Lung Association, 2008). Bronchodilators are given on an as needed basis or on a regular basis

depending on the severity of COPD. Beta₂-agonists (short acting and long acting) and anticholinergics are examples of bronchodilators used by individuals who have COPD (Chee & Sin, 2008). Beta₂- agonists have been found to improve FEV1 and symptoms among patients with COPD often leading to a decrease in hospitalization and a reduced number of patients requiring treatments for exacerbation. Some side effects of this medication include resting tachycardia or rapid heart rate, and the potential of arrhythmia in susceptible individuals (Global Initiative for Chronic Obstructive Lung Disease, 2015). Despite this, the *American College of Chest Physicians* and the *Canadian Thoracic Society Guideline* recommend the use of long-acting Beta₂- agonists in patients with moderate to severe COPD to prevent acute moderate to severe exacerbations (Criner et al., 2015).

The anticholinergic, Tiotropium, has been associated with a reduction in the severity of exacerbations and related hospitalizations in patients with COPD and an increase in lung function (Halpin, Decramer, Celli, Kesten, Liu & Tashkin, 2012). This pharmacologic treatment has also improved symptoms and patient health status. The main side effects of this medication is dryness of the mouth, increased risk of glaucoma, and urinary retention (Hanania & Donohue, 2007). When comparing Beta₂- agonists monotherapy and short-acting muscarinic antagonist (anticholinergic) monotherapy, the *American College of Chest Physicians* and the *Canadian Thoracic Society Guideline* recommend the usage of short-acting muscarinic antagonist monotherapy for individuals who have moderate to severe COPD, in order to prevent mild to moderate acute exacerbations (Criner et al., 2015). However, it has been recommended that the use of short acting Beta₂- agonists together with short-acting muscarinic antagonist (anticholinergic) is far more effective in preventing acute moderate exacerbations than the usage of short acting Beta₂- agonists alone (Criner et al., 2015; Chee & Sin, 2008). When it comes to reducing symptoms and improving FEV1, the usage of these two drugs in combination is far more effective than using either drug alone (Global Initiative for Chronic Obstructive Lung Disease, 2015).

Corticosteroids are another type of pharmaceuticals used to manage COPD. Inhaled corticosteroids improve symptoms and lung function, as well as reduce the severity of exacerbations in individuals with moderate to severe COPD (Gartlehner, Hansen Carson & Lohr, 2006). However, inhaled corticosteroids are associated with a high risk of side effects such as the

onset of oral candidiasis, hoarse voice, burning skin, and an increased risk of pneumonia (Global Initiative for Chronic Obstructive Lung Disease, 2015). For reducing exacerbations and improving lung function in individuals with moderate to very severe COPD, inhaled corticosteroids are often used in combination with bronchodilators (Cazzola & Dahl, 2004). For individuals who experience an acute exacerbation of COPD in either an outpatient or inpatient setting, systemic corticosteroids administered either orally or intravenously should be provided. This is in order to prevent the occurrence of subsequent episodes of exacerbation, in the first 30 days following the initial exacerbation but not going beyond (Criner et al., 2015).

Phosphodiesterase-4- inhibitors such as Roflumilast, have been used for individuals suffering from moderate to severe COPD, with chronic bronchitis, and who have a history of at least one exacerbation in the previous year (Wedzicha, Calverley & Rabe, 2016). Roflumilast has been found to reduce moderate and severe exacerbations by 20% in people who have chronic bronchitis, severe and very severe COPD (Wedzicha et al., 2013). The side effects of Phosphodiesterase-4- inhibitors have been shown to be more harmful than any inhaled medication for COPD. These side effects include nausea, reduced appetite, abdominal pain, diarrhea, sleep disturbances, and headaches (Global Initiative for Chronic Obstructive Lung Disease, 2015).

Although the evidence for the prevention of acute exacerbation through the usage of vaccines is contradictory, many guidelines recommend that COPD patients receive the influenza vaccine (Criner et al., 2015). In some cases, the administration of the influenza vaccine to COPD patients has led to the reduction in serious illness and death (O'Donnell et al., 2008). For patients who are 65 years of age or older and are suffering from COPD, the pneumococcal polysaccharide vaccine is recommended (Global Initiative for Chronic Obstructive Lung Disease, 2015).

2.5.2 Non-pharmaceutical treatments

Non- pharmaceutical measures for treating COPD include pulmonary rehabilitation, non-invasive ventilation (NIV), oxygen therapy, lung volume reduction surgery, bronchoscopic lung volume reduction and lung transplantation (Global Initiative for Chronic Obstructive Lung Disease, 2015). Pulmonary rehabilitation is a multidisciplinary program that is considered the standard of care for individuals who continue to exhibit COPD symptoms despite receiving

bronchodilators (Health Quality Ontario & Ministry of Health and Long- Term Care, 2015; O'Donnell et al., 2008). Its primary goals consist of reducing symptoms, improving quality of life and increasing the physical and emotional participation of COPD patients in their everyday activities (American Lung Association, 2008). Pulmonary rehabilitation consists of exercise training, smoking cessation programs, patient education including general information on COPD, self-management skills, ways of approaching therapy, information pertaining to medical treatment and strategies to reduce dyspnea, as well as nutritional support (Ries et al., 2007; Qaseem et al., 2007). Pulmonary rehabilitation has been found to be effective in reducing the frequency of hospitalization, intensity of breathlessness, and COPD related anxiety and depression (Global Initiative for Chronic Obstructive Lung Disease, 2015). For people with moderate, severe, or very severe COPD who experienced a recent exacerbation (within 4 weeks), the *American College of Chest Physicians* and the *Canadian Thoracic Society Guideline* recommends the usage of pulmonary rehabilitation to prevent the recurrence of acute exacerbations (Criner et al., 2015). In Ontario, pulmonary rehabilitation can only be provided to less than 2% of all COPD individuals (including stable, moderate-to severe, or post-exacerbation) who require this program (Bowen et al., 2015). One reason for the lack of available pulmonary rehabilitation programs is attributed to the rapid increase of Canadians who have been diagnosed with COPD in the recent years (Camp et al., 2015). Given the increase in COPD cases, the number of currently available programs is unable to meet the demand of the individuals needs. In addition, despite the various sources that fund pulmonary rehabilitation programs, it has been reported that seventy-five percent of programs identified only a single funding source (Camp et al., 2015). Currently, only a very small number of individuals have access to these programs and are being helped. Although there has been an increase in pulmonary rehabilitation programs in Ontario since 2005 (43 in 2015 vs. 21 in 2005), continual efforts need to occur to improve access to these programs for all individuals who have COPD (Bowen et al., 2015).

Bronchoscopic lung volume reduction (BLVR) is used for patients suffering from severe COPD (Global Initiative for Chronic Obstructive Lung Disease, 2015). It is currently unclear what the long-term benefits of BLVR are in COPD patients. The studies that have examined the long-term benefits for patients with COPD who have had BLVR provide contradictory results

(Ingenito, Wood & Utz, 2008). BLVR modestly improves lung function and exercise tolerance at the expense of an increase in exacerbation frequency (Global Initiative for Chronic Obstructive Lung Disease, 2015).

Lung Volume Reduction Surgery (LVRS) is another form of treatment used whereby some of the most severely damaged lung tissue are removed (American Lung Association, 2008). This is done to reduce hyperinflation and to ease the burden on the remaining tissues and chest muscles (American Lung Association, 2008).

It is recommended that for individuals with COPD suffering from hypoxemia, abnormally low levels of oxygen in the blood, oxygen therapy should be administered (O'Donnell et al., 2008; Qaseem et al., 2007). Oxygen therapy can be administered for long periods of time during the day and night (long term oxygen therapy), as ambulatory oxygen, or as short bursts to relieve symptoms of COPD (National Institute for Clinical Excellence, 2004). Ambulatory oxygen refers to the use of oxygen therapy during exercise or activities of daily living (Bradley & O'Neill, 2005). Ambulatory oxygen is used as either part of long term oxygen therapy, or on its own. Uncontrolled usage of oxygen therapy can result in carbon dioxide narcosis, and respiratory arrest (National Institute for Clinical Excellence, 2004). Treatment options have to be tailored to individual patients due to the diversity of COPD, and as such, some options may be less effective for some patients but show greater effectiveness for others.

2.5.3 *Self-management*

An important aspect of managing COPD is self-management. According to the *Chronic Care Model* (Wortz et al., 2012), self-management is the term used to describe the approach for optimizing outcomes and recognizing that the majority of the effort for managing a chronic disease falls to the patient. Although the term “self-management” implies self-care, this is rarely the case, as self-management always includes a partnership with a healthcare professional (Effing et al., 2012). The aim of self-management programs and interventions is to help individuals with COPD gain new skills to carry out disease specific medical regimens, guide changes in health behavior and provide emotional support to assist patients in controlling their disease (Zwerink et al., 2014). Self-care is the term used to describe the skills that patients with COPD need to obtain in order to adhere to treatment regimens and change their health-related

behaviors (Wang, Sung, Yang, Chiang & Perng, 2012). Action plans are essential tools used in self-management (Quebec Asthma and COPD Network, 2013). According to Zwerink et al. (2014), an action plan has been defined as a guideline for participants that describes when and how to change medication when COPD symptoms worsen.

In order for self-management programs to work, they need to include educational and behavioral change dimensions as well as functional links with the healthcare system (Quebec Asthma and COPD Network, 2013). Ideally, self-management programs are trying to elicit behavioral changes, and this cannot happen without an individual having confidence in themselves (Zwerink et al., 2014; Davis, Carrieri-Kohlman, Janson, Gold & Stulbarg, 2006). Self-efficacy is a person's belief that they are able to control, organize, and execute actions within a given domain of functioning. Such actions are necessary to accomplish a goal that they believe to be important (Davis et al., 2006). Some important skills that patients need to acquire for successful self-management include problem solving, decision making, effectively utilizing resources, and forming a partnership with their healthcare provider (Zwerink et al., 2014). Mastering these skills, learning to interpret symptoms and social persuasion have been found to increase self-efficacy, which is important in helping patients manage their condition (Zwerink et al., 2014). To be effective, the education dimension of the programs has to include information about the cause of the disease, prevention and treatment of exacerbations and bronchial infections, and physiotherapy (Worth, 1997).

An example of a self-management program is *Living well with COPD*. This program was developed and delivered by the Montreal Chest Institute, which is a part of the McGill University Health Centre. To help patients manage their disease, *Living well with COPD*, includes a variety of modules that help guide patients into taking the correct actions. Such modules include: *Managing your breathing and saving energy; Understanding how breathing works, Reducing shortness of breath, Breathing techniques, Body positions; Preventing your symptoms and taking your medication; Integrating an action plan into your life* and more (Quebec Asthma and COPD Network, 2013). This program also offers information regarding COPD in the form of brochures. In addition, the information provided is geared towards helping healthcare professionals educate their patients about using self-management programs (Quebec Asthma and COPD Network, 2013). Reporting on the effectiveness and benefits, Cosgrove, MacMahon, Bourbeau, Bradley

and O'Neill (2013) found that there was an increase in knowledge, understanding and self-efficacy after individuals had completed the *Living Well with COPD* self-management program.

The effectiveness of self-management programs has been a recurring theme throughout the literature (Monninkhof et al., 2004; Gadoury et al., 2005; Sedeno, Nault, Hamd & Bourbeau, 2009). Monninkhof et al. (2004) conducted a study evaluating the effectiveness of a self-management education course and a fitness program for patients with COPD. Most patients were found to be pleased and happy with the fitness program, as it helped them increase their exercise capacity. Not only did the program aid in controlling their dyspnea, it also provided a social outlet, which was much needed for patients who lived alone. From the education program, patients learned to listen to their bodies and evenly distribute their energy (Monninkhof et al., 2004). Patients reported that their knowledge of COPD and controlling their symptoms increased throughout the education course. However, COPD related symptoms such as coughing and sputum production did not change for the majority of the participants (Monninkhof et al., 2004). Nonetheless, the program was successful in increasing the self-efficacy, disease specific confidence, coping behavior and self-determination among some of the participants. Similarly, Zwerink et al. (2014) and Sedeno, Nault, Hamd and Bourbeau (2009) found that self-management led to a lower probability of respiratory-related hospitalization. These results are also supported by Gadoury et al. (2005), where it was also found that self-management education can reduce hospitalization rates and emergency room visits among patients with moderate-to-severe COPD.

In order for self-management programs to be successful, they need to include an educational element as well as a physical fitness component specific for individuals with COPD (Monninkhof et al., 2004). Davis et al. (2006) concluded that enhancing self-efficacy is more complex than just providing support or supervisions with exercise or increasing numbers with exercise training session. Similarly, only educating and informing individuals about their disease will not get them to change their health behaviors (Carre et al., 2008; Simpson & Jones, 2013; Monninkhof et al., 2004). Furthermore, self-management programs need to be carefully designed and need to target patients who have the capacity to understand their symptoms and recognize any setbacks that might occur (Wedzicha & Vestbo, 2012). Self-management programs need to

be tailored to the needs of each individual in order to be successful and have a positive impact (Zwerink et al., 2014).

2.6 Personal Impact of Chronic Diseases

2.6.1 *Lived experience with Chronic diseases*

Being diagnosed with a chronic illness can be a life-altering event, which can produce both positive and negative feelings. Kralik (2002) examined the experiences of midlife women suffering from chronic illness, and found that despite it effecting the participants in different ways, receiving the diagnosis was described as a profound event in their lives. Some of the participants saw their illness as a new opportunity to become stronger. One mentions “it’s like a re-birth. All the knowledge you had about yourself, feelings, dreams etc. go through a rather shake-up. You are a new person, the illness has made you stronger in some respect” (p.151). Similarly, Oxlad, Wade, Hallsworth and Koczwara (2008) describe the positive attitudes that some of the participants had adopted after discovering they had breast cancer. For these individuals, their chronic illness, had provided them with an opportunity for self-transformation and growth. Statements such as “I found out that I’m capable of a whole lot more than I thought”, “well, I’ve learned to become, a , a stronger person, and also to, to learn to smell the roses”, and “I think I’m, I’m more um, um I’m kinder to myself” were noted by the participants (p. 162). Furthermore, Mårtensson, Dracup, Canary and Fridlund (2003) noted that the mental component in individuals who had chronic heart failure was not a major restriction in their overall health quality of life.

Rather, Mårtensson et al. (2003) found that physical limitations were attributed to having a poorer health quality of life, for those with chronic heart failure. Similarly, Oxlad et al. (2008) reported that amongst women who had breast cancer, one of the main struggles was having to cope with the low energy levels. This presented a major restriction in the daily lives of these participants. A few of them described the impact that their levels of low energy had by stating “you want to do what you could do before, but you tire”, “Yeah, energy level is pretty low”, and “I’m too tired or, it takes me a lot of time to get through what are basic things” (p. 161). Per Savio and Priyalatha (2014) after receiving their diagnosis participants felt a sense of

helplessness. This feeling was derived from the physical limitations brought on by the disease, as the participants were no longer able to partake in their favorite activities and had become dependent on others. This dependency also brought on feelings of being a burden to their family members and friends (Savio & Priyalatha, 2014).

Perceptions of being “damaged”, loss of familiar self (Kralik, 2002), and an altered sense of identity (Oxlad et al., 2003), were also noted throughout the literature. Statements that depicted this sense of altered identity included “My wig is long, so when I put it on it’s not me anymore”, “You’ve had two breasts all your life, now just to look at yourself, just with one, it’s actually a terrible feeling. I hate it” (Oxlad et al., 2003, p.161). Similarly, Kralik (2002) found that some participants were experiencing a loss of identity and thus, were in the process of grieving their old selves. “I still want to be the old me desperately, and yet I know I can’t. Trying to find the new me is hard...nothing is familiar, everything I knew about myself had changed” (p.149).

Gysels and Higginson (2011) conducted a study describing how participants of various chronic diseases experienced breathlessness. It was noted that those who suffered from cancer described breathlessness as frightening and appearing suddenly. It introduced a sense of panic among those individuals who typically do not experience this emotion. Contrasting, the participants who had COPD expressed that breathlessness was hardly noticeable and that it developed gradually. Similarly, participants who had heart failure, explained that breathlessness developed over time and it’s mostly described in terms of the physical limitations that it imposes, rather than the emotional impact. Similar, to the participants who had cancer, those with motor neurone disease (MND), described breathlessness as being sudden and thus experiences feelings of anxiety and fear. For these participants breathlessness appeared as a constant reminder that MND was a threat to their lives, defeating any attempt at preserving a sense of normality (Gysels & Higginson, 2011).

2.6.2 Lived experience with COPD

Living with COPD is a burden for the majority of patients, as their participation in daily activities and previous hobbies becomes increasingly limited. With the progression of the disease, many patients become socially isolated and rarely leave their home (Guthrie et al., 2001). A study conducted in the UK found that family played a major role in the quality of life of

individuals with severe COPD. Familial relationships affected the patients' quality of life in three broad ways: 1) maintaining a sense of identity; 2) practical help; and 3) the provision of warmth and psychological support. Patients with good relationships with their family were found to have a good quality of life, by being more independent in completing their daily activities, and being more social with friends and family (Guthrie et al., 2001).

These results are supported by Trivedi, Bryson, Udris and Au (2012), who similarly found that caregivers play an important role in ensuring that the individual with COPD adhered to the medical recommendations provided to them, especially smoking cessation. Individuals who had caregivers, either spousal or non-spousal, were less likely to be current smokers when compared to the no caregiver group (Trivedi et al., 2012). The investigators also found that when a spouse encouraged smoking cessation, a 67% decrease in a person's smoking was observed, and when a friend encouraged smoking cessation, a 36% decrease was observed (Trivedi et al., 2012). Positive social support from spouses, family members and friends has also been associated with providing a positive influence in increasing the physical activity levels among COPD-diagnosed individuals (Hartman, ten Hacken, Boezen & de Greed, 2013). Similarly, Ek and Ternstedt (2008) found that having a support system or sharing a connection with a spouse, family members or friends often made life meaningful and provided a sense of belonging for those with COPD.

Unfortunately, many individuals with COPD experience social isolation, feelings of loneliness, and meaninglessness. Despite wanting to maintain the relationship with their family and friends, participants often found themselves having difficulty with social relationships. In the Ek and Ternstedt (2008) study one of the participants claimed “there’s a lot you can’t do... a great deal, and much you have to give up...for example do I have the strength to go out now? No, I don’t have the strength to go out, and then I really wish I could and that makes me sad” (p. 474). Similarly another participant noted that “some of it is the medical aspect...(taking medicine, etc), but that’s the smallest part...the big problem is the social aspect...but no one takes that into account...the healthcare staff never ask about this...but it’s the social aspect that’s important” (Ek and Ternstedt, 2008, p. 475).

Furthermore, Ek and Ternstedt (2008) describe how mental stress, exhaustion, and anxiety often left participants feeling as if life had no meaning for them and made it difficult for

individuals to think about the future. Similar results can be found by Seamark et al. (2004) where feelings of loss with regards to the future and the dreams prior to COPD were experienced among the majority of participants. Statements such as "a complete loss of personal liberty and now I can't walk or do anything", " I can't remember the last time I went out" and " I have a job to undress myself or dress myself, I have to struggle to undress and dress for everything" have been expressed by the participants throughout the study (Seamark et al., 2004, p. 621). Caregivers express similar loss in quality of life to that of the patients. Unable to share the burden with others, most caregivers felt tied down due to the many responsibilities that they have had to undertake (Trivedi et al., 2012).

COPD has often been a source of shame or embarrassment for individuals. Hartman et al. (2013) found this particularly true amongst female participants. Feelings of embarrassment were also prevalent in the study conducted by Guthrie et al. (2001) where one of the participants' stated "you feel such a fool; people stare at you. It's a horrible feeling"(p. 198). These feelings often lead individuals with COPD to isolate themselves and cut off ties with their family and friends. Subsequently, most social contact is then transferred from face-to-face to telephone-based relationships (Seamark et al., 2004).

The inability to breathe can also bring on feelings of shame and embarrassment among most individuals with COPD. Barnett (2005) found that as COPD progressed it became increasingly difficult for the participants to do daily activities such as bathing, and getting dressed, without the assistance of others. This was mostly attributed to the lack of the ability to breathe. Statements such as "I get very upset when my husband helps me. I realize that there is nothing wrong with that, I just find it hard to accept" and "On a bad day I use babywipes to do my vital parts and get dressed" were seen throughout the study (Barnett, 2005, p. 809).

Furthermore, when breathlessness is especially difficult to manage, some individuals do not attempt to leave their bed (Barnett, 2005). Similarly, Ek and Ternstedt (2008) describe an instance of an embarrassing situation that one severely ill women who spent most of her energy towards breathing, and lacked the strength to eat and thus was provided with nutritional supplements through a tube, had experienced due to COPD. "I have one of those tubes in my stomach, and once it leaked and there was food all over the bed and on the floor. And I sat there in my bed in my sticky nightgown and they (the staff) came...it was so embarrassing, but for

them it was normal routine- just make the bed and clean up and wash me off a little...but then you feel really small” (p. 474).

A few of the studies examining the lived experience of those with COPD have found that when these individuals were unable to cope with the struggles of daily life brought on by their disease, they contemplated suicide. In her study, Barnett (2005) described the desire to “end the struggle to breathe” which had been expressed by several of the participants, who had undergone numerous “bad days” (p. 810). Similarly, Ek and Ternstedt (2008) noted that one woman had experienced suicidal thoughts many times, due to her COPD. “At times like this I feel...I only want to cry...and then I think...no, God, ugh!!...this is no fun and I don’t want to live any more... I have nothing to look forward to...I’ve had these thoughts many times” (p. 475). Chang, Dai, Chien and Chan (2016) found a fear of experiencing complications with the lack of oxygen and the outcome being hypoxia. One participant described the fears of experiencing hypoxia during an encounter with an exacerbation attack “I couldn’t breathe...it was just like my neck was squeezed...I was afraid that my heart might stop beating... I needed oxygen right away” (p. 468).

Environmental factors, such as the weather, have been shown to affect the quality of life and living experiences of those who have COPD. An association exists between the decrease in environmental temperatures and the increase in COPD exacerbations among patients. COPD patients often have increased exacerbations and a decline in their lung function during the winter or coldest periods of the year. This has been linked to an increase in winter mortality rates among COPD patients, as well as hospital admissions (Bakerly, Roberts, Thomson & Dyer, 2011). Individuals with this disease have noted that the weather is often described as a barrier that prevents them from going outside and participating in physical activities or pulmonary rehabilitation (Thorpe, Kumar & Johnston, 2014). The Hartman et al. (2013) study found similar results, where low physical activity levels and an increase in symptoms were reported among participants due to poor weather.

Transit systems and transportation can also act as a barrier to receiving services for individuals with COPD. Thorpe, Kumar and Johnston (2014) found that transport and parking were seen as major barriers when attending pulmonary rehabilitation. Often, the lack of availability of transport becomes overwhelming for COPD individuals (Keating, Lee & Holland,

2011). This is supported by Harris, Hayter and Allender (2008) where it was found that transportation was a common concern among the participants. Many patients are unable to travel independently due to the severity of their disease (Taylor, Dawson, Roberts, Sridhar & Partidge, 2007). This is especially true for those individuals on oxygen therapy which further limits their mobility. This often results in them becoming housebound and unable to drive or take public transit (Taylor et al., 2007; Fischer et al., 2007). Although transportation might not present a problem for some, the cost of parking fees or getting a taxi to access services, is a major barrier for others (Thorpe, Kumar & Johnston, 2014; Fischer et al., 2007). Many individuals with COPD refrain from using healthcare services due to the difficulties with public transport, parking, or the location of these services for being too far away (Keating, Lee & Holland, 2011; Taylor et al., 2007; Thorpe, Kumar & Johnston, 2014).

