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## Taking One Step at a Time: Understanding Pulmonary Hypertension through the Voices of the Patients

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Taking One Step at a Time: Understanding  
Pulmonary Hypertension through the Voices of  
the Patients

By  
Rena J. Mohammed

A Major Research Paper submitted to the Department of Sociology  
in partial fulfilment of the requirements  
for the degree of Master of Arts

Wilfrid Laurier University  
Waterloo, Ontario  
September 2016

## Table of Contents

Abstract .....	1
Acknowledgements .....	2
Introduction .....	3
Literature Review .....	7
End-of-Life Issues .....	7
Challenges Associated with Chronic and Rare Diseases .....	8
Illness Experience .....	10
Coping with Chronic Illness .....	12
Previous Pulmonary Hypertension Research .....	15
Methodology .....	18
Philosophical Assumptions .....	18
Interpretive/Theoretical Frameworks .....	18
Sample .....	20
Data Collection .....	23
Data Analysis .....	25
Ethics .....	26
Power .....	27
Findings .....	28
1. The Diagnosis Experience .....	29
1.1 “Downplaying” .....	29
1.2 “The Waiting Game” .....	30
1.3 “Life Sentence” .....	33
2. Day-to-Day Life .....	37
2.1 “Loss” .....	37
2.2 “Changed Personal Relationships” .....	42
2.3 “Invisibility” .....	47
3. Resilience and Coping .....	50
3.1 “Acing the Walking Tests” .....	50
3.2 “Continuing to Travel” .....	52
3.3 “Advocacy” .....	55
Discussion .....	60
Limitations .....	69
Conclusion .....	70
Appendices .....	73
Appendix A: Interview Questions .....	73
Appendix B: Recruitment Letter .....	74
Appendix C: Informed Consent Statement .....	75
References .....	78

## Abstract

This paper presents and discusses the findings of a qualitative thematic analysis of interviews with eight Pulmonary Hypertension patients who discussed their illness experiences. This is an important topic to research, as Pulmonary Hypertension is a rare, invisible and potentially terminal illness about which little substantive research in both the medical and social scientific fields has been done. The diagnosis experience, day-to-day life, and resilience and coping are the three dominant themes found in these interviews. The analysis of these themes indicates that the participants in this study who are living with Pulmonary Hypertension have been able to maintain a positive approach to life throughout their illness experiences, despite the hardships they have faced and the challenges Pulmonary Hypertension has posed to them.

*Keywords:* Pulmonary Hypertension, chronic illness, rare illness, terminal illness, positivity in illness, invisibility and illness, diagnosis, resilience, coping

## **Acknowledgements**

I am greatly honoured to have worked on this Major Research Paper with my supervisor, Dr. Dana Sawchuk. Her knowledge, advice and desire to see me succeed have made the experience of writing this paper an enjoyable one. I would also like to thank my reader, Dr. Jeffrey Aguinaldo, for his guidance and instruction pertaining to qualitative research. I am forever grateful to my participants who so willingly shared their Pulmonary Hypertension experiences, struggles and triumphs with me. Finally, I would like to acknowledge my biggest supporters, my parents, for their infinite love and unwavering support. I could not have done this without them. Thank you.

## Taking One Step at a Time: Understanding Pulmonary Hypertension through the Voices of the Patients

Disease surrounds us everywhere. Cancer, heart disease, obesity, mental illness and physical disability –we all know someone, or have encountered someone with some kind of disease. Keeping this in mind, we must also be aware that we have likely encountered people who are living with diseases that we cannot visibly see or recognize. Those around us could very well be suffering, appearing to be healthy without displaying any outward, physical symptoms. Disease is not always visible to the human eye. It can manifest itself aggressively internally, while outwardly, the person appears to be in good health.

Pulmonary Hypertension is one of these diseases that is very rarely noticed or perceived by simply looking at the person who has it. Pulmonary Hypertension, with its invisibility and its rareness, has been neglected in areas such as awareness, recognition, and research by both medical professionals and the general public. I have chosen the topic of Pulmonary Hypertension for my major research paper because of my personal experience with the disease. My mom was diagnosed with Pulmonary Hypertension and I am familiar with her daily struggles as a result of this disease.

To start, it is necessary to identify what exactly Pulmonary Hypertension is, since so few people are familiar with the condition. Pulmonary Hypertension is a life-threatening and rare disease affecting the arteries of the lungs. Pulmonary Hypertension means that there is continuous high blood pressure in the lungs, which results in an enlargement of the heart. As a result, this can lead to heart failure. The symptoms of

Pulmonary Hypertension are plentiful and have vast effects on the body. Symptoms include:

persistent or unexplained shortness of breath; chest pain; bluish lips, hands and feet; dizziness upon standing, climbing stairs, straightening up from a bent position, or even while just sitting; fainting (also called syncope); fatigue/loss of energy; and swollen ankles and legs (also called edema) (The Pulmonary Hypertension Association of Canada, 2015).

There are five kinds of Pulmonary Hypertension: IPAH/PAH (Idiopathic Pulmonary Arterial Hypertension/Pulmonary Arterial Hypertension); Pulmonary Venous Hypertension associated with left heart disease; Pulmonary Hypertension associated with Hypoxemia; Pulmonary Hypertension due to chronic thrombotic and/or embolic disease; and Pulmonary Hypertension due to miscellaneous causes (Hargett & Tapson, 2008). Idiopathic Pulmonary Hypertension is the rarest form of Pulmonary Hypertension, where no known cause of the disease can be established. In Canada, approximately 5,000 people have been diagnosed with Pulmonary Hypertension (The Pulmonary Hypertension Association of Canada, 2015).

To confirm diagnosis of Pulmonary Hypertension, there are four methods (National Heart, Lung, and Blood Institute, 2011). The first is echocardiography, which uses sound to estimate the pressure in the pulmonary arteries. The second is a chest x-ray, which can show enlargement of the pulmonary arteries and right ventricle. A third way to confirm a diagnosis of Pulmonary Hypertension is through an electrocardiogram (EKG), which records the electrical activity and rhythm of the heart. Finally, Pulmonary Hypertension can be confirmed through right heart catheterization, where the pressure of

the pulmonary arteries is measured, in addition to indicating how well the heart is pumping blood to the rest of the body. This is an invasive procedure where a catheter tube is inserted into a blood vessel in the groin or neck (National Heart, Lung, and Blood Institute, 2011).

To discover the severity of Pulmonary Hypertension, a six-minute walk test is used, as well as a cardiopulmonary exercise test. The six-minute walk test “measures the distance you can quickly walk in six minutes”, whereas the cardiopulmonary exercise test measures “how well your lungs and heart work while you exercise on a treadmill or bicycle” (National Heart, Lung, and Blood Institute, 2011, p.1).

Different treatments exist for different cases and severities of Pulmonary Hypertension. These treatments include oral treatments, inhaled treatments, intravenous treatments, and subcutaneous treatments (infusion pumps) (The Pulmonary Hypertension Association of Canada, 2015).

Besides the fact that it is so rarely seen in Canada, Pulmonary Hypertension is very difficult to diagnose because it shares many of its symptoms with other conditions. As a result, many people are misdiagnosed. This is a serious situation because the average life expectancy of a Pulmonary Hypertension patient is less than three years if the patient goes without treatment (The Pulmonary Hypertension Association of Canada, 2015). This is ironic because many patients spend two to three years of their life seeking an accurate diagnosis. It is crucial, therefore, to raise awareness and further understanding of Pulmonary Hypertension, so that patients can live longer.

This major research paper constitutes a first step in contributing to this awareness and understanding. After a review of the literature, the methods used to gather this data



will be explained. Following that, a detailed account of the findings from the interviews will be presented. Finally, the relevance and implications of this research will be discussed in addition to the limitations of this study.

## Literature Review

Although there has been very little social scientific research done on Pulmonary Hypertension, several existing bodies of literature on chronic diseases are relevant to this current study. These include work in areas such as end-of-life issues, challenges associated with chronic and rare diseases, the illness experience, coping with chronic illness, and previous Pulmonary Hypertension research.

### *End-of-Life Issues*

A great deal of the research in the social sciences that has been done on chronic diseases pertains to end-of-life issues. These end-of-life issues most often include euthanasia and physician-assisted suicide for the chronically ill. Euthanasia, according to Diaconsecu (2012) is when a physician deliberately and compassionately kills a patient who suffers from an incurable disease, who will inevitably die from the disease anyhow.

Advocates for euthanasia do recognize that today's technology and medicine can allow chronically ill patients to live longer; however, they believe that the quality of life of these patients will likely be diminished. Karlsson, Milberg and Strang (2012) interviewed dying cancer patients. The participants interviewed who supported euthanasia provided reasons such as not wanting to suffer any longer than they already have, "mistrust in the provision of help", and a feeling of meaninglessness they experienced as a result of being chronically ill (Karlsson et al., 2012).

On the other hand of the debate, there are several reasons that drive people in today's society to strongly oppose euthanasia. Karlsson et al.'s (2012) qualitative interviews with chronically ill cancer patients also revealed reasons why chronically ill patients do not support euthanasia. There were three reasons why patients who were

interviewed did not desire to be euthanized. These reasons were that patients gave meaning to their suffering, their suffering was not intolerable, and patients trusted in the support of healthcare (Karlsson et al., 2012).

Although in this research I am not directly investigating attitudes towards end-of-life issues and euthanasia, the themes of dying and quality of life in this previous research are suggestive of areas that deserve exploration in the context of Pulmonary Hypertension.

### *Challenges Associated with Chronic and Rare Diseases*

A rare disease, according to The Rare Disease Foundation (2015), is one that affects fewer than 1 in 2,000 people. Pulmonary Hypertension, then, classifies as a rare disease, as there are only estimated to be approximately 5,000 Canadians in total who have been diagnosed with Pulmonary Hypertension (The Pulmonary Hypertension Association of Canada, 2015). Kole and Faurisson (2010) state that “[b]arriers in access to care for rare disease patients include barriers in scientific knowledge, organisation barriers, financial barriers and personal barriers” (p. 224). In addition, they note that lack of research has caused a delay in establishing scientific knowledge that we need in order to identify causes for rare diseases, which results in diseases being underdiagnosed, misdiagnosed, and delayed diagnosis, leading to lack of appropriate treatment (Kole & Faurisson, 2010). Furthermore, “[h]ealth professionals’ unfamiliarity with rare diseases also leads to a lack of referral to specialised services due to an inability to identify what is appropriate but also a lack of knowledge about what potential services may be needed or available” (Kole & Faurisson, 2010, p. 224). Such barriers noted by Kole and Faurisson

can only be weakened by increased awareness and recognition of Pulmonary Hypertension among both the general public and medical professionals.

