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Exploring the Lived Experiences of Women with Chronic Obstructive Pulmonary Disease

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Abstract

Currently, there are many barriers to women seeking diagnosis and treatment for chronic obstructive pulmonary disease (COPD). These barriers include greater under-diagnosis and fewer medical consultations. Often thought of as a "male smoker's" disease, in the past decade there has been a sharp increase in the number of COPD cases in women. This research explored the lived experiences of women with COPD through diagnosis and treatment. This research used van Manen’s hermeneutic phenomenological methodology guided by a critical theory paradigm. The results highlighted the experiences of women with COPD, what women want from their care, and recommendations to better support women’s journeys with COPD. Without access to information and timely diagnosis, women with COPD are unable to improve their quality of life. By exploring the experiences of women with COPD, this research can help support the development of solutions to allow women to receive better support through their COPD journeys.

Keywords

Chronic obstructive pulmonary disease (COPD), Pulmonary rehabilitation, Provider, Phenomenology, Lived experiences, Critical theory, Women’s health

Summary for Lay Audience

Currently, there are many barriers to women seeking diagnosis and treatment for Chronic Obstructive Pulmonary Disease (COPD). These barriers include less diagnosis and less visits with a doctor, among others. COPD is a lifelong disease that affects the lungs and ability to breathe freely. This causes extreme discomfort and a lower quality of life. COPD can cause a recurring cough, breathlessness, and tiredness. There is no cure for COPD; treatments for the disease are used to manage symptoms. As such, the quality of life of a person living with COPD can depend on the care that is being received. Often thought of as a "male smoker's" disease, in the past decade there has been a sharp increase in the number of COPD cases in women. Despite limited research on the sex and gender differences surrounding COPD, there is no research that focuses on women’s experiences through their diagnosis and treatment journeys.

Our study explored women’s experiences through their diagnosis and treatment journeys. This research sought to understand these experiences and explore ways to improve their journeys. This was done by conducting one-on-one interviews with women with COPD to gain an understanding about their experiences directly from them.

The findings from this research highlighted different aspects that make up women’s experiences living with COPD. Women in this study shared their stories and discussed ways their journey could have been improved. Participants expressed the desire to be understood by providers and treated holistically as ways to improve their diagnosis and treatment journeys. The importance of increased awareness and education to the public around COPD was emphasized. These topics can be used to create recommendations to better support women through their COPD journeys.

This study is timely and focuses on the experiences of women with COPD from women living it. Allowing them to use their voice and share what is important to their journey with COPD will allow us to better support women with similar experiences. It is important to share the voice of women with COPD in a space where it had previously been ignored, in the hopes to improve their journeys.

Authorship Statement

The primary researcher (MD) and Supervisor (SLS) designed the research project. Recruitment was completed by MD with support from SLS and the Lung Health Foundation. Data collection was completed by MD; MD conducted all interviews. All data was analyzed by MD and an additional research team member (Elvira Shah). MD drafted the thesis with feedback from SLS and the advisory committee.

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Chapter 1

1 Introduction

Currently, there are many barriers to women seeking diagnosis and treatment for chronic obstructive pulmonary disease (COPD). These barriers include greater under-diagnosis, fewer medical consultations, fewer spirometry tests, and delayed diagnosis (Gut-Gobert et al., 2019). COPD is a chronic disease that causes obstructions in the small airways of the lungs leading to extreme discomfort and decreased quality of life. Often thought of as a "male smoker's" disease, in the past decade there has been a sharp increase in the number of COPD cases in women (Townsend et al., 2012). A systematic review done in 2015 of worldwide COPD prevalence found 9.23% in men and 6.16% in women (Ntritsos et al., 2018). In 2018 the difference in North America between men and women was almost statistically insignificant at 8.07% in men and 7.30% in women, demonstrating the increase in COPD in women has come to almost equal the prevalence in men (Ntritsos et al., 2018). Albeit minimal, current literature explores the sex differences between males and females in terms of presentation and rates of diagnosis of COPD. A study by Silveyra et al. (2021), highlighted the differences between males and females in patients with COPD. The authors explained that females tend to develop COPD earlier in life and have more frequent exacerbations than males, which leads to more frequent hospitalizations (Silveyra et al., 2021). As well, it has been discovered that females are less likely to produce sputum when presenting with a cough (Gut-Gobert et al., 2019). Despite these known sex differences in the presentation of COPD, little is known about women's experiences from their perspectives through their diagnosis and treatment journey.

COPD can cause a persistent cough with phlegm, persistent wheezing, breathlessness, and tiredness. There is no cure for COPD; treatments for the disease are used to manage symptoms and prevent exacerbations (World Health Organization, 2023). Exacerbations are defined as worsening symptoms like dyspnea, cough, or sputum over a 14-day period, this can be accompanied by tachypnea and/or tachycardia (Agusti et al., 2023). As such, the quality of life of a person living with COPD can vary greatly and depends on the care received (Townsend et al., 2012). To improve quality of life and experience with the health system, it is important to understand patients' experiences with their disease and the care they receive.

COPD is a multifaceted disease that affects the daily lives of those living with it (Sigurgeirsdottir et al., 2019; Yohannes & Alexopoulos, 2014; Giacomini et al., 2012). Symptoms may be experienced more severely for some, depending on their medical history and other factors (Giacomini et al., 2012). COPD can negatively affect individuals' physical and psychosocial well-being (Sigurgeirsdottir et al., 2019). In the literature, individuals have described their physical limitations affecting their ability to participate with family and in social activities, to perform important activities to them, and a loss of energy in their daily lives (Sigurgeirsdottir et al., 2019). The effect on psychosocial well-being can involve relationships and social life, loss of freedom, and a fear of breathlessness (Sigurgeirsdottir et al., 2019). Many individuals have described being housebound to avoid triggers and the inability to participate in activities they once enjoyed (van der Meide, 2020). This creates isolation from others and an inability to keep up relationships (van der Meide, 2020). The literature on experiences with COPD does not account for gender considerations and how women may have different experiences. Given this, it is important to explore women's experiences in hopes of improving the quality of life of those with COPD through better care.

Quality of life of those with COPD depends on a variety of factors (Giacomini et al., 2012). There is research to show that the quality of life of women with COPD is more impacted and can look different than that of men (Gut-Gobert et al., 2019). Women are more likely to experience more frequent exacerbations, delayed diagnosis, depression, and anxiety which all impact their quality of life (Gut-Gobert et al., 2019; Zysman & Raherison-Semjen, 2022). For example, COPD is an invisible disease without a proper diagnosis many women can have misunderstandings with family and friends which puts a strain on relationships (Gut-Gobert et al., 2019). As well, without a diagnosis many women have to suffer with symptoms without proper treatment. Treatments for COPD are used to reduce exacerbations and improve symptoms, without proper treatment that is right for the patient there is risk for disease severity to increase. This highlights the importance of timely diagnosis and effective treatments to reduce exacerbations and improve the quality of life of women with COPD. This study will explore the experiences of women with COPD through the diagnosis and treatment process to help us understand ways to improve care and therefore improve quality of life.

1.1 Research Questions and Objectives

The goal of this research was to explore the experiences of women with COPD throughout their diagnosis and treatment journey. This research will be useful in supporting the development of solutions to allow women to receive better care for COPD. This research answered the following question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD?

There were three objectives of this research:

1. Understand the experiences of women during the diagnosis and treatment of their disease,
2. Explore ways to improve women's experience with their COPD journey, and
3. Provide recommendations to better support women's journey with COPD.

1.2 Rationale

COPD is one of the leading causes of death among female smokers (Pirie et al., 2013; Thun et al., 2013). There is no cure for COPD, therefore timely treatment for COPD is important to prevent premature death, decrease hospitalizations, and minimize exacerbations (World Health Organization 2023). There are many barriers affecting women's abilities to receive a timely diagnosis and treatment (Gut-Gobert et al., 2019). For decades COPD was understood as a "male's disease" (Townsend et al., 2012). Many of the symptoms recognized and treatments provided by physicians are based on this assumption. It is therefore important to explore care experiences of women living with COPD from their perspectives to better understand what can be done to improve their experience. To our knowledge, there have not been any studies that explore these experiences through qualitative methods. This study will provide women with a voice and share what is important to their journey with COPD. Ultimately, we hope this can be used to improve women's experiences with their COPD journey. This research will allow us to understand what better care can look like for women with COPD through their experiences and opinions and give us the ability to provide recommendations to better support women's journeys with COPD. Considering the growing effect of COPD on the aging population it is important to focus on improving the experience of COPD for individuals with the disease now and in the future.

1.3. Structure of thesis

The first chapter of this thesis was used to introduce the topic and describe the key issues explored. The second chapter provides an overview of the literature on the main issues considered in this research and presents the gaps in the literature. The third chapter discusses the methodology and methods used to guide this project and to analyze the data collected. In the fourth chapter, the findings from the analysis are presented. This chapter presents 10 themes. In chapter 5, the findings as they pertain to the research objectives and with the current literature are discussed. The final chapter discusses the implications for this research in practice and policy, future directions for research, and a summary of the research project.

Chapter 2

2 Literature Review

This chapter presents the literature that guided the research. The research question guiding this project is: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD?

This chapter starts off by describing COPD, its effects on society and its causes. Next, the diagnosis and treatment of COPD are presented. This chapter explores the sex and gender differences in the presentation, diagnosis, treatment, and experience of COPD throughout each section. I finish by discussing the implications of women and COPD and the current gaps in the literature and how my research aims to fill these gaps.

2.1 Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is a chronic disease that causes obstructions in the small airways of the lungs. COPD can cause a persistent cough with phlegm, persistent wheezing, dyspnea, and tiredness (Chapman et al., 2003; Agusti et al., 2023). COPD is defined in the literature as “a heterogeneous lung condition characterized by chronic respiratory symptoms (dyspnea, cough, expectoration, and/or exacerbations) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive, airflow obstruction” (Agusti et al. 2023, p. 1). These symptoms are due to abnormalities in the airways that cause airflow obstruction (Agusti et al. 2023). COPD is most often caused by gene-environment interactions that damage the small airways of the lungs, most commonly caused by inhalation of chemicals through smoking or factory work (Agusti et al. 2022). This leads to progressive lung function decline and inability to inhale and exhale completely (Rabe & Watz 2017; Agusti et al. 2023). The progression of symptoms often leads to exhaustion, low physical ability, and poor quality of life (Chapman et al., 2003; Gut-Gobert et al., 2019). Individuals with COPD have reported having to give up on regular physical activity, changing their lifestyles and feeling isolated from others (van der Meide et al., 2020).

There has been an increase of women with COPD in the last two decades (Silveyra et al., 2021), this emphasizes the importance to look at how COPD effects women, as previous research on the disease often excluded women (Barnes, 2016; Silveyra et al., 2021). Sex can be defined as biological differences between males and females in terms of chromosomal, hormonal, physiological, and anatomical features (Silveyra et al., 2021). These differences can be seen in the presentation of COPD, and the effectiveness of various treatments (Rogliani et al., 2022). A study by Silveyra et al. (2021), highlights the differences between males and females in patients with COPD. They explain that females tend to develop COPD earlier in life and have more frequent exacerbations than males, which leads to more frequent hospitalizations (Silveyra et al., 2021). One theory proposed by Silveyra et al. (2021), is that sex hormones may contribute to the susceptibility of COPD. They performed a study on mice exposed to cigarette smoke and found that the estrogen in female mice mediates a higher rate of peripheral airway obstruction which directly relates to the development of COPD (Silveyra, 2021). This indicated that female mice were at risk for worse airway obstructions when exposed to cigarette smoke and therefore higher rates of exacerbations and hospitalizations than males (Silverya et al., 2021).

It has been noted that females typically have thicker, smaller airways which can contribute to an increase in airway obstructions (Gut-Gobert et al., 2019). As well, females are more likely to suffer from exacerbations due to this (Gut-Gobert et al., 2019). Others have also found that females have different clinic-radiological phenotypes than males (Silverya et al., 2021). Phenotype affects COPD by presenting symptoms such as dyspnea or cough (Silverya et al., 2021). As well, they discovered that females are less likely to produce sputum when presenting with a cough (Gut-Gobert et al., 2019).