The majority of the studies presented have been conducted among the general population of individuals diagnosed with COPD. Very little literature focuses on the lived experiences and coping strategies of veterans and/or their spouses suffering from COPD, providing a large gap in knowledge regarding these subpopulations.

2.6.3 Veterans and spouses of veterans with COPD

Smoking is the greatest risk factor for COPD, with an estimated 80-90% of cases being attributed to cigarette smoking (Murphy et al., 2011). The risk is increased two-fold for veterans who work in the armed forces (Murphy et al., 2011; Panos, Krywkowski-Mohn, Sherman & Lach, 2013). This is partially due to the combat experiences and risky behaviors (i.e. smoking) that veterans often adopt. Panos et al. (2013) conducted a qualitative study exploring the veteran's perceptions about COPD and the effect it had on their health. The authors also looked at the veteran's healthcare needs to understand COPD from their perspective, and to inform development of a patient centered COPD management program. They queried the VHA Decision Support System for the names of all veterans with a diagnosis of COPD served at the Cincinnati VAMC. Similar to Seamark et al. (2004), the authors found that nearly all the participants noted the negative effects that the symptoms had on their daily lives and activities. One participant stated "I was a pretty active guy and now I get to coughing and it's like I can't get my breath at all. Like something shuts down my chest" (p.336). Another noted how they were very active but

since they developed COPD, their life had been halted “I been very active my whole life just about. Marines, I always played basketball, football, tennis, racket ball. I mean my quality of life [now] has dropped down to zero” (p.336).

Comparable to Hernandez et al. (2009), Panos et al. (2013) also found that the limitations and restrictions infringed upon the veterans due to COPD affected their relationship and interaction with their families and friends. This often led the participants to feel depressed and a reduction in self-worth and self-image. One of the participants expressed “I feel guilty ‘cuz I can’t do some of the housework” (p.338). Some of the participants remembered the days prior to developing COPD with fondness and nostalgia trying their best to persevere and maintain that sense of normality despite the breathing limitations. “I’ve adapted to this lifestyle. I’ve made myself overcome the problem. Adapt and overcome... That’s what I’ve done, that’s how I live” (p. 338). It was also found that many of the participants were confused between COPD, chronic bronchitis, emphysema and asthma. Many underestimated the severity of their disease by “toughing it out” when episodes of extreme breathlessness occurred. One of the participants stated “I tough it out...do the best I can. Sometimes it [breathlessness] scares the hell out of me, making me think I’m gonna suffocate” another said “I put mine [treatments] off as long as I can... well, the breathing attacks, I put mine off as long as I can” (p. 338).

Mulhall, Lach, Krzywkowski-Mohn, Welge and Panos (2013) sent out surveys to veterans with COPD who received care at the Cincinnati VAMC for the fiscal year 2008. Similar to Panos et al. (2013), the authors found that 89% of the veterans reported being limited in their daily activities due to difficulty breathing. Some of the limitations experienced by the participants included: recreational activities, work, household chores, as well as the need for increased assistance. In addition to the physical limitations, 22% of the veterans noted a change in the relationship that they had with their friends, while 12% noted a change in the relationship with their families. Comparable to Ek & Ternstedt (2008), Barnett (2005), and Seamark et al. (2004), Mulhall et al. (2013) found that most participants (77%), expressed negative feelings related to COPD. Approximately 42% of the veterans expressed feelings of depression, 40% felt helpless, 30% expressed fear, and 27% saw a reduction in self-worth. Contrasting Seamark et al. (2004) and Ek and Ternstedt (2008), 23% of the participants reported feeling no negative emotions.

This could perhaps be partially attributed to the culture of silence that many military personnel have had to adopt.

2.6.3.1 Veterans and the culture of silence

The majority of studies have focused on American veterans living with COPD, highlighting a big gap in the literature with regards to the lived experiences of Canadian veterans. It is important that further research focus on trying to understand the lived experiences of Canadian veterans with COPD, as there currently is an underrepresentation of this population in the literature. This study focuses on the experiences of Canadian veterans and/or spouses of Canadian veterans with COPD, contributing to the closing of the gap in the literature. An extensive literature search was conducted using online databases including Pubmed, University of Western Ontario Libraries, and Google Scholar, on the lived experiences of spouses of veterans with COPD. There was no evidence of studies that looked at the lived experiences of this subpopulation. This presents a huge gap in the literature and further research is needed in order to fully understand what it is like living with COPD from various perspectives. It is only by focusing future research on veterans and/or their spouses with COPD, and understanding the impact that this disease has on their lives, that the inconsistencies and gaps found in the literature can be addressed.

The lack of studies examining the lived experiences of veterans with COPD can be partially attributed to their culture of silence. As the defining feature of veterans is their past military service, most veterans are deeply influenced by their military culture (Harding, 2016). Among others, one of the things that is most valued by military culture is stoicism, or emotional restraint, as a result of which military personnel have had to adopt a warrior like mentality (Weiss, Coll & Metal, 2011; Petrovich, 2012; Hall, 2011; Meyer, 2015). Much like warriors, the military seeks to transform men and women into disciplined, mission-oriented individuals, who are able to confront challenges and face situations that present to be life-threatening and dangerous (Petrovich, 2012). Thus, they are taught to be self-sufficient, independent, and ignore any physical ‘warning signs’ (Higate, 2000a, as cited in Petrovich, 2012, p.870). In addition, most military personnel are taught to ‘soldier up’ and ‘get through tough times on their own’ (Dahn, 2008, as cited in Hall, 2011, p. 15).

Due to having to adopt this warrior like mentality, many veterans even after completing their service, see the importance of having to keep up appearances of stability and their ability to handle any challenges that they may encounter (Hall, 2011). Petrovich (2012) has found that veterans might even adopt a mindset where being emotionally vulnerable, and having to seek help, is keenly discouraged. Similarly, per Hall (2011), feelings of fear are actively denied and kept in secret by veterans, as this does not promote warrior like attitudes. However, the warrior like philosophy that many military personnel have adopted, has a major impact on the type of care that they seek and receive (Meyer, 2015). As self-reliance is valued in military culture, admitting and seeking help is often seen as a weakness (Harding, 2016), because it endorses a sense of helplessness (Meyer, 2015). It often becomes difficult for veterans to share their mental or physical pain brought on by a disease such as COPD (Australian Centre for Posttraumatic Mental Health, 2012; Petrovich, 2012). As such, some veterans prefer to stay silent and not disclose their struggles.

2.7 COPD and Health Information

Health information is essential in helping individuals with COPD not only to understand their diagnosis but also manage it. In order to receive the most appropriate type of information regarding their disease, it is important that individuals with COPD use their healthcare providers as the primary source of this information (Gardiner et al., 2009). Hernandez et al. (2009) identified that 60% of the participants received their information from healthcare professionals. Similarly, Guo, Huang and Hsu (2014) found that the majority of patients received their information primarily from physicians and nurses. However, throughout the literature, individuals with COPD reported seeking other avenues to obtain information about their condition. This comes as a result of feeling that healthcare professionals provide insufficient information on the function and use of spirometry, smoking cessation, as well as the impact and management of COPD (Disler et al., 2014; Guo, Huang & Hsu, 2014; Wilson, O'Neill, Reilly, MacMahon & Bradley, 2007; Rodgers, Dyas, Molyneux, Ward & Revill, 2007).

The majority of individuals with COPD use the Internet as a way of obtaining more information about their disease (Delgado, Gazzotti, Santoro, Caryalho, Jardim & Nascimento, 2015; Hernandez et al., 2009). Hernandez et al. (2009) identified that 49% of participants

reported using the Internet as their main method for attaining information about their COPD. In a study done in Sao Paulo, 58.5% of the participants reported that the Internet helped them with regards to obtaining more knowledge about their disease (Delgado et al., 2015). Although the Internet provides a quick and easy way to obtain information, it is difficult for users to determine which websites are accurate and which provide misleading information (Kunst & Khan, 2002). The risk with using the Internet as a primary source of information is the quality of the information that is given. This is due in part to the lack of the monitoring that occurs on certain websites (Kunst & Khan, 2002). In a study conducted by Delgado et al. (2015), 5% of the participants acknowledged that the information on the Internet about COPD was inaccurate and incorrect.

Additional sources of information included brochures or leaflets provided by secondary care, rehabilitation sessions and family members (Rogers et al., 2007). Hernandez et al. (2009) found that 23% of the participants used healthcare organizations, clinics and rehabilitation sessions as sources of information. Similarly, in a study conducted by Rodgers et al. (2007) the majority of participants used brochures and leaflets recommended by rehabilitation sessions they had attended. Nonetheless, not all individuals with COPD use healthcare brochures and pamphlets as their primary source of information. Some individuals use their own experiences or the experiences of peers, friends, family and acquaintances as sources (Hernandez et al., 2009; Earle, 2010).

Due to the lack of information provided to COPD patients from their healthcare providers, they often use other sources to gain a better understanding of their condition. Patients voice a clear need for more information in order to understand the medical aspect of COPD as well as the impact it will have on their lives. Parker, Goldman and Eaton (2008) identified that the majority of the participants had never heard of COPD prior to being presented with information about it. Only a few of the participants had heard of 'spirometry testing'; the majority stated that they had undergone a "breathing test". Even if they knew they had undergone a 'spirometry test', none of the participants knew what the numbers indicated, the reason they had it or what the results were. Parker et al. (2008) were surprised at how the majority of the participants lacked basic information about COPD other than knowing it was a lung disease that they were unable to name.

Similar results were found by Wilson, O'Neill, Reilly, MacMahon and Bradley (2007), where most of the participants were unclear about the etiology of COPD. Healthcare professionals seemed to agree that the majority of their patients have a poor understanding of their disease or the medications used (Wilson et al., 2007). Rodgers et al. (2007) found that the phrase "chronic obstructive pulmonary disease" had been unfamiliar to some patients prior to attending rehabilitation sessions, despite the fact that they were referred by a healthcare provider.

COPD is often confused with other respiratory diseases such as asthma (Gardiner et al., 2009). For these individuals, Gardiner et al. (2009) found that there was often confusion regarding the progressive nature of the condition, and uncertainty of the implication that COPD might have on the participants' lives. Disler et al. (2014) found similar results with participants stating: "At the beginning we weren't told that it was a general decline. We were just told this is what you've got, get on with it" (p. 1186). It had not been until they had gone to pulmonary rehabilitation that patients realized the seriousness of COPD: "In the pulmonary rehab, all of us found out for the first time that we were not going to cure or reverse emphysema.... My doctor had not said anything like that to me" (p.1186). Likewise, in the Gardiner et al. (2009) study, some participants expressed hope that the medication they were using would permanently stop any decline in lung function.

Across studies, participants have been found to lack the appropriate knowledge and information to help them understand, cope and manage their COPD. Individuals with this condition have been found to express a need and desire to learn more about their condition (Delgado et al., 2015; Hernandez et al., 2009; Wilson et al., 2007). Some studies have found that there is a shift between the patient's perception and the reality of the level of knowledge of COPD (Hernandez et al., 2009). Although most patients feel they are well informed, when actually tested on their knowledge of COPD it becomes clear that this is not the case for the majority of them (Hernandez et al., 2009). Wilson et al. (2007) found that the majority of patients with COPD would like to obtain information from knowledgeable individuals regardless of their professional background, with the condition that the information is explained in layman's terms. Similar findings have been noted by Rodgers et al. (2007), where patients expressed the need for brochures or leaflets to be written in a clear language and not be based on medical terminology.

Carre et al. (2008) conducted a study looking at whether knowledge and awareness of COPD could be increased if participants with, or, at risk of COPD were provided with a leaflet. The leaflet was written in plain language and was 500 words in length. There was an increase in knowledge among the participants from the baseline to the follow-up interview. At baseline, participants had poor knowledge regarding the causes, clinical signs, diagnostic procedures and treatments available. At their follow-up interview, three months after receiving the leaflet the participants had a significant improvement in all of these areas.

While patients need information about their disease, it is equally important that their family members receive the same information. According to Hernandez et al., (2009), 63% of the participants included in their study believed that educating the public about COPD was equally important and that it would decrease the stigma around it. Similar results were found in the study by Rodgers et al. (2007) where patients communicated the need for their family and friends to get more information about the disease and understand the terminology used in diagnosis.

In order to increase treatment adherence, improve disease management, and better symptom control among COPD patients, it is important that primary caregivers and healthcare professionals provide more information to patients (Delgado et al., 2015). It is evident across multiple studies that patients lack the necessary knowledge and information to help them understand their condition and manage it (Hernandez et al., 2009; Wilson et al., 2007; Rodgers, et al., 2007; Guo, Huang & Hsu, 2014; Gardiner et al., 2009). There is a gap between the information that healthcare professionals are providing, and the information that patients need. Due to this, many patients underestimate the severity of COPD, and are unable to cope or manage it, or seek other avenues for obtaining information (Delgado et al., 2015; Parker, Goldman & Eaton, 2008; Hernandez et al., 2009; Wilson et al., 2007; Gardiner et al., 2009). In many cases, the lack of information was a cause of great concern for the future among individuals with COPD (Gardiner et al., 2009; Disler et al., 2014).

While other sources, such as brochures or leaflets, the Internet, the media, and personal experiences, are available for patients, it is suggested that their healthcare provider be the primary source of information (Gardiner et al., 2009). This is primarily to overcome the issue of misleading information presented by some of these sources. Multiple studies show that patients are open to receiving more information about their condition, and this is especially true if it

comes from a healthcare professional (Hernandez et al., 2009; Rodgers et al., 2007). There is a gap in the literature regarding the role of information and patient education for COPD, and the management of this disease. To help improve the management of COPD among patients, it is essential that this gap in knowledge and information be addressed.

2.8 Health and support services in Ontario

In Ontario multiple self-management programs are offered to individuals who suffer from COPD. These programs provide emotional support, educational tools, and various coping strategies. *BreathWorks*, a program operated and delivered by the Lung Association, is a national COPD program that offers information and support for individuals with this disease and their families (The Lung Association, 2015). This program provides various educational tools on how to better manage COPD. Through readily available fact sheets those with COPD, are instructed on how to better control their breathing, their flare-ups, and manage their energy. In addition, they offer various resources that explain what COPD is, and how to access nearby pulmonary rehabilitation programs and educational centers (The Lung Association, 2015). For individuals who wish to maintain their anonymity, *BreathWorks* offers a free of charge, confidential telephone line, where all the questions regarding COPD can be answered by a certified Respiratory Educator. Support and counseling is provided to individuals with COPD and their families, through the *BreathWorks* Support Group. During these support groups the participants are free to discuss the impact and challenges of COPD in a safe and comfortable environment.

The COLD program at St. Joseph's Hospital in London, Ontario provides counseling and educational resources for individuals suffering from COPD (St. Joseph's Health Care London, 2014). Certified Chronic Respiratory Educators, help individuals with COPD and their families gain a better understanding of their disease by providing knowledge and education on it . Similarly, the COPD education program delivered at Rouge Valley Ajax and Pickering hospital campus helps individuals cope with their COPD on a daily basis. Led by a registered practical nurse with expertise in treating patients with COPD, the classes that are offered include various coping strategies to help manage COPD on a day-to-day basis (Rouge Valley Health System, 2016).

The Veterans Independence Program delivered by Veterans Affairs Canada, helps veterans remain self-sufficient and independent. This program offers multiple services including ground

maintenance such as snow removal, housekeeping, and transportation if veterans are unable to participate in social activities due to their disability (Veterans Affairs Canada, 2016). In addition, personal care services such as bathing, dressing, and eating; and access to nutrition via Meals on Wheels, are offered to veterans who are unable to participate in daily functions. Access is granted only if a need for these services is identified through the assessment process. To be eligible veterans have to meet one of the following criteria: qualified for a disability benefit; qualified for the War Veterans Allowance; recipient of Prisoner of War Compensation; veterans who are eligible for, but unable to access, a Contract Bed (Priority Access Bed); the primary caregiver for an eligible Veteran or civilian; or low-income or disabled survivor of an eligible Veteran or civilian (Veterans Affairs Canada, 2016). In order to receive a disability benefit a veteran has to have a diagnosed medical condition and be able to show that the condition or disability is related to service. War Veterans Allowance are provided to low-income veterans or their families. The allowance is calculated based on income (Veterans Affairs Canada, 2016). Nevertheless, the services provided on this program are delivered on an as needed basis.

2.9 Study Rationale and Objectives

The number of individuals with COPD in recent years has risen, and with the predicted increase in the number of older persons, these numbers are predicted to grow (O'Donnell et al., 2008). Despite the various health services, initiatives and strategies present to assist with the coping and management of COPD, very little focus has been placed on gaining an understanding of the lived experiences of individuals with this disease. Additionally, there appears to be a further gap in understanding the lived experiences of veterans and/or their spouses with COPD. Given that individuals who are 65 years of age and older (Crighton et al., 2015), and veterans (Murphy et al., 2011) are most at risk for developing COPD, it is important that further research be conducted in order to provide these individuals with a voice and learn of their experiences with this disease and the services provided to them. It is only by understanding the daily barriers that these individuals face, their general knowledge of their illness and the awareness of the services provided to them, that we will then be able to identify where the research gaps lie and propose and recommend effective and efficient strategies. The proposed study will aim to address this gap in knowledge by attempting to understand the lived experiences of under-

represented groups such as veterans and/or their spouses with COPD. This study will also aim to address the current gap in health information by trying to understand the knowledge and experiences of the participants with the services, information and strategies provided to them for coping with and managing their COPD.

2.10 Conclusion

The status of COPD has risen considerably in recent years, making it currently the fourth leading cause of death. Eighty to ninety percent of the cases of COPD are due to smoking, however other factors also include being exposed to indoor and outdoor pollutants, occupational hazard, and genetics. Military personnel are twice more likely to develop this disease due to their environment and risky behaviors such as smoking. Numerous pharmaceutical and non-pharmaceutical strategies are in place to help individuals manage and cope. However, the knowledge and understanding about this disease is seriously lacking among the majority of those who have it. The majority of the information is obtained through their primary healthcare provider, and is not sufficient. Although, there is a lot of information in the literature regarding the lived experiences of individuals who have COPD, there is very little research on the lived experiences of Canadian veterans and/or their spouses with this disease. A major gap also exists in trying to understand the experiences that veterans and/or their spouses have with the information that is provided to them regarding COPD, the services, and strategies used to help manage it.

3. METHODOLOGY

This chapter describes the methodology and methods used in conducting this study. This chapter begins with an overview of the paradigm and qualitative methodology used. It then provides a summary of phenomenology as an inquiry, the theoretical framework, data collection, and data analysis used in the study. This chapter also includes the quality criteria used to evaluate this study as well as my pre-understandings and suppositions.

3.1 Paradigm stance

Paradigmatically, this study is within the constructivist-interpretivist paradigm. Researchers that locate themselves within this paradigm seek to understand the lived experiences of individuals, while respecting the unique perspectives of these individuals (Carpenter & Suto, 2008). The main goal of this paradigm is to understand how individuals interpret or make meaning of social phenomena (Carpenter & Suto, 2008).

Ontologically, people who identify with this paradigm tend to fall more on the relativist spectrum, thus believing in multiple realities (Guba & Lincoln, 1994; Kafle, 2013). In this study there is the belief that there is no one over arching "truth" that exists, but rather individuals make their own reality, which is subject to change as they become more informed (Lavery, 200).

Epistemologically, this paradigm is subjective, as it believes that there is a relationship between the knower and the known (Guba & Lincoln, 1994; Lavery, 200; Kafle, 2013). Knowledge is believed to be created through the interaction between participants and researchers (Guba & Lincoln, 1994).

Methodologically, the primary aim is to understand and reconstruct experiences and knowledge (Lavery, 200). The values and beliefs of the researcher are seen as being important and therefore, are incorporated in the study (Guba & Lincoln, 1994). Contrasting the paradigms where the researcher is encouraged to be objective and cast aside their values and beliefs, this paradigm stance encourages the researcher to make their values and beliefs explicit (Guba & Lincoln, 1994).

3.2 Phenomenology

3.2.1 *Phenomenology*

Phenomenology is the study of the lived experience (van Manen, 2014). Phenomenological research is founded in the philosophical literature (Kafle, 2013). The underpinnings of phenomenology are informed by hermeneutics and interpretivism (Carpenter & Suto, 2008). There are two main types of phenomenology: interpretive and descriptive (Carpenter & Suto, 2008).

As a philosophy, phenomenology was initially developed by Edmund Husserl and Martin Heidegger (Heidegger, 1996; Husserl, 2012). Often known as the father of phenomenology, Husserl studied phenomena as they appeared through consciousness (Husserl, 2012). The structures of consciousness are described as essences, which make an experience unique from others and help view the phenomenon for what it really is (Lavery, 2003; Husserl, 2012). For Husserl, access to the structures of consciousness was not a matter of generalization, rather the key to understanding a phenomenon (Lavery, 2003).

Husserl focused primarily on epistemological questions of knowing with experience being the fundamental source of knowledge (Koch, 1995). Referred to as transcendental phenomenology, according to Husserl, the goal of this approach was to be rigorous and unbiased (Flood, 2010). For this to be achieved, Husserl created phenomenological reduction where the researcher had to strip away and put aside (bracket) all the social and cultural contexts, and pre-suppositions that they had in an attempt to encounter the phenomenon as free and as unprejudiced as possible (Speziale, Streubert & Carpenter, 2011). Husserl's phenomenology is also known as descriptive phenomenology due to the rich descriptions of the phenomenon that are produced in his works (Dowling, 2007).

Heidegger, is known as the father of interpretive phenomenology (Dowling, 2007). Focusing more on existential- ontological questions, Heidegger, explored how individuals came to understand a phenomenon (Koch, 1995). Similar to Husserl, Heidegger deemed that the primary concern of phenomenology was studying human experience as it were lived (Smythe, Ironside, Sims, Swensons & Spence, 2008). For Heidegger, 'pre-understandings' or 'fore-conceptions' are used to describe the meaning and organization of a culture. According to Heidegger, these 'fore-

conceptions' include practices such as language; that already exist in the world before we begin to understand (Koch, 1995). Therefore, Heidegger believed that the researcher cannot just bracket or disregard their background, values and beliefs, and as such should make these "pre-understandings" known (Koch, 1995; Smythe et al., 2008).

The research method shouldn't be purely descriptive but rather hermeneutic (interpretive) in nature (Speziale et al., 2011). The researcher needs to become aware and account for their "pre-understandings" and interpretive influences (Smythe et al., 2008). For this to occur, Heidegger created the hermeneutical circle to demonstrate that understanding was a reciprocal activity (Dowling, 2007). In the hermeneutical circle, the researcher tries to understand the lived experiences first by examining their own pre-understandings, and then, moving back and forth between the parts and the whole of the experience (Earle, 2010; Crist & Tanner, 2003).

A student of Heidegger, Gadamer based his philosophical assumptions primarily on Heidegger's work despite being influenced by both Heidegger and Husserl (Lavery, 2003). Similar to Heidegger, Gadamer believed that language and understanding were essential structural aspects of human "being-in-the world" (Lavery, 2003). Unlike Heidegger, Gadamer tried to seek out how understanding became possible (Dobrosavljev, 2002). At the center of Gadamerian philosophy existed the notion of the "fusing of horizons" whereby there was the potential to generate shared meaning between partners in dialogue (Sammel, 2003; Dobrosavljev, 2002; Dowling, 2007). Our pre-understandings or prejudices enter into any dialogical situation with us, as they are anchored in our social and individual histories therefore, the idea of bracketing becomes impossible (Sammel, 2003; Fleming, Gaidys & Robb, 2003).