Since Pulmonary Hypertension is a chronic and rare disease, it is important to look at previous social scientific research done in the area of such diseases. Kutner, Steiner, Corbett, Jahnigen, and Barton (1999) interviewed chronically ill adults in the Denver area in 1995 and found that they expressed “a loss of independence and a fear of becoming a burden” in their everyday lives (p. 1348). Additionally, Kutner et al. (1999) discovered in their interviews with chronically ill patients that having a chronic illness resulted in changes to patients’ interactions and roles with important people in their lives.

Advocacy groups play a vital role in the support of people with rare diseases. Dunkle, Pines and Saltonstall (2010) note that these groups are composed of people who wish to improve scientific understanding and treatments for patients who are living with rare diseases. Additionally, Dunkle et al. (2010) mention the importance of ensuring that patients with rare diseases have access to treatments they need, regardless of their insurance plans. Moreover, “[T]he essence of effective advocacy is to identify the issues that are of importance to the constituent community, and then to advocate policies and programs that address those issues” (Dunkle et al., 2010, p. 517).

In understanding Pulmonary Hypertension patients’ experiences with having a *rare* chronic illness, then, it is necessary to investigate their perceptions of the social services offered to them as a result of having Pulmonary Hypertension. Additionally, it is important to understand whether or not they feel that enough is being done for Pulmonary Hypertension patients with regards to advocacy and awareness. It is also crucial to understand if there are any perceived barriers to social support, for example, support

groups and therapy for coping, since these individuals' illness is so rare. To understand a Pulmonary Hypertension patient's views on having a rare disease, it is also important to explore the patient's involvement or un-involvement with advocacy groups designed to help them cope with their rare illness. Overall, it would be valuable to discover patients' possible concerns in relation to the rarity of their disease, and if they perceive that the advocacy and awareness generated for Pulmonary Hypertension adequately address their concerns.

One of the challenges in having a chronic illness relates to a phenomenon Kutner et al. (1999) refer to as "doctor shopping" –visiting physician after physician, in search of an accurate diagnosis. "Increased patient satisfaction is linked with decreased frequency of 'doctor shopping', increased compliance, and decreased malpractice litigation" (Kutner et al. 1999, p. 1342). 51% of patients surveyed by the Pulmonary Hypertension Association of Canada stated that their family doctor did not initially recognize the symptoms of Pulmonary Hypertension. Perhaps this "doctor shopping" is a common struggle which Pulmonary Hypertension patients share with other chronically ill people. If 'doctor shopping' is prevalent among Pulmonary Hypertension patients, how long were these patients seeking a correct diagnosis and how were patients feeling during the process of trying to be correctly diagnosed?

### *Illness Experience*

It is clear that much work has been done in the area of chronic diseases, rare diseases, and end-of-life issues. Work has been done less frequently, however, on the actual experiences of people who have these chronic diseases. It is important to pay

attention to the lived experiences and actual feelings of people with chronic diseases in order to truly understand exactly how being ill has affected their lives.

Media outlets have done work which focuses on the experience of chronically ill patients. For example, in 2010, CTV (2010) interviewed a woman named Maria O’Kane, who had a severe case of esophageal cancer. In this interview, O’Kane expressed her fears about her cancer returning, in addition to her fear of dying from esophageal cancer (CTV, 2010). She also expressed worry about what will happen to her children if she were to die from the cancer should it return (CTV, 2010). It is important to look at the emotions and experiences like Maria O’Kane’s in order to try to understand what exactly chronically ill patients feel and think on a day-to-day basis.

Aside from such non-academic treatments of chronic illness, there is some existing literature pertaining to what is known as the “illness experience,” which can be defined as focusing on “the consequences of illness on self and identity, on the loss of self or of control and on identity and personal narratives” (Pierret, 2003, p. 8). Cobb and Hamera (1986) interviewed two people with ALS several times for the duration of one year in order to understand how ALS has affected them in terms of relationships with family, friends and the healthcare system. The first participant, Participant A, stated that she received great support from her children, but felt her disease was causing distress for her daughter (Cobb & Hamera, 1986). Also, Participant A said that she felt as if she were a “caregiving burden” to her husband, and noted that she isolated herself from her friends because her friends started to “shy away” from her as her health began to decline (Cobb & Hamera, 1986). Participant B told Cobb and Hamera (1986) that having ALS caused her friends to treat her more nicely than they ever had before, due to guilt and pity her

friends held for her. She also had to rely on her husband way more than she ever had before, with regards to household income and emotional support (Cobb & Hamera, 1986).

The results of Cobb and Hamera (1986) align with what Pierret (2003) deems to be important in studying illness experience. Both Participant A and Participant B experienced a shift from independence to having to rely on other people. According to Pierret (2003), this loss of independence can lead to the ill person feeling stigmatized and hiding their illness from others. It is impossible to capture the full scope of emotional experiences of patients with chronic diseases through polls and surveys, which is why more qualitative studies such as Cobb and Hamera's are needed. Studies such as this are the only way we will ever come close to understanding what it is like to experience chronic diseases, but no qualitative illness experience research has been done specifically in the area of Pulmonary Hypertension.

### *Coping with Chronic Illness*

Living with a chronic disease generally means that the person with the disease will need to rely on social support in some way or another. Payne and Ellis-Hill (2001) refer to studies conducted on social support and breast cancer and conclude that social support is integral for a breast cancer patient to survive psychologically and physically. For these breast cancer patients, the opportunity to confide in people was something that they needed to cope with their illness experience. In addition to having someone to confide in, the breast cancer patients who were receiving chemotherapy stated that they needed support in three other main areas: people who were there for them emotionally,

physically and spiritually, people who could give them help, and people who could provide advice and information for them (Payne & Ellis Hill, 2001).

Martz and Livneh's (2007) theoretical work explores the different ways that people with chronic diseases and disabilities cope. They concluded that coping can take many forms. Coping, according to Martz and Livneh (2007) can be positive, where the patient thinks positively and tries to grow from their circumstance. On the other hand, coping can be negative, where the patient avoids situations and their circumstance brings constant stress into their lives (Martz & Livneh, 2007). Coping can also be both positive and negative, over time, for people living with chronic illnesses and disabilities – "[m]any people have reported, over time, of positive perspectives and experiences in their lives (eg., a greater appreciation for life, relationships, their own strengths; newly found meanings in life)" (Martz & Livneh, 2007, p. xvii). It is important to note that coping with a chronic illness or disability is dependent on several factors. Two of these important factors highlighted by Martz and Livneh (2007) include who the ill individual is, and how long the individual has been affected by their condition.

McGrath (2004), like Martz and Livneh (2007), was interested in how people cope with chronic illness. McGrath (2004) interviewed ill hospice patients and survivors about what helps them to be positive throughout illness, and what hinders their positivity. One of McGrath's (2004) most significant findings is that positivity is a process: "[p]ositiveness is not a given but rather a process that needs to be continuously negotiated depending on the changing situation of the patient" (p. 27). McGrath's findings align with Martz and Livneh's, being that positivity in illness is not automatic and certainly does not come easy -- coping with illness in a positive manner takes time. McGrath (2007)



describes this process of coping positively as a re-negotiation, where ill individuals must continuously re-negotiate their positivity by allowing themselves to feel both positive and negative emotions throughout their illness experience. Coping positively with illness is rarely immediate, and is something which must be worked constantly at in order to attain.

In a similar manner, Eaton, Bradley and Morrissey (2014) followed the lead of Seligman (2008), and studied how positivity in illness affects quality of life for people who are chronically ill. Eaton et al. (2014) examined “illnesses that are highly prevalent, incur substantial costs, have ranging severity and involve significant impairment and disability” (p. 474). Eaton et al. (2014) chose three illnesses to examine in their study: Chronic Obtrusive Pulmonary Disease (COPD), diabetes and arthritis. Their study examined the role of gratitude and forgiveness (positive inclinations) and how they affect quality of life outcomes (Eaton et al., 2014). Through their research, Eaton et al. (2014) discovered that “[m]oderate to strong positive associations were found between both predispositions and affective states” (p. 479). Positive attitudes can, and often do, improve the quality of life and life satisfaction of the chronically ill.

Coping positively with any adversity in life, especially illness, is often associated with religion and spirituality. According to Koenig, D. Larson and S. Larson (2001), several studies have shown that there are higher rates of depression among people with chronic illnesses. For some people, religion is used as a means of coping with this illness-related depression. To demonstrate this point, Koenig et al. (2001) refers to sociologist David Moberg, who stated that “[s]tudies of happiness, morale, and personal adjustment have generally shown a direct relationship between good adjustment and such indicators of religiosity as church membership and attendance, Bible reading, regular listening to

religious broadcasts, belief in an afterlife, and religious faith” (p. 353). As such, it would make sense to investigate if patients with Pulmonary Hypertension use religion as a coping mechanism and whether this has an effect on their attitudes toward their illnesses. Further, Koenig et al. (2001) conducted open-ended interviews with 100 elderly people to discover how they have coped with stress and hardships caused by illness throughout their lives. In their findings, it was revealed that two-thirds of women and one-third of men in the study coped with their struggles and illness through religiosity (Koenig et al., 2001). Religion, as demonstrated by Koenig and Moberg, can play a crucial role in positively coping with illness.

#### *Previous Pulmonary Hypertension Research*

To my knowledge, there is only one other social scientific study conducted about Pulmonary Hypertension. “The Impact of Pulmonary Hypertension on Canadians” is a study that was conducted by The Pulmonary Hypertension Association of Canada (2014) from September 12 to October 25, 2013. This survey was an online poll across Canada, which received responses from 118 Pulmonary Hypertension patients, and 61 caregivers for Pulmonary Hypertension patients, resulting in 179 respondents in total (The Pulmonary Hypertension Association of Canada, 2014).

According to the Pulmonary Hypertension Association of Canada (2014), this was the first study to occur in Canada which measured the impact of Pulmonary Hypertension on both patients and caregivers. This quantitative survey examined areas such as diagnosis, physical burdens (fatigue, for example), social impacts (effect on intimate relationships, for example), financial impacts and treatment gaps. According to this study, “51% of patients surveyed state that their family doctor did not initially recognize the

symptoms of Pulmonary Hypertension and thus did not direct them into the various routes for Pulmonary Hypertension-specific care” (The Pulmonary Hypertension Association of Canada, 2014, p. 9). Additionally, many patients who participated in the survey indicated that the time span from when they first started experiencing the symptoms of Pulmonary Hypertension to their correct diagnosis was two years or longer (The Pulmonary Hypertension Association of Canada, 2014). It is important to note that Pulmonary Hypertension can also be diagnosed by chance as well. “Not uncommonly, PH [Pulmonary Hypertension] is diagnosed by chance, when a diagnostic test performed for a reason other than PH evaluation, such as a chest x-ray or electrocardiogram, reveals typical signs of PH” (Preston, 2013, p. 3). This corroborates the findings of The Pulmonary Hypertension Association of Canada that often Pulmonary Hypertension is not initially recognized, and can be discovered in a patient unintentionally when testing for other illnesses to explain the symptoms. Perhaps these trends in diagnosing Pulmonary Hypertension relate to the prevalence of “doctor shopping”.