A distinct characteristic of COPD is exacerbation. Exacerbations can be defined as worsening symptoms like dyspnea, cough, or sputum over a 14-day period, this can be accompanied by tachypnea and/or tachycardia (Agusti et al., 2023). Along with the acute symptoms, exacerbations can cause severe exhaustion afterward that affects the quality of life of patients (Goërtz et al., 2018). Many patients reported their inability to leave their homes, socialize with others, and attend usual activities following an exacerbation (Goërtz et al., 2018). Increasing frequency of exacerbations can lead to poor lung function, decreased quality of life, and increased mortality (Ritchie & Wedzicha, 2020). Exacerbations are mainly caused by infections or bacteria in the lungs that cause inflammation in the airways (Johns et al., 2014). Some individuals can be more susceptible to exacerbations if they have other comorbidities (such as heart failure, blindness, depression and pulmonary cancer) affecting their health (Westerik et al., 2017). Patients can be treated for exacerbations by their primary care doctor and, in more severe or urgent cases, the emergency department (Agusti et al., 2023; Ritchie & Wedzicha, 2020). Antibiotics and inhaled steroids can be prescribed by a primary care physician following a mild exacerbation (Viniol & Vogelmeier, 2018). If the exacerbation is more severe, emergency physicians will treat them with bronchodilators, corticosteroids and supplemental oxygen to promote breathing (Viniol & Vogelmeier, 2018). Exacerbations are important to describe as they can be frequent occurrence for those with COPD. As well, females tend to have more frequent exacerbations than males, which leads to more frequent hospitalizations (Silverya et al., 2021).

COPD frequency is increasing in North America and around the world. It is currently the third leading cause of death worldwide (World Health Organization, 2023). It is also one of the leading causes of death for women in the United States (World Health Organization, 2023). Furthermore, the number of deaths in 2019 was 30% higher than in 1990 globally (Li et al., 2023). The increase in cases has been documented specifically in women, previously the prevalence of COPD was lower in women than in men but recently this has now almost evened out in developed countries (Agusti et al., 2023). As well, a study done by Mannino et al. (2002) found that the death rates among women with COPD have increased in the 21st century and surpassed that of men in 2000 to present. COPD is on its way to becoming a global health crisis (Labonte et al., 2016; World Health Organization, 2022). A greater focus on and understanding of gender and its effects on COPD diagnosis and treatment is needed.

2.2 COPD Diagnosis and Treatment

There is no cure for COPD, therefore long-term treatment aims to decrease the frequency of exacerbations and hospital visits (World Health Organization, 2022). As such, the quality of life of a person living with COPD can vary greatly depending on the care that is accessible and received (Townsend et al., 2012). Often women experience a delay in diagnosis that disallows them from receiving early intervention for their COPD (Gut-Gobert et al., 2019). There has also been research that presents the differences in effectiveness of treatments in males and females

(Rogliani et al., 2022). This gap in diagnosis and treatment decreases the quality of life of women with COPD. To improve quality of life and experience with the health system, it is important to look at the diagnosis and treatment process of COPD.

A COPD diagnosis is considered in patients with dyspnea, chronic cough, sputum, or a history of respiratory infections along with a history of smoking and/or other environmental factors (Agusti et al. 2023). If a patient presents with these symptoms and history, a spirometry test is needed to confirm the diagnosis (Agusti et al., 2023). This test is given via breathing tube to evaluate airflow obstruction and severity of COPD (Johns et al., 2014). This tests the forced expiratory volume (FEV) of a patient, this is how much air one can breathe in or out and how easy and fast it is to exhale all the air out of your lungs (Johns et al., 2014). If FEV is in a certain range (FEV=50-80%) the patient will be diagnosed with COPD (Johns et al., 2014), if the FEV is not below 80%, but the patient presents with the correct symptoms and history, another spirometry test will be given later (Agusti et al., 2023). Without a confirmed diagnosis, instances of acute disease may be misdiagnosed as other respiratory issues and may not be treated properly (Csikesz & Gartman, 2014). This can lead to frequent exacerbations, overall lung function decline and higher rates of mortality (Labonte et al., 2016). As well, early diagnosis is important to improve quality of life by extending the length of treatment received, allowing patients to improve their breathing with inhalers and exercises and decrease the frequency of exacerbations (Csikes & Gartman, 2014).

Women have been underdiagnosed (Gut-Gobert et al., 2019), received fewer spirometry tests and fewer medical consultations. In a study done by Gut-Gobert et al. (2019), both women and men were asked about their care and treatment of COPD. Women reported feeling like they had a delay in their diagnosis more than men reported a delay. This study also found that women were more likely to receive a differential diagnosis of bronchitis or pneumonia. The author posits this could be due to the reporting of symptoms from women such as fatigue and depression which may lead physicians to steer away from COPD as a diagnosis as these are not typical symptoms seen in men. As well, Chapman et al. (2001) speaks about the differences in care coming from a gender bias upheld by many physicians. This study was done by surveying physicians about diagnosing anonymous cases and suggesting follow-up diagnostic tests. The results of the study found that COPD was the most probable diagnosis more often for men than women (58% vs.

42% respectively). After a spirometry test was requested and abnormal results were retrieved, the differences between diagnosis of COPD for men and women lessened but were still present at 74% vs. 66%, respectively (Chapman et al., 2001). Asthma was a more likely differential diagnosis for women than men. Their findings strongly suggest an implicit gender bias in the diagnosis of COPD. As there is no cure for COPD, the goal of treatment is immediate relief of symptoms and to improve quality of life over time (Postma et al., 2011; World Health Organization, 2023). Many publications state that smoking cessation is arguably the most important intervention for patients with COPD, and will be the first recommendation (Agusti et al., 2023). There is evidence that smoking cessation reduces lung function decline at any stage of COPD, however, the greatest impact can be seen through early intervention (Welte et al., 2015). There are gender considerations to keep in mind when talking about smoking cessation. Women with COPD are significantly more likely to have anxiety and depression than men (Gut-Gobert et al., 2019). This affects smoking cessation as it becomes more difficult when faced with these psychological issues. This is something that should be taken into consideration when treating women verse men.

The next recommendation is usually inhaled therapy (Agusti et al., 2023). Inhalers can be used to provide immediate relief from bouts of coughing and dyspnea or for daily use to improve symptoms over time (Agusti et al., 2023). The choice and compatibility of an inhaler is important for effectiveness and relief of symptoms. As well, regularly assessing the effectiveness and compatibility of the inhaler ensures continued relief of symptoms (Agusti et al., 2023). This assessment can be done by a primary care physician or respirologist, ensuring continued relief as it matches the inhaler to the patient (Agusti et al., 2023). Patients can be prescribed inhalers for daily use, typically anticholinergic and inhalers for emergencies (rescue inhaler), typically beta-agonists (Agusti et al., 2023). There is also evidence that the use of inhaled therapy through long-acting bronchodilators at early intervention can slow the progression of lung function decline (Welte et al., 2015). However, a study done by Rogliani et al. (2022), looked at how multiple treatments for asthma and COPD affected males and females differently. They did a systematic review of sex-related differences in the effectiveness of various treatments for COPD. From their research, they found that many therapies' effectiveness was different by sex. Specifically, one studies pre-clinical findings were that inhaled corticosteroids were less effective in the females in the study than the males. Overall, 28% of the evidence across the studies reported that males responded better to all COPD treatments than females (Rogliani et al., 2022). Rogliani et al. (2022), postulate that this is likely due to the differences in pathophysiology between males and females. The treatments that currently exist for COPD are generally based on a ‘male model’ and do not account for these differences in anatomy (Rogliani et al., 2022). The authors conclude by explaining that there is such a lack of research being done with female verse male patients that it is hard to tell, but the preliminary findings suggest a difference in effectiveness of treatments (Rogliani et al., 2022).

Other lifestyle changes like increasing physical activity can have a positive effect on symptoms, however, it can be difficult for patients to maintain this once the disease progresses to a severe level (Spruit et al., 2016). This is because many exercises cause fatigue and breathlessness in patients who already experience these symptoms caused by their COPD and therefore can make it difficult to complete (Spruit et al., 2016). Other non-pharmacological treatments include vaccinations for influenza, RSV, and pneumonia, pulmonary rehabilitation, oxygen therapy and ventilation support for more severe patients (Agusti et al., 2023). The literature highlights the importance of early interventions mentioned above to improve quality of life and slow the progression of the disease (Welte et al., 2015; Ramsey & Sullivan, 2004; Sun & Zhou, 2019). Many studies have shown that early intervention can allow individuals to reduce their symptoms thus improving their quality of life earlier (Welte et al., 2015; Ramsey & Sullivan, 2004; Sun & Zhou, 2019). As well, early interventions have been shown to have a greater impact on lung function and reduction of symptoms (Welte et al., 2015). Considering this, it is important to take into consideration the potential delay in diagnosis and the sex differences in the effectiveness of treatment when creating practice guidelines for COPD. By doing this, women will have access to early interventions to improve their quality of life and prevent frequent exacerbations where they may not have previously.

A sign of disease progression is frequent exacerbations (Halpin et al., 2012), which can be treated by a family physician or in the emergency department depending on the severity of the exacerbation and diagnosis of other comorbidities (Agusti et al., 2023). In the ER, patients with hypoxemia (a low level of oxygen in the blood) (Kent et al., 2011) will receive oxygen and may be admitted for further monitoring of symptoms (Agusti et al., 2023). Patients with an acute exacerbation will also be given inhaled bronchodilators to improve air flow, as well as corticosteroids and antibiotics if presenting with increased sputum and dyspnea (Sagana et al., 2022). Depending on severity of the exacerbation, patients may be admitted to hospital for further treatment or discharged once symptoms alleviate (Sagana et al., 2022). In terms of gender, women are more likely to have frequent exacerbations than men (Gut-Gobert et al., 2019). According to the literature this is likely due to the higher frequency of anxiety and depression in women which is a risk factor for frequent exacerbations (Gut-Gobert et al., 2019). Others, discuss that females have a higher sensitivity to smoke and therefore a higher severity of COPD and FEV1 decline is more rapid in women than men (Tashkin et al., 1996; Silveyra et al., 2021).

2.3 Experience of Living with COPD

COPD is a multifaceted disease that affects the daily lives of those living with it (Sigurgeirsdottir et al., 2019, Yohannes & Alexopoulos, 2014, Giacomini et al., 2012). Symptoms may be experienced more severely and therefore quality of life varies among patients and depends on a variety of elements (Giacomini et al., 2012). COPD can negatively affect individuals' physical and psychosocial well-being (Sigurgeirsdottir et al., 2019). The effect on psychosocial well-being can involve relationships and social life, loss of freedom, and a fear of breathlessness (Sigurgeirsdottir et al., 2019). In the literature, individuals have described their physical limitations affecting their ability to participate with family and in social activities, to perform treasured activities to them, and a loss of energy in their daily lives (Sigurgeirsdottir et al., 2019). This all causes a negative psychosocial well-being. Participants in a study by Sigurgeirsdottir et al., (2019) cite a positive mindset, accepting help, a healthy lifestyle, and continued professional help as important to them and their well-being (Sigurgeirsdottir et al., 2019).

COPD patients also experience breathlessness which had a physical effect on their wellbeing (Sigurgeirsdottir et al., 2019, Yohannes & Alexopoulos, 2014, Giacomini et al., 2012). This is facilitated by other COPD symptoms such as dyspnea, increased mucus production, and frequent coughing fits (Sigurgeirsdottir et al., 2019). This is a common symptom shared by individuals with COPD that reduces their ability to participate in daily life (Sigurgeirsdottir et al., 2019). Often individuals will need help completing tasks they once found easy (Sigurgeirsdottir et al., 2019). The inability to complete these tasks on their own can cause feelings of frustration and anger towards their disease and situation (Giacomini et al., 2012). Also, the fear of breathlessness can cause anxiety and depression that last throughout the progression of the disease (Sigurgeirsdottir et al., 2019).

Anxiety and depression are common among individuals with COPD, they may suffer for reasons beyond the fear of breathlessness (Yohannes & Alexopoulos, 2014). This can come from the sadness and vulnerability felt due to the change in lifestyle and participation in previously enjoyable activities (Giacomini et al., 2012). As well, anxiety can be caused by the panic over breathlessness, ending up in hospital, having an exacerbation, or death and the progression of their disease (Giacomini et al., 2012). Despite the high prevalence of these mental health issues, especially in women with COPD, it is estimated that less than 1/3rd of those suffering are receiving appropriate treatment for mental health (Yohannes & Alexopoulos, 2014). Some reasons for this cited in the literature are a lack of knowledge and reluctance to receive treatment, a lack of standard diagnostic processes, and a scarcity of resources for mental health (Yohannes & Alexopoulos, 2014, Giacomini et al., 2012). As mentioned previously, women with COPD are more likely to suffer from depression and anxiety and have a reduced quality of life (Gut-Gobert et al., 2019). However, there is a lack of literature on their specific experiences seeking treatment and support for their mental health.

With an emphasis on care and providers we can see in the literature that individuals with COPD often describe poor relationships with their healthcare providers (Giacomini et al., 2012). Participants in this study have explained they felt hastiness, poor listening, and a lack of compassion from providers (Giacomini et al., 2012). Other issues participants discussed about their provider was a focus on objective health outcomes; many explained they felt their suffering seemed invisible to their provider due to this (Giacomini et al., 2012). In terms of patient experience, studies have found that women reported less frequently than men that their doctors were sympathetic to their COPD and potential diagnosis (Martinez et al., 2012). Despite these experiences, women rated their overall satisfaction with care similar to men (Martinez et al., 2012). However, there is a lack of literature on experiences with COPD specific to women. This study will remove this gap in the literature by sharing the experiences with COPD of the women interviewed.