However unlike Heidegger, Gadamer believed that there was no hidden, or fixed meaning in the text that was waiting to be discovered by the reader (Sammel, 2003). Rather, the goal was to explore new opportunities that can produce new meanings based on the dialogue between the text/reader and speaker/listener (Sammel, 2003). Understanding is created by the interplay between the speakers, or text and reader in a concrete situation (Dobrosavljev, 2002). Therefore, hermeneutic phenomenology became less about creating a procedure of understanding and more about clarifying the conditions in which understanding takes place (Sammel, 2003).

3.2.2 *Phenomenology as a methodology (van Manen)*

van Manen distinguishes between phenomenology as a philosophy and phenomenology as a social science endeavor (Kafle, 2013). For van Manen, hermeneutical phenomenology became less philosophical and more methodological, as it sought to transform, inform, and reform the relationship between being and practice (Sloan & Bowe, 2014).

Hermeneutical phenomenology as developed by van Manen combines both Husserl's descriptive phenomenology as well as Heidegger's interpretive phenomenology (Dowling, 2007). According to van Manen, hermeneutical phenomenology is about discovering the world of individuals or groups as they experience it through their life stories (Kafle, 2013). It seeks to understand and construct a possible interpretation of the nature of a human experience through the use of rich, textual descriptions of the phenomenon (Kafle, 2013). Similar to Heidegger, van Manen did not believe that our pre-supposition, values and beliefs are able to be bracketed and as a result, it is important that they are being explicitly stated (Dowling, 2007; Earle, 2010). van Manen believed that by trying to forget what we already know, the preunderstandings might resurface into the researcher's reflections (Earle, 2010). van Manen's approach to hermeneutical phenomenology followed the philosophical underpinnings of both Husserl and Heidegger (van Manen, 2014).

According to van Manen one of the most important features of phenomenology is wonder (2003). Wonder is viewed as inducing the reader's interest in wanting to know more about a certain phenomenon and trying to further understand it. In order for a phenomenological text to lead the reader to human understanding it must first lead the reader to wonder. Important questions to ask are "how an individual sees things", "what is important in their world" and "how do they interact with their environment" (van Manen, 2003, p.62).

Another important feature that defines hermeneutical phenomenology, are the "lived experiences". Lived experience is a methodological notion, the main goal of which is to provide insight into the meanings of phenomena in people's lives (van Manen, 2014). For van Manen, phenomenology as an inquiry involves both interpretive and descriptive elements and for that reason, it is often referred to as interpretive-descriptive phenomenology (van Manen, 2014).

3.2.3 *Why hermeneutical phenomenology*

As an approach, phenomenology aims to study the reality and world of others as they experience it (van Manen, 1984). Hermeneutic phenomenology focuses specifically on the lived experiences of individuals and the influence these experiences have on the decisions they make (Flood, 2010). Through detailed descriptions, this study sought to understand the experiences of Canadian veterans and/or their spouses living with COPD. It additionally aimed to understand the participants' experiences with the information and services provided to them. Given that this study focused on the lived experiences of the participants through rich and detailed descriptions, hermeneutic phenomenology informed by van Manen (1984) is thought to be the most applicable methodology for this thesis study (Flood, 2010).

Hermeneutic phenomenology seeks to acquire insightful descriptions of the way people experience the world (van Manen, 1984). Through rich descriptions, it allows the researcher to come to a deeper understanding of the meanings that participants put on their everyday lived experiences (van Manen, 1984; van Manen, 2014). "Since our everyday lived experience is so taken for granted as to go unnoticed, it is often through breakdowns that the researcher achieves flashes of insight into the lived world" (Leonard, 1989, p.52). Given that this study tries to understand the lived experiences and impact of COPD, ensuring that an emphasis is placed on the day-to-day activities and life of the participants is important.

In keeping with van Manen's (2014) hermeneutical phenomenology the researcher came in with pre-understandings of COPD and its impact on individuals' lives prior to conducting the study. The thematic analysis set out by van Manen (2014) allowed the researcher to interpret the participants' experiences in a detailed manner, in addition to understanding the implications for practice. Contrasting Husserl (2012) and Heidegger (1996) which focus on philosophical reflections, van Manen's methodological approach to phenomenology seeks to inform practice (Sloan and Bowe, 2014). The insights gained through this study can have various implications for health practices, by raising awareness of the needs of Canadian veterans and/or their spouses with COPD.

3.2.4 Key concepts in hermeneutical phenomenology

van Manen (2014) developed various quality criteria to evaluate hermeneutical studies. These criteria include: heuristic questioning, descriptive richness, interpretive depth, distinctive rigor, strong and addressive meaning, experiential awakening, and inceptual epiphany.

Heuristic questioning: A good phenomenological study induces the sense of wonder in the reader. It makes them question what the experience is like. In addition, a well written phenomenological text is supposed to question attentiveness. It is supposed to invoke *ti estin* the wonder of “what this is” and *hoti estin* the wonder that something exists at all (van Manen, 2014, p. 355).

Descriptive richness: A phenomenological study and text is supposed to contain rich material that provides deep insight and understanding into the world and lived experiences of individuals (van Manen, 2014).

Interpretive depth- A well written phenomenological text entices the reader and draws them in, much like a piece of art or poetry (van Manen, 2007). The quality of a phenomenological study is judged by its ability to provide the reader with a deeper understanding of the world of others through the discoveries of the researcher (Finlay, n.d). Thus, for the interpretive depth criteria, van Manen (2014, p. 356) poses the question “does the text offer reflective insights that go beyond the taken-for-granted understandings of everyday life?”

Distinctive rigor- In a phenomenological study rigor is maintained by ensuring that the text reflects the meaning of the phenomenon (van Manen, 2014).

Strong and addressive meaning- A good phenomenological text has the ability to speak out to the readers by reaching and addressing their sense of being. A well written text has reached strong and addressive meaning when it generates a sense of reality for its readers (van Manen, 2014)

Experiential awakening- Through the use of vocative and presentative language, a phenomenological text is supposed to awaken a pre-reflective experience in the readers. In other words, the reader is able to recognize the phenomena through either own experiences or by imagining the situation (Finlay, n.d).

Inceptual epiphany- Phenomenology does not offer theories, nor does it provide explanations (van Manen, 2003). The purpose of phenomenology is to provide us with insights and a deeper understanding in the world of others.

3.3 Theoretical Framework

A unique aspect of phenomenology is that it does not use theory as a way to interpret findings or explain phenomena. However, phenomenologists are able to use theory when theory aids in providing a deeper understanding of a human phenomenon (van Manen, 2014). While many researchers studying COPD are familiar with the GOLD framework, due to it not being a theoretical framework rather a medical guideline, I have chosen to use the *Individual and Family Self-Management Theory*. This is a descriptive, self-management, theory developed by Ryan and Sawin (2009) for individuals suffering from chronic diseases. In this theory self-management is viewed as a complex phenomenon that consists of three dimensions: context, process, and outcomes.

One aim of this study was to gain a better understanding of the knowledge and experiences of the participants with the services, information, and strategies provided to them for coping with and managing their COPD. The following theory provides insight into the complex phenomenon of self-management and granted an understanding of the experiences of managing COPD. From the *Individual and Family Self-Management Theory* it is important to understand that all three dimensions (context, process, and outcomes) are interlinked and that they all influence and are influenced by one another. Ultimately, influencing how an individual experience, copes, and manages their chronic disease, i.e COPD.

The context dimension is characterized by the risk and protective factors that affect self-management. This includes factors such a physiological, functional or structural characteristics of the disease, and the treatment or prevention that might affect the behaviors needed for self-management. Environmental factors, transportation, access to healthcare and information, living and work conditions can also influence behaviors of self-management and lived experiences of those with COPD.

The process dimension provides insight into how the information the participants of this study receive can influence the way they approach managing COPD. People are more likely to engage in the recommended self-management behaviors if they have sufficient information. This

is especially true if the information that is provided is consistent with the individuals' health beliefs.

The last dimension discussed in this theory is outcome. Proximal or short-term outcomes include engaging in self-management behaviours that are specific to a health condition, or risk, in addition to managing the symptoms of the disease. Proximal outcomes include but are not limited to matters such as the cost associated with achieving the care needed to manage chronic diseases, like COPD. Conversely, distal or long-term outcomes are related to the successful achievement of proximal outcome which include quality of life with a chronic disease such as COPD, health status and direct and indirect cost of health.

3.4 Methods

3.4.1 Qualitative Research

The qualitative approach is best fitted within the goals of this study. This approach primarily focuses on exploring and understanding the meaning individuals and groups assign to social and human problems (Carpenter & Suto, 2008). It is only by using this approach that in-depth knowledge and insight regarding the daily experiences of the participants and their level of awareness of the information and services provided can be achieved; thus answering the research questions sufficiently.

3.4.2 Study Sample and recruitment

Purposeful sampling was conducted as it is consistent with phenomenology and most suited for this type of research (Wright- St. Clair, 2014; Creswell, 2012; van Manen, 2014). Purposeful sampling seeks to identify individuals who are able to provide rich accounts of the phenomenon of interest, due to their experiences with the phenomenon (Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood, 2015; Wright- St. Clair, 2014). The literature usually recommends a sample size of 10 participants (Creswell, 2012), however due to the complex nature of the population, only 2 veteran spouses with COPD, 3 veterans with COPD, and 3 veteran spouses without COPD were included in this study.

This study specifically targeted veterans and/or their spouses, who have been diagnosed with COPD. Veteran spouses who did not have COPD also provided their input regarding the lived experiences of their partner with COPD. Although this was not the primary intent of this study, their insight into the lives of the participants who had COPD provided a deeper meaning and understanding regarding what it is like to live with this disease. For the purpose of this study, the demographic information of the spouses without COPD was not taken. However, the input provided during the interviews was analyzed and utilized as data.

Recruitment of the participants occurred in the branches of the Royal Canadian Legion and other Veterans Services Clubs, including the Royal Canadian Air Force Association; Army, Navy, Air Force Veterans in Canada; Army, Navy, Air Force Veterans; HMCS Prevost; Veterans Affairs Canada; and Naval Club of Toronto; at Seniors Clubs; and the Lung Association. Recruitment was achieved through advertisements at relevant stores, i.e. pharmacies, health supply stores and on community noticeboards. To ensure participant diversity, which is important for providing a deeper understanding of the phenomenon (van Manen, 2014), both male and female auxiliaries, as well as veterans of different military ranks were included in the study.

Gatekeepers are defined as the initial contact of the researcher, who often introduce the researcher to the potential participants (Creswell, 2012). The gatekeepers for this study were representatives from each of the organisations outlined above. They were contacted via email, telephone, or face-to-face interaction. The gatekeepers were provided with a research outline (Appendix A) developed by the researcher that discussed the purpose of the study. After acquiring their permission to attend held meetings or events, the study was introduced to the veterans and/or their spouses, and individuals were then invited to participate. A recruitment poster (Appendix E) was also presented and posted in the identified organisations with information about the research study and the researcher. Alongside the recruitment poster (Appendix E), a sign-up sheet (Appendix F) was provided to each Legion branch, Veterans Services Club, Seniors Clubs and Lung Association. This allowed interested members who were unable to contact the researcher to participate in the study. The individuals provided their name and phone number or email. During the first meeting, the interested individuals were provided with more details about the study, and given a letter of information and consent letter (Appendix

B) and asked to fill out their demographic information (Appendix C or Appendix D). A meeting was organized in the location and time of their choice, for the conduction of the interviews.

The inclusion criteria included: Canadian veteran or spouse of a Canadian veteran residing in Ontario, 65 + years of age, current or former smokers, with a COPD diagnosis (including chronic bronchitis or emphysema) and English-speaking. Individuals who did not fulfill these criteria were not eligible to participate. Due to limitations in resources, only individuals who were able to communicate in fluent English were asked to participate, as it is not appropriate to misinterpret individuals' experiences due to language barriers.

3.4.3 Data Collection

The primary method of data collection was in-depth, semi-structured interviews however reflexive journaling detailing observations was also taken throughout the study. The semi-structured interviews not only helped to uncover a rich and deep understanding of a particular phenomenon, but also created a dialogue between the participant and the researcher about the meaning of this phenomenon (Earle, 2010). To ensure that the participants felt comfortable the interviews were conducted at a location of their choice.

An interview guide, with open-ended questions was developed and used to help facilitate the interview process (Appendix G and Appendix H). During the interviews, the participants were asked to give an in-depth description of their day-to-day activities and experiences with COPD. Participants were also asked about their experiences with the healthcare services and information provided to them, and were allowed to share as much information as they wished. The following questions guided the interview: 1) What is it like living with COPD? 2) What are your experiences with the health services you receive to help you manage your COPD? 3) How have the health services that you use provided you with information about COPD? During the interview process, verbal probes were used, to encourage the participants to provide more detailed descriptions of their initial answers to gain a better understanding of their experiences. With the approval of the participants, all interviews were audio-recorded and subsequently transcribed verbatim to ensure accuracy.

Reflexive journaling was taken throughout the study detailing the researcher's biases, beliefs, and pre-suppositions, as well as any unexpected turns or challenges that occurred, to ensure honesty and transparency (Tracy, 2010). For example, in the beginning of the study I wrote my

thoughts on phenomenology, the paradigm stance, as well as the study topic. Throughout the study, I noted the changes that had occurred, obstacles, and reflected on the information that I had gathered, and the influence it would have on my interpretation of the data.

3.5 Data analysis

Data analysis began and continued concurrently with the data collection process, ensuring consistency with the phenomenological methodology (van Manen, 2014). As the hermeneutic phenomenological data analysis process is inductive and iterative, the strategies of immersion and crystallization were carried out (Wright-St. Clair, 2014; Crabtree & Miller, 1999). A major requirement of immersion is "listening deeply" to the participants, taken field notes and data itself (Crabtree & Miller, 1999). In this study immersion was performed by listening to the audio files, and reading the transcripts and field notes repeatedly, until familiarization occurred. Once familiarization had occurred, the data were then reviewed for general themes. During the crystallization process, patterns and themes between and across texts were identified, allowing data to be coded and further analyzed (Crabtree & Miller, 1999; van Manen, 2014).

3.5.1 Thematic Analysis- Reading the data

The aim of the analysis of a phenomenological text is not to discover or explain causation, rather the goal is to clarify the meanings of phenomena from lived experience (Penner & McClement, 2008). van Manen (2014) views themes as being the structures of experience and for this reason, van Manen's approach to thematic data analysis was used. Analysis occurred at three levels: wholistic reading, selective reading, and detailed reading

3.5.1.1 Wholistic Reading

During the wholistic reading stage, the transcripts as well as the observation notes were read as a whole. Throughout this process, the question "how can the main significance of the text as a whole be captured?" (van Manen, 2014, p. 320) was posed. The aim was to gain insight into each participant's experience and to understand what characteristics were specific to each individual's perspective. To understand the story of each participant, reflective questions such as 'what do the participants deem as important?', 'how do the participants cope with their disease?', 'how do the participants understand COPD?', and 'what are their experiences with the information that is

provided to them, regarding COPD', were also asked. Simple phrases that best described the text as a whole were formulated and written down. Appendix J, provides examples of the participants stories that were conducted during this phase of the analysis.

3.5.1.2 Selective reading

In the selective approach, the text was read multiple times in order to ensure familiarization. The question asked was “what statements, phrases or words best described the phenomenon or experience?” (van Manen, 2014, p.320). The researcher proceeded to highlight the phrases that best described the experiences of the participants and identified potential emerging themes or words that were deemed as meaningful. In the context of this study, words or phrases were deemed meaningful if they provided insight into the lived experiences with COPD or on the usage of healthcare services, information, or strategies.

First cycle and second cycle coding were completed during this phase of the analysis (Saldana, 2015). During, the first cycle of coding the aim was to assign specific codes to the data (Saldana, 2015; Miles, Huberman, Saldana, 2013). The second cycle of coding was completed by using the identified codes and clustering them together to create categories, which were then further analyzed for the emergence of themes (Saldana, 2015; Miles et al., 2013). A variation of coding techniques was used during both the first and second cycle of coding. Initial, In Vivo, emotion, and descriptive coding techniques were used to complete the first cycle of coding, whereas, the pattern and focused coding techniques were used for the second cycle of coding (Saldana, 2015; Miles et al., 2013).

3.5.1.2.1 First cycle of coding

Various coding techniques were used to code the transcripts manually. Initial coding, also known as open-ended coding, was used to help the researcher become familiarized with the data. This coding technique allowed the researcher to code freely, without reflecting on what should or should not be coded (Saldana, 2015). For example, one of the initial open codes was “denial of disease”, as one of the participants on numerous occasions inferred to not being able to accept their COPD.

In Vivo coding allows the participants' voices to be prioritized and honored, as their words become the codes themselves (Saldana, 2015; Miles et al., 2013). This coding technique aligns

with phenomenological research, as it allows the voices of the participants to be heard and their story to be told directly (Miles et al., 2013). When one of the participants expressed what it was like not being able to hug his grandson due to his disease, his direct quote was used as a code, as it provided insight into his experiences with, as well as the impact it has had on his familial life.

Emotion coding refers to codes that represent the feelings participants have with certain experiences (Saldana, 2015). This coding technique was used to capture the participants' feelings about the services, and information that were provided to them. For example, one of the participants expressed negative feelings with the lack of information offered by his doctor.

Lastly, descriptive coding was used to ensure that the researcher remained informed of the different topics that appeared throughout the interviews (Saldana, 2015). For example, if participants spoke about receiving information from their healthcare providers, or any other sources, this was coded as "Information Source".

Committee members simultaneously conducted open coding for 3 of the interviews. This was done to ensure validity and to guarantee that the data was reviewed by at least two different individuals, thus confirming inter-coder reliability. The simultaneous open coding helped to assure study rigor (Tracy, 2010) and ensure that coding, patterns and themes were consistent among the research team.

3.5.1.2.2 Second cycle of coding

After the completion of the first cycle of coding for all of the transcripts, the codes were then categorized. A combination of both pattern coding and focused coding techniques were used during this stage of the analysis (Saldana, 2015). By combining similarly coded data, pattern coding was used to help organize the information, as well as provide a better understanding of it (Saldana, 2015). All of the information that pertained to the effects of COPD were clustered together and a better understanding of how COPD had impacted the lives of the participants was obtained. For example, all of the data that pertained to the emotional effect that COPD has had on the lives of the participants, such as feelings of hope, loss of identity, fear of distressing others, and loss of joy, were under the category "Feelings". Focused coding technique was used to categorize the data and the first cycle codes based on thematic similarities (Saldana, 2015). First cycle codes regarding sources used to receive information were grouped under the category 'Information Source'. Appendix K provides an example of second cycle coding.

3.5.1.3 Detailed (line-by-line) reading

After the completion of first and second cycle of coding, every sentence of the transcript was looked at individually while asking the question “what is this sentence revealing about the phenomenon and the experiences described” (van Manen, 2014, p.320). Re-reading the transcripts line-by-line allowed for further insight on how each sentence contributed to the understanding of the lived experiences of the participants with COPD, or their use of information and health and support services. Additional codes and themes that were not previously identified, were added to ensure all data from the transcripts were included in the analysis.

Member checks were conducted to ensure that the true representation of the participants’ experience had been captured by the researcher, as well as ascertain study rigor (van Manen, 2014; Kosh, 2008). During member checking, the researcher summarized the main topics that were discussed during the interviews. The researcher then proceeded to ask the participants whether the summary was an accurate representation of their experiences and the participants were encouraged to provide their input. Notes from each member check were added to the original interview data and were analyzed. Member checking was completed with 4 of the 5 participants, and 2 of the 3 participants’ spouses. Member checking was conducted in-person with 3 of the participants, and 2 of the participant’s spouses, and over the telephone with one participant. The missing member check was due to the death of one of the participants during the study.

3.6 Application of Quality Criteria

This study used van Manen’s (2014) qualitative quality criteria an evaluation method.

3.6.1 Heuristic questioning

Not much is known of the experiences of veterans and/or their spouses with this particular disease. This study prompts the readers to ask themselves “what it might be like to live with this debilitating disease”, “what are the experiences that one goes through when they have COPD” and “what are their experiences with the information and healthcare services that are provided to veterans and/or their spouses with COPD”. Through in-depth interviews of their experiences, this study provides a glimpse in the lives of veterans and/or their spouses with COPD.

3.6.2 Descriptive richness

Through open-ended questions and allowing the participants to talk freely of their experiences with COPD and of the information they are provided, the researcher was able to obtain rich detailed descriptions of the phenomenon. During the data collection phase, probing questions such as “can you tell me what you felt in that moment” or “can you describe that moment in further detail” were posed to ensure descriptive richness of the phenomenon as lived by the veterans and/or their spouses with COPD.

3.6.3 Interpretive depth

Through the rich descriptions of the phenomenon by the participants, the researcher was able to discover and gain a deeper understanding of some of the challenges that veterans and/or their spouses with COPD encounter, the type of services that they use, as well as their knowledge and understanding of this disease. The participants provided rich details of the physical and emotional restrictions that COPD places on their lives. One does not often think of the impact that trivial tasks such as walking upstairs, could have on their lives. For many of the participants of this study, this however was not the case. They shared how a simple task such as walking up and down stairs, can be quite restricting as it forces them to stop multiple times to catch their breath. Upon reaching the top of the stairs, the participants noted how it is very difficult for them to talk, as they are unable to breathe.

3.6.4 Distinctive rigor

Maintaining rigor is an important aspect of any research study, including phenomenology. Various measures were taken to ensure that the following research study was rigorous in nature. This was ensured by always keeping in mind the purpose of the study, the phenomenon that is trying to be understood and basing the interview questions on the lived experiences of the participants. Two interviews were conducted with the participants to ensure that the richness of the data was captured. Adhering to the phenomenological viewpoint, the types of questions asked were open-ended and descriptive in nature. To ensure transcript accuracy all interviews were audio-recorded and transcribed verbatim. The transcripts were then given to the participant to look over and ensure that no details regarding their experiences were missing. Observation and reflexive notes were also taken during the interview and immediately afterwards to capture

non-verbal communications. In addition, the researcher kept detailed notes of every meeting and event that was attended throughout the study.

3.6.5 Strong and addressive meaning

This study provided a deeper understanding into the reality of veterans and/or their spouses who struggle to breathe on a daily basis because of COPD. COPD is quickly rising to become the third leading cause of death world wide (O'Donnell et al., 2008). If not diagnosed with it themselves, the majority of individuals are able to identify with the participants of this study as they might know someone who has it.

3.6.6 Experiential awakening

Some things are so much part of us that we rarely ever think about them; breathing is such an example. It is human nature to often take for granted things that we consider part of our everyday function, but it is in those moments of distress that breathing takes on a different meaning. Although many of us throughout our lives, for a brief moment have experienced what it is like to gasp for air, for individuals with COPD this encompasses their daily living. This study awakened the pre-reflective experiences in the reader by providing them with anecdotes and extensive detail of the daily lives of veterans and/or their spouses with COPD. It is through these anecdotes and rich details on the participant's daily lives, that readers are able to relate with the participants of this study.

3.6.7 Inceptual epiphany

“Phenomenology seeks to understand how insights into our ordinary or healthy existence can help us understand in what way existence can be disturbed and become extraordinary” (van Manen, 2003, p.61). This study provides original insight into the complex, and extraordinary world of Canadian veterans and/or their spouses living with COPD. Similar to many of us, the participants of this study were not attentive to how breathing, such an innate humane experience, could change their worldview until they developed COPD. Consequently, for many of them the world that they had previously known, has now become more limiting and restricting. Through their descriptions of current activities, and the reminiscing of past ones, the participants of this study illuminated the impact of COPD, and their experiences with the information and services

provided to them. Providing a better understanding into how their lives had been changed because of this disease.