I have built on this research conducted by The Pulmonary Hypertension Association of Canada by conducting qualitative interviews with Pulmonary Hypertension patients. I asked questions from the same categories in addition to asking questions from different categories that this quantitative survey conducted by The Pulmonary Hypertension Association of Canada did not cover. The new questions I asked the participants relate to some of the themes identified in the more general literature cited above: the feelings patients were feeling leading to their correct diagnosis, the feelings patients experienced after being properly diagnosed, how the patients’ daily routines and interpersonal relationships have been affected due to having Pulmonary Hypertension,

how they cope with having Pulmonary Hypertension, and what the difficulties are in having an invisible (for the most part), rare chronic illness.

This study conducted by The Pulmonary Hypertension Association of Canada is a good start to understanding the experiences of Pulmonary Hypertension patients. It is limited, though, in that the data collected is quantitative data and, therefore consists more of statistics and less about attaching personal sentiment to experiences. My qualitative research adds depth, voice and personal experience to the research that has already been conducted by The Pulmonary Hypertension Association of Canada, in addition to filling the gaps in questions that were not asked. I chose to only focus on interviewing Pulmonary Hypertension patients, rather than interviewing patients and caregivers. This is because I wanted to know, in rich detail, the experiences unique to the people who are living the firsthand effects of Pulmonary Hypertension.

## **Methodology**

### *Philosophical Assumptions*

My philosophical assumptions in this project are both ontological and epistemological. Creswell (2007) notes “[t]he ontological issue relates to the nature of reality and its characteristics. When researchers conduct qualitative research, they are embracing the idea of multiple realities” (p. 20). I am seeking to understand the realities of multiple Pulmonary Hypertension patients, not just one patient -- this qualifies as a type of ontological assumption. I believe that there are several different realities of Pulmonary Hypertension which are constructed by the patients as a result of their history with the disease. My philosophical assumption, therefore, is also epistemological as I am “trying to get as close as possible to the participants being studied” (Creswell, 2007, p. 20). I am interested in learning the subjective experiences of individuals living with Pulmonary Hypertension, and I have done this through in-depth, one-on-one interviews with my participants. I am relying on quotations from the participants as evidence (Creswell, 2007). I believe patients know what they know (“truth”) about Pulmonary Hypertension as a result of their own individual experiences with the illness. My philosophical assumptions have consequently influenced my methods.

### *Interpretive/Theoretical Frameworks*

There are two theoretical and interpretive frameworks which have framed my research and data. First, I rely on the transformative framework, which means “[k]nowledge is not neutral and it reflects the power and social relationships within society, and thus the purpose of knowledge construction is to aid people to improve society” (Creswell, 2007, p. 25). My goal was to accurately articulate the varying

experiences of patients with Pulmonary Hypertension so that they have their voices heard. These people, in terms of having this disease, are not powerful within society, because their disease is either very rarely acknowledged or completely ignored. In the very least, perhaps framing my research as transformative will allow for more discussion about Pulmonary Hypertension to take place, as this research has given these participants the opportunity to voice the challenges they experience in living with a rare, chronic and potentially terminal disease.

Next, I have utilized standpoint theory to represent my participants' experiences with Pulmonary Hypertension. According to Ryan (2005), standpoint theory "is one that gives light to the specific circumstances and insider knowledge available only to members of a certain collective standpoint" (p. 1). Furthermore, Borland (2009) notes that when we approach matters from the stance of the marginalized person or group, we are more likely to recognize the importance of that standpoint and therefore likely to create more knowledge about that particular stance. Standpoint theory is relevant to my research because I have interviewed people living under similar circumstances due to their disease. I would agree that to some extent I am an insider, as my mom also has Pulmonary Hypertension. I hold a different standpoint than my participants, because I do not suffer from Pulmonary Hypertension. I have seen Pulmonary Hypertension up close throughout the past seven years, but having the disease is not my own experience. This gives me a similar, yet still totally different, standpoint from my participants. Standpoint theory links back to my ontological assumptions that there are multiple realities of Pulmonary Hypertension, which are constructed by people who regard their subjective experiences as "truth" of Pulmonary Hypertension.

The medical definition of Pulmonary Hypertension does not shed light on the ways in which having Pulmonary Hypertension impacts various aspects of patients' lives -- it simply describes what happens to the patients' bodies. The patients' perspectives are also important to understand, as effects caused by Pulmonary Hypertension on the body have significant implications on how Pulmonary Hypertension patients live and experience life. Helman (1981) makes the distinction between disease and illness. Disease, according to Helman (1981), "refers to abnormalities of the structure and function of body organs and systems" whereas illness means "what the patient feels when he [sic] goes to the doctor" (p. 548). Disease, therefore, pertains to the body and pertains to the medical definition of Pulmonary Hypertension. In contrast, illness relates to the patient's experience with the disease and, as influenced by my philosophical and theoretical frameworks above, is what I am seeking to understand through this research.

### *Sample*

The Pulmonary Hypertension Association of Canada is how I have obtained my sample of eight individuals interviewed. The Pulmonary Hypertension Association of Canada is a charitable organization which exists to support Canadians living with Pulmonary Hypertension. The Pulmonary Hypertension Association of Canada's (2015) mission is "[t]o empower the Canadian Pulmonary Hypertension community through awareness, advocacy, education, research and patient support" and their vision is "[a] better life for all Canadians affected by Pulmonary Hypertension". The Pulmonary Hypertension Association of Canada (2015) is composed of patients, caregivers, doctors and nurses who together, offer patients and caregivers support groups, raise awareness, raise money for research and offer community members several ways of becoming

involved with its organization to better the lives of Canadians with Pulmonary Hypertension.

I became a member of The Pulmonary Hypertension Association of Canada in 2011. Being a member consists of receiving invitations to support group meetings, receiving invitations to fundraising events held by other members, and receiving monthly newsletters with updates in Pulmonary Hypertension news. Being a member of The Pulmonary Hypertension Association of Canada inspired me to begin my own fundraising initiatives for the organization. The Pulmonary Hypertension Association of Canada has been the sole tool in my networking with other Pulmonary Hypertension patients. The organization has granted me access to and knowledge of people who are living with Pulmonary Hypertension. My sample for my major research paper consists of the patients I have met and heard of through my fundraisers and through The Pulmonary Hypertension Association of Canada.

I personally knew or had heard of only four individuals with Pulmonary Hypertension. For the remainder of my sample, I relied on snowball sampling. According to Cohen and Arieli (2011):

SSM [snowball sampling methodology], or chain-referral sampling, is a distinct method of convenience sampling which has been proven to be especially useful in conducting research in marginalized societies. This method is commonly used to locate, access, and involve people from specific populations in cases where the researcher anticipates difficulties in creating a representative sample of the research population. It has been suggested that SSM is probably the most effective method to access hidden and/or hard to reach populations. (p. 426).



Because so few people are diagnosed with Pulmonary Hypertension, the Pulmonary Hypertension community is in fact a marginalized group. Snowball sampling was convenient for my research because I was referred to four more people with Pulmonary Hypertension whom I did not know and had not heard of. Having interviewed eight participants does not mean that all my participants' answers will speak for the entire Pulmonary Hypertension community of patients, but it does mean that a broader range of experiences could be represented with more than the four initial participants I recruited on my own.

I had no specific age range or gender requirements I was looking for in my participants. I was open to interviewing anyone with Pulmonary Hypertension. According to The Pulmonary Hypertension Association of Canada (2015), Pulmonary Hypertension “can strike anyone, regardless of age, gender or race”. I did, however, predict that most of my participants would be middle-aged females, as Pulmonary Hypertension “most commonly affects women 40-60” (The Pulmonary Hypertension Association of Canada, 2015). I was correct in this prediction, with all eight of my participants falling in to the middle-aged, female category. It was hard for me to establish a set of criteria my participants must fulfil in order for me to interview them, as there are already so few Pulmonary Hypertension patients in Canada to begin with.

I also think that it is important to identify who I did *not* interview for my major research paper. I chose not to interview my mom, and there are several reasons for this. The main reason is that to some extent, I know her full story, as I have lived her journey with her. This could alter the quality of how I portray her experience, and blur the line between her own experience as a patient and my own experience as her caregiver. In

addition, my mom is even more of a rare case of Pulmonary Hypertension than her fellow patients. My mom is the only patient in the world doctors know of whose heart actually stops as a result of her Pulmonary Hypertension-induced syncope. As a result of this unique turn of the illness in addition to the inability for anyone to explain why this happens to my mom only, I did not think it would be beneficial to include my mom in my interviews because her responses may lead to confusion for the readers as to what Pulmonary Hypertension is, how it [usually] manifests itself and exists, and what effects it has on the patients. Lastly, I did not wish to interview my mom because of the close, pre-existing tie I have with her. I did not have close ties with any of my other participants, as I had only met some of them once before my interviews and met the others at the time of the interviews.

I provided my participants with honoraria for agreeing to talk with me for my major research paper. I wanted to show my gratitude for their willingness to participate, since they took the time out of their day, and since I asked them questions that were very personal and required significant reflection. I gave my participants a gift card of \$20 to Starbucks for agreeing to speak with me, in addition to buying the participant a beverage to drink during the interview if the interview was conducted in person.

### *Data Collection*

The interviews were recorded with a digital audio recorder and later transcribed by me. The in-person interviews took place wherever the participants felt comfortable talking to me. Four in-person interviews were conducted with participants in the Greater Toronto Area (GTA) or close by. The participants I interviewed in-person ended up all choosing to meet me at local coffee shops. For the four participants who lived more than

an hour and a half away, or who had complex schedules, Skype and video chat interviews were conducted.

My interviews ranged in length from 15 minutes to 51 minutes, with most interviews approximately 45 minutes. For ethical reasons, I was prepared to terminate interviews in the event that a participant mentioned to me that they were not feeling well or were too emotional during the interview; however, this did not occur.