2.4 Gender Considerations in COPD

Sex is the biological characteristics that distinguish males and females (Silveyra et al., 2021). The literature explores the differences in biological characteristics that affect COPD through the presence of different symptoms, severity and frequency of exacerbations, and outcomes and hospitalisations. While sex refers to our biological characteristics, gender refers to the characteristics society uses to distinguish between masculine and feminine traits. These include social, cultural, behavioural, and environmental factors that impact one's identity (Silveyra et al., 2021). Sex and gender are related in healthcare as the sex differences we see between males and females can lead to social changes in the way those who are female presenting are diagnosed and treated. There is a severe lack of research on sex and gender considerations for the implementation of chronic disease management within primary care (Rogliani et al., 2022). Given the increase of COPD in women in the last two decades, we are moving away from the idea that COPD is a "white man's" disease. There has also been an increase in deaths of COPD in women compared to men (Agusti et al., 2023). This is likely due to an increased use of tobacco in women and changes in occupational hazards exposed to women. Due to changes in sex and gender roles and more single parent households in recent years, a larger number of women are found with industry jobs that expose them to occupational hazards (Blanc et al., 2009). In a study done by Sadhra et al. (2017), they found jobs such as furnace installation and construction increased the risk of COPD by 22% from vapors, gases, dusts, and fumes. Also, in developing countries, there are links to biomass fuels in homes and COPD in individuals who have never smoked (Blanc et al., 2009). This may increase the rate of COPD in women as they are more likely to be spending time at home in the kitchen in developing countries (Blanc et al., 2009). Women with COPD are often misdiagnosed and disproportionally suffer from comorbid conditions, including anxiety and depression (Gut-Gobert et al., 2019). Although there is a clear increase in cases in women presented in the literature, the practice of diagnosing and treating women has not changed. Symptoms women are more likely to report (fatigue and depression) are still not considered in a COPD diagnosis (Gut-Gobert et al., 2019). As well, treatment for COPD is the same for men and women despite earlier demonstration that effectiveness might be different (Rogliani et al., 2022). Therefore, physicians should consider COPD in the differential diagnosis of women with pulmonary symptoms, regardless of tobacco or pollutant exposure histories. Women also reported more difficulties than men when trying to reach their primary care doctor, and the time spent with their provider to be insufficient. Women were more likely than men to obtain information about the disease, diagnosis, and treatment from outside sources such as support groups and online resources. Conversely, Men were more likely than women to obtain information from their providers than to do outside research.

The sex differences between males and females found in the literature in the presentation of COPD and treatment options have been outlined. The scholarship in this area indicates that there are differences, and they should be considered when diagnosing and treating COPD. This can be done by considering a wider array of symptoms, such as fatigue and depression, when diagnosing women. As well, assessing different treatments with the patient to ensure individual effectiveness. It is then outlined that many women (gender identity) experience a delay in diagnosis and therefore treatment. The mention of sex is important as in previous decades COPD was only recognized and researched in males. This translates now to how women are treated and diagnosed (whether they are female or not) because they present a certain way and therefore physicians who may have bias from previous history of the disease would treat them differently than men. This is likely why we are seeing increased misdiagnosis in women and lack of effective treatment (Chapman et al., 2001).

2.5 Gaps in the Literature

This literature has guided the exploration of the research question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD?

The objectives of the study are to 1) Understand the experiences of women during the diagnosis and treatment of their disease, 2) Explore ways to improve women's experience with their COPD journey, and 3) Provide recommendations to better support women's journey with COPD. Research has been undertaken on the sex and potential gender differences that need to be considered in COPD care, however, the literature lacks insights into women's experiences with diagnosis and treatment. This includes experiences with getting a diagnosis, interacting with their providers, support, and effective treatments. Despite an overall awareness of the differences in symptoms and prognosis for females and quality of life for women, it is undetermined how these have influenced care experiences for women with COPD. With the increase in COPD cases and deaths in women, it is important to elicit these experiences to further improve care and move towards equity within the healthcare system.

This study will look at these experiences and what better care looks like to women with COPD. There is also a lack of input in COPD practice guidelines and policies from women concerning their experience with COPD and what is important to them. Sex and gender considerations for the implementation of care for COPD are severely lacking in the literature and women's voices are missing. This increases the gap in care for women with COPD and further propagates a gender bias from physicians in their care circle.

2.6 Summary

This chapter summarized the topics important to understanding this thesis and the background for conducting this research. These topics include the presentation and symptoms of COPD and its epidemiology, the diagnosis and treatment of COPD, the sex differences in the presentation and effectiveness of treatment, and the gender considerations in COPD. This chapter demonstrated that there is a need to explore the experiences of patients, specifically women with an aim to improving support for women through their COPD journey.

Chapter 3

3 Methods and Methodology

In this chapter, I outline the paradigm and methodology that was chosen for my research study (Sections 3.1 and 3.2). I provide details on the data collection and participant recruitment (3.2.1 and 3.3) and outline my guiding criteria for quality used throughout my research (3.5). This chapter describes the process used to answer the overall research question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD?

3.1 Paradigm

Paradigm represents the way individuals view the world and reality; it is important to identify a paradigm when producing qualitative research before choosing a methodology (Guba & Lincoln, 1994). There are three questions that can be asked to guide when choosing a paradigm: 1) ontology, 2) epistemology, and 3) methodology (Guba & Lincoln, 1994). Ontology has to do with the nature of reality and being, epistemology is about the relationship between the researcher and the participant, and methodology looks at how the researcher can go about investigating a topic (Ponterotto, 2005). In choosing a paradigm I had to think about these three questions and my values and beliefs on the political, educational, social, and health systems in our society. A critical theory paradigm, described below, was chosen to guide this research. My beliefs that our experiences are shaped by structures in power align strongly with this paradigm. Ponterotto (2005), describes critical theory as being one in which researcher's values are central to the purpose and methods of research.

A critical theory paradigm assumes that reality is shaped by various structural forces that can determine an individual's thinking and behaviour (Paradis et al., 2020). These forces include social, political, cultural, economic, ethnic, and gender constructs. This paradigm assumes that these forces present themselves unconsciously in an individual (Paradis et al., 2020). Critical theory acknowledges that due to these forces there is no objective reality and that individuals will experience events differently based on these forces (Kincheloe et al., 2017). Critical theory is an effective choice for this research as this research looks directly at the gender constructs that effect the care received by women with COPD.

With the use of critical theory, the bias that has previously occurred in the diagnosis and treatment of COPD of women can be explored. A critical theory paradigm acknowledges the structures that oppress women, shaping their experiences such as, economic, political, and social (Aranda, 2017). By looking at this research through this paradigm the experience of being a woman with COPD can be explored based on these structures. Critical theory allows a critique of social structures that shape and challenge women going through the diagnosis and treatment process (Kincheloe et al., 2017). As well, acknowledge gender roles and their effect on the individual realities of people (Paradis et al., 2020). Exploring the experience of women with COPD through a critical theory paradigm allows us to look at the structures at play that may be shaping the way women are receiving COPD care.

3.2 Methodology

Critical theory uses a dialogic/dialectic transaction of inquiry, emphasizing the importance of a dialogue between the researcher and the participant to investigate a specific topic (Ponterro, 2005). This can be represented in many forms of qualitative research, but a phenomenological methodology was chosen to conduct my study. This methodology looks at the rigourous description of a phenomenon of interest. Phenomenology was chosen because the focus of this research is on experiences of living with COPD as a woman.

There are many different philosophers known for exploring and practicing phenomenology; Husserl, Heidegger, Merleu Ponty, Gadamer etc. (Dowling, 2007). Max van Manen developed a hermeneutic approach that combines the objectivist and alethic circle to acknowledge the experience of a phenomenon as a whole experience and the researcher’s role in the research process. He does not share Husserl’s view of bracketing and asks: “If we simply try to forget or ignore what we already “know,” we might find that the presupposition persistently creeps back into our reflections” (van Manen, 1997 pg. 39). Instead, he wants the researcher to make explicit their understandings, beliefs, and assumptions. This is done not to try and forget these assumptions, but to hold them at bay and challenge this knowledge. The knowledge we already have will be challenged once we learn more about a phenomenon from someone living it (van Manen, 1997).

The goal of this phenomenology is to transform the lived experience into a textual expression of its essence, in such a way that the meaning of the text represents a reviving reflection and a reflexive appropriation of something significant. The reflexive appropriation is a way to guide action and challenge what we already know about a phenomenon from an outside perspective (Boström et al., 2017). When we are living our daily lives, we often do not stop and dwell on what is happening and how we feel about it (van Manen, 1997). Phenomenology allows us to explore the experiences we live through to describe where the reader can grasp the nature and significance of this phenomenon (van Manen, 1997).

This type of hermeneutic phenomenology was chosen because van Manen describes it as a human science approach that combines the description of an experience with an interpretation of it (Dowling, 2007). This allowed me to describe the experience of being a woman with COPD and receiving care as described by those living it. I then could interpret this description with a critical theory lens. A critical theory lens was used to challenge the structures present in today's healthcare system. These structures overlook women's experiences as being important or different from that of a man. As mentioned above, van Manen does not include bracketing, defined as removing your own bias and opinions from the research and welcomes the pre-understanding one has of a phenomenon (van Manen, 1997). This falls in line with critical theory methodologies that use researcher's values and biases to affect the research process (Ponterotto, 2005).

Max van Manen's approach to hermeneutic phenomenology involved first orienting oneself to the phenomenon. He suggests that having a deep interest in a topic will allow one to choose a phenomenon to explore (van Manen, 1997). I have chosen the phenomenon of women living with COPD through the diagnosis and treatment journey. To orient oneself implies not just an interest, but also station or vantage point in life (van Manen, 1997). Therefore, my orientation is that I am a woman researcher pursuing a master's degree, interested in COPD care. This is because I have a distant, but dear family member living with COPD who had issues receiving a diagnosis and subsequent treatment. Their issues arose at the beginning of their COPD journey, three years ago, they have since received effective treatment and continue to live with COPD.

One of the goals of my research was to explore and challenge these pre-assumptions, but not forget that they are there and are meaningful to me as a knowledge co-creator in this phenomenological approach.

3.2.1 Recruitment

Recruitment was done through the Lung Health Foundation, beginning late December 2023 once ethics had been approved. The Lung Health Foundation is an organization that supports and empowers individuals living with lung disease. They have community initiatives, educational programs, and research. The Lung Health Foundation has supported the development of 10 support groups across Ontario that I was able to contact. I connected with the director of community programs and partnerships at the foundation; the foundation maintains a list of individuals willing to participate in research projects. The director emailed our recruitment email to this list of individuals. The recruitment email was sent out to approximately 80 individuals. My goal was to recruit 8-12 participants. A sample size of 8-12 was chosen based on experts in the qualitative research field and recommendations by van Manen for phenomenology. Van Manen suggests for a phenomenological study to use anywhere between 3-25 participants, depending on the phenomenon being studied (van Manen, 1997). Other experts in qualitative research such as Ray (1994) recommend 6-12 participants for a phenomenological study. This is similar to Creswell’s (1998) and Marshall et al.’s recommendations (2013), who all agree to any number between 6-12. The inclusion criteria for my study were: identify as a woman, have been diagnosed with COPD for at least one year and undergone any form of treatment (such as inhalers, steroids, respiratory therapy, and pulmonary rehabilitation). All participants were given $15 gift cards for their participation in an interview.

3.3 Data Collection

Critical theory emphasizes a dialectic approach that involves a conversation about the systems that affect one’s lived experience (Ponterotto, 2005). In keeping with critical theory methodologies, data collection had to involve direct interaction with participants. Phenomenology requires in-depth inquiry into everyone's experiences. To understand how gender factors into the care being received by women with COPD in depth inquiry into the experiences through the diagnosis and treatment process of women living with COPD was required.

3.3.1 Interviews

One-on-one semi-structured interviews were conducted to gather narratives. Interviews lasted between 20-75 minutes and were done over the phone or on a video call, each participant was interviewed once. A semi-structured format was used to guide the interviews. This allowed for flexibility and open conversation between the interviewer and participant while focusing the interview on the experience of women with COPD. In developing an interview guide I used three types of questioning as outlined by Bevan (2014) in their article on interviewing for phenomenological description. These included descriptive/narrative questions such as "Describe the story of your diagnosis. Describe the events that led up to it and the actual diagnosis itself." Descriptive and structural questions such as: "Tell me about your COPD treatment." Lastly, imaginative variation such as: "Describe changes you would have made to your care." These types of questions allowed the participant to describe the full extent of the phenomenon which made it clear for me to understand (Bevan, 2014). In addition to these types of questions, demographic questions were asked at the beginning of every interview. These included: age, years since diagnosis, and whether the participant was a smoker or not (see Appendix A for the interview guide). The interviews were audio-recorded and transcribed verbatim by me.