3.6.8 Ethical Considerations

Due to the nature of COPD, prolonged periods of talking can lead to physical discomfort and fatigue amongst the participants and a possibility of the increase in their symptoms of breathlessness, coughing or wheezing. During each interview, the participants were asked how they felt and were reminded that they had the right to withdraw from the study during any point in time, although none of the participants chose to do so. Ethics approval to conduct this research study was obtained by Western University Health Science Research Ethics Board (REB) (Appendix I).

3.7 Self-reflexivity

Adhering to the goals of hermeneutic phenomenology, it is important that as the researcher, I am transparent about the pre-understandings, biases and beliefs (van Manen, 2014). My interest in COPD started when I was volunteering at Scarborough General Hospital in Toronto, while I was pursuing my undergraduate degree. My role at the patient care unit was to help the patients by providing them companionship. During one of my shifts, the first thing I noticed when I entered the room of one individual was the oxygen tank beside her bed. After a brief introduction, she began to tell me her story. I later asked her about the oxygen tank and what it was that she had. I was in my first year of university and we had just started to study chronic diseases. When she mentioned COPD, I had a vague idea of what it was but was not very knowledgeable about what it was like to live with this condition. She explained how she was at home and started to experience a pain in her chest. Suddenly, she could not breathe. The harder she tried to fill her lungs with air, the harder it became for her. Feeling helpless, she called 911 to get an ambulance sent to her home and was immediately hospitalised. I wanted to ask her more about it but, seeing that she was getting tired, and struggled when trying to talk to me, I let her rest and said we will continue the conversation next time. When I arrived the following week, I was disappointed to discover that she had been discharged, so my questions remained unanswered.

My next opportunity to learn more about this disease came during one of my classes. We were required to select a disease to examine, together with a technological advancement that

assisted people with the management of this condition. I took this opportunity to learn more about this disease. My research showed that this was not an uncommon illness at all and I became more intrigued by it. However, it wasn't until graduate school that the opportunity to look deeper into this disease and understand it better presented itself. I wanted to learn more about this condition, but not just from the literature; I wanted to hear and understand what individuals suffering from it had to say. I wanted to hear their stories. As I read the literature on this condition, I noticed that although veterans were twice more likely to develop it, few studies were focused on them. This piqued my curiosity, as to why this was. I decided to pursue this further and thought that it would be interesting to understand COPD from their perspective.

Although I learned about the clinical perspective of the condition from my classes and the literature, I believe I learned far more from the woman in the hospital. If it wasn't for her, I would not have become so eager to try to understand COPD. I reflected on the strength it took for her to talk to me and to tell me how she felt every time she gasped for air and coughed. If it wasn't for her, I would not have become so interested in learning more and truly understanding this condition from the perspectives of those who have it.

3.8 Conclusion

This chapter described my paradigm stance, the methodology and methods, and quality criteria to evaluate the study. Contrasting the original founders of phenomenology (Heidegger, Husserl, and Gadamer), van Manen's hermeneutical phenomenology is viewed as being more action sensitive and less philosophical; thus aligning better with the purpose of this study and thus, answering the research questions. The *Individual and Family Self-Management Theory*, was chosen as the most suitable theoretical framework for this kind of study as it provides insight into managing and coping with a chronic disease, such as COPD. As this study, was specifically focused on the lived experiences of veterans and/or their spouses with COPD, purposeful sampling was used, to ensure rich accounts of the phenomenon. To ensure rigor, the researcher's actions were guided by the research questions and getting a better understanding on the experiences with COPD. Various measures such as conducting two interviews to ensure that the experiences of the participants were captured in rich detail, the interview guide was based on the experiences of the participants with COPD, as well as the information, and services that was provided to them, were taken. In addition, the researcher kept detailed observation notes to

capture non-verbal communication, reflexive notes to capture her biases and pre-understandings, and notes of every meeting and event that was attended throughout the study. Van Manen's (2014) quality criteria was chosen for evaluating this study, as it was the best fit for a hermeneutical phenomenological study, such as this one. To ensure transparency, this study concluded with a self-reflexive piece written by the researcher that outlines the interest in the topic.

4. FINDINGS

This study aimed to understand the lived experiences of older Canadian veterans and/or their spouses living with COPD. It also aimed to understand the participants' knowledge and experiences with health services, information and the strategies employed during living and coping with COPD. The results were derived through in-depth, thematic analysis of participants' stories and are presented as key themes.

4.1 Participant Characteristics

A total of eight participants agreed to be part of this study. As noted in the methodology section, the spouses of veterans, who did not have COPD themselves, provided input regarding the lived experiences of their partner with this condition, thereby providing a deeper understanding of what it is like to live with this disease. Table 1 provides a synopsis of the participants, including whether they were a primary (participant meeting eligibility criteria) or secondary (spouse of actual participant) contributor to the study, their gender, veteran status and the number of interviews completed with this participant.

Table 1: Participant Characteristics

Participant number	Gender	Veteran status	Number of interviews
1	Male	Veteran (army)	1
1a	Female	Spouse of participant 1	1
2	Female	Spouse of veteran	2
3	Male	Veteran (navy)	2
3a	Female	Spouse of participant 3	2
4	Male	Spouse of veteran	2
5	Male	Veteran (navy)	1

5a	Female	Spouse of participant 5	1
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Three dyads (participant and their spouse) felt more comfortable to be interviewed at their homes. Due to geographical distance one participant was interviewed over the phone. Additionally, one participant was interviewed at a Veteran’s club that they frequent. To capture non-verbal communication and observation, reflexive notes were taken by the researcher throughout and immediately after the interview.

One participant and two dyads were interviewed in London, Ontario. One dyad was interviewed in Toronto, Ontario. The interviews were conducted between March and November 2016. As noted in Table 1, two participants and one dyad were interviewed twice to ensure that more information regarding their experiences was captured. One participant died during the process of this study and as a result was only interviewed once. While, another participant and his spouse, were only interviewed once, due to the fairly detailed nature of the first interview and did not require a subsequent follow-up. The interviews were on average forty-five minutes in length which is consistent with the length of time recommended in the literature (Raworth, Sweetman, Narayan, Rowlands & Hopkins, 2012).

More information about the participants’ socio-demographic status can be found in Appendix L. More information regarding the experiences of the participants with community and healthcare services as well as information provided to them, can be found in Appendix M.

4.2 Emerging Themes

Three key themes emerged related to the lived experiences of participants with COPD. The themes include: I don’t feel so good, having to stop and rest, we’re walking a marathon. Two main themes emerged regarding the knowledge and experience of information, and healthcare and support services available. The themes include: they had good service, and ignorance is bliss when it comes to being informed. Each of these themes contained multiple sub-themes.

4.3 Lived experience with COPD

4.3.1 I don't feel so good

In the context of this study, the theme, I don't feel so good, refers to the participants' experiences with their initial diagnosis of COPD. This includes sub-themes such as here are your lungs, it snuck up on me slowly, and what will be will be.

4.3.1.1 Here are your lungs

Receiving a COPD diagnosis can be a difficult experience for patients. Most participants in the study, received their diagnosis of COPD after performing a series of breathing tests.

They filled me full of gas then I went into the machine again and they showed me a picture 'here are your lungs. See all that yellow stuff? That's gas. All this part here is not being used. This is dead'. One half of the upper lung (participant 3).

Similarly, participant 4 stated:

It got to the point where I had to take a series of tests at the hospital at the doctor's request and that's when I found out. When it was identified to me directly. 'You have a problem with your lungs'...I was shown a graph that's one thing I remember.... One of the specialists made the point of saying 'okay here is the graph of a normal person up until the point of demise. Here is your graph' and it showed me going down much faster than the average person.

In contrast to participants 3 and 4, participant 2 was initially diagnosed and treated for a different disease. It wasn't until a few years later that she was diagnosed with COPD.

The only reason I was tested extensively at the time was because I was working for a doctor and she said...she thought I had asthma and she sent me for the tests...One day the doctor happened to mention COPD which hadn't been in the mix before (participant 2).

Meanwhile, participant 5 took the initiative to let his doctor know that something was wrong.

I'm talking to the Respiriologist. I just say 'you know I don't feel so good' 'well come on in I'll look at your lungs'. Scope in the ears and 'Cough. Breathe'. You know what I mean? 'Uhh... that's you don't sound too good. Not too bad. You've got pretty good lungs'. And I'm spitting up stuff and I'm hacking and 'ohh here try these pills (participant 5).

4.3.1.2 It snuck up on me slowly

For some of the study participants, learning that they had COPD did not come as unexpected news. Some of the participants felt no immediate impact when they learned their diagnosis. “It wasn’t at all of a sudden ‘WOW you’ve got COPD’...It was a gradual thing so there was no immediate impact...It wasn’t an AHA moment” (participant 2). Participant 5 stated that it was like finding out he had a toothache: “it snuck up on me slowly...It was like ‘oh I’m okay and I have a toothache”.

However, not all participants felt this way about their diagnosis. Contrastingly, participant 4 recalled receiving the diagnosis as a key moment in his life.

I would say that was one of the key times when the doctor had me in and I went to the test and he said ‘here’s the picture’. I looked at it and I went in and I came out and I said to myself ‘I’ve got a problem’ (participant 4).

The information received was very difficult for participant 4 to process and as a result he immediately smoked in order to relieve the stress. As he explained, “the information came to me in the more intense manner...I came out from the hospital got in my car and lit up a cigarette” (participant 4). Similarly, for the third participant's wife, a COPD diagnosis for her husband came as a shock at first as she “never thought he would have this problem because he was always active”.

Nonetheless, most participants felt that they already had a sense of something being wrong prior to receiving the diagnosis. “I remember that there is something wrong...I couldn’t play and I couldn’t march at the same time so I knew that there’s something wrong” (participant 3). Agreeing, participant 5 stated: “I had a breathing problem that I was obviously cognizant of the fact that I had a breathing problem”. Perhaps the fact that the participants were already aware of a potential problem contributed to the lack of impact when receiving the diagnosis. For participant 2, receiving a COPD diagnosis provided relief. “It was just okay that’s why I’ve been having trouble...It was just that ‘alright that’s the name of it. That’s the name of the problem of what I’ve been having” (participant 2).

4.3.1.3 What will be will be

For individuals who are diagnosed with a progressive, chronic disease, acceptance can often be difficult. Adapting attitudes such as “what will be will be” (participant 3) and “well that’s

life” (participant 4), the participants of this study reached a point where they came to terms with their disease. This is partly because they felt they had no other choice. “What am I supposed to do quit living all together?” (participant 3). “I have to accept it...I have it. I got it because I smoked heavily. So it’s not going to change. So I’m not going to worry too much about it” (participant 4). For the fourth participant, acceptance also came from adapting an insouciant attitude: “I really don’t think about it...I don’t think ‘holy cow my breathing is bad’...It’s something that I accept”. Similarly, participant 5 stated: “you accept the fact that this is COPD...I just accept it”. The spouses of the participants also reported reaching the point of accepting their spouses’ disease by expressing the notion that “you can’t run away from it... I have accepted it” (wife of participant 5). Agreeing, participant 3’s wife stated:

We just kind of take everything in our stride ... We have always said ‘if you come up against a brick wall hey take another route’... We have always just got up and get going again no matter what (wife of participant 3).

However, there were some differences regarding acceptance among the participants. For example, despite not accepting her diagnosis, participant 2 had accepted the help her doctor provided. “I complain to my doctor about all the medications I’m on and he just says to me ‘would you rather have the alternative?’ and that’s the whole thing you accept the help that’s given you”. Participant 2 still found herself unable to get over the frustration and anger of having COPD. Additionally, participant 2 had difficulty emotionally accepting her diagnosis because she was also caring for someone else. As she explained: “something that’s I suppose keeping me from accepting my failing health and uhh saying that I need support is the fact that I am the support of my daughter” (participant 2). Another factor that could play a role in having difficulty accepting COPD is that “one doesn’t want to admit they are getting old and feeble” (participant 2). Continually forgetting her limitations, participant 2 viewed herself as being her worst enemy in not accepting her failing health. She explained:

I continually conveniently forget that I can’t do this or I can’t do that anymore...I don’t say no when people ask me (chuckle) to do things and I know I should...I know I am my worst enemy in not accepting it and slowing down a little bit. I push myself to the point of near collapse (participant 2)

Additionally, participant 2 viewed COPD as an unbeatable challenge.

It’s something of a defeat...It’s something I can’t beat...The word ‘acceptance’ means alright I’ve given up. I’ve given in, and to me I can’t accept that...To me

staying frustrated means staying alive...I'm still fighting it and I probably will right until the bitter end (participant 2).

It is important to note that throughout the course of this study, participant 2, became more accepting.

4.3.2 Having to stop and rest

In the context of this study, having to stop and rest refers to strategies (pharmaceutical or otherwise) that are used by the participants to help cope with COPD. This includes self-management strategies. I'm on all the medications that I should be, and I have to learn to live with it were the sub-themes that emerged from the overarching theme of having to stop and rest.

4.3.2.1 I'm on all the medications that I should be

Puffers were identified as the most frequently used pharmaceutical treatment by the participants. As participant 1's wife explained, "You've had to take medications, the two puffers, morning and night". Similarly, participant 4 stated, "I have a couple of puffers". "Salbutamol inhaler, Symbicort inhaler and Spiriva inhaler" (participant 2) as well as the "Spiriva inhaler and Advair inhaler" (participant 5), were specifically distinguished as the primarily used pharmaceutical measures.

Oxygen therapy was the most frequently used non-pharmaceutical measure to treat COPD. All but one participants admitted to using oxygen at some point. Participant 1 had used oxygen therapy in the past; during the interview, it was identified that he would start using oxygen during the night. Meanwhile, participant 3 temporarily used oxygen therapy to recover from an injury. "Once he had his knee done and he had to come home. His oxygen levels were so low he had to come home and we had oxygen here" (wife of participant 3). Similarly, participant 4 indicated that "[he] was on oxygen for a period of time". Unlike the other participants, participant 5 used oxygen daily.

Despite receiving treatments to limit the development of COPD, some participants revealed that their disease is progressing to a point where they are no longer able to manage it. For example, participant 2 revealed that despite the best efforts of the specialists, there is nothing more that can be done for her situation.

I've gotten along very well until just about the last oh I would say the last three years... It was extremely well managed up to that point then I really got into difficulty with it... According to the specialists that I have seen everything is being done that can be done at the moment... They reviewed all of the medication I was taking and they said that I'm on all the medications that I should be. And there's (chuckle) there's no more medications to deal with... I have reached a point where it's not being managed... I'm getting worse (participant 2)

Likewise, participant 3 stated that his condition "has gotten worse in the last few years" and that due to its progressive nature, he will return to using the services of his physician. On the other hand, participant 4 felt that when it came to COPD, "[he] just [doesn't] think there is anything other than trying to arrest it".

In addition to managing the symptoms of COPD, one of the participants struggled to cope with the side effects produced by the medication used to treat it. Participant 1's wife stated that "because you're (participant 1) taking puffers you've developed like a dry mouth syndrome. That's aggravating... sometimes wakes you up even in the night". Trying to alleviate the side-effects of the treatments, participant 1 and his wife have tried to adapt other measures such as "sprays and mouth rinse [and] humidifiers running". Other participants that also used puffers did not indicate that they suffered from any known side-effects.

4.3.2.2 I have to learn to live with it

The participants of this study have tried to cope with COPD by adopting various self-management approaches. Two of the participants reported using humour as a method of coping: "Ahh how do I cope with it? I think I have a pretty good sense of humour... I'm able to laugh at myself" (participant 2). Similarly, participant 5 expressed, "I like putting people at ease". The participants' sense of humour was prevalent even throughout the interviews as they tried to lighten the mood during emotionally heavy parts of the conversation. Two participants even tried to put the researcher at ease by making remarks such as:

Here I was hoping you had some answers. I'm disappointed. Darn it (jokingly). Darn it (jokingly). Here I thought I had a Florence Nightingale to show up here. Gonna lay down the wand and say 'here's your problem'. Well I will in 4-5 years. Could you come back? (participant 5).

Most participants tried to cope with the challenges of COPD by being vigilant and not over exerting themselves. "How do I cope with the challenges? I just weight them and don't do them... If I feel this is a challenge that I know that I can't do, so I just don't do it" (participant 3).

Similarly, participant 1's wife acknowledged the fact that when her husband encountered a challenge he would not push himself, for example, with “walking you wouldn't push it you'd go at a pace that was comfortable”. On the other hand, Participant 4 believed that he had done everything possible to prolong the progression of COPD by ceasing to smoke. Similarly, participant 2 stated:

I do everything that I'm supposed to do...I know when I have reached a point when I have to stop and rest and put my feet up for a while... I know that I'm doing everything that I can to cope with it...I take my medication religiously

The participants not only have to cope with the physical challenges associated with COPD but they have also had to psychologically adapt to living with the disease. “I had to get used to the idea that I wasn't going to drop dead in the middle of the next block” (participant 1). All participants identified having to learn to live with COPD and adjusting their behaviour as well as how they approach certain situations. “It's just something that is there and I have to live accordingly...I have to respond to the fact that I'm getting short of breath or I am short of breath” (participant 4). Agreeing, participant 2 stated: “I have to learn to live with it...I just have to modify my behavior...I need to remind myself to relax and slow down...I'm trying to be sensible and limit my activity”. “I found it unnerving at first but I've gotten used to it” (participant 1).

Additionally, most participants and their spouses acknowledged that they have had to slow down in many aspects of their lives. Having to slow down is more predominant when the participants encounter physical activities: “If you're going fast you slow down...It's where some of us make four laps around the TD water house you would make one maybe in that time” (wife of participant 1). Sharing a similar experience, participant 3's wife shared:

(participant 3) used to walk way ahead of me and I used to think 'oh no slow down'. Now I look around and he isn't there and he is 15 feet behind...Sometimes I get going ahead of him and then all of a sudden I have to look around and he's not there so I have to go back (laughter) and pick him up.

Three of the participants recognized the fact that they have had to slow down in all aspects of their lives, not just when they were participating in physical activities. “I would say that things that you would have to contend with is you have had to slow down in all respect” (wife of participant 1). For participant 4 this has meant having to cease doing certain activities: “I am much much slower than I used to be...I guess I slow down on my activity, maybe cease doing it”.

Similarly, participant 5 expressed: “I found out I had to go slowly and slowly and slowly... You slow down... [I] just wanna go slow. Catch my breath. Catch my breath... [the] vigor is gone”.

In addition to having to slow down, for one of the participants, having COPD has meant having to learn to compensate and plan ahead.

You’ve learned to compensate quite nicely... We had to plan a little longer if you’re going to get dressed up and go somewhere... When you’re into full musket and regalia we plan to a little farther ahead because it’s tiring (wife of participant 1).

Similarly, participant 4 also described that he now “pretty well [had] to plan” ahead of time for his day. For participant 2, however, planning comes in the form of trying not to over exert herself with extra activities. She explained, “I’ve made a plan (laughter) hasn’t worked very well but I made a plan. I thought ‘Oh I will... I will be active one day and then rest the next’ and work that way so that I don’t get absolutely exhausted”.

Despite the physical struggle, staying active has shown to be an important aspect of all participants’ lives, whether it being taking up a hobby such as downhill skiing (participant 1), or playing golf (participants 2 and 3), doing daily exercises (participant 2) or merely getting out. COPD does not deter them from finding various ways to stay active.

I get out. Try and get out every day. Do something. Something physical... I do a light program of stretches every morning... I try to get out every day. I try to walk... I’ll go to the mall and for instance I’ll go into the Walmart store and take a cart and walk around the perimeter of the store just for the sake of walking... If you stop being active you turn into an armchair (participant 2).

Similar to participant 2, participant 4 described going out shopping with his wife as a means of getting some exercise. When asked about being active, participant 3 responded with, “Active as hell! Yea!”. Needless to say, for these participants being active was a very important part of their lives.

4.3.3 We’re walking a marathon

Differing from the previous theme, rather than focusing on coping strategies, the theme we’re walking a marathon, provided further insight and a better understanding of the participants’ experiences with this disease. It includes the following sub-themes life isn’t normal, it’s maddening, and I’ve never really talked about it like this.

4.3.3.1 Life isn't normal

COPD has had a big impact on the lives of the participants. All of the participants reported having symptoms such as “breathlessness”, “short of breath” (sic) or “gasping for air” as one of the main struggles of having COPD. Four of the participants found themselves constantly coughing or having to clear their throat. As participant 5 explained, “I sit there and cough, cough, cough”. Unlike the other participants, participant 5 was the only one to report having to “continually spit up mucus”. He described it as a “deep deep pull of mucus...[that] appears to have come way down from the bottom of [the] lungs”. Due to the low levels of oxygen, participant 1’s wife recalled how her husband would often experience muscle weariness as well as drowsiness.

Both participant 3 and 4 stated that when they were in a state of inactivity, they would not feel the symptoms of COPD. As participant 3 explained, “I’m just sitting there enjoying myself, nothing’s happening. Everything’s fine”. Similarly, participant 4 stated, “I’m okay when I’m sitting”. Once the participants started to participate in strenuous activities they experienced feelings of tiredness, loss of energy, fatigue, and loss of strength. As participant 4 expressed, “the minute I start to exert myself above and beyond the normal, I can feel it...I have a work bench and now I just don’t seem to have the energy to do anything”.

Three of the participants described their inability to walk up or down stairs without being physically impacted by COPD. Participant 4 explained, “If I walk up the side of the stairs as an example by the time I get to the top I’m pretty exhausted...I’ll walk up the set of stairs and if they’re long I’ll pause half way. Just stand there...maybe sometimes I’ll go up and stop twice”. Having a similar experience participant 3 stated, “when I go from the bottom to the top of the stairs I gotta (sic) stop for a minute cuz (sic) I can’t even talk”. Participant 3’s wife further explained:

if he comes up from the lower level where he has all his office stuff, if he goes right up to the top floor he can’t even speak. I can hear him coming... I can hear. If I happen to be upstairs, I can hear him by the time he gets going up from here to the top. I can hear him gasping.

Similarly, participant 5’s wife described her husband having to stop multiple times before reaching the top of the stairs, walking from their basement.

Three of the participants also described the inability to walk long distances. Participant 1's wife explained, "if you require to walk a long way you'd tire easily". Sharing a similar experience participant 4 stated, "When I could walk long distance it...it would exhaust me to a certain degree". The fifth participant described how he was unable to walk as far or as fast without having to stop multiple times to catch his breath.

Despite the physical impact that COPD has had on their lives two participants reported not experiencing pain. Participant 3 described experiencing the symptoms of COPD as "physically you're still hurting but there is no pain...It's not like a door slamming or hurting yourself". Similarly, participant 2 stated, "I'm not in a great deal of pain". Two of the participants vividly remembered how active they were prior to COPD. As participant 2 stated, "I did whatever I felt like doing and I was very physical". Sharing a similar experience participant 4 revealed that prior to COPD, he was quite active, as opposed to his current state of not being able to walk up the stairs without stopping a few times.

Apart from the physical impact, COPD was found to have an impact on the daily activities and overall quality of life of the participants. Demonstrating how truly debilitating COPD can be to individuals who suffer from it, participant 5 shared how he spent most of the day between his bed and his chair. "I'm coming and going to bed... I'll be up for a couple of hours and going to bed...but that's my day. It's between the chair and the bed" (participant 5). Agreeing, participant 3's wife explained, "it affects day to day life there is no doubt about it".