I chose to conduct in-depth, semi-structured interviews (see *Appendix A* for interview questions). According to Galletta (2013), “[s]emi-structured interviews allow for the exploration of lived experience as narrated in the interview in relation to theoretical variables of interest” (p. 9). Semi-structured interviews were appropriate because one participant’s experience of Pulmonary Hypertension is not the exact same as another -- semi-structured interviews allowed for the participants to elaborate or expand on a question or topic that I brought up, and allowed the participants to answer the questions I posed in their own terms while adding their own context. A semi-structured interview gave the participants a better opportunity to narrate their own unique, individual experiences with Pulmonary Hypertension. Barriball and While (1994) say semi-structured interviews “are well suited for the exploration of the perceptions and opinions of the respondents regarding complex and sometimes sensitive issues and enable probing for more information and clarification of answers” (p. 330). Choosing to conduct semi-structured interviews reverts back to my philosophical assumptions -- that there are multiple realities of Pulmonary Hypertension, which required conversing with these participants in detail to understand their unique illness experiences. A semi-structured interview allowed me not only to understand the experiences of these Pulmonary

Hypertension patients, but permitted me to ask follow-up questions in cases where I was unclear about the participants' responses, or if I wished the participants to elaborate more on a particular topic.

### *Data Analysis*

I was not looking to find specific themes within my thematic analysis therefore it made sense for me to take an inductive approach to my data. I coded the data I collected into themes that recurred from the participants' responses of their experiences of Pulmonary Hypertension. "Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data" (Braun & Clarke, 2006, p. 5). Furthermore, "[a] theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p. 10).

While there are several different approaches to thematic analysis, the work of Mayan (2009) has influenced how I have conducted my analysis. I have utilized Mayan's (2009) sequenced approach of coding, categorizing, memoing and theorizing. By "coding", Mayan (2009) refers to writing words, assigning words and underlining words in the data (p. 88). "Categorizing" occurs when certain codes that "fit" with one another are grouped together (Mayan, 2009). Memoing, then, is when the analytical process begins -- thinking about what the codes and categories mean (Mayan, 2009). Lastly, the theorizing in Mayan's (2009) methods takes place when speculation and possible explanations occur. In combination with Mayan's approach, I have been inspired, too, by the work of Braun and Clarke (2006) with regards to my coding; I have followed their

step-by-step process of ensuring that “[t]hemes have been checked against each other and back to the original data step” and that “[t]hemes are internally coherent, consistent, and distinctive” (p. 96).

I was interested in finding common themes because while these experiences of my participants are not generalizable to the whole Pulmonary Hypertension community, the themes and common feelings may be very relatable to members of the community. Finding common themes in my data may contribute to Pulmonary Hypertension patients feeling a bit less marginalized by realizing that aspects of their experiences can be relatable to some aspects of other patients’ experiences. The possible social implication for my research is ultimately awareness. I hope that my major research paper ignites more discussion about Pulmonary Hypertension, ideally among both the general public and among healthcare professionals. This is important because Pulmonary Hypertension patients are a marginalized group, due to the rarity and invisibility of their illness. Broader awareness of Pulmonary Hypertension is something that could eventually lead to decreased marginalization of these patients. On a larger scale, increased awareness of Pulmonary Hypertension could possibly lead to more research, which could, in the long run, lead to a cure being found one day for Pulmonary Hypertension.

### *Ethics*

Ethics clearance from the Wilfrid Laurier University Research Ethics Board (REB) was obtained before data collection. As part of the ethics application process, I submitted a list of my interview questions (see *Appendix A*), a recruitment letter (see *Appendix B*) and an informed consent statement (see *Appendix C*), which I e-mailed to my participants before I interviewed them.

Since the Pulmonary Hypertension community is so small, remaining anonymous in my research was assumed to be important to some participants. I provided three options for participants -- a) to use their names in publications and presentations resulting from this research, b) to not use their names in quoted materials, or c) to not use either names or quotations in publications and presentations resulting from this research. Two of the participants chose to remain anonymous and agreed to be quoted as long as the quotations did not contain identifying information. The other six participants did not wish to remain anonymous, granting me permission to use their names.

### *Power*

To conclude this section, I will talk about power and its role in my research paper. I am not a person who suffers from this rare, chronic disease. As a result, I will never fully understand what it is like to live with Pulmonary Hypertension. I am, however, a member of the Pulmonary Hypertension community therefore I did have the capacity to empathize with some of the experiences my participants have shared with me. Because of my standpoint, I am not blindly speaking about the experiences of my participants. I have been able to relate on some level to what my participants have told me, and was able to relate some of what my participants have lived through to certain experiences I know my mom has lived through. I am privileged and have power in the sense that I do not have this disease. That being said, being part of the Pulmonary Hypertension community gives me what I interpret to be a middle-ground position, where I am not a privileged *outsider* who is framing the experiences of my participants without a history and relatability to the disease.

## Findings

There are three primary themes in this data. Each theme illustrates the different ways in which the people I have interviewed have constructed their illness experience with Pulmonary Hypertension. The first theme that has emerged from this data is *The Diagnosis Experience*. In this theme, participants discussed their diagnosis of Pulmonary Hypertension with regards to downplaying the symptoms they were initially experiencing, the complex process of receiving an accurate diagnosis, and the life expectancies that they were given following their correct diagnoses. The second theme discovered, *Day-to-Day Life*, refers to the ways in which these individuals with Pulmonary Hypertension have experienced changes in their everyday lives, with a focus on loss, restrictions, personal relationships, and the implications which accompany having what is, for the most part, an invisible illness. *Resilience and Coping* is the third theme, which pertains to the ways these people with Pulmonary Hypertension manage their lifestyle changes and all that accompanies living with a rare, potentially terminal illness. Specifically, this theme encompasses the participants' determination in their health assessments, their willpower to continue traveling, and their devotion to activism, research and raising awareness for Pulmonary Hypertension. All of these themes portray how these participants with Pulmonary Hypertension have constructed their individual illness experiences. Equally important, these themes showcase the overarching theme of the incredible positivity and coping abilities these individuals possess despite the struggles, challenges and barriers associated with having this rare and chronic illness.

## 1. The Diagnosis Experience

### 1.1 “Downplaying”

All participants in this study experienced *downplaying*, in some capacity, leading up to and during the time of their diagnoses. This downplaying includes confusing symptoms for other conditions, giving the symptoms time to hopefully fade away on their own, and not realizing how serious Pulmonary Hypertension was at the time of diagnosis. Attributing the symptoms of Pulmonary Hypertension to other conditions was a common experience among several of the participants interviewed. Nicole, for example, said:

I was working as a teacher and so I'd just always be tired and started noticing the breathlessness but nothing alarming, then I was trying to work out and I just couldn't—I didn't have the stamina to continue...it was really weird and I was just like, oh I'm out of shape, I'm out of shape, I guess this is what happens when you hit 40.

Similarly, Marion downplayed the symptoms of breathlessness by attributing them to weight-associated problems. Marion stated “I thought I was overweight. I was experiencing asthma issues and allergy issues -- the asthma issues I had since I was a child...but I didn't go to a doctor. I was overweight, I was out of shape”.

Amanda, having just given birth to twins, had thought her breathlessness was a result of giving birth. She experienced this for a few months before asking her doctor during her routine physical, “I know I have weight to lose after having the twins, could this be why?” Carol, too, was experiencing her Pulmonary Hypertension symptoms after the birth of her son in 2004. She started experiencing blackouts and shortness of breath. Carol said her and her husband thought that she “had extra weight from the pregnancy”



and they thought it could be asthma due to prior incidents where she “coughed herself sick”.

Downplaying among these participants did not only occur up to the time of diagnosis, but occurred after diagnosis, too. In particular, the severity and seriousness of having Pulmonary Hypertension was underestimated or unknown to several of the individuals in this study. A participant shared that once she was diagnosed with Pulmonary Hypertension, she “didn’t realize how serious it was at all”, and turned to Google to provide her with information on the severity of her condition. Likewise, when Nicole was diagnosed, she said that she “heard hypertension and just didn’t think anything of it” -- until, like the unnamed participant mentioned before, she Googled the illness and discovered its seriousness. Additionally, Loretta admitted her shock after she was diagnosed because she “didn’t really think it was a big deal” in the beginning. Another participant noted that when she received her diagnosis, she “didn’t know about the disease at all”. This participant “searched on the internet and realized how serious the disease can be”.

### 1.2 *“The Waiting Game”*

In all cases of my participants, the initial downplaying of their symptoms eventually was transformed into body consciousness, where these participants recognized that something was not right with their bodies. The newfound understandings of their bodies led these participants to take a proactive approach to their health, actively seeking help from medical professionals to understand their symptoms and receive a diagnosis. While some participants received a diagnosis relatively quickly and often due to the insight and action of their family doctors, some of these participants experienced Kutner

et al.'s (1999) 'doctor shopping', where they visited multiple doctors without receiving an accurate diagnosis -- leading to a frustrating and potentially life-threatening "waiting game".

Interestingly enough, once some of these participants began to proactively seek help for their symptoms, some of their doctors and medical professionals participated in downplaying too, where the symptoms of these patients were dismissed and excused by the doctors they were relying on for answers. For example, Carolyn gave birth to her son in February of 1996 and started experiencing her shortness of breath in September of that year. She then went to her doctor saying that she was short of breath. Carolyn's doctor told her that the shortness of breath was probably due to the extra weight gain, which she noted was only ten pounds. One month later, Carolyn went back to her doctor ten pounds lighter and even more short of breath. Carolyn constantly phoned her doctor, telling him that she was feeling worse each day than the last. She recalls:

I would phone the doctor and say I'm even worse today than I was yesterday, and you know, because of the type of person I am, I would have a shower and get ready, and look half decent going to his office, so he would just truly, no word of a lie, just look at me and say hey, well you look good, and he would just pat my leg. That was it.

Carolyn felt that her proactive approach to her health was undermined by her doctor, whom she felt quickly dismissed her symptoms due to the fact that she appeared to be well on the outside.

Equally as concerning is Carol's experience with a medical professional who downplayed her Pulmonary Hypertension symptoms. Carol was a new mother at the time

she started to experience her Pulmonary Hypertension symptoms. She was experiencing severe edema at this time, which is a build-up of fluid in the body. Carol recalls:

I went in to the walk-in clinic and got sent home and was told that the fluid was just part of motherhood and I needed to deal with it. And I had left there crying and I said to my husband, I know something is wrong. I don't know what it is, but something's wrong and I don't care that a doctor told me otherwise.

This doctor was dismissive of Carol's concerns and displayed a true lack of compassion and interest in the well-being of his patient.

It seems that the downplaying and dismissing of both Carolyn's and Carol's symptoms by medical professionals ultimately led to doctor shopping and a long quest for an accurate diagnosis. Carolyn's experience with the doctor telling her that she "looked good" is one factor which led to her long experience with doctor shopping.

Carolyn started experiencing her shortness of breath in September of 1996. When asked if she experienced doctor shopping, Carolyn explained:

My family doctor sent me to the cardiologist, the cardiologist sent me to the blood doctor, the blood doctor sent me to the lung doctor, the lung doctor sent me to the pulmonologist. Originally, they diagnosed me with umm, Pulmonary Embolism, so that would have been in January.