3.4 Data Analysis

Thematic analysis as described by van Manen involves reflecting on the essential themes that characterize the phenomenon (van Manen, 1990). Thematic analysis is a flexible way of interpreting data in relation to, in my case, a participant's lived experience with a particular phenomenon. van Manen's thematic analysis was used to interpret data. There are three approaches to his analysis: the wholistic approach, selective reading approach, and detailed reading approach (van Manen, 1997). I chose the selective reading approach because it allowed me to focus on sentences or phrases that seemed particularly essential or revealing about the experience of women living with COPD. These phrases were chosen based on the importance they held to the participant and their experience. This approach involved reading and re-reading the transcripts from my interviews several times, this step is called immersion. The practice of immersion is suggested by van Manen in phenomenological research to be able to better understand the experiences described and what matters most to the participants regarding their COPD diagnosis and treatment. The method of immersion can be seen in other researchers' work who have used van Manen's phenomenology, such as Chen et al., 2020 and Van der Meide, 2020. During the immersion phase I took notes on emerging ideas and points emphasized by participants.

After completing immersion, all transcripts (100%) were inductively coded using line-by-line coding; a second research team member (master's student) coded two transcripts (17%). We met to discuss initial thoughts, findings, and codes; codes were merged and reduced from 250 to 75. Two more transcripts were coded with the new coding scheme. A preliminary codebook with definitions and examples was created; four of the transcripts (33%) were re-coded to examine the applicability of the codebook. The coded transcripts and codebook were reviewed by the project primary investigator (PI; Sibbald). The research team met to discuss and refine the themes and subthemes; a new iteration of the codebook was created. This version of the codebook was reviewed by the three senior researchers on my thesis advisory committee. This was crucial as we discussed the importance of the themes and ways to fit the topics I felt important to participants within my objectives. All 12 transcripts were then coded a final time, deductively using the codebook. In total, all transcripts were coded three times to solidify themes and ensure the experience was captured fully as described by participants.

The next step to this approach was to isolate thematic statements during my reading, this was done by asking myself "what statements or phrases seem particularly essential or revealing about the phenomenon or experience being described" (van Manen, 1997, p. 93). These statements were highlighted in the text. The last step was to create phenomenological text based on the common themes that make up the experience of living with COPD through diagnosis and treatment as a woman. Van Manen suggests four conditions to guide this writing. The text needs to be oriented, strong, rich, and deep (van Manen, 1997). This final step of analysis represented a more sophisticated understanding of the data through continual interaction with the data and the reflection and description of what it means to be a woman living with COPD through their diagnosis and treatment journey.

3.4.1 Reflexivity

Self-reflexivity is the ability of a researcher to be honest with their feelings and beliefs about the research being conducted (Tracy, 2010). There are many ways to go about reflexivity when doing phenomenology. Van Manen highlights the importance of one's experiences and pre-understanding with a specific phenomenon. He suggests acknowledging this and letting it guide one's research. "If we simply try to forget or ignore what we already "know," we might find that the presupposition persistently creeps back into our reflections" (van Manen, 1997). He suggests orienting oneself with the phenomenon and acknowledging the assumptions and bias one has of a topic and why it is meaningful to them (van Manen, 1997).

As mentioned previously, I have a relative whom has COPD and had difficulty receiving a diagnosis and subsequent treatment at the beginning of her journey. This was the motivation for my research into the experiences of women with COPD through their diagnosis and treatment journey. After hearing her story and doing research into the sex and gender considerations for COPD, I felt frustrated about the care experiences of women with COPD. I also felt frustration towards the lack of literature and women's voices on these experiences. This motivated me to explore this further to learn from their experience and in doing so to synthesize recommendations to improve care. The lack of women's voices in the literature made me want to share these voices.

By acknowledging my assumptions and motivation for my research I was able to understand the lens in which I could question participants and analyze their responses. Reflexivity is an important aspect of qualitative research especially when interacting directly with participants as it allows for bias to be acknowledged and used in the research (Tracy, 2010). I practiced reflexivity by keeping a reflexive journal throughout the data collection and analysis process. Recording my thoughts and influences helped me increase sincerity and therefore rigor in my work (Tracy, 2010). This insight authenticated and humanized my pursuit of knowledge to increase transparency of the research.

3.4.2 Ethical Considerations

This study was approved by Health Sciences Research Ethics Board (HSREB), protocol #123287. Participants were provided with an LOI that explained the study before collecting signed consent forms. All interviews were audio-recorded with consent from participants.

3.5 Quality Criteria

It is important to exercise approaches to qualitative research that promote and enhance its quality (Tracy, 2010). To do this, Tracy's eight "big tent" criteria was used, these are: 1) worthy topic, 2) rich rigour, 3) sincerity, 4) credibility, 5) resonance, 6) significant contribution, 7) ethics, and 8) meaningful coherence.

The topic I have chosen has proven to be a worthy topic based on the timeliness of it, there has been a rise in cases and deaths of COPD in women in the last two decades (Agusti et al., 2023), this study allowed me to investigate what it is like to live with COPD as a woman and be able to report these experiences to improve care for women. Tracy outlines that a worthy topic can arise from timely societal events. This is a gap in the literature and has been for cardiovascular and other respiratory diseases. Promoting rich rigour according to Tracy involves choosing an appropriate method for the question and a sample size that follows this. A sample size of 8-12 was chosen based on experts in the qualitative research field and recommendations by van Manen for phenomenology. Van Manen suggests for a phenomenological study to use anywhere between 3-25 participants, depending on the phenomenon being studied (van Manen, 1997). Other experts in qualitative research such as Ray (1994) recommend 6-12 participants for a phenomenological study. This is similar to Creswell's (1998) and Marshall et al.'s recommendations (2013), who all agree to any number between 6-12. From my research into phenomenology and my decision to use specifically van Manen's hermeneutic phenomenology to explore the lived experiences of my participants, I have chosen a method that allows me to look at my research question effectively. Throughout my research I have kept a reflexive journal that allowed me to be honest and transparent about my thoughts, feelings, and bias before and during this process. This promotes sincerity in my research as described by Tracy by having notions of authenticity and genuineness. By participating in phenomenological writing as the product of my research I have created a thick description of the experiences lived by my participants. One of the most important ways to promote credibility is through thick description (Tracy, 2010) which can be seen in my phenomenological writing in the details and nuances I have provided about my topic.

While phenomenology often provides a rich description of a particular experience of interest, there are themes that arose from my research that can be transferred to the care of other chronic diseases and other experiences faced by women in the healthcare system. The systems that effect women in society do not stop at the diagnosis and treatment of COPD but can be seen in all aspects of life (Gupta et al., 2023). Highlighting this transferability aids my research in promoting resonance as described by Tracy. Significant contribution, as suggested by Schwandt (1996), proposes that good quality research supplements the probing of social problems this is outlined by Tracy to promote this quality criteria. This research adds methodological significance by using phenomenology to explore the lived experiences of women with COPD. This method is not often used when talking about the differences in care between men and women, a quantitative approach is typically seen in the literature.

This study received ethics approval by Western's Health Sciences Research Ethics Board (Study ID #123287). This is an example of procedural ethics, following a set procedure created by a governing board to ensure ethical research. Procedural ethics promotes not only ethical criteria, by following these procedures, but also leads to more credible data (Tracy, 2010). Lastly, I was able to enhance my research using meaningful coherence, used to meaningfully connect the literature and findings to the objectives and research question. This was done by conducting data collection and analysis that achieved my stated purpose and used methods that accompany critical theory and my research question well (Tracy, 2010).

3.6 Summary

This chapter discussed the rationale behind the methodology and paradigm chosen for this study. The most effective approach for this study was to follow van Manen's hermeneutic phenomenological approach guided by a critical theory paradigm because it allowed for the exploration of experiences of women with COPD and the political, educational, social, and health systems that interact to create these experiences. This methodology allowed interpretation of these experiences and described them as a phenomenon (van Manen, 1990).

Chapter 4

4 Results

In this chapter, the findings from the data collected from one-on-one semi-structured interviews are presented. This chapter starts off by outlining the characteristics of the participants interviewed (Section 4.1). I then describe the main findings from the interviews. The results are presented in accordance with the research objectives (Sections 4.2, 4.3, 4.4), presented through themes and subthemes. The study results address the three main objectives of the study that answer the research question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD?

4.1 Demographics

A recruitment email was sent out to 80 individuals, of which 16 responses were received (20%) and 12 consented to be interviewed (response rate = 15%). All participants had been diagnosed with COPD for at least one year and were currently receiving treatment. Their ages ranged from 62-87 (median age was 75.5). The average time since diagnosis of COPD was 9.75 years (median of 10 years). Sixty six percent (n=9) smoked prior to their diagnosis. Demographic information is presented in Table 1.

Table 1: Participant Characteristics

Participant Characteristics	**N**
Age (years)	
60-69	1 (8%)
70-74	2 (17%)
75-79	6 (50%)
80-84	2 (17%)
85-89	1 (8%)
Years since diagnosis	
1-4	3 (25%)
5-9	3 (25%)
10-14	4 (33%)
15-19	1 (8%)

20-24	1 (8%)
Smoking history	
Smoker	9 (66%)
Non-smoker	3 (33%)
Total	12

The results are presented according to the three objectives set out at the beginning of this study. Through the coding process, 10 themes and 25 subthemes were formed (see table 2 for a summary and appendix B for full table). The three objectives were: 1) Understand the experiences of women during the diagnosis and treatment of their disease, 2) Explore ways to improve women's experience with their COPD journey, and 3) Provide recommendations to better support women's journey with COPD.

Throughout this chapter participant's providers are referenced. 'Provider' includes any healthcare professional that interacted with the participant (family doctor, respiratory therapist, hospital staff, clinic staff, and nurses). Most participants referenced their provider as their family doctor, however in some cases respiratory therapists and other specialists were referred to.

Table 2: Objectives and theme descriptions

Objectives	**Theme**	**Description**
1. Experiences through diagnosis and treatment	Waiting and wondering	Descriptions of diagnosis experience, including the time before the diagnosis.
	Seeking information	Participants' interaction with information about COPD in general and their disease and prognosis, including a lack of information.
	Adjusting to the disease	Adjustments after receiving COPD diagnosis. Acts of resilience, feelings of blame and stigma about COPD.
	Interacting with providers	Participants descriptions of their experiences with their

		provider. Including their engagement, changes to treatment, and perceptions of their provider’s priorities.
	Adapting daily life	Descriptions of participants’ daily life with COPD.
	Navigating the system	Participants’ feelings towards the current healthcare system and its failures towards patients.
2. What women want from their COPD care	To be understood by providers	Participants’ descriptions of what they want from their provider.
	To be treated holistically	Participants’ descriptions of what they want from their treatment plan.
3. Recommendations for better care for women with COPD	Improving awareness around COPD	Participants’ concerns over a lack of awareness around COPD from their friends, family, providers, and the public.
	Educating the public on COPD	Participant’s emphasis on education surrounding COPD for themselves and the public.

4.2 Experiences through diagnosis and treatment

The first objective explored was experiences through diagnosis and treatment; all the women interviewed have unique experiences of diagnosis and treatment, but there are similarities that make up the phenomenon of living with COPD, these include: 1) waiting and wondering, 2) seeking information, 3) adjusting to the disease, 4) interacting with providers, 5) adapting daily life, and 6) navigating the system.

Waiting and wondering

Experiencing the diagnosis was described in many ways, however there were two main points in time (subthemes) that women in this study commonly experienced challenges pre-diagnosis and during diagnosis.

The time before the diagnosis was described by some participants as a time they knew was coming. Participants described noticing symptoms related to COPD, but being diagnosed with another similar disease, such as bronchitis, asthma, and heart issues, prior to their COPD diagnosis.

> *But in 2017 when I came* [to Florida] *I had bronchitis again and the doctor said every year you're going to come here in Florida you're going to get bronchitis, because of the change of weather, because the north is cold and the change of weather.* (Participant 4)

Along with a differential diagnosis some participants described having symptoms such as "*heart palpitations", "worsening breathing"*, and "*emphysema on an x-ray"* overlooked by providers and not spoken about until years later when a diagnosis was made. A couple of participants had either overlooked symptoms by hospital/clinic staff or worsening breathing coupled with years of smoking and had been waiting for an official diagnosis from a doctor for years.

> *Oh, just what I said before, the diagnosis took a long time...even when I knew it might be coming. Maybe if they had diagnosed me sooner, I wouldn't have been suffering from the breathing problems for so long.* (Participant 1)

Following pre-diagnosis, participants described their experiences during diagnosis, who provided the diagnosis, the steps that followed, and how it felt to hear the words *"you have COPD*". Many participants had feelings of "*surprise"* or "*shock"* following the diagnosis. Even though some felt they knew it was coming, it was still a shock to be told the official diagnosis from a doctor. Participant 4 who was diagnosed for years with bronchitis recalled the experience of how her doctor told her she had COPD; "*My family doctor in August of 2017, he told me I had COPD stage 2 and that's all he said.*" (Participant 4)

Many participants had heard of COPD prior to their diagnosis but did not know much more about it.