Most participants' found that not only does COPD affect their daily activities, it also impacted the things that they used to enjoy doing the most, their hobbies. Participant 2 described how much she used to enjoy playing golf and that she played five times a week. Despite not being able to walk around the golf course, COPD did not deter participant 2 from playing. She explained, "I'm going to play golf this summer. I have to take a cart of course; I can't walk anymore but I can still play...I will continue to play till they cut me off". Sharing a similar experience, participant 3 and 1 continued to participate in their favourite hobbies as well, golf and downhill skiing respectively.

However, their COPD did limit the type of activities the participants were able to conduct. Prior to COPD, participant 2 used to love singing. She shared, "One of the things it has taken away from me is my music... I lost my voice...because of the severe cough that accompanied the

Asthma and COPD it ruined my vocal cords so I can't sing anymore". Similarly, participant 3's wife recalled how her husband used to participate in parades by playing the trumpet with his band, "He used to march in parades...used to play the trumpet...they used to march and he could blow his trumpet and then all of a sudden he decided he couldn't do both. He could either play or he could march". Participant 3 further explained, "I couldn't participate in the parade I just went and sat down and watched it". Similarly, due to COPD, participant 5 was unable to partake in his favourite pass-time activity, repairing his house. As participant 5 shared his story he stated, "I wanna do a little bit of a wiring job downstairs on my cellar and I wanna put a time switch in and gee I got started and I had to go sit down". A similar situation occurred when the participant tried to fix the control box of his sauna. As he stated:

I have a sauna [in] this house, I built it, and I have a control box. I got it off and I gotta put in a timer in there and a time clock and thermostat. I have to find a chair to sit down...Sit there. Come on that little bit of work and you gotta sit down?
(Participant 5).

Many of the participants have described COPD as being "limiting" (participant 2), and "restrictive" (participant 4 and 5) in nature. As participant 3 explained, "you have to know your own control...you're only in control of what you can do and what you can't do...when you get short of breath you quit... you just can't do what you wanna do". For participant 4 having COPD meant being "restricted in my activities...It means I will always be under the guidance of the medical profession". Similarly, participant 5 stated, "for a person who used to be active, multitask, do a whole bunch of things at once, now I can't even do one thing". One of the activities that participants struggled with the most was walking. Participant 2 shared "I can't even walk a block". Something, as simple as "walking from the car into a store" (participant 2) presented to be a big challenge for most participants. As participant 2 explained "walking around a large store and most of the stores these days are large...it becomes an effort...while walking from one end of the house to the other makes me breathless sometimes". Similarly, participant 3 shared how he and his wife "used to walk from here [their house], up to the university (deep sigh). Now we can't get to the corner store...two blocks and it's enough". Adding to this, participant 3's wife stated:

you just walk so far and you stop...we went to Toronto umm on the train last fall and we started out in about a block in a half then we had to stop and ...see if there

was a box transfer or something. He had to sit down for a few minutes...If you're out anywhere and you have to stop and just find a place to sit for a bit.

Jokingly, participant 3 added, "we're walking on a marathon". Sharing a similar experience participant 4 explained, "usually when we go shopping at the food store the first thing I do is I grab a cart and I use that to walk around and that helps me with my breathing". The wife of participant 5 shared that during shopping trips with her husband he had to stop often due to his inability to walk for long periods of time. Aside from walking, participant 5 shared his struggles to complete minor chores around the house such as "yard work... electrical work...cutting hedges... grass mowing...even setting a ladder is a struggle". Relatedly, participant 2 shared that during one of the weekly Euchre games played at a veterans' club that she attended, she was unable to fulfil her responsibility of setting up the game. Having to leave it to someone else the participant was left feeling "devastated".

Participant 2 and 5 shared that among other things, COPD had also affected their occupation. Participant 2 explained, "I kept working until I was 63 and my work involved physical exercise. I taught exercise to ambulatory seniors in several nursing homes around the area". Unfortunately, due to the progression of her disease, she was forced to stop, expressing "I used to teach aerobics... I can't anymore...I can no longer do aerobics". Participant 5, continued to work despite not being able to perform the same tasks as prior to the progression of his COPD. He explained:

I never quit working...As they needed me I was on-call...I was able to do these things but I was actually cheating because I had no ability to do what I used to do...they (contractors and coworkers) would do the heavy lifting and I would just stand back and observe...I would have done some heavy lifting before...I now found myself having to just observe and they took care of me...The habit for me of not being a lazy guy. I'm a worker. Had two-three-four jobs at one time. It's sorta hard all of a sudden to be in this place it's a different world (participant 5).

How the participants experienced the severity of the COPD symptoms was also dependent on the weather. Due to the hot summer that occurred while this study was being conducted, many of the participants mentioned the impact the weather had on their breathing. As participant 2 recalled, "It has become very bad this summer...the weather has been so very very very difficult for me...the hot weather made it difficult to breathe". Despite having air conditioning at home

and in the car, participant 2 continued to struggle because as she stated, “my lungs like it but my skin doesn’t...I’m cold all the time”.

The impact of COPD is not only felt by the individuals who suffer from it but also from their caregivers. Caring for someone who had COPD can often be quite challenging especially when the caregiver also suffers from it, as was the case of participant 2. She shared the following experience, despite it being somewhat difficult to share:

I think what the turning point was, was my husband’s illness... I managed all of his medication and yea I nursed him right up until the end...I was pushed beyond my physical limits... it was 4 years of 24 hours nursing... at the end maybe 20 hours of sleep a week. It was difficult... at that time I weighed 110 pounds and my husband was a lot more than that and I had to lift him... Bathe him... dress him... I don’t regret it because I know he lived a lot longer because I cared for him... that was the...the straw that broke the camel’s back... I can admit now that it uhhh that was the final straw... That’s what made it worse.

Similarly, participant 4 shared how his spouse provided him with the necessary emotional support to overcome his frustration with COPD. “I just vent and my poor wife has to put up with my venting sometimes”. Contrary, to the previous experiences, despite the difficult nature of it, participant 5’s wife stated, “It’s not a burden...it’s a little extra work for me...it’s a lot of extra work taking you for a shower a couple of times a week...[but] no no it’s not a burden”.

The majority of the participants and their spouses expressed that to them COPD had become a daily part of their lives, thus not putting much thought to this disease. Participant 3 claimed that he was “so used to it I just don’t call them symptoms. I just live with it”. Similarly, participant 3’s wife stated:

Some days you think ‘oh no not again’...Now we’re so used to it that you can’t even think when you didn’t have it really... We’re just so used to it now that you just think ‘Ahhhhh’... That’s the thing you learn to live with it (wife of participant 3).

4.3.3.2 It’s maddening

Regardless of the struggles that the participants have had to face because of COPD, a few expressed feelings of hope. For participant 1, hope came in the form of wishfully thinking that their health was improving. Contrastingly, participant 2 hoped that despite the challenges, she would be able to enjoy one of her favourite hobbies, playing golf. In the case of participant 4,

hope was for the future, as he explained, “I hope that I don’t lay in a hospital bed with people pumping mucus out of me the last few minutes”.

Irrespective of the feelings of hope, COPD was found to have had a big emotional impact on the participants. Most of the participants described COPD as being a “nuisance” (participants 1 and 5), “unnerving” (participant 1), “annoying” (participants 4 and 5) and even a “selfish wonder” (participant 3). Three of the participants expressed the inability to get passed the feelings of frustration, anger, and aggravation. As participant 2 stated, “I’m still in the frustration stage...I’m still angry...It’s my own fault that it’s impacting me as much as it [COPD] is...I wish it hadn’t happened...it was frustrating more than anything to have...[I am] just frustrated that I can’t do anything”. Similarly, participant 4 felt that “subconsciously it’s the frustration of not being able to do anything” that led him to often vent to his spouse, proceeding to refer to COPD as “annoying” and “maddening”. Participant 5 expressed that there was a “certain aggravation with the COPD”. He continued to explain that his aggravation stemmed from not being able to partake in activities that he used to participate in prior to COPD. Participant 2 went as far as referring to COPD as being a “punishment”.

Apart from being described as “annoying” and even ‘selfish’, having COPD brought on disheartening feelings among the participants. Participant 4 stated, “from a mental standpoint it is quite depressing...I admit not the bestest things await you as you get older”. Agreeing, participant 5 expressed, “it’s a bad feeling...it’s a sad way to go with COPD”. The participants’ spouses also felt the emotional impact. Participant 3’s wife expressed, “I wish you didn’t have it”. Similarly, participant 5’s wife shared that, “life isn’t normal really...it’s very difficult”.

Apart from the struggles associated with having COPD, two of the participants were quite cognizant of the distress that their disease brought to others. “It’s sometimes distressing to the people that I’m with when I start to...to uhhh when my breathing becomes laboured...I am very conscious of that...I don’t like to distress people” (participant 2). Sharing a similar experience participant 5 stated, “I can’t even take out the garbage can. I [start] huffing and puff and everybody’s got tears in their eyes watching me trying to struggle...I look like an old poop”.

Most of the participants associated COPD with a loss. As participant 1 explained, “you lose character”. Similarly, participant 2 expressed, “I’m less of a person than I was...I’m wearing out and I can’t get new parts”. Participant 5 shared that since the progression of his COPD, he has

not been the same. He stated, “it won’t be the same old me no more that’s for sure”. His family members have also noticed a change in him, as he explained, “I had a grandson and a granddaughter over here in August so they go ‘old grandpa is not the way he used to be’. They came up to visit me. Yea they saw that old grandpa wasn’t his normal self”.

Along with a loss of identity, some participants also experienced feelings of uselessness. Participant 2 shared that she used to “thrive on being useful”. Similarly, participant 5 viewed his inability to participate in activities that he used to partake in as demeaning. He explained, “I’m useless...It’s demeaning... If you can’t do something that you’re used to doing it’s very demeaning... You don’t feel good about it”.

Some of the participants also expressed experiencing loss of joy. As participant 2 explained, “I don’t enjoy activities the way I used to because it’s such an effort...It’s more I’ve got to get out and do things”. Walking and running, were identified as examples of previously providing joy to the participants. Participant 3 stated, “walking and running...those are the two things I miss the most”. Additionally, participant 3’s wife stated, “It’s just the pleasure of being able to walk”. One of the times when participant 4 was able to grasp the debilitating nature of COPD was when he found himself sitting alone in a chair staring outside his window. As he shared:

My wife and I used to walk a lot with dogs. We enjoyed that. It got to a point where I couldn’t do it. I guess that would be one of the times when I would think about ‘wow this isn’t good’... I sit in a chair and kind of stare off in space and my mind is working on the fact that I would like to go out and walk a half a mile (participant 4).

Another major loss that was identified by two of the participants was the loss of music. For participants 2 and 3 in particular music played a big role in their lives. The inability to enjoy it has been shown to be somewhat devastating for the participants. As participant 2 shared:

Because of my respiratory problems, I can no longer sing and that’s... has been devastating...it was a very large part of my life...music was a very large part of my life and that I regret...I’ve mourned that for a long time... It makes me cry when I hear music and can’t sing along...one of the joys of my life.

Sharing a similar experience participant 3 recalled the times when he used to play his trumpet with his band “I enjoyed it immensely. I travelled a lot with the band”. Unable to blow enough air in the trumpet, participant 3 had to stop playing it. He further elaborated on missing being able to play his trumpet, stating, “I miss it sure”.

It is not only the activities that the participants missed the most, but the simple things in life that filled them with joy. As participant 4 described, “simple things like hugging my grandson, I used to enjoy it. I can’t do it now. Have to have it done for me.” He further elaborated, “I missed a lot in the last few years...I’m retired and that’s the time I can go do things. Go places. I’ve lost all that”. Similarly, participant 5 expressed, “It’s a heck of a life...(whispering) what a way to live...those kind of things that you’d normally do after 65 years old. That’s forget it”. Sharing the same feeling of loss, participant 5’s wife conveyed “the life changes completely afterwards... it’s not the same”.

4.3.3.3 I’ve never really talked about it like this

Despite undergoing similar experiences, two of the participants acknowledged that there is a lack of discussion with regards to COPD. Participant 2 shared how she had never opened up about COPD, prior to this study; “I’ve never really talked about it like this”. Participant 5 shared how during one of his visits at the hospital he ran into some of his friends from the legion, unaware that they also suffered from COPD. Attesting to the lack of discussion, participant 5 stated, “some of my fellow legion guys are over there. Yea we see each other and I wave like ‘Hi’ ‘What are you doing here?’ ‘Oh. Same thing huh?’ ‘You’re doing a blow test too?’ ‘yea’ ‘you got COPD?’ ‘yea’ ‘Okay. Know what you mean’”.

4.4 Lived experience of information and health and support services available

4.4.1 They had good service

The theme, they had good service, refers to the participants’ experience with the use of health and support services that help them manage and cope with COPD. The following sub-themes are included my doctor is very very thorough, high degree of confidence in our medical staff, there is no COPD relief, I don’t feel the need for outside support, if it wasn’t for the wife I would be at an old age home now, and I do what I feel like doing.

4.4.1.1 My doctor is very very thorough

When using health services, almost all participants had positive experiences. Most stated that they “have been treated very effectively” (participant 1) and expressed satisfaction with the services given by healthcare providers. “I’m monitored by my family doctor who was excellent”,

expressed participant 2. Sharing the same sentiments, participant 1 and 5 stated: “our family services are exemplary” and “I’m very happy with getting treatment, seeing the doctor, quite a few specialists. They’re all within reach”. Three of the participants explained that they would not change anything about the services provided to them. Participant 2 stated:

No, I don’t think so...My doctor is very very thorough...He has seen that I have what necessary tests were available...He periodically will set up appointments for me to take the pulmonary tests and that usually occurs within a couple of weeks. It’s not a long waiting list...He has given me a lot of support

The majority of the participants and their spouses recognized having easy and quick access to the necessary healthcare services: “I have no difficulty in accessing my family doctor whatsoever” (participant 2). Similarly, participant 1's wife communicated how the physician would generally see her husband quickly when he required her services. Agreeing, participant 5's wife expressed her satisfaction by stating that “[they] never had any trouble waiting for doctors...everything has been taken care of almost immediately...[they] had good service”.

Unfortunately, not all participants had positive experiences with their primary healthcare providers. Participant 3 explained the strained relationship that he has had in the past with this primary healthcare provider: “I don’t have good rapport with that doctor...I was going to a doctor yearly and last year he said ‘you’re not getting any better but you’re not getting any worse, so there’s no sense in coming back’. I didn’t go back.” After having a disagreement with one of the doctors regarding the interpretation of a breathing test, participant 4 ceased seeing that doctor all together.

4.4.1.2 High degree of confidence in our medical staff

Overall, the participants and their spouses felt that they could trust their healthcare provider’s judgment in offering them the best care possible. The first participant expressed this by stating: “we seem to have a great or high degree of confidence in our medical staff”. Expressing the same sentiment, participant 5’s wife stated: “trust the doctors that they are able to do the best they could”. Interestingly, participant 3 trusted their physician to also recommend programs dedicated to helping manage COPD: “I imagine if there was some sort of program there he’d [doctor] probably say”.

4.4.1.3 There's no COPD relief

All participants primarily relied on doctors and specialists to help them manage their COPD. None of the participants mentioned using any specific programs or services which are geared towards helping those with COPD. However, it is worth noting that the first participant did utilize the services provided by the Veterans Independence Program offered by Veterans Affairs Canada. The fifth participant expressed a desire to use the same services; however, a lack of “war time” background deemed him as being ineligible. Upon further questioning about his knowledge regarding other services provided by Veterans Affairs for veterans with COPD, participant 5 responded by saying: “I’ve never seen them advertise anything for this particular thing...I’m ignorant of the fact...There’s no COPD relief”.

4.4.1.4 I don't feel the need for outside support

Three of the participants were satisfied with the services provided to them by their healthcare providers and felt no desire to seek new services. For two of the participants, the desire to not seek new services stemmed from not feeling the need for help outside the healthcare providers. Participant 1’s wife explained, “we haven’t felt the need to request any particular [services]”. Sharing the same sentiments, participant 2 stated: “I don’t feel the need for outside support...I don’t feel the need to become a part of them yet”. Conversely, participant 3 did not believe that programs and services geared towards COPD would be of any benefit. He stated:

I haven’t had anybody come in and say ‘Hey. How are you today’. I don’t need that...What kind of program is going to help ya? Who’s got the program? ...What are they going to do to me?... What are they going to do for me? (participant 3).

4.4.1.5 If it wasn't for the wife I would be at an old age home now

Given the debilitating nature of COPD, the majority of participants depended on either their spouses or external services such as support programs to help them with strenuous activities. Veterans Affairs had provided support to participant 1 through the Veterans Independence Program. This program provides a stipend twice a year to ensure that veterans in need do not participate in any laborious activities. As participant 1 explained, “a fellow comes and cuts the grass and does minor things to tidy up”. To further elaborate on her husband’s comment participant 1’s wife explained that he’s “had help from Veterans Affairs with things that were

very tiring such as snow removal and mowing the lawn...and gardens...and if there is you know any general maintenance”.

In addition to relying on Veteran Services, participant 1 was also heavily dependent on his spouse. Due to the loss of his licence, the participant’s wife became the sole driver helping her husband attend required programs or meetings. Praising his wife and explaining the struggle of being unable to drive, participant 1 stated: “I have the best chauffeur in the world. She sits besides me and whenever I want to or have to go to something then...uhhh it becomes even more of a chore because it takes two of us to go to one place”. Similarly, participant 5 explained the extent of dependency on his wife by stating: “if it wasn’t for the wife I would be at an old age home now”. To elaborate on her husband’s remark participant 5’s wife added: “I’m having to go shopping...I have to bathe him. He’s not able to bath anymore... Showering. I have to do that. Make meals. I have to look after your feet. [participant 5] has a problem with the feet also...I look after your face”. Unlike participant 1 and 5, the second participant depended on a housekeeper to come in once a week to help with the household cleaning.

4.4.1.6 I do what I feel like doing

Despite their struggles, some participants continued to maintain their independence. In the context of this study, independence is defined as the ability to participate in various activities without requiring the help of others. The first participant’s wife explained how “some of them [activities] are together and some of them are individual that [participant 1] goes to and I don’t. Some I go to and he doesn’t”. Similarly, participant 2 described how she has “always been a helper, a caregiver and it’s very hard to become the person who needs that care”. Upon further questioning, participant 2 provided examples of how she tried to maintain her independence, stating:

I do what I feel like doing...I do all the laundry...I do minor things around the house... I do all the grocery shopping...I do all the cooking...In the winter time I have to drive my daughter to work because she can no longer drive (participant 2)

4.4.2 Ignorance is bliss when it comes to being informed

For the purpose of this study, the key theme, ignorance is bliss when it comes to being informed, refers to the participants’ experience with receiving, using, and the understanding of

COPD. This theme includes the following sub-themes: we'd rely on the doctor, talking to our doctor, to be honest I didn't know what COPD was, and what's there to know.

4.4.2.1 We'd rely on the doctor

All participants used their physicians as a primary source of information. When questions regarding COPD arose, the participants relied on their physician to provide them with the necessary information and answers. "What ever questions I have I ask my doctor or whoever he sends me to and they answer", stated participant 2. Likewise, participant 1 stated: "I would expect that I could visit my family doctor I guess and make an appointment for and be prepared to discuss it [COPD]". Adding to her husband's comment, participant 1's wife elaborated by saying: "your biggest source of and first line of defense was your family doctor...he would've provided you with a lot of information at the time...We'd rely on the doctor to recommend some program or send us for somewhere for information". When questioned regarding the primary source of information for COPD, participant 3 responded with: "I guess what the doctor tells ya". Similarly, participants 4 and 5 identified "talking to the doctor" and the "Respirologist" as their sources of obtaining information.

The first participant's wife was also identified as a potential source of information for this couple. "As a nurse I know a considerable amount about it"- she stated. When asked about any other sources of information, participant 1's wife stated that it can include "reading something in the newspaper". Upon further reflection she also identified the Lung Association as a potential source of information: "if you read what they send...there's probably information there". Similarly, participant 4 expressed how the "Cancer Society has sent blankets advertising out they would touch on COPD".

Most participants also indicated using the Internet as a means of getting more information. Participant 1 admittedly stated, "absolutely we have". Agreeing, his wife indicated that "you can find no ends of information on the Internet to you". She further elaborated by explaining that they had used the Internet, "maybe initially when [they] first realized that it [COPD] was what [participant 1] was suffering from". Participant 4 planned to use the Internet in the future if the need arose: "we have a computer and the Internet is full of information on everything in it. I'm sure I can go in there and spend much time reading about the disease and what it is". Agreeing, participant 5 stated: "I guess I could go to the Internet. That's how easy it is". Contrary to the

previous participants, participant 2 disclosed that she disliked using computers despite having one, and therefore had not been using the Internet as a source of information.

4.4.2.2 Talking to my doctor

Most participants identified talking to their doctor and asking questions as the most frequently used format of obtaining and receiving information. Participant 2 expressed her preference of this format despite also getting information through books. Similarly, participant 3 stated, “oral...talking to my doctor”, as the preferred format of receiving information.

Aside from talking to his doctor, participant 4 also identified receiving information through pamphlets. He disclosed the following: “I’ve [got] certain medications like I mentioned, the puffers. Along with that the drug store gives you a pamphlet on what the puffer is for”. While participant 5’s wife admitted to having received a book explaining COPD when participant 5 was initially diagnosed. “I even have a little book. I went through it”, she explained. Additionally, participant 5’s wife affirmed that she learned a lot about COPD through observation. She explained how she became more knowledgeable about the disease by watching her husband and sister-in law suffer from it.

4.4.2.3 To be honest I didn’t know what COPD was

Participant 1 had no previous knowledge of any COPD related programs that could be potential sources of information. When questioned about the type of information he would like to receive regarding COPD, after a 15 second pause, participant 1 responded with “where would you go to do this?”. Regardless, the participant’s wife was aware of the existence of programs that help individuals manage and cope with COPD. She explicated: “I know they used to have a program called COLD”. Similarly, the second participant was aware of the general existence of COPD managing programs but was unable to name any specific examples. She explained by saying: “I am aware that there are programs out there yes! I’m not specifically aware of any program. I am aware that they’re out there...I could find them... I’m quite sure through the Lung Association...Through hospitals”.

Most participants, however, had a limited understanding of COPD. Due to her profession as a nurse, participant 1's wife had a clearer understanding of COPD and recognized that it was an

umbrella term that encompassed multiple lung diseases. Participant 2 had a similar understanding of COPD as she explained by stating the following:

I'm aware of what the condition is and how to manage it...I believe I understand it...It's a progressive condition...covers several different respiratory diseases: asthma, bronchitis...It's a blanket term for respiratory disease...It's a degenerative thing...there's no stopping it (participant 2)

Conversely, participant 3 had limited knowledge of COPD and was not aware of the disease until receiving his diagnosis. He understood that “there's no cure” and that “one half...the upper part of one lung is not operation now because of that [COPD]”. Similarly, participant 4 also understood that COPD is “not reversible” and that their condition will progress with age. Contrary to the other participants, participant 5 did not believe that he had a firm understanding of COPD. He stated: “to be honest I didn't know what COPD was...I heard the word many times but it didn't sync into my brain with whether it was good, or bad, or evil... I still don't know what I've got”. It appeared that participant 5's wife also had very limited knowledge of COPD as she stated: “well I don't know more than you do”. It is also important to note that despite her knowledge and understanding of COPD, participant 1's wife misconstrued the symptoms in the beginning stages of the disease. She attributed her husband's forceful clearing of the throat to his military background. She addressed her husband by saying:

I can recall when you cleared your throat every time you were to speak and quite harshly (demonstration) like that you know...forcefully and then you'd say something and then you'd might have to do it again. I thought it was because you were used to being in command and you wanted to make yourself heard...and then I discovered that it was the other way. It was the condition (wife of participant 1).