It wasn't until April of 1997 that Carolyn finally received a legitimate and correct diagnosis of her condition.

Carol, whose symptoms were also dismissed and downplayed by a doctor, experienced doctor shopping, too. As mentioned before, Carol was experiencing edema. In addition, she started having blackouts and shortness of breath after the birth of her son

in 2004. She went to the doctor, who sent her to a neurologist. She was told she had syncope and it was recommended for her to cut caffeine out of her diet and to not get up too quickly, in an attempt to reduce her blackouts. Carol said that these suggestions “did help, but not for the reasons that they thought”. She remembers:

Between the four-year span of my son and my daughter, I had a bunch of symptoms but no one ever linked them together, not even my family doctor. So I would see different doctors and nobody did -- nobody knew -- the neurologist never questioned anything or linked anything other than the fact that he said I had syncope.

In 2008, four years after Carol started experiencing her symptoms, she was correctly diagnosed with Pulmonary Hypertension.

One participant was diagnosed with Pulmonary Hypertension in 2007. She mentioned that she had experienced her symptoms for almost 20 years before being correctly diagnosed. This participant said that she was not experiencing doctor shopping around the time that she was diagnosed, but she did when she was a child, around seven or eight years old. Diagnosis was such a long experience for this participant because on top of Pulmonary Hypertension, she also has a secondary lung disease which is undiagnosed.

### 1.3 “*Life Sentence*”

Sometimes, part of being diagnosed with a chronic and potentially terminal illness is receiving a time frame in which your condition is expected to worsen. Along with this, can come a “life sentence” where you are in turn, expected to die due to this illness. Some

of the participants in this research have received this “life sentence” with their diagnoses, where they were given shortened life expectancies as a result of their illness.

When asked to describe how she felt when she was first diagnosed with Pulmonary Hypertension, Marion said she was devastated. A large contributor to her devastation was that she was given a life expectancy from her doctors along with her diagnosis. She reflected that “life was no longer going to be as it was. Days were numbered. I was given a three- to five-year sentence as we called it at that time”. Now, Marion is at the five-year mark of her “sentence”: “We’re at five years now...they all kind of hit this panic mode, this bump, and they wanna wrap me in cotton batting”. Marion’s ultimate concern with this time frame is her family and their well-being.

Amanda’s reaction once she was diagnosed with Pulmonary Hypertension was very similar to Marion’s initial reaction. Amanda said:

I was scared. Young kids and just knowing what I had been reading on the internet. And I had been on the correct websites, not the ones that had misinformation....But just knowing that it is a life-limiting illness and not knowing what life would look like for me and my family, it was scary.

Amanda, like Marion, feared the negative implications that this life-threatening illness could have on her family.

Once another participant was diagnosed with Pulmonary Hypertension, she was shocked and sad, and mentioned that “she didn’t know how lethal it was”. Having been diagnosed with this chronic and possibly terminal illness, she felt the pressure of a “life sentence”, too. She noted that after being diagnosed with Pulmonary Hypertension, she

was “thinking about all the things that any young person thinks about, all their hopes and dreams, and thinking that I wasn’t going to achieve them”. She continued, saying:

I kind of had a situational depression at the time, like it wasn’t going to get any better, feeling pretty discouraged and down...it was pretty depressing. You know, it’s just the proverbial rug was pulled out from under me, so there was a bit of depression there, just feeling overwhelmed by it all.

This participant feared that because of the severity of her diagnosis that she would no longer be able to accomplish what she had planned on accomplishing in her life.

A particularly dramatic situation occurred in Carolyn’s case. As soon as she was finally correctly diagnosed with Pulmonary Hypertension, her doctors wanted her to take a medication which could have resulted in her instant death, as a result of her blood pressure being lowered so much that she could, in her words, “flat line”. Carolyn was not left with much of a choice of whether or not to take this medication as the doctors did not think she was going to even survive the night without the medication. Carolyn disclosed:

After they gave me that night to live and I survived the night, they gave me a week to live, so when I survived the week, I was at the hospital, went home, you know, to die, and um so now I’m at home and my husband and I are crying ourselves to sleep each night thinking we’re not gonna see each other tomorrow... I survived the month and then after I survived a month they gave me six months to live...After I survived six months they gave me a year and after they gave me a year they gave me two years, after two years they gave me five years, and after five years now they’ve said you’ll be here a long time.

Clearly, the multiple “life sentences” which occurred in Carolyn’s Pulmonary Hypertension experience took a terrible emotional toll not only on Carolyn, but on her husband as well.

Nicole mentioned that the hardest part of being diagnosed with Pulmonary Hypertension was the life expectancy. She said:

Just thinking about the life expectancy or the prognosis is kind of grim but I just don’t go there. But it’s hard not to go there because it’s always in your face and especially if you’re -- I’m part of some PH groups on Facebook and you know, you see some people typing away and you know that it’s there and we all have a life expectancy whether we are diagnosed with something or not, umm, but this one is just kind of more in your face and it’s always there.

In Nicole’s experience, it is hard to ignore the “life sentence” that accompanies this chronic, life-endangering illness.

Finally, Carol also received a “life sentence”. Carol said:

When I got diagnosed, I was told by a cardiologist that I needed a lung transplant or I would be dead in two years which was not accurate information, umm so I left the cardiologist office and I was a mess because I thought, here I am with a four year old and a three week old and I need a lung.

Carol’s “life sentence” was distressful for her because she was a mother to two young children and on top of that, distressful because her life expectancy given to her by this cardiologist was incorrect. Several of these participants received “life sentences” which were accompanied with worry, panic, depression, stress and sadness at the times of their

diagnoses. Receiving “life sentences” has caused some of these participants to question themselves, in terms of their goals, capabilities and familial responsibilities.

## 2. Day-to-Day Life

### 2.1 “Loss”

Several variations of “loss” have occurred in the everyday lives of the Pulmonary Hypertension patients interviewed for this research. This loss is apparent in vital aspects of life, such as energy, independence and employment.

One major way in which loss of energy has manifested in the everyday lives of some of these participants is a lack of energy to maintain a household. When talking with Marion, she admitted that having Pulmonary Hypertension has contributed to a loss in her energy, meaning she cannot do everything in a day that she used to be able to do before the onset of her illness. Marion said:

I was an on-the-go person, in to everything, did everything. Now, I pick and choose what I’m doing today and what I didn’t do today, is for tomorrow.

Standards around the house –my house –used to be always as clean as I could get it. Now, if there’s a bit of dust here or there or the floor’s not vacuumed, so be it – you come to see me, you come to see my floor and my dust bunnies.

Marion has lowered her standards of housework as a result of her lack of energy caused by her Pulmonary Hypertension. In addition, her identification as someone who is always “on-the-go” has been compromised because of Pulmonary Hypertension.

Similarly, Nicole noted that her ability to maintain her household has been compromised because of Pulmonary Hypertension. She said “My husband’s had to pick up pretty much all the slack in the house...we have a big house, so we’ve always toyed



with the idea of having someone come in and clean because he's really having to do it all". Nicole's lack of energy has resulted in her husband taking over the maintenance of their home. Another participant revealed that one of the biggest ways her life has changed since being diagnosed with Pulmonary Hypertension is in terms of housework. As she said: "I still help take care of my kids, I just do less housework. That's probably the biggest change...I just do whatever I can and try not to overwork". This participant understands her limits when it comes to her energy and contributes what she can to the maintenance of the house, but she stops when she needs to stop.

Carol, like Marion and Nicole, also experiences difficulty when it comes to housework because of the low energy that comes with the territory of having Pulmonary Hypertension. Carol reflected that "it's overwhelming for people to look at a house and realize how much you have to do when you have no energy to do it, and when you do have the energy, that's where you're spending it". Every few months, Carol has someone come in to do a big clean in her house. Because Carol's energy has been affected by Pulmonary Hypertension, it has become a challenge for her to meet all the demands of running a household. Furthermore, when asked to describe her experience with Pulmonary Hypertension in one word, one participant said "Tired. That's my experience - I just feel tired all the time". It is clear from these participants' responses that it is often difficult to meet the demands of everyday life due to the fatigue caused by Pulmonary Hypertension.

Another challenge that is a component of several of these participants' illness experiences is a loss of independence. One participant recalled:

At the time, I was in a different province than my family...I was in the middle of a bachelor's degree and was living -- you know, I'd lived pretty independently for, um, 7 years at that point -- and so I didn't have any family or partner down there and my parents had to come pick me up and take me back to Ontario and I, um, had to live with them because I couldn't really do a lot of things for myself...I felt like I was a guest in my parents' home and so that was difficult. I had a little bit of privacy, but not much, and no independence.

This participant was forced to surrender her independence in terms of where she lived in addition to having to rely on her parents for care she had not had to rely on them for in several years. She elaborated "I didn't want to be incapacitated, I didn't like being dependant and not being able to basically care for myself, so that was the hardest part for me". This participant's self-understanding changed, as she became more dependent with the progression of her disease.

Carol's loss of independence stemmed from the constant blackouts she was experiencing because of her Pulmonary Hypertension. Carol explained:

The bad part was that I kinda started hiding my blackouts from my husband...when I would have a blackout he would get nervous because we had a new baby, and he would make his parents come stay with me and I was losing my independence and I didn't want to do that.

Carol, determined to preserve her independence, took a risk by not telling her husband about her blackouts so that she did not have to be watched by her husband's parents.

Loss of employment is something that many of these Pulmonary Hypertension patients have also experienced due to their illness. Marion agreed that her ability to work

was compromised since being diagnosed with Pulmonary Hypertension, saying “Yes, absolutely no work. I went into having PH on a senior level -- my [lung] pressures were over 100, so I wasn’t in the position to work at that point”. Because of how severe her Pulmonary Hypertension was when she was diagnosed, Marion had to give up her job.

Amanda has experienced a total loss of the ability to work as a result of being on oxygen. She explained:

I was working downtown so the thought of commuting, and then I worked at a hospital...and so I had never seen anyone else working there that used oxygen, and they told me that you can’t -- it’s not safe to be working with kids in the capacity that I was using oxygen. And then also my endurance, and I was experiencing all that fatigue and, um, shortness of breath with walking...I could go at a very slow pace for a really long time waking, but not if I had to bend down.

As much as Amanda’s oxygen gave her the capacity to breath, the oxygen incapacitated her in the sense that it prevented her from being able to perform her job safely.