> *Basically, he called me and... said: "Oh you have COPD" and I've heard of COPD, but it didn't click...and it was left at that, and I haven't had any follow up from him...it freaked me out a little bit, the big diagnosis and then the not knowing anything.* (Participant 2)

This interaction left participants feeling confused and unsure of how to proceed following the diagnosis. Participants highlighted the enormity of a diagnosis like this and the "*lacking"* feeling some participants felt from their diagnosis experience.

Seeking information

Many participants were not sure whose role it was to provide them with information or if they were supposed to do the research themselves. These experiences included information about COPD in general, their own disease and prognosis, outside programs and support, and lifestyle changes. Participants experienced information seeking in three ways (subthemes): 1) lack of information provided, 2) doing your own research, and 3) receiving information.

Many women felt they were not provided with enough or any information regarding COPD and their disease. Learning about their own disease was important to participants. Many explained they did not know what stage they were at or how their disease would progress over time; "*Ya just learning about COPD. I never got information from my doctor when I was diagnosed. And I feel like sometimes I don't really know what's going on with my disease and progression."* (Participant 2)

The lack of information was expressed by participants at follow-up appointments, and at the hospital following a discharge; "*Then I was discharged with no discharge instructions at all...I felt like I was missing a lot."* (Participant 1)

The lack of information left participants feeling "*frustrated"* and "*lost"* about where to go from there and in what ways they could make their lives better despite the disease. The lack of information was an added burden as participants had to resort to doing their own research in a landscape (the internet) where not everything you read may be true.

> *So, I don't know, maybe it's the fact that I was not a part of anything at the beginning like the rehab or the Westpark program. I do wish my doctor gave me some information, because before* [these programs] *I was feeling hopeless and confused.* (Participant 8)

Participants described doing their own research when they felt they were not getting enough from their provider, or they wanted to know everything possible. This research included learning about the symptoms and progression of COPD, alternative treatments, and organizations that provide support for those diagnosed with the disease.

> *The Lung Health foundation is great, and they have been amazing, but I found them after, through my own research, and it would be great for that to be available for everyone.* (Participant 6)

Even when they found the information they were looking for, they acknowledged that not everyone has access and resources to find it. While doing their own research, participants acknowledged the amount of misinformation on the internet and how they navigated it to find what they need and believe is reliable.

> *Well, my best source of knowledge is YouTube, honestly... There are so many respiratory groups there that you can follow and learn new things from, and you know you sort out whether it's valid or not* [information] *but lots of times there are little nuggets of information that are helpful.* (Participant 12)

This research has provided them with "*confidence"* and "*relief".* This has also allowed them to find support groups and lung health activities where they can meet more people and gain information from professionals and other patients going through similar experiences at these groups and activities.

On the other side, participants described experiences in which they received information from their provider, outside sources such as pulmonary rehabilitation centers, and other lung health organizations. Participants were referred to some of these activities and organizations by their providers (family doctor or respiratory therapist). In some cases, participants described their providers as being thorough and forthcoming with results; "*He really sent me to the hospital* [following breathing problems], *and I did get a follow up and my family doctor gave me all the results* [from pulmonary tests] *and explained them to me."* (Participant 11)

A large source of information for participants was through their pulmonary rehabilitation program. Not only were they able to get information from other individuals with COPD, but also from the clinicians. Participant 4 who has been a part of a pulmonary rehabilitation program several times described her experience there:

> *When I came back, I went one more time to the rehab center and I really liked it because they do a lot of exercises, they have machines, there's a track, and there's classes, also, where we get more information. So, I enjoyed that, to learn how to breathe properly, how to use your inhaler properly, and also just for support.* (Participant 4)

Participants described feeling a sense of control over the disease through learning ways to handle coughing fits and mitigate symptoms, such as breathlessness and fatigue.

Adjusting to the disease

After receiving a chronic disease diagnosis, participants had to adjust to a new reality. The theme of adjusting to the disease encompassed participants' descriptions of their experiences after diagnosis and how they continued living their lives despite life altering news. This adjustment came in all forms and was encompassed by two subthemes: 1) resilience and 2) blame and stigma.

Resilience described the women's ability to live with their COPD diagnosis and continue living despite it. All the women have described showing and discussed resilience and agreed that resilience is a huge aspect to a better quality of life. The words "*keep going*" were used frequently in reference to continuing to live their lives after the COPD diagnosis; "*It was a bit scary, but I decided that I just had to keep going...*" (Participant 8)

A lot of these women found "*happiness*" and *"joy"* in their lives either through continuing to do the things they love or finding new passions and activities to replace ones they may not be able to do anymore. Another aspect of resilience was living and doing things "*despite*" the disease. Participant 9, who was diagnosed almost 20 years ago, described her experience being told her prognosis; "*I asked how long I could expect to live, and he said about 10 years or so. And that was almost 20 years ago, so, you know...I'm doing pretty well despite my COPD.*" (Participant 9)

The positive attitudes expressed by many participants despite what they are going through demonstrate this theme of resilience.

Blame and stigma came up across interviews in two different ways. Women described either blaming themselves for having COPD and the life choices they made or experiencing others blaming them based on the stigma around smoking and lung disease. Since most participants were long time smokers they were not surprised when they received this diagnosis. They admitted to feeling blame towards themselves for smoking for so many years.

> *I have to admit I did not take very good care of my health; I was a smoker for years, I have not smoked in 6 years and...it's just all coming to a head, and I know that. I'm not blaming anybody but myself.* (Participant 1)

Participants experienced many varieties of stigma around COPD and its attributes. This stigma came from family and friends, providers (anyone giving care to participants), and strangers at the store. This stigma has a lot to do with how you end up with COPD and the blame that comes with a smoking addiction and lung disease. Experiencing this stigma only hurt participants and in the cases of those who never smoked was wrong; "*No there's just a stigma around COPD that we brought it on ourselves... and you're just not treated well because of it.*" (Participant 3)

As well, multiple women described thoughts and feelings that come with being put on oxygen. This is a step participants described that many had to take in later stages of the disease, many talked about doing everything to avoid oxygen and the feelings they had when they did have to eventually go on it. The word "*shame*" came up in reference to being put on oxygen. Participants described using oxygen as a loss of control over their disease. They also talked about how it changed the way others looked at and thought of them. Often feeling more frail because of the oxygen, despite how much it can help "*And, sometimes you have to keep struggling to keep that independence because I think people sometimes underestimate* [us]. *They see it as a limiting thing* (COPD)*.*" (Participant 12)

Interacting with providers

Throughout living with COPD, participants talked about all the doctors and nurses they've had to interact with, which comes with treating a chronic disease. Some experiences were negative, and some were positive. Participants described their experiences with their providers in multiple ways which can be divided into these four subthemes: 1) engagement from provider, 2) different priorities, 3) advocacy, and 4) changes to treatment.

Engagement from providers captures participants' experiences with providers whether positive or negative. Some participants described not feeling heard by providers and being "*ignored"; "So, I was in the emergency ward, no pain, no nothing, all I felt was pressure on my chest. Right? They didn't even acknowledge it* [pressure in chest]. *I kept saying that and nobody picked up on it."* (Participant 2)

Participant 3 described the reaction her respirologist had, who was in denial about her concerns over side effects of a particular treatment.

> *The very first respirologist I had got very upset with me and said his medications don't cause side effects and yada yada yada. Just completely disregarding and ignoring my problems.* (Participant 3)

Others had opposite experiences, describing their providers as "*thorough", "detail oriented", "caring",* and "*respectful"*.

> *She was so thorough, so detailed, so patient. Oh god and then I had her again during the last of the pandemic and she was fantastic, oh everything under the sun, the best doctor I've had in my entire life.* (Participant 7)

While these are completely different experiences, participants agreed on the importance of their relationship with their provider and how it impacted their feelings towards their disease.

In speaking about the experiences participants had with their providers, many spoke of the perception that their providers had different motivations or priorities than them. Participants described that their goals sometimes differed from that of the provider, and they did not necessarily see eye to eye on treatment options. Participants emphasized the importance of having the same priorities as the provider. Participant 8 shared her experience with previous doctors that thought oxygen and a lung transplant were the best options for her. She did not agree with this and explained finding a new doctor that was more in line with her desires:

> *And I think the doctors that I have now are quite in line and they're quite specific. They agree with me, with my goal to keep off oxygen and no lung transplants. They actually*

> *listen sometimes. I had problems with that before, with my other doctors, they wanted something different for me.* (Participant 8)

Other participants described feeling unprioritized by their providers. They described their providers as "*being busy*" or "*not having time for them*", "o*verlooking symptoms*" or *"concerns"*, and "*not placing importance on their patient*."

> *Ya I mean just because a lot felt like it was passed over you know* [symptoms prior to diagnosis]*? They did see something in my chest and just overlooked it.* (Participant 2)

This impacted not only the relationship with their providers, but their feelings towards themselves, the disease and its effect on their feelings of worth.

Feeling unprioritized by providers also affected patients' motivations and trust. Often participants described feeling they needed to advocate for themselves to make sure they were getting the proper treatment and that nothing was being overlooked; "*Sometimes it feels like even the doctors, even the ones I like, no one is there just for you, it is up to you to advocate and get information..."* (Participant 8)

Two participants described experiences in which they were continuously sick or were having repeat exacerbations. Their providers would continue to prescribe antibiotics to solve this issue. It was not until they advocated to get more testing done that they found out the underlying issue and were able to solve it permanently. Participants emphasized the importance of advocating for yourself with the fear that if they had not advocated, nothing would have changed, and they may have still been in that "*endless cycle"*.

> *And I think in May I said to him, I'm doing everything I can to try and be well and I don't understand why I can't seem to get any better... So, he had me take this test. And that's when they found out about this other A chroma that was in my lungs and then he talked to the respirologist and then made a referral to him and so that started the process of me being on a nebulizer with the antibiotics... I just sort of feel like we were going to still be on the path of you know, rounds of antibiotics if I hadn't said anything.* (Participant 9)

Participants wanted other women to understand the importance of advocacy and to know that you must speak up for yourself in any situation where you feel something might be wrong;

"but...I do find you have to advocate for yourself...Because if you don't ask, the doctor won't tell you anything." (Participant 4)

Participants explained they have had multiple changes to their treatment since they were diagnosed. Participants described a few reasons for these changes, one being their personal experiences with the inhalers or antibiotics they were prescribed. Some participants said they were experiencing side effects from their inhalers and spoke to their doctors about changing them; *"I have a different respirologist now. And she just switched my prescription* [inhaler]. *Because nothing had ever been done for the side effects I was feeling."* (Participant 10)

Another reason for a change in treatment was due to their lifestyle, often participants were prescribed a daily inhaler upon diagnosis. Some were then prescribed another inhaler to be used when they were exercising, if this was an important aspect of their life. Participant 7 who loves hiking described her experience; "*Ya, it was after I was talking to him about if I should be hiking you know with this* (COPD), *and he gave it to me at that point* (rescue inhaler)." (Participant 7)

Participants who have had COPD for multiple years talked about getting treatment that was new or updated and that their doctors kept up with the evolving landscape of COPD treatments; *"As new inhalers came out then they would get changed. And some inhalers were better than others and I'm sure it's a personal thing."* (Participant 1)

This was a positive experience that participants talked about in relation to a connection with their provider and feeling they were receiving personalized care. Some participants also talked about this in relation to being listened to by their providers concerning their experiences with different treatments.

Adapting daily life

Participants all agreed that COPD is a very difficult disease to live with and that their daily lives changed drastically when they started having symptoms or were diagnosed. Many aspects of their daily life were described and encompassed in the subthemes: 1) breathlessness, 2) forced lifestyle change, and 3) mental health.

Breathlessness is a central concept to the experience of COPD described by participants, as it profoundly affects daily life. How participants were affected by it came up in all interviews.

Participants described "*heavy breathing", "a difficult time breathing"*, and "*not being able to catch my breath"* as things that encompass breathlessness. Many explained not being able to participate in activities they otherwise would, due to breathlessness; *"...grocery shopping I can't do anymore, I go online and order it. I can't walk those floors of the grocery store and I get out of breath right away."* (Participant 1)

Many participants stated that as their disease got worse, so did their breathing. Often explaining that every day was different that "*some days are better than others",* this greatly impacted their plans for the day; *"Yes, my breathing's not as good today. I don't know until I wake up in the morning whether I'm going to have a good day or a bad day."* (Participant 11)

Breathlessness often precipitated a forced lifestyle change. Participants described having to change their routines and activities. Some described participating in workouts for those with COPD, which is not something they previously did. The biggest lifestyle change of course was quitting smoking. Participant 6 who smoked heavily during difficult times in her life described her experience trying to quit smoking after her diagnosis:

> *I couldn't quit smoking right away. I just tried like 15 times to go cold turkey...And, I cut down. Like cut down to one cigarette every couple of days. And so, it was gradual. And then I stayed at about five cigarettes for a long time. So, those are the changes that I had to make.* (Participant 6)

Not only were leisure activities affected by participants' COPD, but their work life as well. Participant 8 who previously worked in a dental office described having to stop working due to her COPD and the risk COVID-19 posed; *"You know, (...) I couldn't work anymore because of COVID and my diagnosis."* (Participant 8)

Participants did not welcome lifestyle changes, but many described understanding why things had to change. Participants also described their feelings towards these lifestyle changes and how they affected their overall mental health.