The majority of the participants understood that smoking was a major risk factor in the development of their COPD. They identified various influences that had attributed to their smoking patterns. Family was recognized as one of the biggest influences for participant 1. It was revealed that participant 1 grew up in a smoking environment, as his father was a smoker. Along with his father, participant 1's first wife was also a smoker further influencing his smoking habits. Similarly, participant 2 also lived in a smoking environment as her late husband was a heavy smoker.

Despite the familial and spousal influences, the largest factor that contributed to the smoking patterns of the participants was identified as social pressure. Participant 1 recalled how “it was the thing to do”. Sharing similar feelings as her husband, participant 1’s wife stated that “it was a very social thing to do...everyone was doing it”. This was especially true for individuals who were in the Armed Forces, such as in the case of participant 1. Similarly, participant 2 affirmed that one of the reasons they would smoke was to be socially accepted. She explained how one “would have a cocktail on one hand and a cigarette on the other”. Participant 4 remembered how “all of the movie stars did it...and promoted it very much”. Participant 4 went to further explain how he “grew up in an era where it was the thing to do. A man had to have a cigarette in his hand”.

As a very socially acceptable activity, it was somewhat of the norm for doctors to also participate in smoking. Participant 4 recalled how he would smoke with his doctor in his office. He explained:

the thing was that I knew him [doctor] fairly well and he and I would sit in his office and have a cigarette. He smoked right along with me. When I was in there talking to him it usually got around to my lungs, not all the time but a good number of times

Despite the doctor’s efforts in advising against smoking, it was his actions that had the biggest impact on participant 4. Participant 4 explained how he

knew where his [doctor] car was parked and would walk and look in and his ashtray was just overflowing. I’d say ‘well I checked your vehicle and your ashtray is overflowing again so you’re not making any effort into quitting’

When confronting the doctor for the lack of effort into quitting, participant 4 continued to claim that “[the doctor would] laugh and I’d laugh”. Despite warning against smoking many doctors would smoke themselves when encountering social situations. This inevitably defeated the purpose of their efforts against smoking cessations, as patients such as participant 4, would disregard their advice against smoking.

Easy access to cigarettes was found to be another influential factor, especially for those who served in the Military. As participant 1’s wife recalled, those who were in the Army “were provided with cigarettes very inexpensively”. Adding to his wife’s comment, Participant 1 was able to share that he was provided with “360 cigarettes for a dollar” if he wore his uniform. Two of the participants identified the lack of knowledge and information as contributors to the

prevalent smoking culture. Participant 1's wife expressed that they "didn't know back then" and there wasn't much advertised" regarding the negative effects of smoking. In fact, participant 4 made the point to state that most of the advertisements were geared towards promoting smoking rather than its cessation. He stated: "I've led a good life. It's unfortunate that I and many others were subjected to the advertising to smoke".

Given the smoking culture and lack of knowledge, most participants were not able to stop smoking until years later. For participant 1, it was his wife's superior who was the largest influence in his smoking cessation. Once participant 1's wife started working for a doctor, who was a strong advocate against smoking, many of the employees and their spouses, subsequently stopped. For participant 2, she was her own driving force when it came to her smoking cessation. She stated: "one day I just said 'no I quit'. I did, no problem". Trying to encourage her husband to stop as well, participant 2 recalled how she did not allow him to smoke inside the house. She stated: "after I quit he [spouse] had to go outside to smoke. I wouldn't let him smoke in the house and I nagged him about quitting. As all smokers I became very righteous about it". Similarly, participant 3's wife remembered that participant 3 "just quit completely".

Despite the doctor's best efforts to get participant 4 to terminate smoking, it wasn't until his retirement that this participant was able to stop. Participant 4 explained that he had been a heavy smoker for the majority of his life. He stated: "I smoked very heavily during my youth, during my middle age". Due to his addiction, participant 4, was not able to stop smoking, despite knowing the consequences. He said:

When I got to middle age and a little older, all of a sudden it's not good for you anymore. Well I didn't listen, I took this whole thing at the back of my mind 'it can't happen to me'...I still carried on because I was addicted" (participant 4)

It was the pleasure that participant 4 derived from smoking that did not deter him from doing it. As he explained: "I enjoyed very much smoking... I smoked everything. I smoked pipes, cigars, cigarettes, and I enjoyed it... yea the smoking isn't good for me but that's not going to deter me from the smoking". To portray the extent of his addiction, participant 4 shared a story of when he used to work:

I had an office. I had a desk and I had staff and they would answer the phones and if it was for me it would be directed my way. I would not answer the phone until I went and got a cigarette. I would do this without thinking...It was an unconscious reaction to a given situation (participant 4).

Despite the pleasure derived from smoking, many years later, participant 4 portrayed signs of regret and “wished he hadn’t done it”. Similarly, participant 1’s wife recalled how her husband expressed the same feelings of regret.

For participant 3, it was his occupation as a fire-fighter that affected the development of his COPD. It was the lack of breathing apparatuses that led participant 3 to being subjected to various noxious gases that would affect his lungs. He shared the following story:

I had two fires back to back like one on a Friday one on a Sunday...Saturday. No Saturday and Sunday. And one was plastics burning. You know like wiring...plastic wiring... and that really cut my throat good. And then the following day I had a fire in the (name of place) and I had to go upstairs to make a search for bodies without any of the breathing apparatus and that was a mattress burning you know the mattresses. You know the uhh stuff in the... no there is Styrofoam now back then it was padded and it was heavy and gave out heavy smoke...I went to the doctor the following Monday and he says take some 4 days off you’ve scorched your larynx near your lungs (participant 3).

Regardless of her smoking background, participant 2 believed that the air pollution in her environment played a role in the development of her COPD. She shared how:

actually it became a problem when we... when my husband came back from the Middle East and we moved to South-Western Ontario. And I really think the quality of air here umm had an impact on my already weaken respiratory system... If you look at the geography of London we’re at a peninsula. And the prevailing winds blow all that nasty stuff that they produce over at Detroit and South of us in Ohio across to us. So our quality of air here is not good...It was after we moved here that I was diagnosed. Several years after...I didn’t have any problems before that. It’s a theory.

Almost all participants were satisfied with their knowledge of COPD. Participant 3, in particular, saw that there was no benefit to additional information and gaining more knowledge. He claimed that

well there is nothing more to know? It’s just there and it’s not going to go away and it’s not going to be cured. Why beat against the bush?... I don’t need to know anymore...All I need to know is there’s no cure and it’s slowly getting bad bad bad.

Similarly, participant 5 stated that obtaining more information on COPD was something that he did not want to know about and that “ignorance is bliss”. He claimed to want to “stay blind to the fact and let life go on”.

Despite the desire to not learn more about their disease, the participants' were generally receiving limited amounts of information about COPD from their healthcare providers. As participant 1's wife explained, "nowhere I guess... I don't see that we get a lot of information". For participant 5, the healthcare provider did not offer enough information regarding the impact of COPD. The participant recalled "I never had it all explained, what's the by-product". Participant 5 also indicated that his doctor did not explain in detail what it meant to have COPD. "I've never had anyone to sit down and describe 'oh when you have COPD this is what you could expect. Don't expect to be active'. His wife recalled that when the participant was initially diagnosed, they received a booklet explaining COPD. However, since the diagnosis, the only information that the participant had received was the summary of his X-ray results. "No pamphlets, no reading material...the only thing I get is my little summary reports of what's my condition or my X-ray was". The lack of information on COPD had left participant 5 feeling frustrated. He expressed that "It's frustrating because I don't know what the other side effects is...This is a strange subject...Unknown information...I still complain about it".

4.4.2.4 What's there to know?

Majority of the participants took on a passive approach when seeking information. Participant 1's wife stated that they would ask the doctor to provide them with more information, once the disease progressed. On the other hand, participant 3 believed that there was nothing more he could know as he expressed: "what's to know? I know there is no cure so there's no sense in looking for more information". Similarly, participant 4 did not see any benefits to pursuing more information and therefore it was not his priority. He stated: "I have never really looked into a medical journal or anything like that in relation to COPD...I don't see the point in pursuing it...what's the point?" Feeling similarly, participant 5 stated that "It's obviously something not very high on my priority list... Do I really want to know? What's there to know?". Contrary to other participants, the second participant had taken an active role in learning more about her disease. She expressed that "I'm capable of doing research myself...I have looked into it myself".

4.5 Conclusion

This chapter has provided insight into the lived experiences of the participants, with COPD, the healthcare services and the information that is provided to them. The majority of the participants knew that something was wrong with their health prior to receiving their diagnosis. As a result, learning that they had COPD did not come as an initial shock. In fact, all but one participant had reached the point of acceptance. Most of the participants felt that they had no other choice but to accept their disease. All of the participants identified the use of puffers and oxygen therapy as means of treating COPD. Two of the participants used humour as a coping strategy, however most tried to manage the challenges of COPD by being vigilant and not over exerting themselves.

All participants stated breathlessness, short of breath or gasping for air, as one of the main struggles of having COPD. The majority reported being limited in their activities. Apart from the physical limitations, COPD had a major emotional impact on the participants. Most of the participants felt that having COPD was a nuisance, unnerving, and annoying. Unable to get past the stages of anger and frustration, living with COPD brought on disheartening feelings among the participants. Most participants associated COPD with a loss of identity, feelings of uselessness as well as loss of joy.

Almost all of the participants expressed their satisfaction with their healthcare providers and the use of the healthcare services. The participants and their spouses felt that they were able to trust their healthcare provider's judgment in offering them the best care possible. None of the participants mentioned using any specific programs or services outside those provided by their doctor. Some of the participants felt no desire to seek new services, outside of their healthcare provider. However, given the debilitating nature of COPD, the majority of participants depended on either their spouses or external services such as the Veterans Independence Program, to help them with strenuous activities. Despite the limitations and struggles associated with COPD, some of the participants continued to maintain their independence. When questions regarding COPD arose, the participants relied on their physician to provide them with the necessary information. However, some participants indicated using other means of obtaining information, such as other family members and the Internet. The most preferred format of acquiring and receiving information was identified as talking to the doctor. Although other means such as booklets and

pamphlets were used, almost all of the participants identified talking to their doctor as a way of receiving information.

Most participants, however, had a limited understanding of COPD. They understood that there was no cure and that COPD would progress, and that smoking was a major risk factor in the development of their disease. Almost all participants were satisfied with their knowledge of COPD. Two of the participants even expressed no benefit to further gaining knowledge and information on COPD. In general, the participants were receiving limited amounts of information about COPD from their healthcare providers. Despite the limited information received, most of the participants took on a passive approach when seeking information. Some of the participants felt that seeking more information on COPD was not a priority and there was no point in pursuing it. Being a debilitating disease, COPD, has had a major impact on all of the participants and their spouses.

5 DISCUSSION

There is a limited understanding of the lived experiences of veterans and/or their spouses with COPD. Various community and local health services are made available to help individuals diagnosed and living with COPD. In order to better assist in the development and delivery of COPD services for veterans and/or their spouses, it is important to first understand their experiences of the information and services available to them.

5.1 Lived experience with COPD

5.1.1 I don't feel so good

The diagnosis process for COPD can be long and tedious, with individuals often undertaking a series of tests. The experiences obtained from being diagnosed with a chronic disease such as COPD can affect perception and acceptance of the disease (Lindgren, Storli & Wiklund-Gustin, 2014). In their study, Lindgren et al. (2014) noted that the diagnostic process was experienced as prolonged and unclear, leaving the participants feeling overwhelmed, and unaccepting of their disease. Contrary, most participants, in the present study, had positive experiences with receiving their COPD diagnosis. After performing a series of tests, the participants were shown an X-ray of their deteriorating lungs. For the participants of this study the diagnosis of COPD did not come as a surprise, as they had begun to feel the negative impact prior to being diagnosed. Subsequently, the majority of the participants were quite accepting of their diagnosis. Only one participant had yet to accept their diagnosis. Similarly, Jankowska- Polanska, Kasprzyk, Chudiak and Uchmanowicz (2016) found that most participants in their study were accepting of their COPD.

5.1.2 Having to stop and rest

Aside from the medical treatments recommended by the doctors, the participants did not do much in terms of coping with, or engaging in self-management programs geared towards COPD. Self-management programs specifically help guide changes in health behavior and provide emotional support for individuals with this disease (Zwerink et al., 2014). Furthermore, self-management programs provide educational resources to better understand the symptoms of COPD, and offer information on the causes of the disease, prevention, and treatment (Worth,

1997). In a systematic review conducted by Effing et al. (2007), there was a significant reduction in hospitalizations among individuals with COPD who attended self-management programs. Another positive effect of these programs is the decrease in doctor and nurse visits due to the increased health education of this population. In addition, Effing et al. (2007) found an improvement in health-related quality of life among those individuals with COPD using self-management programs.

Despite the literature on the positive effects of using self-management programs to cope with COPD, the participants of this study did not see the benefits. Most of the participants were not aware of the existence and value of these programs. Some participants simply did not believe that they had reached the stage in their disease where they would require the help and support of these programs. Knowing that there is no cure available, a few of the participants believed that aside from the pharmaceutical medication, there is little that can be done to help. This lack of desire to seek help can be partly attributed to the participants' military background and culture. The Australian Centre for Posttraumatic Mental Health (2012) noted that because of having to grow up with a culture that instilled strength, veterans may hold the belief that if their health problems cannot be resolved, little can be done to help them improve. This can lead to a serious missed opportunity for veterans to gain a better understanding, and knowledge on how to cope and manage their COPD.

Rather than engaging with self-management programs, the participants used various other methods to cope with COPD. A few of the participants used humour as a coping mechanism. Despite the difficult situations, they were still able to put themselves and others at ease by having a good sense of humor. In addition, most of the participants were able to manage the challenges of COPD by being vigilant and not overly exerting themselves. Having to both physically and mentally adapt to this disease, the majority of the participants had to slow down in all aspects of their life, plan ahead, limit their number of activities, and learn to adjust their behavior when presented with a challenge.

5.1.3 We're walking a marathon

This study has demonstrated the impact that COPD has had on almost every aspect of the lives of veterans and/ or their spouses. Many of the participants who participated in this study reported respiratory symptoms such as breathlessness, coughing, spitting up phlegm, and the

clearing of the throat, as the main struggles of having COPD. This study also revealed that many of the participants felt limited in performing activities such as walking up the stairs, or household chores. As a result of being unable to continue their favorite recreational activities, for example singing, or playing a musical instrument, many participants ceased engaging in these activities altogether. Other authors have found similar results whereby these respiratory symptoms have inhibited individuals with COPD from conducting their daily routine and recreational activities (Panos et al., 2013; Mulhall et al., 2013; International Association of Fire Fighters, 2010; Guthrie et al., 2001; Seamark et al., 2004) and have led individuals to isolate themselves from their families and friends (Seamark et al., 2004; Panos et al., 2013). In the current study, however, despite the limitations presented to them, the participants had adapted new strategies to continue being active and to remain socially engaged. In a study conducted by Guthrie et al. (2001), it was found that those individuals who did not isolate themselves from their family and friends, had a better quality of life, by being more active and independent in completing their daily activities. Similarly, the findings of this study demonstrated that the majority of the participants reported performing recreational activities with their spouses, such as walking or even shopping, and did not express experiencing feelings of isolation and loneliness. Despite not having her spouse around, participant 2 remained quite active, and similar to the other participants did not express any feelings of isolation.

In addition to the physical impact, most individuals who suffer from COPD experience emotional distress. Some of the most common feelings experienced by individuals who have COPD include loneliness, embarrassment, loss, and feelings that life has no meaning (Ek & Ternstedt, 2008; Seamark et al., 2004; Hartman et al., 2013; Guthrie et al., 2001). In their study, Ek and Ternstedt (2008) found that those with COPD felt that their life had no meaning due to the extensive mental stress and anxiety experienced. In contrast, participants in this study did not express having feelings of loneliness and meaninglessness. However, they did voice feelings of uselessness. Despite having the support of their families and friends, participants who were being limited and restricted in their daily activities and functions, felt unwanted and demeaned. For many of the participants of this study, their occupation required them to be in positions of leadership, where others would seek help from them. With COPD, the participants often found themselves being in the position of dependence where they would seek help from

others. This change in status could provide a possible explanation as to why the feelings of uselessness arose for the participants.

With regard to feelings, most of the participants of this study felt a loss of identity, loss of joy brought on by their inability to engage in recreational activities, as well as loss of dreams and plans for the future. Some of the participants expressed not being their 'old selves' because they were not able to participate in activities that brought them a sense of identity and joy, such as music, or working multiple jobs simultaneously. This loss of identity often left the participants feeling devastated. Some of the participants expressed not being able to experience the simple things such as, a hug from a very close family member, or planning for their retirement with their spouses, in the same way. These results are further supported by Seamark et al. (2004), where the participants experienced similar feelings of loss with regards to their work, recreational activities, and ultimately, their dreams for the future.

In addition to loss, the feeling of embarrassment was also frequently experienced. This feeling predominantly occurred in situations where the onset of the symptoms would appear, thus distressing the people around the participants. In the present study, the participants were very cognizant of the distress that their symptoms would bring to others, causing them to feel a sense of embarrassment. Similar results have been found by Guthrie et al. (2001), where the participants felt foolish for the distress that COPD had caused others. In order to remove the stigmatization around COPD (Halding & Heggdal, 2011), health and social services need to further effectively and efficiently raise awareness about this disease. As more individuals become informed about COPD, stigmatization associated with this disease will be reduced.

Anger and frustration are among the most commonly experienced feelings by those who suffer from COPD. For the participants of this study, these feelings primarily arose due to not being able to partake in the same activities as they did prior to COPD. Similarly, Bailey (2004) described the emotional distress and frustration that one of the participants experienced after not being able to complete a seemingly trivial task such as searching for documents, without overexerting himself. The findings of this study support what has been found throughout the literature (Panos et al., 2013; Mulhall et al., 2013; Guthrie et al., 2001; Seamark et al., 2004; Bailey, 2004). COPD has a major impact on the lives of veterans, and their spouses by physically limiting their daily activities, in addition to causing them great emotional distress.

In the literature, not a lot of focus is placed on the lack of open discussion that occurs with COPD. Distinct from other studies, ‘I’ve never really talked about it like this’ among the participants emerged as a sub-theme. Talking about the limitations and emotional distress of COPD is especially hard for veterans, as the culture that they had been caught valued strength (Australian Centre for Posttraumatic Mental Health, 2012). The participants shared that this study was the first time they openly talked about the impact that COPD has had on their lives, including their experiences with healthcare services and information provided.

Perhaps this lack of discussion is more predominant among veterans due to the military culture they have had to adopt. In most cases veterans join the military services at a relatively young age, shaping their values, attitudes and beliefs (Australian Centre for Posttraumatic Mental Health, 2012). The military praises strength and the ability to adapt and overcome hardships. Consequently, seeking help and talking about the struggles of a debilitating disease such as COPD are sometimes seen as a sign of weakness. (Australian Centre for Posttraumatic Mental Health, 2012). The participants of this study acknowledged that there is a serious lack of discussion regarding COPD. For example, one of the participants was not aware that other members of his veteran club were suffering from COPD. It was only after running into them in the hospital and being treated for the same symptoms that he realized he was not the only one, attesting to the serious lack of awareness and discussion. This culture of silence may leave veterans experiencing feelings of isolation; unaware that many of their fellow comrades suffer from the same disease and experience similar physical and emotional distress. They may also become less aware of the help and support that could be provided to them, decreasing their quality of life.

5.2 Knowledge and experience of information and health and support services available

5.2.1 Knowledge and experience of health and support services

Expressing positive experiences, all of the participants trusted and primarily relied on doctors to help with COPD management. Similar results were noted by Gallefoss and Bakke (2000) whereby most participants with COPD, trusted their physicians and were satisfied with the care provided to them. In this study, only one of the participants relied on Veteran Affairs Canada, by using their Veterans Independence Program to help with household chores and general

maintenance. In the present study, one of the participants was unable to complete chores, and relied on domestic services to help her with heavy cleaning. This is in accordance with O'Brien, Ward, Jones, McMillan and Lordan (2003), whereby 7-9% of the participants, relied on domestic help services to complete household chores. Aside, from their healthcare providers, and the occasional help of services provided to aid in household chores, the participants did not report using any programs or the services of health organizations in aiding them manage COPD.

Being satisfied with management at the basic level (medical recommended treatments), the participants did not express any desire to seek out support programs for COPD. For some, this desire to not seek new services was a result of accepting their disease, and as such they saw no value in seeking further help outside of their healthcare provider. For others it was perhaps a state of denial, as they did not feel the need for help external to their medical providers. A possible reason for this self-reliance towards coping with COPD could also be due to the military culture, as veterans have been taught to adopt a strong persona (Australian Centre for Posttraumatic Mental Health, 2012).

5.2.2 Knowledge and experience of information available

The majority of the participants had a very basic understanding of COPD. They understood that it was a lung disease, that there was treatment but no cure, and for some that it was a progressive disease. Most participants understood the etiology of COPD, and attributed it mostly to smoking. Beyond this, not much was known about how COPD affected the lungs, the impact of this disease on their daily lives, and strategies or programs available to manage it. Similar results have been found throughout the literature. Hernandez et al. (2009) found that when tested, the participants' knowledge regarding COPD was found to be limited. Similarly, Gardiner et al. (2009) found that there was confusion regarding the progressive nature of the disease and the general impact, limitations and restriction that COPD would have on the participants' lives. Healthcare providers also recognize the lack of understanding regarding COPD, and the medication used to treat it (Wilson et al., 2007).

It is important for individuals with COPD to receive accurate information about this disease in order to understand it, treat it, and cope with it. Several studies throughout the literature (Delgado et al., 2015; Hernandez et al., 2009; Wilson et al, 2007; Guo et al., 2014; Gardiner et al., 2009) have found that patients use their healthcare professionals as a primary source for

receiving information. As mentioned previously, all of the participants used their physicians as their main source of receiving information regarding COPD. However, other avenues of obtaining information were also evident among the participants of this study. Due to his spouse being a nurse, and having sufficient knowledge on COPD, one of the participants relied on her for any additional information. Furthermore, some participants relied on the information that is sent out by health organizations such as the Lung Association, or the Cancer Society. Similarly, Hernandez et al. (2009) found that as many as 23% of their participants used healthcare organizations as a source of information. It was noted by Earle (2010) that some of the individuals with COPD relied on their own personal experiences with the disease, and the personal experiences of others as a source of information. This study found a similar result as one of the participants' spouses identified learning about COPD and its impact by observing her husband and sister-in-law who were also affected by this disease.

Using the Internet as a source of information is another very popular avenue chosen by the participants of this study. Most of the participants acknowledged using the Internet in the initial stages of COPD, or once they had received the diagnosis. Those individuals who had not used the Internet identified it as a potential source of information should the need arise. Most of the participants found the internet an accessible means of receiving information. Delgado et al. (2015) found that 58.5 % of the participants reported obtaining more information and knowledge of COPD by using the Internet. Similarly, Hernandez et al. (2009) found that 49% of their participants used the Internet as a primary source of attaining information with regards to their COPD. Despite the Internet being a relatively easy avenue for receiving information, as it was identified by the participants of this study, the danger of the accuracy of the information arises. Kunst and Khan (2002) revealed that regardless of the vast amount of information on COPD, substantial gaps exist related to the credibility and the accuracy of COPD content provided on websites.