Due to Loretta’s experience with Pulmonary Hypertension, she is also not able to work anymore, and hasn’t for the last three years. Loretta’s loss of ability to work has changed the structure of her day-to-day routine. Pulmonary Hypertension has taken away Carolyn’s ability to work as well, which she mentioned has affected her financially. Finally, in the beginning of her journey with Pulmonary Hypertension after being diagnosed, Nicole was on oxygen full-time. She found herself unable to continue working, and recalled:

Life's changed just in the sense that I stopped working...I was a teacher for 12 years. I taught grade six and I really enjoyed that and I miss it...I'm not working anymore and so that plays on my emotional well-being".

Nicole experiences an emotional consequence of not being able to work because she truly enjoyed her job as a teacher, but was unable to continue working as a result of her Pulmonary Hypertension. Additionally, Nicole experienced a loss in her identity -- she has had to come to terms with the fact that she is no longer a teacher.

On the other hand, although one participant's ability to work was affected by Pulmonary Hypertension during the time she was diagnosed, today she is able to work. "For the first couple of years when I was diagnosed I didn't work. I was on disability but then once I was well enough to go back, I could go back. It wasn't a problem". Initially, she had lost her ability to work, but once her condition became more stable, this participant was able to regain her independence by starting to work again. Carol's experience with her loss of ability to work is similar to this participant's experience. Carol was not able to work early on in her diagnosis. She noted:

When I was able to get back to work, changes started happening, it was actually for the best...Um, because your mind -- my mind -- got used, so it helped to occupy [me]. The days are too long if you can't do anything.

Carol's condition luckily improved and she was able to regain her lost ability to work. Another participant stated "I didn't even, um, take much disability leave, I just continued working, but I was working more from home at the beginning. Once I got better I was able to go to the office everyday". It is clear, even for the participants who are able to work today, that Pulmonary Hypertension can have varying effects on one's ability to

work -- eliminating this possibility completely, or disrupting or altering the ability to work in some capacity.

## 2.2 *“Changed Personal Relationships”*

The personal relationships these participants have with their partners, families and friends have undoubtedly undergone changes because of Pulmonary Hypertension. Some of these relationships have improved, while some have weakened. It is important to look at how relationships are affected by Pulmonary Hypertension because friends, family and partners are all very important components of the everyday lives of these specific Pulmonary Hypertension patients.

In one woman’s experience, she experienced both positive and negative changes in her relationships with her friends, where she was pleasantly surprised with the support she received from some friends. On the other hand, some of her friends had distanced themselves from her because of her illness.

As she reflected:

I guess at the beginning it was an eye opener in a few ways. I mean, there were people that I didn’t realize cared about me so much and kind of came out of the wood work and were very supportive and were very, umm, kind, and it was really lovely to get that support. And then there were people who just kind of fell off the map, you know, understandable. I know a few people who are uncomfortable around illness and didn’t know what to say and that sort of thing and, you know, others that were just kind of casual friends and didn’t know what to say.

Nicole experienced the disappearance of friends in her life as well. When asked if her social life has changed since being diagnosed with Pulmonary Hypertension, Nicole said:

I feel it has in the sense that I just don't feel like going out...I find that some people have kinda fallen off the face of the earth... I've read a lot about like when you are diagnosed with a chronic illness that some people, some friends, just kind of disappear. I don't know if it's that they can't handle it or it's something that we give off that throws them away, I don't know.

In Nicole's case, she chooses to not go out and socialize as much, but has also noticed that some of her friends have chosen to not socialize as much with her since her diagnosis. Loretta also noticed a drastic change in her social life since being diagnosed with Pulmonary Hypertension. She, like Nicole, chooses not to go out as much as she used to before she was diagnosed with Pulmonary Hypertension because she finds that she does not have as much energy to do so.

For Carol, her social life has changed too because of Pulmonary Hypertension – she has strict fluid and salt intake restrictions which she must follow in order to maintain her current state of health:

I just pulled away from some people...for example, people on my street, because they drink a lot, they party a lot...I wasn't that person anymore. I couldn't sit out and drink a bottle of wine with them anymore on a Friday night, or eat chips and drink, you know, the salty food, so once in a while I'd go out and sit around. That was fine, but you've gotta remove yourself from some of those temptations...it was easier for me just to not go out.

Carol feels it is easier to remove herself from these particular social situations, as the strict diet she must follow clashes with the interests and activities of her friends.

In contrast, Amanda stated:

My friends are very understanding. I don't feel like I've lost any friends because of it. My friends from work -- we still keep in touch, still get together...I think I'm really lucky. I really value friends and I haven't pulled back from them in any way because of how I feel emotionally.

Amanda has managed to keep her friendships -- her friends did not distance themselves from her, and she has not distanced herself from them, despite how Pulmonary Hypertension makes her feel emotionally. Likewise, Carolyn said she is "still very social --still involved in everything". She mentioned, for example, that before her interview took place, she had friends over to play Rummoli at her house. Marion noted that her social life has remained the same for the most part, too.

Marriage and family life are other aspects of day-to-day life that have undergone different degrees of change for this sample of Pulmonary Hypertension patients.

According to Marion, she said that when she was diagnosed:

My husband went in to panic mode, eldest daughter did about the same thing. Youngest daughter, I still think she's somewhat in denial. She still thinks mom is invincible. We talk through it, we work through it, we're very open about our feelings. At this point, I would say I'm still the driving force and the part that's holding the family together.

Since being diagnosed with Pulmonary Hypertension, Marion has been the glue that holds her family together. Marion's role in her family is to make sure that everyone else is calm.

Amanda stated that she has noticed change in two important relationships since being diagnosed with Pulmonary Hypertension. The first change she described is the change that occurred in her marriage with her husband. She explained:

My marriage -- my husband -- I know you have your vows in sickness and in health, but I don't feel like he signed up for this -- I know I didn't -- um, but it's life. And our marriage has been tested. I've seen him pull away a little bit and I think our marriage would be quite different if I didn't have PH.

Amanda's relationship with her husband has changed due to her illness. Though they love each other and committed to love each other in sickness and in health, neither Amanda nor her husband expected to actually be tested by this vow they made to each other.

The second relationship that has changed for Amanda after being diagnosed with Pulmonary Hypertension is the relationship she has with her parents. Amanda said, "I still feel like that little kid who has to abide by what mom and dad say". Amanda is grateful for the help she receives from her parents, but acknowledges the new ways she has to rely and depend on them. Her self-understanding as an autonomous adult has changed into identifying as a child under her parents' care, as a result of her illness. On the flip side of this, Amanda stated "I feel protective of them because I don't want them to worry too much...it's a balancing act and sort of a little bit of a dance". Amanda's parents are protective of her, however she is protective of them as well, because she does not want her parents worrying about her and her health all the time.



Another family relationship that has changed due to dependence on family members is the relationship between Loretta and her parents. Loretta has had to depend on her parents more since being diagnosed with Pulmonary Hypertension, which has ultimately brought them closer together as a family.

Nicole's relationship with her husband and children is different now that she has Pulmonary Hypertension. Nicole mentioned her kids, saying:

You know, with the kids, like I said, there are some things that I just can't do with them, and that part really is a bummer...you kind of get in to funks like mood wise, and that kinda just affects everyone because you can take it out on the people who are closest to you, usually.

The activities Nicole can participate in with her children are now limited. When Nicole is having an off-day emotionally, she admits that her moods have a direct impact on her family, too.

Similarly, Carol mentioned that she is no longer able to do certain activities with her children. The hardest part of having Pulmonary Hypertension, Carol explained, is "not being able to do things with my kids, and my kids not understanding why I didn't skip rope or hoola hoop or kick the soccer ball, or why mommy was always sleeping". Carol longs to be able to do activities like this with her children, but simply cannot because of her illness. Carol also described change in her marriage with her husband. She said that her husband has been amazing through her whole illness, and that the communication part of their relationship has remained excellent. The way Carol's relationship with her husband has changed since being diagnosed with Pulmonary Hypertension pertains to their sex life together. Carol stated:

It affects your stamina sexually, so your love life is affected...It was hard to get over the fact that I didn't have the energy I had before -- we went through spells where I was telling him I was tired all the time, so we were never intimate. Then you realize, like, you have to work at it, and when you are intimate, certain positions -- to be blunt -- work better than others, because if you're exerting yourself then it's gonna be worse.

Navigating their intimate life together has been a significant challenge in the relationship between Carol and her husband, and is an obstacle they have since learned to work around.

### 2.3 *"Invisibility"*

The majority of these participants mentioned that either the hardest part of having Pulmonary Hypertension, or what they wish the general public could know about Pulmonary Hypertension, is related to the invisible nature of the disease. It is often quite difficult to notice someone who has Pulmonary Hypertension by just looking at them, unless the person is someone who uses oxygen.

Marion mentioned that there have been a few instances where conflicts have arisen because she does not appear to be ill. She recalled:

Some people within our community don't think I'm sick at all because I don't look sick, so that makes a little bit of a buffer here and there. When you go out to do something and people look at you like well, why aren't you doing it? Well, I can't. When you say, I can't do this, I gotta go home, they kind of look at you.

Because Marion does not look sick, she is expected to be able to do everything else that healthy people are able to do. Perhaps because of these conflicts, Marion stated:

The general public needs to know that it is an invisible disease and that you are sick, and not to question invisible diseases, like your parking pass when you jump out of your truck and you're okay, then you go through the mall and get your groceries, and you can be crawling, trying to get back out. They need to be non-judgemental to people who don't look sick.

To Marion, it is important that people not jump to conclusions about her state of health, just because she appears to be in good health on the outside.

Carolyn's story about her doctor dismissing her because she "looked good" speaks wonders to the invisibility of Pulmonary Hypertension, especially since this judgement came from a medical professional. Perhaps because of experiences like this, Carolyn also wishes that the general public could understand that Pulmonary Hypertension is not always a visible illness. Carolyn stated "I do have a wheelchair parking sticker and years ago when I used it, I had people come up to me and say hey, you can't use this". Strangers who could not visibly notice that Carolyn is sick judged and condemned her for using a wheelchair parking spot. "Looking good" does not always equate to feeling well, though.

In the same way, Nicole would like there to be a better understanding of the invisibility of Pulmonary Hypertension among the general public. Similar to Amanda and Carolyn, Nicole has been ridiculed for using wheelchair parking spaces because she does not appear to be sick. She revealed "I have a parking pass as well...I barely use it because I've been called out on it a few times. It was brutal. One guy was yelling at me from the grocery store...it was so embarrassing". Nicole has experienced judgement and harassment from strangers who do not even consider that she may be ill, since she does

not look it. Moreover, because of this harassment and being embarrassed by people who are too quick to judge her based on her appearance, Nicole is not using her parking pass even though she needs it, which could have a detrimental effect on her health.

The invisibility of Pulmonary Hypertension is also something that Amanda wished the general public could know about the illness. She pointed out the difference in how people perceive her, saying:

Once I had oxygen, it was -- I wouldn't say easier -- but people would understand if I was stopping and they went around me...but before I had it, and now, because I still use the wheelchair space if I have to walk long distances and if I believe I need it, um, you get looks and you get stares...especially since I'm relatively young.