The lifestyle changes had a significant impact on participants' mental health. This was a topic that came up a lot throughout interviews and the impact of COPD in general on mental health. Receiving a diagnosis, changing their lifestyle, and the change to social life all impacted mental health. Many described depression and anxiety as huge changes to their mental health following their diagnosis. They also spoke about how they think this is common among individuals with COPD due to the lifestyle changes and impacts on their social life; "*It was (...) depression, anxiety those are things that are huge with us, just when you can't breathe nothing else matters."* (Participant 3)

Feelings of "*isolation"* and "*loneliness"* were also mentioned, especially if they felt their family and friends did not understand what they were going through or why they had to pull back socially; "*You know it's scary and lonely and it doesn't help your COPD much if you feel that way"* (Participant 5)

Navigating the system

There were a lot of negative experiences that the women felt were in correlation with the system and the system not providing enough or what they thought was enough. Participants described broadly their worries that the healthcare system in Ontario is failing patients and providers. Many talked about feeling neglected in the ER and a lack of time when meeting with their providers. They linked this to the system overall. While this wasn't the case for all participants, some did feel for the providers who are having to work through burnout and being overwhelmed, and that there really is nothing that can be done (that's what they think/feel). Words like "*falling down", "broken",* and "*missing"* were all used to describe the current healthcare system and the failures participants experienced; *"I just think the whole system is falling down and missing a lot.*" (Participant 1); *"So that's our medical system. It's broken...Our system is broken and has been broken for a long time."* (Participant 11)

Accompanying these thoughts were feelings of frustration; *"That it's the government and the system* [causing these problems with care] *so none of us are really sure but a lot of us are very frustrated at the way the system is."* (Participant 3)

The frustration towards the healthcare system was referenced a lot when speaking about negative experiences, especially in hospitals. Many participants had compassion and understanding for providers having to work through burnout and being overwhelmed and placed no blame on them for the outcomes they experienced. More specifically, women who did not have a primary care provider expressed feelings of frustration towards receiving care through walk in clinics.

> *I haven't been able to get a family doctor, so I go to a clinic which are very good, but you see different doctors every time you go. They don't know your history and as I said they're very good, but they're limited so that's how I get my inhalers and that's about it from them.* (Participant 1)

4.3 What women want from their COPD care

The second objective explored what women believed the best care for COPD is to them. This objective encompassed themes that emerged about what is important to participant's care that they did not already experience or have only experienced with some providers. There is overlap with subthemes from the first objective because what the women in this study discussed wanting is based off the experiences they had and how they want to improve their experience. This is divided into the following themes: 1) to be understood by providers and 2) to be treated holistically. Appendix B shows these themes and their subthemes.

To be understood by providers

Many women had different experiences with doctors, nurses, and other hospital staff, going through this helped them to realize what is important to them and what they want the experience with their provider to be if everything were to go right or if they were to have the most optimal care. The subthemes presented under this theme represent the wants and expectations of participants in this study, of care. These subthemes are: 1) proactive information sharing and 2) acknowledgement of needs.

Many participants felt it was the job of their provider to inform them on COPD and their disease, prognosis, and treatment options. Many women felt that a sit-down discussion with their provider would have been helpful to make them feel more confident about their experience and how to move forward; "*(...) I would have liked him* (provider) *to do a follow up just sit me down with a little education about it* [COPD]*."* (Participant 2)

They expressed that if they did not get information from an outside source, they would have been missing a lot. Participants felt this was something they needed more of and something all patients should have access to. Participant 4, who had the ability to go to a rehabilitation center and learn from the professionals there. She described the importance of the information she learned and how not everyone would receive that:

> *Because I find that something that is lacking (...) like when the doctor tells you ok, you have this* [COPD] *if he doesn't send you to a rehab center (...) I don't know how people would know how to stop those coughing fits... (*Participant 4)

Participants outlined the reason information is so important is to ultimately help them manage their disease which can change the quality of life of someone with COPD.

> *And it's because any information and new knowledge that we can get to people helps people to manage and deal with things better even if it's something (...) as simple as making sure that you regularly do your medication, so that you regularly do these things can be real game changers for people.* (Participant 12)

Another reason information is important is it helps participants to feel confident about moving forward in their disease and that they would be doing everything they can to improve their lives and the progression of the disease.

Participants felt they were not being heard; they felt they were being treated in a way they did not like. Overall, what many of them wanted was to feel "*important", "prioritized", "respected",* and *"heard";* "*Everyone should treat you like a person not just your disease and it's nice to get paid attention to"* (Participant 2)

Participants described wanting these things in relation to past experiences with providers and how well they were treated by them.

> *She was so thorough, so detailed, so patient. Oh god and then I had her again during the last of the pandemic and she was fantastic oh everything under the sun, the best doctor I've had in my entire life. She treated me like a person, like I'm her friend and that's what I want.* (Participant 7)

The participants in this study do not think these requests are out of the realm of possibility and believe this is what everyone should experience with their providers.

To be treated holistically

Participants also described what they would want from their treatment plans to feel more supported and engaged in their COPD diagnosis and treatment. This was divided into two subthemes: 1) enhanced confidence and 2) wrap around support.

Wanting to be involved in their treatment plan was something that came up in relation to feeling confident about their treatment and moving forward with their diagnosis. This was expressed through a need to talk about their treatment plan. Many women described the process of receiving treatment as their provider prescribing them inhalers with no discussion or explanation of what they received or any other options. Participants would have liked to feel included through at least a discussion of what they are receiving and what changes to expect; *"(...) to discuss my treatment plan with my doctor*." (Participant 2)

Following those experiences of being prescribed treatments participants also wanted something more personalized. They acknowledged that everyone is different, and some treatments work better for others, so a personalized plan is important; *"I think that we need more personalized care and have someone to talk to on a personal level that understands that everyone is different."* (Participant 10)

In line with personalized care, participants described being referred to pulmonary rehabilitation and activity programs that their providers think would work best for them.

In reference to their mental health, participants emphasized their desire for mental health support whether it be from their provider directly or an outside source. Integrating this into treatment was a desire that was expressed because they already have a relationship with their provider and believe they know them enough to be able to refer them to someone reputable or provide some support themselves; *"And I think in terms of mental help, like I wish my doctor noticed that or it was part of my treatment."* (Participant 5)

Participants talked about how it can be difficult to ask for help for their mental health, they said they would have felt less alone or burdened if their mental health was discussed right from the beginning.

Along with mental health support, it was expressed that support of any kind from a provider was important for the participants' well-being. This was mentioned in relation to quitting smoking, which was the first suggestion providers made to participants, but that support wasn't there to help them act on it; *"Even from doctors, like support from doctors to quit smoking and not blame patients."* (Participant 9)

Many participants spoke about pulmonary rehabilitation and lung health programs that they think are extremely important to find support and that everyone should have this available to them. Support groups are also very wanted in terms of treatment by participants; *“A support group also, because I find somebody that is stage 3 or 4 that is scary you know, and a lot of women are alone and having people already there* [at that stage] *would put me at ease.”* (Participant 4)

Many participants wished they were referred to a support group by their provider as they did not feel they had the capacity or knowledge to do it on their own.

4.4 Recommendations for better care for women with COPD

The third objective explored what participants in the study felt were important topics to improve care for all women with COPD. These topics (subthemes) are the basis for developing recommendations to improve COPD care. The themes presented are: 1) improving awareness around COPD and 2) educating the public on COPD.

Participants uniformly believed that there is a lack of awareness around COPD leading to barriers to treatment and care and poorer experience overall. Many talked about their own lack of knowledge and the lack of knowledge and awareness from family and friends.

> *Very hard for people to understand. Because people seeing you, they see me in a wheelchair and it's like, what are you doing in a wheelchair?... I mean, they think that's just because I'm on oxygen, well, no, it's way more than that.* (Participant 10)

They also spoke about public awareness and the need to increase it to destigmatize COPD and take the blame from patients. These thoughts were often expressed in comparison to other diseases that are more widely known and funded.

> *It's sort of like I wish; you know they talk about dementia. That's mainstream too. And everybody is up in arms about dementia. And it's true, it's a big thing. It's a big thing. But so is this* [COPD]. (Participant 9)

Participants noted an awareness of initiatives surrounding other cardiovascular diseases and its effects on women and how the same attention is not paid to COPD, despite a similar history.

Participants believed that improved education for the public would enhance their overall experience. This was stressed by participants in relation to the public and to providers on COPD, symptoms, prognosis, treatment, and women. Participant 12 described her life as an educator and the value she places on education in everyday life:

> *So, Because I'm an educator from my career. I just think the more you know the better it is. And you know, you learn so much more about the progression of the disease. And also, strategies to help you to manage it* (Participant 12)

Another participant described a campaign for lung cancer and her desire to see something similar to educate the public on the stigma of COPD:

> *I just wish, I think, the Lung Health Foundation at one point tried to have a little campaign, but I think it died. So, someone said they had lung cancer. Usually, the first question the other person will say was, did you smoke? Which is a blame the victim question, right?... And, in their campaign, you know, "ask the right question or something". So, something similar for COPD would be helpful.* (Participant 9)

Lastly, participants explained the importance of education for their ability to advocate for themselves; *"but uh I do find you have to advocate for yourself and that is something that education would help..."* (Participant 4)

4.5 Summary

The goal of this research was to explore the lived experiences of women with COPD through their diagnosis and treatment and understand what they believe would improve their experiences with the hopes of providing recommendations for better support throughout their journeys. A total of 12 participants consented to participate in the study. 10 themes emerged from the analysis under the three objectives set out at the beginning of this study. This chapter summarized those themes. In the next chapter, I will discuss important findings in relation to the current literature and how this study adds to it.

Chapter 5

5 Discussion

The purpose of this research was to answer the question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD? There were three main objectives used to answer this question: 1) Understand the experiences of women during the diagnosis and treatment of their disease, 2) Explore ways to improve women's experience with their COPD journey, and 3) Provide recommendations to better support women's journey with COPD.

This chapter begins by discussing each of the research objectives as they pertain to the findings (Section 5.1). This discussion is supported by the literature and explored through the themes and subthemes that emerged during the analysis. Then I move on to discuss how the findings from this study add to the literature (Section 5.2). Consistent with van Manen’s hermeneutic phenomenology, I discuss my use of a reflexive journal (Section 5.3). The chapter finishes with the potential limitations of the study (Section 5.4).

5.1 Significant Findings

The women interviewed provided stories that gave significant insight into their experience of living with COPD. These women come from a variety of backgrounds and have different motivations for participating in this research, therefore the findings represent a variety of experiences. Within the experience of living with COPD an important aspect is the diagnosis. The diagnosis of COPD allows patients to feel control over their disease and to be able to put a name and reason to their symptoms (Lindgren, 2014). This was highlighted by participants when explaining their experience being diagnosed. Many women described a long waiting period where they experienced symptoms such as breathlessness and coughing before being diagnosed, this is common to COPD patients, in particular women (Arne, 2007). Participants in this study talked about experiencing symptoms for years prior and how this made them feel frustrated and lost during this period. The minimal literature surrounding COPD diagnosis lacks the exploration of this waiting period, therefore the expression of these feelings adds new insight into the experience during this period. After a period of waiting the diagnosis of COPD can still come as a shock and can be scary to patients who are unfamiliar with the disease and its progression (Lindgren, 2014). Many participants in this study echoed these thoughts and feelings when describing their diagnosis story.

Consistent with the literature on experiencing COPD the women in this study described experiencing blame and stigma towards their disease (Halding et al., 2011; Berger et al., 2011). This blame came from friends, family, and providers. This is common in patients with lung diseases that trace back to smoking because many people believe they are self-inflicted (Halding et al., 2011). Along with the stigmatization of COPD in general comes the stigma of using supplemental oxygen. In a study done by Earnst (2002), the author describes adherence to supplemental oxygen in COPD patients being affected by shame or stigma. The women in this study described similar experiences of avoiding supplemental oxygen as much as possible. In previous studies this was described as general shame towards using oxygen and did not take into consideration how gender might play a role (Arne et al., 2007). In our study the women specifically talked about using oxygen as synonymous with looking and feeling frail and incapable by others, these experiences were not expressed in previous studies.