As a consequence of the inadequate information provided by healthcare providers, individuals resort to the Internet as a way to attain more knowledge of COPD. (Disler et al., 2014; Guo et al., 2014; Wilson et al., 2007; Rodgers et al., 2007). There was a limited amount of information provided to most of the participants in the current study by their healthcare providers. For one of the participants, the information provided by their physician was extremely

limited, resulting in feelings of frustration with the lack of knowledge regarding COPD, and its impact. Most of the participants of this study seemed to have a very limited understanding of what COPD is, and potential treatment and management strategies. Some of the participants were not aware of the existence of COPD, until they had been diagnosed with this disease.

In the literature, the majority of individuals who have COPD would like to know more about their disease, provided that the information is delivered by a healthcare professional (Wilson et al., 2007). Rodgers et al. (2007) found similar results where the participants were open to receiving more information if it was delivered in layman's terms. In the present study, however, participants did not express any desire to obtain more information or knowledge. The majority of the participants accepted COPD for what it was, and felt no need to learn more about it. Others attributed the phrase "ignorance is bliss", and failing to recognize the benefit for further information. Most of the participants in this study took a rather passive approach to seeking more information. In spite of the limited amount of knowledge, the majority did not see the benefit to learning more about their COPD.

5.3 Limitations and challenges

This study had several limitations. There were various challenges that arose with the recruitment of the participants for this study. Despite the numerous efforts made, the researcher was unable to reach the recommended number of 10 individuals. Difficulties with recruiting veterans to participate in research studies have been noted throughout the literature (Erickson et al., 2013; Dhanani, 2002; Resio et al., 2004). Dhananin (2002) found that some of the reasons that it is difficult to recruit older veterans include transportation problems, multiple medical conditions, and increased difficulty with communication. Due to older age, some of the potential participants might have had difficulty hearing which could provide a possible explanation to not wanting to participate, as it could put them in an uncomfortable situation.

Another possible explanation could be the lack of trust and comfort associated with uncovering their personal story to a researcher. As a result of their military culture and experiences, it becomes difficult for veterans to entrust another individual with their troubles and discussing the limitations brought on by a disease such as COPD (Australian Centre for Posttraumatic Mental Health, 2012). The same could apply to spouses of veterans who might have adopted the same values, beliefs, and attitudes. Per Erickson et al. (2013) one of the reasons

why military veterans or their spouses refuse to partake in research studies was due to lack of trust. During recruitment, the researcher met with a potential participant And although reluctant at first to entrust the researcher with his experiences with COPD, he agreed to take part in the study. His wife however, was not comfortable with her husband talking about his COPD, and thus he withdrew. On hearing about this incident one of his friends who also met the eligibility criteria decided that there was nothing good worth mentioning about COPD. He also felt uncomfortable opening about the struggles and sharing his experiences. Despite the researchers many efforts to persuade them otherwise, the individuals did not trust or feel comfortable enough with the researcher to share their experiences. Similarly, Bayley et al. (2014) found that people are less likely to participate or volunteer for a research study due to the stigma associated with their illness.

Additionally, there is a declining number of veterans, especially older (WWII) veterans. Throughout the recruitment process the researcher approached numerous veteran clubs, health organizations, and individuals in the hopes of getting more participants and gaining more insight into the experiences of veterans and/or their spouses with COPD. During the recruitment process, many of the veteran clubs that were approached noted a decrease in memberships, especially from older veterans. Due to this decline in memberships from veterans, many veteran clubs had opened their doors and welcomed the public to become members. Although this was a great way for the veteran clubs to maintain support, when it came to recruiting participants a few of the individuals who had COPD were not included in the study as they did not meet the eligibility criteria of the study. However, although very willing and eager to help, most gatekeepers, and leaders of organizations referred the researcher to Parkwoods Hospital or other hospitals and long-term care facilities, where most of the veterans now resided. As this study was focused particularly on the experiences of veterans in the community, the researcher was unable to recruit at hospitals, or long-term care facilities.

The researcher was welcomed to join any events and meetings held to raise awareness of the study. The researcher attended numerous meetings and events such as general meetings, and support groups, held at various veteran clubs and health organizations in London Ontario, as well as Toronto, Ontario. Posters were also distributed through the various clubs, health organizations, and community notice boards as a means of obtaining more participants. In

addition to putting up posters throughout their organization, the Lung Association in London, Ontario circulated details of the study through social media (i.e Facebook). Awareness of the study was also raised through word of mouth from various members of the veteran clubs. Furthermore, the District Nurse Officer at Veterans Affairs, London District, provided details about the study, and ways to contact the researcher to his patients.

In an effort to reach the desired number of participants the study was expanded from London, to Ontario at large through the previously mentioned methods. However, despite all the efforts it was very difficult to try and recruit the recommended number of 10 participants. This can be attributed partly due to the declining number of older veterans especially in the community, and their culture of silence.

Additionally, another reason for the small number of participants can also be due to the very specific nature of the research itself. Recruiting veterans with COPD, presented a challenge as most of the individuals who have this disease reside in hospitals or long-term healthcare facilities. As the aim of this study was to understand the experiences of veterans who lived in community dwellings with the services that are provided to them, being unable to recruit at hospitals and long-term healthcare facilities was a major restriction for attaining more participants.

Another challenge that was presented throughout this study was the weather. Most of the recruitment process occurred during the summer, which presented a difficult challenge for those with COPD. As the hot weather directly affected their breathing and increased the symptoms, most individuals with COPD chose to stay at home and not attend the activities held at their veteran clubs, substantially reducing the number of individuals who were aware of the study. This was especially evident during the summer where activities were held at clubs, and there would be a noticeably reduced number of individuals who attended. Due to the limited number of individuals participating, some clubs had to cancel their annual summer events. In addition, a good part of the veteran clubs, and senior clubs throughout London, Ontario and Toronto, Ontario did not operate in the summer. These factors made recruiting participants especially difficult.

Trying to recruit military veterans has been shown to be challenging for researchers. For their study, Resio et al. (2004) recruited Gulf War Veterans and found that of the total number of

individuals identified as being eligible only 13.7% were contacted, and a total of 3.5% were ultimately enrolled. Similarly, Bayley et al. (2014) found that from a total pool of 11,337 veterans, 445 participants were contacted, and only 24 individuals were enrolled in the study. Dhanani (2002) found that World War II veterans are generally more reluctant to participate in studies than younger veterans. Dhanani (2002) explored 5 recruitment strategies in their study: 1) liaisons with community centers; 2) mailings to veteran membership organizations; 3) newspaper advertisements; 4) VA on-site recruitment; and 5) word of mouth. The authors found that the most successful recruitment strategy depended on various factors including the war period the veterans fought in. The strategies that resulted in the most participation were word of mouth and liaisons with community centers. Veterans aged 65 years of age and older, were more likely to respond to community center strategies, as they provide a lot of programs geared towards older individuals. Although supporting the recruitment methods of this study, the researcher was unable to recruit the desired volume of participants.

Although the participants' ethnic background was not a focus for this study, the majority of the participants were Caucasian. This could affect the results of this study as individuals of different cultural backgrounds may have different experiences with the healthcare system and information provided to them. It is important that further research be conducted and is inclusive of veterans or spouses of veterans of different cultural backgrounds to understand if their experiences with COPD, the healthcare services and information, differs from the current participants' experiences.

5.4 Contributions and recommendations

Despite being one of the subpopulations most at risk for developing COPD (Murphy et al., 2011) there has been a lack of research focused on veterans and/or their spouses with this disease. Furthermore, most of the studies that have investigated the effects of COPD among military personnel have looked at it from a purely quantitative perspective without necessarily focusing on the impact of COPD. Additionally, the information that is gained regarding the effects of COPD on veterans came from research studies conducted among US veterans. To fill this gap, this study focused specifically on the lived experiences of military veterans and/or their spouses with COPD in Ontario, Canada. Furthermore, this study contributes to the literature, by providing insight and reflecting on the experiences of Canadian veterans and spouses of

Canadian veterans, with the healthcare system and information provided to them. This could have several implications for health practices as it identifies what this subpopulation needs to better understand COPD, how to manage, and cope with their disease.

This study demonstrates the importance of patient education, awareness of self-management programs, as well as various support services being made available to veterans with COPD. Patient education has been defined as: any set of planned education activities designed to improve patients' health behaviours and/ or health status. The main purpose of patient education is to improve, or maintain health, and contribute to slow deterioration (Loring, 1992, as cited in Riemsma, Kirwan, Taal & Rasker, 2003, p.2). Patient education is essential as it provides information and helps individuals understand what the disease is, its etiology, and the impact of it on their lives.

In order to be successful, patient education and awareness strategies have to occur at various levels. Strategies targeting young individuals who smoke should occur at the preventative/primarily level. Approaches occurring at the secondary level should inform individuals of the first signs of COPD. Awareness strategies undertaken in the tertiary level should encourage the use of self-management programs (Lorig, 2001). At the primary stage patient education and awareness strategies act as preventative measures. Given that military personnel are twice more likely to develop COPD, it is important that they are informed on the dangers of this disease, and take preventative measures. Presently, smoking remains an integral part of military culture, with the relatively easy access to and cheap prices of cigarettes (Haddock et al, 2013). One preventative measure against the occurrence of COPD is eliminating the tobacco culture that the military has adopted. Increasing tobacco control and decreasing access to cigarettes in the military can lead to a reduction in the tobacco culture, and decrease in the incidence of respiratory diseases such as COPD (Haddock et al, 2013; Reid, Rynard & Burkhalter, 2015). Other preventative measures include increasing knowledge of COPD in general, its etiology and impact.

Most programs focus on educating individuals once they have been diagnosed with COPD, but not on preventative measures (Zwerink et al., 2014). The best preventative measures occur through open discussion and understanding the first-hand experiences of those who have it. More discussion around the impact of COPD needs to occur in order to reduce stigmatization of it.

Many veterans do not talk about the impact that this disease has on them, and they often feel embarrassed, or have a fear of distressing others once the symptoms start. The Lung Association has support groups for individuals who have various respiratory diseases, including COPD, to talk about their experiences in an open and safe environment. Similar support groups should be made available to veterans or spouses of veterans specifically, as it is often difficult for them to discuss the challenges of COPD. These support groups can occur at clubs dedicated to veterans, to create a more comfortable environment to discuss the limitations that COPD brings to their lives. As there is a serious lack of discussion regarding COPD, it is important that individuals who have it share their story.

Secondary patient education measures aim to inform individuals on early detection and to recognize the first signs and symptoms of COPD (Lorig, 2001). As most individuals do not seek help until the later stages of COPD (American Lung Association, 2008), it is important that they understand the early signs and symptoms of this disease. Healthcare practitioners are used as the primary source of information for most veterans. As a result, they should inform high risk veterans (i.e heavy smokers, and those prone to respiratory disease) on the warning signs of COPD. Patient education tools such as pamphlets, books, or a recommendation of a credible website should be provided upon diagnosis. Most of the participants of this study had very limited knowledge on COPD, and its debilitating nature. Thus, it is important that they are informed as to what the disease is and its implications on their lives.

Tertiary measures of patient education include the promotion of self-management programs (Loring, 2001). Currently, in Ontario, various services exist to help individuals with COPD cope with this disease. Programs led by hospitals such as the *COLD program* at St. Joseph's Hospital in London, and the *COPD program* at Rouge Valley Ajax and Pickering hospital campus, are a few programs among many others. Many of these programs include patient education, support, and management skills designed to aid the patient in coping with COPD. Similarly, the Lung Association's *BreathWorks* program is a confidential, free of charge information service that is offered to the residents of Ontario. This program allows individuals to ask any questions regarding their diagnosis, symptoms of COPD, treatments and management of this disease. In addition, *BreathWorks* provides information on how to make living with COPD easier. The issue lies in the level of awareness of the benefits of these programs, from the perspective of veterans.

Many of the participants of this study were not even aware that such programs existed, much less on the benefits that it could bring them. By having representatives of these programs attend meetings or events at veteran clubs such as the Royal Canadian Legions, information and awareness regarding the importance of self-management programs could transpire.

Furthermore, there should be an increased awareness of the services that are provided to veterans with COPD. Currently, Veteran Affairs Canada through the Veterans Independence Program, provides services to those veterans who qualify for either a disability benefit, or war veterans allowance, or are recipients of Prisoner of War Compensation (Veterans Affairs Canada, 2016). This program provides various services such as: ground maintenance services, housekeeping services, personal care and access to nutrition. Additionally, they provide transportation services and intermediate care service when the need for greater nursing or personal assistance occurs (Veterans Affairs Canada, 2016). Similar to the self-management programs, most of the participants of this study were not aware that such services were made available to them. To the researchers' knowledge there are no additional services that are provided by Veterans Affairs Canada to veterans with COPD aside from the Veterans Independence Program. This presents a problem to those veterans who have COPD and are ineligible, as was the case of participant 5 of this study. It is important to note that in the case of participant 5, miscommunications could have occurred between the individual and Veteran Affairs Canada, as to what the eligibility criteria entails. Clearer guidelines, and an increase in services for veterans with COPD, who do not necessarily fit the eligibility criteria are recommended.

5.5 Recommendations for future research

This study focused on the lived experiences of veterans or spouses of veterans with COPD in Ontario. In addition, it also explored the participants' experiences with the healthcare services and information that is being provided to them. Despite there being an increase in research studies that focus on veterans, a large gap in the literature regarding the lived experiences or coping strategies of veterans with COPD still exists. It is recommended that further research be conducted in this area. Furthermore, most of the research that has been developed has primarily focused on American veterans, creating a gap in knowledge regarding Canadian veterans.

Therefore, to help close this gap, it is recommended that future research be focused on Canadian veterans, or spouses of Canadian veterans.

Although most of the participants of this study reported positive experiences with access to and the delivery of healthcare, the majority of the participants were Caucasian. Additional research needs to be conducted with a more culturally diverse population, as their experiences with the healthcare system and the information that is provided to them may differ.

It is recommended that studies looking at the experiences of veterans with healthcare and information involve a larger sample size and include different geographic locations within Canada. Access to, and utilization of healthcare services varies within Canada. Those who live in rural areas or remote communities often have difficulty with accessing the necessary services and facilities needed to better their health (Public Health Agency of Canada, 2008). It would be beneficial to explore the experiences of veterans, or spouses of veterans living in rural and remote communities with varying access to, and utilization of healthcare services, and the delivery of information. It is recommended that research using comparative methods be conducted to examine the difference and similarities in experiences of veterans living in urban and rural places with the services and information that is provided. Furthermore, it would be beneficial to examine whether access to, and delivery of information and healthcare services, impacts the way that veterans experience their COPD. Although this study focused both on the lived experiences of veterans and/or spouses of veterans, it is recommended that in the future a comparative study be conducted to explore the similarities and differences of experience between veterans and spouses of veterans. Despite, it being dubbed as a ‘difficult’ population, research should focus on veterans or spouses of veterans, as their experiences and stories are quite remarkable.

One of the main challenges that occurred in this study was the difficulty in recruiting veterans, despite the various measures that were taken. Similar findings have been found throughout the literature (Erickson et al., 2013; Resio et al., 2004; Bayley et al., 2014; Dhanani, 2002). Although presented as a major limitation, the findings of this study provide better insight into the nature of research recruitment, especially with a ‘difficult’ population such as veterans. It was after frequent interaction with veterans, through various meetings and events, that they were able to trust the researcher, and agree to share their story. The experiences and stories

shared by the participants of this study were rich in detail and extremely rewarding. Thus, it is recommended that despite the difficult nature of the research, that future researchers, develop a rapport with them, prior to conducting the study.

5.6 Conclusion

As the number of individuals with COPD increases, the need to better understand their experiences with this disease develops (United Nations, 2015). This hermeneutical phenomenological study provided greater insight into the lives of Canadian veterans and/or their spouses with COPD. The majority of the participants for this study were both physically and emotionally impacted by COPD. This disease limited the type of recreational activities that the participants were able to participate in, as well as affecting their daily routine, and health-related quality of life. Despite their satisfaction with the health care provided, most participants had very limited knowledge and understanding of COPD and the services available to them. Greater awareness needs to be raised of the impact of COPD, and the services that are available to manage, and cope with it. Many of the participants did not know the type of services that are made available to them, and did not see any potential benefits to attending them. As a result, there is also a need for awareness on the importance and benefits of self-management programs. While the experiences with healthcare were generally positive, there needs to be an improvement of patient education by healthcare providers, and awareness on the benefits of attending services geared towards COPD.

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APPENDICES

Appendix A

Research Proposal

Project Title: Living with COPD through the eyes of veterans and their spouses residing in Ontario

Principle Investigator:

Dr. Deborah Fitzsimmons, PhD

School of Health Studies, Western University

Phone number

Student Investigator:

Erisa Deda

Masters of Health Information Science Student

phone number

Email address

Background: Chronic Obstructive Pulmonary Disease (COPD) is often neglected by individuals until it has reached an advanced stage. Smoking accounts for the majority of the COPD cases, making it the biggest risk factor. This risk is increased by two-fold for veterans. Although various community and local health services, initiatives and strategies are made available to aid with the coping and management of COPD, very little focus has been placed on gaining an understanding of the lived experiences of veterans or their spouses with COPD.

Purpose: The purpose of this study is to get a better understanding of the lived experiences of veterans or their spouses with COPD residing in Ontario. This study will gain a better understanding of the experiences of the participants with the services, information and strategies provided to them for coping and managing COPD.

Research Plan: This qualitative study is going to use hermeneutic phenomenology as its methodological approach. Participants will be asked to participate in a semi-structured individual interview, lasting approximately an hour, to discuss their experiences with COPD as well as the information and services provided to them for managing COPD. The following questions will guide the interview: 1. What is it like living with COPD? 2. What are your experiences with the health services you receive to help you manage

your COPD? 3. How have the health services that you use provided you with information about COPD? Data will be analyzed using the principles of Heideggerian phenomenology.

Significance: The focus of this study is to obtain a better understanding of the experiences of veterans or their spouses living with COPD, and the information and services provided to them. By having a better understanding of these experiences, this study has the potential to inform and raise awareness of these services and hopefully improve the development and delivery of COPD services for veterans or their spouses.

Appendix B

Letter of Information

Living with COPD through the eyes of veterans and their spouses residing in Ontario

Principal Investigator:

Deborah Fitzsimmons, PhD

Address

phone number

Co-Investigator:

Erisa Deda, MHIS candidate

Address

Phone number

Conflict of Interest

There are no known conflicts of interest to report.

Introduction

You are being invited to participate in this research study about the experiences of veterans or their spouses living with Chronic Obstructive Pulmonary Disease (COPD). This information will provide us with a better understanding of what it is like to live with COPD, and the information and health services available to you to help you manage your COPD.

The purpose of this letter is to help you decide whether to take part in this study by providing you with information to help you make your decision.

Before agreeing to take part in this study it is important that you understand all of the information provided to you in this letter.

Purpose of the Study

COPD is a chronic condition that most frequently results from smoking, and military veterans have been shown to be more likely to have been smokers, which increases their risk of getting COPD.

However, very little research has been done looking specifically at veterans and their families. We would like to talk to you to find out about your experience of living with this disease.

There are a number of health services available to help manage COPD. We would like to find out which of these services you are aware of, and which you use to help manage your COPD.

Who can be included in the study?

Can you answer ‘Yes’ to all of the following questions:

- Do you live in Ontario
- Are you 65 years of age or older
- Have you been diagnosed with COPD (including chronic bronchitis or emphysema)
- Are you a Canadian veterans or the spouse of a military veteran?
- Are you a current or former smoker,
- Do you speak English well?

If you answered ‘Yes’ to each of these questions, then we would like to talk to you and include you in the study.

Who cannot be included in this study?

If you were not able to answer ‘Yes’ to all of the questions above, then we thank you for your interest in our work, but at this time you are not eligible to take part in the study.

Study Procedures – What is involved if you choose to participate?

If you chose to take part in this study, you will be asked to meet and chat with Erisa Deda for no more than an hour. During this time, you will be asked to talk about your experiences with COPD and the information and health services available and used by you for your COPD. This conversation will be held at a location and time of your choosing, either in a private setting such as your home, or a more public setting such as a café, club or shopping mall. With your permission the conversation will be recorded to ensure that we include the information you provide accurately. You have the right to let the researcher know if you want to stop the recording at any point during the discussion and you are very welcome to participate even if you do not wish to be recorded.

Confidentiality

Information collected in this study will be kept confidential and will only be used for this study.

The results of this study may be presented or published, however, your name will never be disclosed. All information will be kept strictly confidential and will be stored in a locked filing cabinet, in a locked research office at the University of Western Ontario. As per the University of Western's policy the study data will be kept for a minimum of 5 years. Representatives from the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

Voluntary Participation

Taking part in this study is completely voluntary and you may wish to decline participation, refuse to answer any questions or withdraw from the study at any point in time without any consequences. If you wish to withdraw from the study, all information provided up to that point will not be used in the study. Please note that if you choose to partake in the following study, none of your legal rights will be waived by signing the Consent Form.

Risks – What are the possible risks if you participate?

There are no foreseeable risks involved for those who chose to take part in this study. We know that COPD can make prolonged talking tiring. During the conversation you will be reminded that you have the right to refuse to answer any questions or dwell on any topics that you may find upsetting in any way, and you will be encouraged to take periodic breaks to ensure your comfort.

Benefits

You do not directly benefit from participating in this research study. However, we hope that with your help we can gain a better understand of what it is like to live with COPD, and about the health services available to you. By having a better understanding of these experiences, we hope that this study can help to make people aware of this condition, and to support the delivery of services to help manage this condition.

Questions About the Study

If you have any questions about this study or if you require any further information regarding your participation in this study, please contact Erisa Deda at *phone number* or through email: *email address*

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics (519) 661-3036, email: ethics@uwo.ca.

Other Information

Please note the consent form attached to this document. If you are interested in taking part in this study, please sign the consent form and return it to, Erisa Deda, graduate student at the University of Western Ontario, *phone number*, email: *email address*

This letter is yours to keep.

If you are interested in the results of this study, we are happy to provide you with our general findings once the study has been completed.

Consent Form

Project Title: Living with COPD through the eyes of veterans and their spouses residing in Ontario

Study Investigators Names:

Dr Deborah Fitzsimmons, PhD

Erisa Deda

I have read the Letter of Information and I have been provided information regarding the nature of this study. I have been given the opportunity to ask questions. All questions have been answered to my satisfaction and I agree to participate in this study.

Participant's Name (please print):

Participant's Signature:

Date:

Person Obtaining Consent (please print):

Signature:

Date:

Appendix C

Demographic Information- veterans

Section A: General Information

1. How many years have you lived in Ontario? _____ years

2. Are you: _____ male _____ female _____ other

3. In which year were you born? _____

4. What is your current marital status (check one):

_____ single	_____ married
_____ widowed	_____ divorced
_____ separated	_____ common-law

5. What are your current living arrangements? Do you live (check one):

_____ alone
_____ with your spouse or partner
_____ with another member of your family (e.g., child; grandchild)
_____ with a friend or roommate
_____ or with someone other than mentioned above

 (please specify: _____)

6. Do you currently have a caregiver or helper? _____ yes _____ no

If yes, who is your caregiver or helper (check one):

_____ relative	_____ health professional
_____ friend	_____ other (please specify:

 _____)

7. How often do you leave your home (check one)?

_____ nearly every day	_____ once every two weeks
_____ 3 to 5 days per week	_____ once per month
_____ 1 to 2 days per week	_____ less than once per month
_____ mostly on weekends	_____ almost never

8. In which of these military services have you served in?
_____ Navy _____ Air Force _____ Army
9. What is your military rank? _____
10. Have you ever been deployed? If yes, where have you served? (Please provide your answer in the blank space below):

Section B: Health Information

11. How would you best describe your current health status? (Check the one that best describes how you feel):
_____ Excellent _____ Very Good _____ Good
_____ Fair _____ Bad _____ Very Bad
_____ Extremely Bad
12. Approximately, how many times have you been admitted to the hospital this past year?