Amanda was perceived to be sick because she was using oxygen therefore she was not questioned for using the wheelchair parking spaces. Now, Amanda is not on oxygen anymore, but is judged for using the wheelchair spaces because there is no visual indication that she has Pulmonary Hypertension. Loretta's wish for the general public is the same as Amanda's -- she wishes that people could understand that Pulmonary Hypertension is an invisible illness. Loretta is on oxygen full-time. She said "For me, it's obvious there's a lung issue, but for other people, they don't necessarily have that visibility". It is important to Loretta that all people with Pulmonary Hypertension receive the same acknowledgement of having the illness, despite the visibility or invisibility of their illness.

Carol's experience with the invisibility of Pulmonary Hypertension relates to the use of oxygen and how it signifies to others that someone is ill. Carol reflected:

It's one of those unseen illnesses. It's funny, um, I did a fundraiser at my work and with everyone knowing I had Pulmonary Hypertension, and it was nothing. Then, I brought in a lady who was on oxygen, and when they realized we had the same disease -- like, they questioned me. We were like, yeah, we have the same disease. It's funny how someone with oxygen, they automatically understood her as being sick, but for me, it wasn't the same -- but we were the same.

In Carol's experience, the people at her work did not comprehend how sick she actually was. The woman she brought with her who was on oxygen served as a visual indication that Pulmonary Hypertension is in fact a serious illness, even though all people with Pulmonary Hypertension may not look ill.

### 3. Resilience and Coping

Despite the struggles in various areas of life that these participants have obviously experienced due to their Pulmonary Hypertension, the interviews with these eight participants revealed an overwhelming amount of resilience and strength. This resilience is obvious in the participants' experiences with their health assessment tests, during travel, and through participation in advocacy, awareness and support initiatives as a means of coping.

#### 3.1 *"Acing the Walking Tests"*

All the participants, when asked about their experiences with the six-minute walking tests that are used to assess their health and the progression of their disease, displayed either indifference or distaste towards the tests. Despite these attitudes towards the test, these participants demonstrate resilience in how they choose to perform in the six-minute walks. Marion expressed:

I don't like doing them, but you've got to do them to get that baseline. The six-minute walk test, I take it as a challenge to see how much further I can get, but emotionally I just do it because I have to, because I feel it's a waste of time...that's one of the tests that doctors really rely on, but somebody could blow that test so easily. You can choose not to walk and not go your hardest at it -- I've always gone at it the hardest I can, full tilt, and sometimes at the end I'm almost down the wall and coughing up -- I'm just about ready to throw up...so I know the test itself can be skewed and that bothers me and it goes through my mind as I'm doing the walk test, but I give it everything I've got.

Marion's resilience during these tests is remarkable. Despite the fact that she does not like to do the walking test, she tries her hardest every time, eager to prove what she can do. Marion does point out that it is easy to throw the test, which is important because the six-minute walking test may not be as accurate as medical professionals think it is.

Although the six-minute walking tests do not have an impact on Carolyn emotionally, she expressed that "physically, it just knocks me down because I do it very quickly, like I speed walk...for maybe another 30 seconds after I sit down I can't speak". Carolyn is another Pulmonary Hypertension patient who is determined to do her best in every walking test she participates in. Like Marion, Carolyn does not think that the six-minute walking test is an accurate measure of her condition, because walking on a flat surface for Carolyn is not as much of a challenge.

When asked about her experience with the six-minute walking tests, Amanda said:

I remember a few times where something surprised me and I would, you know, feel a bit teary because what does this mean? Is it worse than last time? What are they gonna say? And then I just sorta stop myself because I know if you get upset it just makes breathing harder, so that's usually enough to just pull me out of it and get whatever done that needs to be done.

Amanda also puts all her effort into doing well at the six minute walk tests, exerting herself as much as she possibly can. Her experiences with wondering if she did worse than the last test speaks to the emotional impact these walking tests can have on Pulmonary Hypertension patients.

Resilience is also apparent after hearing Nicole's experience with her six minute walking tests. When asked about her encounters with the tests, Nicole admitted:

I hate them. And I know it's gonna sound strange, but I hate them but I generally do well at them -- I just don't like it. I don't like walking in front of somebody. I don't ever have to stop and I get very, very out of breath because I always try to beat my last record, but that's just a personal thing...I want to be able to walk as far as I can and maybe that's just like a personal message to myself that I can do it.

Although Nicole truly does not enjoy the six minute walking tests, like several other participants in this research, she tries her best during the tests and draws strength from how well she performs.

### 3.2 *"Continuing to Travel"*

Traveling is an area in which these Pulmonary Hypertension patients have shown true resilience. Numerous participants in this research have found ways to travel the

world, despite their doctors' recommendations to avoid travel due to their illness, and obstacles their illness creates for travel. When she was asked if she still travels since being diagnosed with Pulmonary Hypertension, Marion said:

Has it stopped me? No. Can you make it happen? Yes. Are people scared to do it? They're terrified. But you gotta take that jump...when we went on this last cruise, I was ATVing, I went in the swimming pool on this ship -- I did it all.

Carolyn, too, is resilient and resourceful when it comes to accomplishing her dreams of traveling. Carolyn explained:

I still zip line, I climb the mountains...I don't want it to ever stop me. Climbing in Athens and Hawaii, my kids would pull me and my husband would push me and you know, as long as they don't mind doing that, then I'm gonna keep on doing it. You take one step at a time.

Carolyn's patience, along with the cooperation and support from her family are means which have helped her to visit 55 countries and complete excursions and activities which are difficult for her to do as a result of having Pulmonary Hypertension. Carol takes a similar approach to traveling as Carolyn does. Carol makes sure that she and her family take one trip a year together, because she is unsure of how long she will be able to continue to travel for. Carol is taking advantage of the fact that Pulmonary Hypertension has not yet caused her health to deteriorate significantly. She is determined to travel as much as she can with her family to create lasting memories with them.

Marion did not let having Pulmonary Hypertension stop her from swimming and ATVing, but, she had to get creative with how she would travel because she was using



oxygen during her travels. Marion explained that her oxygen pump could not get wet, and she could not be disconnected from her oxygen for long:

I found a way to make it happen...I found a company that makes an aquapack, I put my pump in there, taped up my site, and I was gone! I tested it at home, wearing it all day in the house to see the way it worked, if it was going to restrict the flow from my pump. I had it in the bathtub, I had it in the shower, and it never got wet.

Marion's oxygen pump posed as a challenge to her travels, but she was determined enough to creatively work her way around this obstacle in order to keep traveling.

Amanda is also a person who displayed resilience by still deciding to travel with oxygen. She said:

Once I had oxygen it was very hard to plan stuff. We took less trips in those years than we would have, although we did get back to Florida with me on oxygen and that was very hard –it was very difficult. The flight was very painful to be in the air with oxygen because I have a limited amount, so I was trying to conserve it...when we got there they heard a hiss from the liquid tank they had delivered to the resort and so they emptied it –they called the fire department and they emptied my supply of oxygen, so the company had to come at 2:30 in the morning to deliver me something else to use.

Regardless of the difficulties that traveling with oxygen posed to Amanda, she was still strong-minded enough to continue traveling. Even though she was on oxygen shortly after her diagnosis, Loretta still chose to travel, too. She went to Paris and Seattle, which

she did not think she would ever do. Loretta is yet another Pulmonary Hypertension patient who does not let the inconvenience of using oxygen her disrupt her plans to travel.

Another participant noted that she is not on oxygen, so traveling for her is not difficult for her in that sense. She did say, however, that having Pulmonary Hypertension requires a significant amount of planning if you intend on traveling. She reflected “You do have to take all medication in its original packaging, which is my entire carry-on -- it’s just filled with medication...it’s tedious, but honestly not that big of a deal in the grand scheme of things”. Even though this participant noted the cumbersome task of making sure all her medication is in their correct packaging for traveling, she still does not think that this is large enough reason to deter her from traveling. Nicole, like this participant, continues to travel, but noted the rigorous planning that travel requires because of Pulmonary Hypertension. The ability to travel is most definitely an aspect of life that is hindered by having Pulmonary Hypertension, but these patients are ultimately able to overcome the varying obstacles they face in this respect.

### 3.3 “*Advocacy*”

An additional aspect of resilience and coping demonstrated by these participants is their devotion to generating awareness about Pulmonary Hypertension and to providing advocacy and support for those living with Pulmonary Hypertension. Several of these particular participants have dedicated their time and resources in order to assist other Pulmonary Hypertension patients with ways to cope with their illness, as well as taking a proactive approach in spreading the word about Pulmonary Hypertension to the general public and medical professionals.

Marion took initiative to start-up a support group in London, Ontario, close to where she lives. Marion recalled that she and another Pulmonary Hypertension patient in the area “formed the support group in London...There was no support group; there was nothing for me when I first started, but they suggested there was a need in that area and we jumped on it”. For Marion, the lack of support offered to her to cope with having Pulmonary Hypertension motivated her to form a support group of her own.

Like Marion, Loretta also started a support group for Pulmonary Hypertension patients. Loretta started this support group in 2009, in the Toronto area. Loretta said “I wanted to meet other people with similar diseases -- this was way back before Facebook was even popular -- I just started using it and I found a girl and we just met up, and decided to meet every month”. Loretta combatted the feeling of isolation that often comes with having an illness like Pulmonary Hypertension by using a social network to connect with other Pulmonary Hypertension patients and plan monthly support group meetings for patients to attend. Furthermore, Loretta explained “I think it’s important to give back and to be able to help others not feel isolated...connecting with other patients is the most important for me”. Loretta’s desire to connect with other Pulmonary Hypertension patients has resulted in the successful formation of the Toronto support group for people coping with Pulmonary Hypertension.

For Carolyn, raising funds for Pulmonary Hypertension awareness is important through her pub fundraisers:

How that began was I was visiting my daughter overseas and her boyfriend lives just outside of London and I was visiting his parents and they took me to a Sunday night quiz night. I had never been to one...we did the 50 questions and it

was fun...we raised 350 pounds to go towards something, and I thought oh my gosh, I'm going to do this back home...everybody's gonna love it.

Ever since experiencing her first quiz night in England, Carolyn has been committed to hosting regular quiz nights in her hometown to raise money and awareness for Pulmonary Hypertension.