The findings highlighted the importance of receiving information to the participants surrounding COPD. To our knowledge, there is no literature on women's experiences receiving information for their COPD from providers. In our study participants described feelings of frustration and fear with the lack of information they were given about COPD in general and the progression of their disease. Receiving information from providers can improve the patient-provider relationship and increase confidence with disease management (Mills & Sullivan, 1999; Husson et al., 2011). Many women talked about turning to their pulmonary rehabilitation (PR) programs to provide missing information and support. In recent years there has been a lot of positive literature on the benefits of PR to patients with COPD (Lamberton & Mosher, 2024). Studies have shown a decrease in hospital readmissions, improvement in exercise capacity, and quality of life (Lamberton & Mosher, 2024, Moore et al., 2016). However, there are issues with access to PR programs (Alwakeel et al., 2022). This was experienced by some participants in this study who live in more remote areas and are not able to get to the closest PR clinic to them. A couple of women also said they were not referred to a rehabilitation clinic until they asked their providers about it. These findings emphasize a large gap between the best care for COPD and what is being received. This study also adds to the literature the importance of PR programs as described by patient's experiences.

The women in this study also talked about their experiences with their providers. Since COPD is a chronic disease that often involves interacting with different providers consistently this engagement is central to their experience. Consistent with the literature the women in this study reported having a hard time contacting their provider (Martinez et al., 2012). They also felt they were not of priority to them. In addition, our study found that participants felt they were not being heard or listened to by their providers and other hospital staff regarding their symptoms or concerns of treatment side effects. This can be seen in other studies on women and their provider experiences with chronic pain and in primary care (Johansson, 1996; Werner & Malterud, 2003; Mcrae 2018). When patients have more positive experiences with their physicians it can greatly improve relationships and disease management (Tabler et al., 2014). Women in this study demonstrated that their positive experiences which included feeling respected and prioritized by providers made them feel more confident about their disease and their relationship with their provider. Having this positive relationship allowed them to feel more comfortable advocating for themselves and to talk about changes to treatment. These findings add to the literature around positive and negative experiences with providers from women with COPD.

The second objective aimed to explore ways to improve women's experience with their COPD journey. As mentioned, lack of information played a large role in the experience of women living with COPD, therefore an important ask for better care was to be provided with more information. Receiving information from providers is important to fostering a relationship of trust with patients (Tang & Newcomb, 1998). This was echoed by participants in that they would feel more confident in their providers if they were given more information about COPD and their disease. It became apparent that many participants did not receive what they felt was enough information from their providers and often had to look to outside sources to fill knowledge gaps. Self-management is a large part of living with COPD and without important information this can be very difficult (Simpson & Jones, 2013). We can see a lack of information surrounding COPD by patients is an issue in the literature (Wong et al., 2014). The women interviewed in our study want more information about COPD and their disease progression, there is an opportunity here for providers to connect patients with community support. This could provide more information and improve patient's experiences.

Another way to improve their care experience highlighted by participants was enhancing involvement in their treatment plans. It is important for patients to be involved in their treatment plans for COPD because their physical activity levels, history of exacerbations, lung function, and symptoms are all taken into consideration (Lopez-Campo et al., 2014). Many participants expressed their interest in being more involved in creating a treatment plan, specifically that they felt they knew their body best and would be able to provide valuable input to their providers. Creating a treatment plan also involves patient and provider goals for the progression of the disease. Goal alignment is important to a plan and can make patients feel their input is being taken into consideration, however, this is something that is often missing from patient experiences (Giacomini et al., 2012), which was echoed by the women in this study. They recognize the importance of being involved in their treatment plan and want that from their care. This involvement can facilitate a better relationship between patients and providers and avoid issues with treatment adherence.

Support was emphasized heavily by participants in this study because of its importance to managing a chronic disease. Having support is important to allow patients to improve their quality of life and manage their symptoms (Stoilkova-Hartmann et al., 2018; Gardener et al., 2018). There are many domains in which support is needed for an individual living with COPD (Gardner et al., 2018). The women in this study specifically asked for more mental health support. Many of them talked about their struggles with depression and anxiety which is common in women with COPD (Gut-Gobert et al., 2019). Many participants wished this support was included in their treatment as they have already built a rapport with their providers and trust them to provide it themselves or connect them with support available in the community. Another aspect highlighted was support groups. While they do exist, participants described a hard time finding a support group near them that they felt comfortable being a part of. The support of others with COPD is an important aspect to improving quality of life and disease awareness (Gardener et al., 2018). This provides another opportunity for providers to connect patients to support groups, given they are equipped with more knowledge about what is available in the community.

The third objective of this research was to provide recommendations to better support women's journey with COPD. This can be done by looking at important topics emphasized by our participants. The first is to improve awareness around COPD. Many women described a lack of awareness of COPD by friends and family once they were diagnosed. They also described their own lack of awareness prior to being diagnosed. While many people know smoking is a risk factor for lung cancer a lot of the population does not know about COPD and its effects on the body (Roche, 2016). Not only is there a lack of awareness in the public but also among physicians and patients with the disease surrounding risk factors and gender considerations (Sunblad et al., 2011; Roche, 2016; Baiardini et al., 2018). Increasing public awareness is the first step to better support for women with COPD as it gives more knowledge and power to patients, specifically women to be able to ask for diagnostic tests and treatments (Ramachandran et al., 2016). As well, acknowledging this lack of awareness can help providers understand how to discuss information and other topics surrounding COPD with their patients to hopefully bridge the knowledge gap we are seeing (Ramachandran et al., 2016). We can look to other disease campaigns that increased awareness of women's health such as heart disease and diabetes (Long et al., 2008; George et al., 2016). Participants in our study frequently cited these diseases as having the type of awareness they think COPD needs for women.

In a similar vein, educating the public on COPD is recommended. There is a lot of talk about information or lack thereof being received by the participants in this study. This lack of information as mentioned above creates mistrust between patients and providers and invites fear and frustration around the disease. For these reasons, a lot of the women in our study emphasized a need for more education surrounding COPD to the public, patients, and physicians. Instead of just being provided with information it is important to learn about the disease and self-management (Stoilkova-Hartmann et al., 2018). This can go hand in hand with awareness, once we are able to make the population more aware we can educate them on COPD risk factors and other considerations such as gender, which is focused on in this study. Ultimately, it starts with education and awareness of COPD and COPD in women to get started towards better support for women's journeys with COPD.

5.2 Unique contributions to the literature

Several studies show the sex differences between males and females in the presentation and risk factors for COPD (Silveyra et al., 2021, Gut-Gobert et al., 2019, Rogliani et al., 2022). As well, there is research to show a gender bias in the care that is provided to women with COPD (Chapman et al., 2003). We can see in the literature that there is a higher chance of misdiagnosis, less time with providers, and greater risk for anxiety and depression in women with COPD. Considering our ageing population and the greater risk for more cases of COPD it is an important issue to consider. However, there is a gap in the literature on women’s experiences with COPD through diagnosis and treatment as told by them. This study added the specific context of women and their COPD experiences to the literature. This allowed us to share the voice of the women who participated on their experiences, ways to improve their COPD journeys and how we can provide better support. Listening to their stories and learning about their desires allowed us to highlight important topics we can use to provide recommendations to better support women’s journeys with COPD. These recommendations included more education and awareness of COPD for the public. There has not been a study of this kind done to explore the experiences of women with COPD through their diagnosis and treatment journey. This study adds to the literature real examples of women's experiences gained through their stories and ideas for how they would like their experiences to be improved.

5.3 Reflexivity

The importance of keeping a reflexive journal to the quality of research can be outlined by Tracy (2008). Keeping a reflexive journal allowed me to reflect on this journey and help me to grow as a researcher. Using a reflexive journal allowed me to take my bias and pre-understanding and use it to guide my research as suggested by van Manen (1997) when doing phenomenology. I first laid out my position within this research as a woman researcher interested in COPD care, with a family member with COPD who has had issues receiving a diagnosis and subsequent treatment. Acknowledging this in my reflexive journal gave me the freedom to use this bias and preunderstanding throughout my research and analysis. It also allowed me to better connect with the participants I was interviewing, which lends to my ability to perform qualitative research.

Throughout this process I noticed participants were very willing to share their stories, feelings, and opinions with me on their experiences with COPD. Often participants would acknowledge their desire to help contribute to this research and to spread awareness for COPD. This made me realize that not only does my study contribute to the greater research but allowed these women to share their experiences with the public. I did not understand the importance of this to my participants prior to this research and I think it should be emphasized when talking about the future of patient-centered care.

Finally, my reflexive journal allowed me to acknowledge and explore feelings that I felt during the process and everything I learned. It also allowed me to record feelings during the interviews that cannot be seen in just the transcripts which was important to my analysis. An example of this was during a committee meeting I had. My committee members were not exactly sure how some of the themes I described would fit into the project and suggested that maybe they be taken out. I was able to use my reflexive journal and field notes to describe to them the emphasis that was placed on certain topics by participants that explained why I felt these themes were important to the objectives of this study.

5.4 Limitations

While there were measures taken in line with the literature to ensure quality and rigour consistent with the methodologies used there are a few limitations worth noting. One limitation is the lack of observation to accompany the interviews conducted. To truly know a phenomenon is to immerse yourself into the experience with participants (van Manen, 1997). While conducting one-on-one interviews provides a depth of insight into the experience, it may not provide all the information. A limitation to this study is that there is no observation of the phenomenon. This is due to the feasibility of observing patients with providers, as well as the limits to providing privacy to participants and their medical consultations and information. As well, the logistics and timing of completing this study do not allow for extended observation of the phenomenon.

Another limitation is the social desirability bias that comes with interviews. While one-on-one interviews provide the opportunity for participants to share their experiences without the influence of other individuals with similar stories, there is always still a chance of social desirability bias. This phenomenon is when participants answer questions in certain ways to make themselves look good, as per social context (Bergen and Labonte, 2020). This would have an impact on the data by not providing accurate answers to questions. To resolve this the interviewer provided positive feedback to participants throughout the interview (Bergen and Labonte, 2020). However, this phenomenon cannot be controlled completely and therefore is noted by the researchers as a possible limitation to the study.

It is possible that these findings can be generalized to the other women with COPD or other chronic diseases. However, given the small sample size and the nature of phenomenological research it is not definitive whether they are generalizable. This is also noted to be a limitation of the study.

This study explores women's experiences through their COPD journey through a critical theory lens. This research focuses on the gender constructs that influence these journey's. However, we did not delve into other systems that influence one's experiences, such as, socio-economic status and race. This is identified as a potential limitation, given the capacity of myself as the researcher, the literature on COPD, and the sensitivity of such topics questions surrounding thee systems were omitted from the interviews.

Lastly, while this research focuses on improving experiences for women, we did not interview men, therefore, we cannot know the differences for sure. This would be something to explore in future research.

5.5 Summary

This chapter discussed the findings of this research and how they align or differ from current literature on COPD. This study was effective in answering the research question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD? The findings demonstrate that women have a variety of experiences through their COPD journeys, but commonalities can be seen in the diagnosis, lack of information, desire to be more involved, and appreciation of PR programs, among others. These experiences impact the quality of life of women with COPD and their perspective on their disease. Current research lacks the voices of women on their specific experiences with COPD through their diagnosis and treatment journeys.

The findings of this study explore these experiences and provide recommendations based on women's opinions to improve support for their COPD journey.

This research fills a gap in the literature surrounding COPD and patient experiences. This was done by providing a unique perspective and voice of women to the literature on COPD experiences and what patients believe will improve their journeys. The next chapter will discuss the implications of these findings for practice and policy and provide recommendations for future research.

Chapter 6

6 Significance and Conclusions

This chapter provides the final considerations and conclusions concerning the overall research question; What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD?

6.1 Implications for practice

Although COPD is an important issue worldwide, women's voices are not being considered in the research and advancement of care (Chapman et al., 2001, Gut-Gobert et al., 2019). This research demonstrated the importance of exploring lived experiences of those with COPD and listening to their wants and needs in terms of their journey through diagnosis and treatment. Through our understanding of these experiences, we can better support women through their journeys with COPD based on their wants and needs. Women in this study spoke about a lack of information from providers, the importance of pulmonary rehabilitation (PR) to them, and a lack of mental health support, among others. They expressed a need for these things to change and a want to be consulted and more involved in their treatment. This research also highlighted the struggles that come with COPD and the importance of good care to improve quality of life and patient-provider relationships in chronic disease management. We can adjust the practices currently in place for some women based off the opinions and voices explored in this research study. The participants in this study highlighted more support, more information, and involvement in their treatment plans as important aspects of what better care looks like to them. This provides us with specific action items to better support women with COPD. We can inform providers of these findings to allow them to better meet the needs of their patients. This research highlighted that to better support women through their COPD journey we need to take into consideration their experiences and apply what we have learned to practice.