13. Please check how you would currently rank your Chronic Obstructive Pulmonary Disease (includes: Chronic Bronchitis and Emphysema):
_____ Mild _____ Moderate _____ Severe _____ Very Severe
14. Approximately, for how long have you been living with Chronic Obstructive Pulmonary Disease (includes: chronic bronchitis and emphysema)

15. Are you a current smoker? Please circle the one that best describes your situation
1) No, I have never smoked 2) I have quit within the last 5 years
3) I have quit within the last 6 + years 4) Yes, I currently smoke

Section C: Community Support and Health Service Information

16. Do you currently use any **health services**? _____ yes _____ no

If yes, please list the health services you use:

17. How often do you use these services:

_____ every day	_____ a few times per month
_____ a few times per week	_____ once per month
_____ once per week	_____ rarely

18. How happy/ satisfied are you with the health services provided?

_____ extremely happy/extremely satisfied	_____ happy/satisfied
_____ somewhat happy/satisfied	_____ not happy/dissatisfied
_____ extremely unhappy/extremely dissatisfied	

19. How easy is it for you to access health services?

20. Are the services that you need to help you cope/ manage Chronic Obstructive Pulmonary Disease (including: chronic bronchitis and emphysema) easy to access?

_____ Yes _____ No (please briefly explain why not in the space below):

21. Do the health services that you use, provide you with the enough information to help you cope/ manage Chronic Obstructive Pulmonary Disease (including: chronic bronchitis and emphysema)? Note: If you do not use any health services please skip to the next question

_____ Yes _____ No (please briefly explain why not in the space below):

For office use only:

Reference: _____

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS DEMOGRAPHIC INFORMATION!

Appendix D

Demographic Information- spouses of veterans

Section A: General Information

1. How many years have you lived in Ontario? _____ years

2. Are you: _____ male _____ female _____ other

3. In which year were you born? _____

4. What is your current marital status (check one):

_____ single	_____ married
_____ widowed	_____ divorced
_____ separated	_____ common-law

5. What are your current living arrangements? Do you live (check one):

_____ alone
_____ with your spouse or partner
_____ with another member of your family (e.g., child; grandchild)
_____ with a friend or roommate
_____ or with someone other than mentioned above

(please specify: _____)

6. Do you currently have a caregiver or helper? _____ yes _____ no

 If yes, who is your caregiver or helper (check one):

_____ relative	_____ health professional
_____ friend	_____ other (please specify: _____)

7. How often do you leave your home (check one)?

_____ nearly every day	_____ once every two weeks
_____ 3 to 5 days per week	_____ once per month
_____ 1 to 2 days per week	_____ less than once per month
_____ mostly on weekends	_____ almost never

Spousal Information

8. In which of these military services has your spouse served in?
_____ Navy _____ Air Force _____ Army
9. What is their military rank? _____
10. Have they ever been deployed? If yes, where have they served? (Please provide your answer in the blank space below):
11. Was your spouse a smoker? Please circle the one that best describes their situation
1) No, they have never smoked 2) They have quit within the last 5 years
3) They have quit within the last 6 or more years 4) Yes, they currently smoke
12. If yes, did your spouse smoke before, during or after joining the military?

13. Has your spouse ever been diagnosed with Chronic Obstructive Pulmonary Disease?
Yes _____ No _____

Section B: Health Information

14. How would you best describe your current health status? (Check the one that best describes how you feel):
_____ Excellent _____ Very Good _____ Good
_____ Fair _____ Bad _____ Very Bad
_____ Extremely Bad

15. Approximately, how many times have you been admitted to the hospital this past year?

16. Please check how you would currently rank your Chronic Obstructive Pulmonary Disease (includes: Chronic Bronchitis and Emphysema):

_____ Mild _____ Moderate _____ Severe _____ Very Severe

17. Approximately, for how long have you been living with Chronic Obstructive Pulmonary Disease (includes: chronic bronchitis and emphysema)

18. Are you a current smoker? Please circle the one that best describes your situation

- | | |
|--|--|
| 1) No, I have never smoked | 2) I have quit within the last 5 years |
| 3) I have quit within the last 6 + years | 4) Yes, I currently smoke |

Section C: Community Support and Health Service Information

19. Do you currently use any **health services**? _____ yes _____ no

If yes, please list the health services you use:

20. How often do you use these services:

_____ every day	_____ a few times per month
_____ a few times per week	_____ once per month
_____ once per week	_____ rarely

21. How happy/ satisfied are you with the health services provided?

_____ extremely happy/extremely satisfied	_____ happy/satisfied
_____ somewhat happy/satisfied	_____ not happy/dissatisfied
_____ extremely unhappy/extremely dissatisfied	

22. How easy is it for you to access health services?

23. Are the services that you need to help you cope/ manage Chronic Obstructive Pulmonary Disease (including: chronic bronchitis and emphysema) easy to access?

___ Yes ___ No (please briefly explain why not in the space below):

24. Do the health services that you use, provide you with the enough information to help you cope/ manage Chronic Obstructive Pulmonary Disease (including: chronic bronchitis and emphysema)? Note: If you do not use any health services please skip to the next question

___ Yes ___ No (please briefly explain why not in the space below):

For office use only:

Reference: _____

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS DEMOGRAPHIC INFORMATION!

HELPING VETERANS HAVE A VOICE!



Do you have COPD?

Are you a **military veteran** or the **spouse** of a veteran?

Are you 65 years of age or older and a current or former
smoker?

Are you interested in improving COPD services?

Then I would really like to talk to YOU!

I want to learn more about what it is like for veterans or their
spouses to live with COPD and the services available

**You will be asked to take part in a conversation
that will last no more than an hour**

For more information or to volunteer for this study, please
contact:

Erisa Deda

Western University

Email: *email address*

Telephone number

Erisa Deda

Erisa Deda

Erisa Deda

Erisa Deda

Erisa Deda

**Veterans COPD
study**

**Veterans COPD
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**Veterans COPD
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**Veterans COPD
study**

Phone number

Phone number

Phone number

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Email:

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Appendix G

Interview Guide (veterans)

“Thank you for taking the time to help us with our research study.”

"Before I start the interview, I would like to remind you that your participation in this research study is completely voluntary, and if you wish to withdraw during any point, you may do so, without any consequences. If at any point during this interview you feel any physical or emotional discomfort, please let me know and I will stop and we can reschedule at another time. Please let me know, if at any point you would like to take any breaks. I would also like to inform you that you have the right to refuse to answer any questions, that might cause you any type of discomfort."

“This interview will be tape recorded to make sure that I capture your feedback accurately. The recorder can be turned off at any time if you would like to share something that you do not want to be recorded. I will also be taking notes throughout the interview, and if you would like I would be happy to share them with you once the interview is over.”

TURN ON THE TAPE RECORDER.

Introductory question icebreaker: Please tell me how long you have lived in Ontario and what do you like most about it?

I. LIVED EXPERIENCES OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE

1. What is it like living with COPD?

Probing questions:

- a) Can you describe what it is like having COPD?
- b) Can you describe a normal day to me?
- c) What is your day-to-day routine like?
- d) What do you find most challenging to do in your day-to-day routine because of the COPD?
- e) What do you find most challenging about having COPD?
- f) How do you cope with the challenges that you face because of COPD?
- g) How has having COPD affected you?
- h) How does having COPD impact your everyday life?



- i) Are there any activities that you used to enjoy doing prior to having COPD but do not do anymore? If, yes what type of activities?
- j) What symptoms do you experience the most in any given day?
- k) Can you describe what it is like experiencing these symptoms?
- l) What does having COPD mean to you?

II. EXPERIENCES WITH HEALTH SERVICES

2. What are your experiences with the health services you receive to help you manage your COPD?

Probing questions:

- a) What types of health services do you use to help you manage COPD?
- b) What types of health services are you aware of that can provide help in managing COPD?
- c) Are there any particular health services that you do not use? If yes, what would you say the difference is between these services and the ones you do use?
- d) Please describe your experiences in accessing and using health services.
- e) How frequently do you use these services?
- f) Are these services easy to access?
- g) Describe what it was like the first time you used these services?
- h) Describe what it was like the last time you used these services?
- i) How do you feel about the type of services you receive?
- j) What do you like most about the services provided?
- k) What do you dislike the most about these services?
- l) Would you change anything about the services that are provided to you?
- m) How do these health services help you with coping/managing COPD?
- n) How do these services help you with better understanding COPD?

III. EXPERIENCES WITH INFORMATION PROVIDED

3. How have the health services that you use provided you with information about COPD?

Probing questions:

- a) What do you know/understand about COPD?
- b) What has been your primary source of receiving the information that you need to help you better understand or manage COPD?
- c) What type of information regarding COPD would you like to know more about?
- d) What has been the format of the information that you have received with regards to better understanding COPD and managing/coping with it?
- e) What do you like most about this format?
- f) What do you dislike the most?
- g) Can you tell me about services you haven't used but are aware of?

IV. CONCLUSION

4. Do you have any other thoughts about COPD or the type of information and health services provided to you? Have we missed anything?

Appendix H

Interview Guide- spouses of veterans

“Thank you for taking the time to help us with our research study.”

"Before I start the interview, I would like to remind you that your participation in this research study is completely voluntary, and if you wish to withdraw during any point, you may do so, without any consequences. If at any point during this interview you feel any physical or emotional discomfort, please let me know and I will stop and we can reschedule at another time. Please let me know, if at any point you would like to take any breaks. I would also like to inform you that you have the right to refuse to answer any questions, that might cause you any type of discomfort."

“This interview will be tape recorded to make sure that I capture your feedback accurately. The recorder can be turned off at any time if you would like to share something that you do not want to be recorded. I will also be taking notes throughout the interview, and if you would like I would be happy to share them with you once the interview is over.”

TURN ON THE TAPE RECORDER.

Introductory question icebreaker: Please tell me how long you have lived in Ontario and what do you like most about it?

I. LIVED EXPERIENCES OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE

1. What is it like living with COPD?

Probing questions:

- a) Can you describe what it is like having COPD?
- b) Can you describe a normal day to me?
- c) What is your day-to-day routine like?

- d) What do you find most challenging to do in your day-to-day routine because of the COPD?
- e) What do you find most challenging about having COPD?
- f) How do you cope with the challenges that you face because of COPD?
- g) How has having COPD affected you?
- h) How does having COPD impact your everyday life
- i) Are there any activities that you used to enjoy doing prior to having COPD but do not do anymore? If, yes what type of activities?
- j) What symptoms do you experience the most in any given day?
- k) Can you describe what it is like experiencing these symptoms?
- l) What does having COPD mean to you?

2. Background history of them and partner

Probing questions:

- a) Have you ever smoked in your life?
- b) If yes, were you a regular smoker or a social one?
- c) What was the reason for smoking (i.e was it for social reasons –when you went to social events with their spouse; stress relief, coping mechanism, start because their partner was a smoker)?
- d) What might you think are the reasons that got you to start smoking in the first place?
- e) Was your partner a smoker?
- f) If yes, What kind of smoker? – i.e social, regular, heavy?
- g) If non-smoker: do you think you have been exposed to second-hand smoke?
- h) Where would you have been exposed to second-hand smoke- ie social events; being around smoking partner?
- i) Why do you think you got COPD?
- j) Do you believe it is because of the place you live in now?
- k) When did you first move here?
- l) When were you first diagnosed with COPD?

II. EXPERIENCES WITH HEALTH SERVICES

- 2. What are your experiences with the health services you receive to help you manage your COPD?

Probing questions:

- a) What types of health services do you use to help you manage COPD?
- b) What types of health services are you aware of that can provide help in managing COPD?
- c) Are there any particular health services that you do not use? If yes, what would you say the difference is between these services and the ones you do use?
- d) Please describe your experiences in accessing and using health services.
- e) How frequently do you use these services?
- f) Are these services easy to access?
- g) Describe what it was like the first time you used these services?
- h) Describe what it was like the last time you used these services?
- i) How do you feel about the type of services you receive?
- j) What do you like most about the services provided?
- k) What do you dislike the most about these services?
- l) Would you change anything about the services that are provided to you?
- m) How do these health services help you with coping/managing COPD?
- n) How do these services help you with better understanding COPD?

III. EXPERIENCES WITH INFORMATION PROVIDED

3. How have the health services that you use provided you with information about COPD?

Probing questions:

- a) What do you know/understand about COPD?
- b) What has been your primary source of receiving the information that you need to help you better understand or manage COPD?
- c) What type of information regarding COPD would you like to know more about?
- d) What has been the format of the information that you have received with regards to better understanding COPD and managing/coping with it?
- e) What do you like most about this format?
- f) What do you dislike the most?
- g) Can you tell me about services you haven't used but are aware of?

IV. CONCLUSION

4. Do you have any other thoughts about COPD or the type of information and health services provided to you? Have we missed anything?

Appendix I

Ethics Approval Form



Research Ethics

**Western University Health Science Research Ethics Board
HSREB Amendment Approval Notice**

Principal Investigator: Dr. Deborah Fitzsimmons
Department & Institution: Health Sciences/Faculty of Health Sciences, Western University

Review Type: Delegated
HSREB File Number: 107532
Study Title: Living with COPD through the eyes of veterans and their spouses residing in Ontario

HSREB Amendment Approval Date: June 16, 2016
HSREB Expiry Date: February 18, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Other	Appendix I- Interview guide for the spouses	2016/06/10
Other	Appendix H- Demographic Information for the spouses	2016/06/10
Advertisement	Advertisement- Poster - new version (Received 9Jun16)	
Revised Western University Protocol	Ethics Protocol revised (Received 9Jun16)	
Revised Letter of Information & Consent	Letter of Information revised- clear copy	2016/06/10

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the amendment to the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 0000946-



Ethics Officer, on behalf of Dr. Joseph Gilbert, HSREB Chair

Ethics Officer: Erika Beale Kristya Harris Nicole Kanak Gwae Kelly Viki Tran Karna Doodal

Appendix J

Wholistic reading- Participant stories

Participant	
1	Male. Interview took place at the participant's home. His spouse also wanted to take part in the interview. Not in the best state of health. COPD is not viewed as a disease but condition. Loss of character. Unnerving. Difficult to adapt at first. Uses VIP. Continue to be active. Dependent on wife. Feelings of hope. Doesn't use self-management programs. Trust in physicians. Satisfied in care provided. Strong support system. Has an additional disease.
1 a	Female. Spouse of participant 1. Provides input on the lived experiences of her husband's disease. Not very restrictive. Learned to compensate. Slowing down. Won't push it with activities. Use of VIP program. Don't get a lot of info. Aware of self-management programs. Doctor first source of information.
2	Female. Met at a veteran's club. Full of energy. Very active. Always busy. Restricted. Cognizant of distressing others. Loss of activity enjoyment. Feelings of anger and frustration. Very satisfied with healthcare provided. Knowledgeable of COPD. Independent. Aware of self-management programs. Chooses not to attend them. Not accepting of COPD. Sense of sadness when talking about loss of singing. Emotionally impacted by COPD. Opened up about COPD for the first time. Can't accept it because cares for someone. Acceptance equals defeat. Still fighting it. Cries when hears music. Struggle. Golden years are tarnished. Limited. Has to modify behavior. Doctor is a source of support. COPD is not manageable. Feelings of uselessness.
3	Male. Interview took place at the participant's home. His spouse also wanted to join in the interview. Not forthcoming. Strong. Resilient. Limited in activities. Still plays golf. Can't play trumpet or be in a band. Misses it. Have to know own control. Unable to travel. Copes by weighing the challenges and sees if is able to achieve them. Used to travel with his wife often prior to COPD. Views COPD as a selfish wonder. Doesn't see the benefit to self-management programs. Believes that because there is no cure there is nothing more that can be done. Caused due to his occupation as a

	<p>firefighter. Doctor as a source of information. Live with it. Doctor hasn't provided any information on self-management programs. No interest for more information. Physically still hurting but there is no pain.</p>
3a	<p>Female. Spouse of participant 3. Wanted to join in the interview and provide her feedback on her husband's condition. Restricted in walking. Miss the joy of walking around. Unable to walk up the basement. Unable to talk if he comes up from the basement. Live with it. Used to it. Part of life. Can't remember when he didn't have it. Miss playing the trumpet. Wish he didn't have COPD. Take everything in stride. Tough. Can hear husband gasping for air when walking.</p>
4	<p>Male. Interview occurred on the phone due to geographical distance. Remains active. Suffers from another disease, in addition to COPD. Takes away from lifestyle. Is okay when not exerting self. From a mental standpoint it's depressing. Affects daily life. No energy and motivation. Used to be a very heavy smoker. Got a lot of pleasure from smoking. Addicted to it. Had the mindset that it wouldn't happen to him. Continued to smoked despite knowing the consequences. Acceptance. Did not worry or shame self. Limited and restricted in activities. Does not attend any self-management programs. Does not pursue information. Does not see the point to getting more information. Doctor source of information. Wife is emotional support. Has not gotten information from anywhere. Restricted in walking up the basement. Doesn't think about the limitations of COPD. Emotionally distressed when is unable to walk with his wife, or hugging grandson. Feelings of frustration and annoyance with COPD.</p>
5	<p>Male. Met at the participant's home. Humorous individual. Feelings of aggravation. Very hard working. Frustrated that is unable to work like prior to COPD. Unable to do chores around the house. Nuisance. Restricted in what is able to do. Vigor is gone. Cognizant of distressing others. Emotionally impacted by COPD. Feelings of uselessness. Demeaning. Loss of enjoyment. Doctor source of information. Does not use any self-management programs. Is unaware that they exist. Frustrated with the lack of information provided by doctor. Still doesn't fully comprehend what is the impact of COPD. No desire to seek more information. Ignorance is bliss. Slowing down. Satisfied with the type and efficiency of health services received. Unaware of services from Veterans Affairs. Dependent of wife.</p>

5a	Female. Spouse of participant 5. Expressed a desire to share her input on her husband's experiences with COPD. Has to stop constantly when doing an activity. Unable to walk from the basement. Can hear him coming. Life is not normal. Caring for her husband is not a burden. Has learned about COPD from watching her husband and his sister. Same knowledge regarding COPD as her husband. The doctor provided her with a book on COPD when husband was first diagnosed. It's very difficult. Places trust on doctors. Satisfied with care provided. Has come to accept her husband's illness.
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Appendix K

Second Cycle Coding example

Information source	“reading something in the newspaper”
	Lung Association
	Family members
	“as a nurse I know a considerable amount about it”
	Family doctor
	“your biggest source and first line of defense was your family doctor”
	Internet
	“I would expect that I could visit my family doctor I guess and make an appointment for and be prepared to discuss it [COPD]”
	“whatever questions I have I ask my doctor or whoever he sends me to and they answer”
	“I guess what the doctor tells ya”
	Health organizations
	“cancer society has sent blankets advertising out they would touch on COPD”
	“the drug store gives you a pamphlet on what the puffer is for”

	<p>“you can find no ends of information on the Internet to you”</p>
	<p>“we have a computer and the Internet is full of information on everything in it. I’m sure I can go in there and spend much time reading about the disease and what is it”</p>

Appendix L

Socio-demographic Information

Characteristics	Participants (n=5)
Residence in Ontario (years)	London- 67 years (participant 1) London- 59 years (participant 2) London- 15 years (participant 3) Tillsonburg- 78 years (participant 4) Toronto- 50 years (participant 5)
Gender	Male (n=4) Female (n=1)
Age (years)	81.6 (range 76-92) (SD= 6.2)
Marital Status	
Single	n=0
Widowed	n=1
Separated	n=0
Married	n=4
Divorce	n=0
Common-law	n=0
Living Arrangements	
Alone	n= 0
With spouse/partner	n= 4
Another family member (child, grandchild)	n=1

Friend/roommate	n=0
Someone other than mentioned above	n=0
Caregiver	
Noone	n=3
Relative	n=0
Health professional	n=1
Friend	n=0
Other	n=1 (wife)
Leaving the house	
Nearly every day	n=4
3-5 days per week	n=1
1-2 days per week	n=0
Mostly on weekends	n=0
Once every two weeks	n=0
Once per month	n=0
Less than once per month	n=0
Almost never	n=0
Military service	
Navy	N=2
Army	N= 2 (one is spouse of participant)
Air Force	N=1 (spouse of participant)
Deployment	
No	N=3
Yes	N=2 (one is spouse of participant)

Perception of health status	
Excellent	N=0
Very Good	N=1
Good	N=2
Fair	N= 1
Bad	N= 1
Very bad	N=0
Extremely bad	N=0
Hospitalization in past year	
None	N= 3
Once	N= 2
COPD level	
Mild	N=0
Moderate	N=2
Severe	N= 2
Very Severe	N=0
Living with COPD	
0-5 years	N=0
6-10 years	N=2
11- 20 years	N= 2
21- 30 years	N=0
31- 40 years	N=1
41 + years	N= 0
Smoker	

No, I have never smoked	N= 0
I have quite within the last 5 years	N= 0
I have quit within the last 6 + years	N= 5
Yes, I currently smoke	N= 0

Appendix M

Community and healthcare services, and information used

Characteristics	Participants (n=5)
Health services usage	
Yes	N= 4
No	N=1
Health services (if yes)	
General practitioners	N=4
Specialists	N=1
Community Services	N=1
Frequency of services used	
Everyday	N=0
A few times per week	N=1
Once per week	N=1
A few times per month	N=1
Once per month	N=0
Rarely	N=1
Satisfaction	
Extremely satisfied/happy	N=2
Satisfied/happy	N=2
Somewhat happy/ satisfied	N=0
Not happy/dissatisfied	N=0
Extremely unhappy/extremely dissatisfied	N=0

Access to healthcare services	
Easily accessed	N=4
Not easily accessed	N=0
Access to COPD services	
Easily accessed	N=3
Not easily accessed	N=1
Enough information about COPD	
Happy with the information presented by healthcare providers	N=2
Not enough information presented by the healthcare providers	N=2

CURRUCILUM VITAE

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Education

Masters of Health Information Science
2014- present
The University of Western Ontario
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Related Work Experience

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Publications:

Bouchard M, Amin A, Pinsker E, Khan R, Deda E, Daniels TR. The impact of obesity on the outcome of total ankle replacement. *J Bone Joint Surg (Amer)*. 2015; 97:904-910.

Conference Presentations

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Gerontology 2016: Fostering Innovation in Research on Aging, the 45th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology, Montreal, Quebec, October 20-22, 2016. Poster Presentation

Deda, E., Fitzsimmons, D., Klooseck, M., & Savundranayagam, M. (2016). Living with COPD through the eyes of war veterans residing in London, Ontario. Faculty of Health Science Research Day 2016 and 3- Minute Thesis Competition, University of Western Ontario, London, Ontario, March 22, 2016. Poster Presentation.

Deda, E., Fitzsimmons, D., Klooseck, M., & Savundranayagam, M (2016). Living with COPD through the eyes of war veterans residing in London, Ontario. Crossroads Interdisciplinary Health Research Conference, Dalhousie University, Halifax, Nova Scotia, March 12, 2016. Oral Presentation

Bouchard, M., Amin, A., Pinsker, E., Khan, R., Deda, E & Daniels, T. (2014). The Impact of Obesity on the Outcome of Total Ankle Replacement. AAOS Annual Meeting 2014, Louisiana, New Orleans, March 14, 2014. Paper Presentation

Deda, E. (2014). The link between cell phone usage and sleep deprivation. Population Health and Policy Conference, University of Toronto Scarborough, Toronto, Ontario, March 1, 2014. Poster Presentation