6.2 Implications for policy

While this research focused on the specific experiences of the women in this study, we can use the topics that were emphasized by them to create recommendations for the future of COPD care and management. These topics include awareness and education. This research highlighted the lack of awareness and education surrounding COPD in the public, patients, and providers. Participants in the study acknowledge their own lack of awareness prior to being diagnosed and their perception of others awareness based on the way they were treated by family, friends, and providers. It is important to create more awareness and in turn more education of COPD to emphasize the seriousness of the disease. As well, creating awareness allows for more funding opportunities for future research on disease and care practices. This study also highlighted the importance of awareness for COPD in women. Similar to campaigns for other diseases, it is important for the public, patients, and providers to understand the potential differences between men and women with COPD and to bring attention to COPD in women, as in previous decades it was largely seen in men. Policymakers should include awareness and education of COPD in women included in all COPD education programs for nurses, physicians, respirologists, and other providers that interact with individuals with COPD. As well, creating awareness campaigns for the public to educate them on COPD in women and reduce the stigma against those with the disease.

6.3 Recommendations for future research

This study presented the experiences of twelve women with COPD through their diagnosis and treatment journeys. This study highlighted the importance of awareness for COPD and women and the potential to improve care practices. There were important findings from participant interviews that would be important to explore further to improve chronic disease management of COPD. This first area is pulmonary rehabilitation (PR), many participants discussed the benefits of these programs, but it was touched on that there is a lack of accessibility. This can be seen in the literature and would be important to explore further. We can see the immense benefits PR presents to individuals with COPD and exploring the accessibility issue can allow us to develop solutions. Another important finding was the need for more support within treatment and in general for the participants. It would be important to investigate the types of support that work for COPD patients and what good support looks like to individuals with COPD more in depth. Lastly, in terms of gender considerations for COPD, understanding the differences in care received by men and women would be important to improve care for all with COPD and close some of the gap faced by marginalized populations.

6.4 Conclusion

This research aimed to answer the following question: What are the lived experiences of women with chronic obstructive pulmonary disease (COPD) regarding their diagnosis and treatment, and how do these experiences shape their journey with COPD? This study used van Manen's phenomenology guided by a critical theory paradigm. This was beneficial to understand the lived experiences of women with COPD through the diagnosis and treatment and to explore ways to improve their journey with COPD to create recommendations for better support. This research used one-on-one semi-structured interviews with women with COPD who had/have experienced some form of treatment. Data collection and analysis was iterative and continuous and was guided by van Manen's thematic analysis.

In total there were 12 participants in my study. Findings were analyzed using van Manen's thematic analysis and showed that ten main themes emerged from the data. These themes were: 1) waiting and wondering, 2) seeking information, 3) adjusting to the disease, 4) interacting with providers, 5) adapting daily life, 6) navigating the system, 7) to be understood by providers, 8) to be treated holistically, 9) improving awareness around COPD, and 10) educating the public on COPD.

The findings showed that everyone had a unique experience through diagnosis and treatment of COPD. There were aspects that were common amongst the women in this study, such as waiting time before diagnosis, a lack of information, and stigma against their COPD. These experiences helped us gain insight into the care that is being received compared to the care that is wanted from these women. The importance of information, a timely diagnosis, and provider engagement to the quality of life of women with COPD were identified. The benefits of pulmonary rehabilitation programs throughout the progression of their disease and the increased knowledge about disease management from theses programs was demonstrated, despite the lack of access to these programs. Participants emphasized the need for more information from care providers, the patient involvement in creation of treatment plans, and more support in all forms, such as, mental health. Achieving good care would allow these women living with COPD to feel more confident in their self-management of the disease, improve their relationship with their provider, and improve their quality of life. Finally, this research provided insight into the need for more awareness and education that has allowed us to create recommendations for better care. Improving education on women with COPD and creating awareness campaigns can help support women through their COPD journeys and reduce the blame/stigma that comes with COPD from the public.

This research fills a gap in the literature about patient experiences of women living with COPD. By sharing their voice, we presented what women want to help change the way care and support are provided to women through their COPD journeys.

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Appendices

Appendix A: Interview guide

Interview Guide for Women Living with COPD

Hi good morning/afternoon.

My name is Madeline. I am a master's student working with Dr. Shannon Sibbald, from Western University. I am interviewing women on their experiences with COPD. Thank you for agreeing to participate in this interview. You should have received a letter of information and consent form. Do you have any questions about the information in the letter and have you signed this form?

Today we will talk about your experiences of women with COPD for my research study. The goal of the study is to explore these lived experiences, gain an understanding of what optimal and equitable care looks like to women, and provide recommendations for better care.

The interview will last up to an hour.

The interview will be audio recorded. Everything that you say will be confidential and all data collected will be anonymous. Please keep in mind, your participation is voluntary, and you can decide to stop at any time. (they can decide to skip any or all questions, decline to answer any or end their interview at any point in time).

Do you have any questions? I will need to audio-record our meeting so that I can type out a verbatim transcript of our discussion. Only the audio will be recorded for this interview if you choose to turn your camera on the video will not be recorded. Your name will not appear on that document nor will your name be associated with any responses you may make today during our interview.

May I start the recording?

First, I would like to ask some general questions to get to know you better, only answer those you are comfortable with.

1. How are you doing today?
2. How old are you?
3. Did you smoke?

PROBE: Would you describe yourself as a smoker?

4. How long have you been diagnosed?
5. How would you describe the severity of your disease?

Probe: has your doctor or healthcare provider ever described the severity of your disease to you? If so, how was it described? Do you know your GOLD classification (based on air flow limitations)? For your information a GOLD classification is based on the frequency and severity of your symptoms. Your practitioner may have assigned you a classification to track the progress of your disease.

(GOLD 1 - mild: FEV1 ≥80% predicted, GOLD 2 - moderate: 50% ≤ FEV1 <80% predicted, GOLD 3 - severe: 30% ≤ FEV1 <50% predicted, GOLD 4 - very severe: FEV1 <30% predicted)

In the next set of questions, I would like to ask about your diagnosis. The purpose is to help me better understand this journey for you.

6. Can you tell me the story of your diagnosis.

Probe: Who diagnosed you with COPD?

Probe: How did you connect with this Health Care Provider?

Probe: Can you describe them?

Probe: When were you diagnosed?

7. Can you describe what that diagnosis process was like for you?

Probe: How did you feel about the diagnosis- at the time of diagnosis? In subsequent visits

Probe: What did you think about when you were diagnosed?

Probe: What symptoms did you have?

Probe: What symptoms led you to seek out care?

Probe: What was your experience at that health care appointment like? What was the feel of the appointment?

Probe: What caused you or the physician who diagnosed you to lead to this diagnosis?

Probe: if you could change one thing about the diagnosis process, what would it be?

8. Were you given a spirometry test? For your knowledge a spirometry test is a test given to look at your lung function. The practitioner would have given you a tube attached to a machine to breathe deeply into and record your forced vital capacity.

   Probe: where? How many?

9. What was your life like after you were diagnosed?

   Probe: What lifestyle changes did you make, if any?

10. Have you been into the hospital or ER for your COPD?

    Probe: Describe that experience.

In the next set of questions, I would like to focus on your treatment.

11. Describe what happened after your diagnosis.

    Probe: Was a treatment plan made?

    Probe: Were you consulted on this plan?

Probe: What types of treatment was proposed?

Probe: How did you feel after?

Probe: How soon after did the treatment start?

12. Tell me about your COPD treatment.
13. Describe your care team

Probe: best parts? Worst parts?

Probe: What works well? What doesn't?

Probe: How do you feel about your care team? Would you recommend it to others?

Prove: If you could change one thing about your care team what would it be?

Probe: who provides you care?

Probe: how many providers do you see?

Probe: do your providers talk to one another

In the next set of questions, I would like to focus on equitable care experiences.

14. What did you like or did not like about your care?
15. Is there anything you would change about your COPD care journey?
16. How would you describe your overall experience with just one word.
17. Is there any else about your experiences of diagnosis and treatment that you would like to share that we haven't had a chance to talk about today?

Thank you for your time and patience today in answering these questions.

Appendix B: Table with themes and subthemes

Objectives	**Theme**	**Subtheme**
1) Experiences through diagnosis and treatment	Waiting and wondering	Pre-diagnosis
		Diagnosis
	Seeking information	Lack of information provided
		Doing your own research
		Receiving information
	Adjusting to the disease	Resilience
		Blame and stigma
	Interacting with providers	Engagement from provider
		Different Priorities
		Advocacy
		Changes to treatment
	Adapting daily life	Breathlessness
		Forced lifestyle change
		Mental health
	Navigating the system	N/A
2) What women want from their COPD care	To be understood by providers	Proactive information sharing
		Acknowledgement of needs
	To be treated holistically	Enhance confidence
		Wrap around support
3) Recommendations for better care for women with COPD	Improving awareness around COPD	N/A
	Educating the public on COPD	N/A

Curriculum Vitae

Madeline Dougherty

Education

B. HSc., Honours – Rehabilitation Sciences Sept. 2018 - April 2022

Western University London, ON

MSc., Health Promotion Sept. 2022 – May 2024

Western University London, ON

Professional Certifications

Evaluating Knowledge Translation Strategies in Public Health (2022)
National Collaborating Centre for Methods and Tools

Introduction to Evidence-Informed Decision Making (2022)
National Collaborating Centre for Methods and Tools

Tri-Council Policy Statement 2 Certification (2022) Panel on Research Ethics

Teaching Assistant Training Certification (2022)
Western University Centre for Teaching and Learning

Conference Participation

Re-evaluating Experiences in Rehabilitation presenter. Western University, London, Ontario, January 2023

London Health Research Day presenter. Western University, London, Ontario, June 2023

Trillium Primary Care Conference presenter. Toronto, Ontario, October 2023

Better Breathing Week presenter. Lung Health Foundation. Toronto, Ontario, January 2024

Health and Rehabilitation Sciences Conference presenter. Western University, London, Ontario, February 2024

Research Experience

Research Assistant May 2023 – Present

Western University London, ON

Working with Dr. Anita Kothari at Western University on two scoping reviews. One review is in the field of social prescribing and the other is in the field of scaling science.

- Conducted two comprehensive scoping reviews in the fields of social prescribing and scaling science, demonstrated expertise in systematic literature searches, data extraction, and synthesis.
- Currently publishing a scoping review protocol as first author for our scoping review on social prescribing.
- Organized and facilitated multiple meetings to progress both research projects and coordinated large research teams.

Research & Evaluation Assistant Sept. 2021 – April 2022

Alliance for Healthier Communities Toronto, ON

Participated on a team of six researchers that oversaw multiple projects including analyzing the implementation of social prescribing and research on the equity of the Covid-19 vaccine.

- Successfully completed multiple literature reviews on various topics including loneliness and isolation in seniors, effectiveness of social prescribing, and equity of the Covid-19 vaccine distribution
- Effectively put together a report and presented findings on the literature reviews to the research team and stakeholders

Work Experience

Quality Coordinator May 2019 – August 2022

MediResource Inc. Toronto, ON

- Effectively performed quality analysis on the company’s digital health website that enhanced the usability of the site for clients.
- Updated and published drug and disease articles to the company’s database for use by clients such as Shopper’s Drug Mart that updated them on new information
- Successfully deployed the company’s digital health and fitness website; updated new features and fixed bugs to the final product that created a user-friendly site for clients
- Head the social committee that successfully put on group gatherings to increase the company moral

Teaching Assistant September 2022 – December 2023

Western University London, ON

- Successfully instructed group of 60 students weekly to prepare them for the end of term exam; led students through group discussions to assess knowledge and participation
- Developed important professional relationships with students to identify their learning needs and successfully deliver personalized teaching support
- Integral part of creating exam questions and lesson plans for students

Publications

Dougherty M., Tompkins T., Zibrowski E., Cram J., Ashe M.C., Bhaskar L.T., Card K., Godfrey C., Hebert P., Lacombe R., Muhl C., Mulligan K., Mulvale G., Nelson M., Norman M., Symes B., Teare G., Welch V., Kothari A. (Submitted: 2024). Exploring the incorporation of co-production and policy in social prescribing initiatives: a scoping review protocol. *JMIR Protocols.*

Grants

Sibbald S.L., Savundranayagam M., Zibrowski E., **Dougherty M.** Western Faculty Research Development Fund. “The intersectionality of breathlessness and dyspnoea on health experiences of persons living with COPD". $5680. November 2023.

Sibbald S.L., Savundranayagam M., Nicholson M., Zibrowski E., **Dougherty M.** Lawson Internal Research Fund. "Learning how to breathe: Understanding experiences of patients and caregivers with lung disease". $19,637. December 2023.

Sibbald S.L., Savundranayagam M., Nicholson M., Zibrowski E., **Dougherty M**. WSS-SSHRC Seed. “How we live and breathe: Understanding experiences of patients with lung disease and their informal caregivers”. $24, 806. December 2023.

Awards

Lung Health Foundation Better Breathing Student Travel Award (2023).

Evaluate MSc Award for presentation at the Health and Rehabilitation Sciences Conference (2024).