Advocacy and voice are important components in fighting against Pulmonary Hypertension. By choosing to advocate for Pulmonary Hypertension patients and having their concerns heard, these participants have thereby chosen to fight for their lives and well-being, demonstrating their positive abilities in coping with their illnesses. Nicole has taken initiative in having her voice and concerns heard by becoming an ambassador (someone who is dedicated to making a difference) for The Pulmonary Hypertension Association of Canada. She has been an ambassador for two years and recently participated in a media interview in support of an expensive drug called Opsumit. This drug is proven to improve the quality of life for people living with Pulmonary Hypertension. Coping and resilience, for Nicole, mean taking any opportunity she can to advocate for the best interests of Pulmonary Hypertension patients. Similar to Nicole, another participant, also an ambassador for The Pulmonary Hypertension Association of Canada, makes it a priority in her life to speak on behalf of Pulmonary Hypertension patients so that they can receive the best care and best treatment possible. This participant stated:

I'm an ambassador...we've, uh, tried to make more advocate efforts -- we went out to our MP's to talk about the necessity for patients to have the ability to get access to a drug that would be covered by the province because for now, the

province will only cover the drug if the patient tries other drugs and they didn't work...we think the physicians should have the say to prescribe whatever medication that they believe the patient needs, and then the government should cover that.

This participant has dedicated much time and effort to advocating for the medicinal rights of Pulmonary Hypertension patients and their doctors.

Carol has taken a different approach to advocacy and resilience in her experience with Pulmonary Hypertension. Carol enthusiastically volunteers herself for Pulmonary Hypertension research studies, devoting her time and hoping to contribute to finding an improved way of life for Pulmonary Hypertension patients.

As much as these patients have taken hands-on approaches to coping positively with having Pulmonary Hypertension, through their experiences, they express that there are areas in terms of advocacy, awareness and social services that could stand to be improved. Marion ultimately hopes that through advocacy and awareness, a cure can be found for Pulmonary Hypertension. "Advocacy and awareness isn't going to get us a cure, but it could get us the research money to get on it, if we keep doing the fundraising. Events are making people aware". In Marion's opinion, more fundraising initiatives are needed so that a cure can be found for her and others similar to her.

Another participant would like for advocacy and awareness initiatives to aid in Pulmonary Hypertension patients not feeling so alone. She said "I hope they can know where to look or how to access the support that they need, um, and yeah, just feel less alone in that experience, whether it's connecting to people online, or through support groups". For this participant, it is important for advocacy and awareness efforts to link

Pulmonary Hypertension patients together in an attempt to lessen the feeling of isolation, which often accompanies the illness. Nicole's goals for advocacy and awareness coincide with this desire to reduce isolation caused by Pulmonary Hypertension. Nicole would like for advocacy and awareness to lead to more Canadians with Pulmonary Hypertension to become affiliated with The Pulmonary Hypertension Association of Canada. She said "I think PHA Canada is great. Unfortunately I don't think enough PH Canadian patients take advantage of PHA Canada... probably only 25 percent of the Canadian PH population are involved with PHA Canada". With more involvement with this organization, Pulmonary Hypertension patients could feel less alone in their illness experience.

Amanda stated that through advocacy and awareness, she hopes that treatment options for Pulmonary Hypertension patients will improve:

More options for treatment would be number one, and for the government to stay out of it, in terms of the doctors deciding what treatment is best...I find it really shocking and upsetting that they [the government] would decide what meds to start with, it being the cheapest medication...I just think that it should be left to the specialists to decide what people should take and what course of treatment,

because people are going to suffer and their health is going to suffer.

Amanda would like advocacy and awareness to lead to better treatments for Pulmonary Hypertension patients, so that specialists can choose the best treatments for their patients, rather than the government choosing the cheapest treatments for people living with Pulmonary Hypertension.

## Discussion

Overall, the findings reveal the overwhelmingly positive attitudes that these Pulmonary Hypertension patients possess, despite the rarity, chronicity and potential fatality of their illness. Additionally, these findings indicate how well Pulmonary Hypertension patients can cope with and fight back against their illness. It is evident that through their diagnoses, day-to-day challenges and coping and resilience efforts, this sample of Pulmonary Hypertension patients are able to overcome the challenges and barriers they face in their illness experiences.

It is understandable that these patients, having been diagnosed with such a rare and lethal disease, have at some point experienced emotional turmoil and distress. As a result, several of the participants in this study have undergone changes in their self-understandings and social relationships since being diagnosed with Pulmonary Hypertension. These changes in the self and social relationships are closely aligned with symbolic interactionist theories on illness.

The change in self that has been experienced by a number of these participants aligns with the work of Charmaz (1991), who explains exactly how the self is impacted by chronic illness. Charmaz (1991) says that in illness, “[t]he foundation on which a sense of self is based can be lost, there is nothing to look forward to, and nothing to do” (Conrad & Barker, 2010, p. S71). This perception of the self and of reality, caused by illness, are evident in the initial reactions and emotions some of these participants experienced when they were newly diagnosed with Pulmonary Hypertension. Some of these participants’ senses of self were, rightfully so, affected when they were diagnosed with Pulmonary Hypertension -- their worlds were turned upside down. Illness affected

these participants' senses of selves because it caused many of the participants to experience intense emotions such as devastation, panic, worry, sadness, stress and depression. These emotions are present in the participants' recollections of their diagnosis experiences and especially when they received life expectancies. During these challenging times, they had to learn to work through these new emotions brought on by their illnesses and, consequently, had to accept new self-understandings -- in Amanda's case, identifying as a child once again; in Marion's case, no longer identifying herself as an "on-the-go" person; and in another participant's case, identifying as someone who was no longer fully independent. *All* of these participants' self-understandings have changed, though. Through their emotions and obstacles, these participants were forced to come to terms with the fact that being ill is a part of their identity.

Self-identity also underwent change, as many of these participants were required to stop working because of Pulmonary Hypertension. In today's society, it is common for people identify themselves through their careers. Gini (1998) explains:

Perhaps the easiest way to prove the point that we are affected, labeled and formed by the work we do is to consider its converse. Imagine the now-too-common scenario of a 48 year old bread-winner who has been "reengineered", "downsized" or "five-plus-fived" out of a job...This person is forced to ask the questions: Who am I now? What have I accomplished? What can I do? Who will I become? (p. 709).

Here it is apparent that losing the ability to work, whether it is because of termination or because of illness, causes a person to question their identity and consequently develop a new understanding of self. Now that she cannot work, Nicole stated, "[m]y morning



routine is pretty much just at home on the couch...I question myself and you feel lazy”.

The working component of many of these participants’ identities has been eliminated due to having Pulmonary Hypertension, which means that these particular participants had to accept a new self-identity -- as people who no longer work.

Referring back to the work of Kutner et al. (1999), it is clear that the participants in my study, like Kutner et al.’s participants, experienced change in their previous interactions with family, friends and spouses. Many of these participants’ relationships and roles with the important people in their lives have changed because of having Pulmonary Hypertension. Conrad and Barker (2010), again, draw on the work of Charmaz (1991), who offers insight into understanding how chronic illness affects the social self:

The worlds of some individuals shrink when they are immersed in the day-to-day aspects of managing a chronic illness. They become increasingly cut off from the routines of conventional life—unable to work, spend time with family, socialize with friends, or move about freely. (Conrad & Barker, 2010, p. S71).

This work by Charmaz relates to the day-to-day life experiences and social interactions that have changed for these participants because of Pulmonary Hypertension.

Family life is one major component of day-to-day social interaction that has changed for these participants since being diagnosed with Pulmonary Hypertension. Many of these participants have noted that they are no longer able to participate in activities with their children that they wish they could participate in. This has resulted in these particular participants watching their children do the activities, rather than participate in the activities with them.

In the cases of Carol and Amanda, the interaction with their parents and in-laws changed, as they had to rely on their parents and in-laws more throughout their illness. Amanda noted that she felt that she had returned to playing the role of the “little kid” with her parents as a result of her illness. In a similar way, Carol’s role with her husband’s parents returned to the role of the “little kid”, too, because if she had a blackout, they were required to watch her and take care of her. Marion’s role within her family changed since being diagnosed with Pulmonary Hypertension, because now, her role is to hold her family together.

Marriage is also an area in day-to-day life where changes in roles and interactions have occurred. The marital relationships changed for many participants because the participants had to relinquish several of their responsibilities and their spouses had to take on more responsibilities. Several of these participants had to rely on their spouses more with regards to housework, income and childcare since being diagnosed with Pulmonary Hypertension. Carol stopped telling her husband about her blackouts because she did not want to lose her independence by being watched by her in-laws. This is reflective of Pierret’s (2003) theory that loss of independence can lead to the ill person hiding their illness from others.

A number of these participants, because of their illness, have noted a change in social interaction with their friends since they have been diagnosed with Pulmonary Hypertension. Some of the participants who have experienced this change noted that now, they tend to withdraw themselves from social interactions with their friends. This withdrawal also occurred in Cobb and Hamera’s (1986) research with ALS patients. On the other hand, some of these participants’ friends have “fallen off the map”.

Additionally, some participants are simply unable to partake in the activities with their friends that they had enjoyed prior to being diagnosed with Pulmonary Hypertension, such as drinking alcohol and eating certain snacks.

Despite the hardships these Pulmonary Hypertension patients have endured in terms of self-identity, social roles and social interactions, they have been able to develop positive attitudes and positive coping abilities. It is only natural that the initial reactions to being diagnosed with a disease like Pulmonary Hypertension would consist of devastation, sadness and depression. However, like McGrath (2004) discovered, positivity can change depending on the patient and the situation they are in. In addition, Martz and Livneh (2007) found that coping with chronic illness is not *always* positive or *always* negative -- over time, negative coping and predispositions can change into positive coping and predispositions. These particular Pulmonary Hypertension patients who were devastated, sad and depressed when they were diagnosed, experienced a change in positivity once they were able to overcome the initial shock of being diagnosed with a rare and sometimes terminal illness. This “bouncing-back” is not only apparent in the attitudes of the participants, but in the physical condition of them, too. A good example of this is Carolyn, who was told she would not make it through the night once she was finally diagnosed. She took the risk of signing the waiver and taking the medication that could have saved her or could have ended her life. Perhaps her hope and positive attitude are why the medicine worked for Carolyn and she is still alive today, almost 20 years after being diagnosed with Pulmonary Hypertension.

Perhaps these Pulmonary Hypertension patients, like the chronically ill patients Eaton et al (2014) studied, have an overall high satisfaction with life because of their

positive coping abilities. It could be that none of these participants mentioned euthanasia or the desire to die in their interviews because in overcoming their hardships, they, as Martz and Livneh (2007) suggest, have discovered newfound appreciation for life and relationships, realized their strengths, and found a new meaning to life. Additionally, perhaps these participants did not mention end-of-life issues in their interviews because they are now capable of giving meaning to their suffering, as Karlsson et al. (2012) put forward.

It is possible from these theories of positivity in illness and positive coping that this could account for the many participants in this study who are so motivated and inspired to travel. The positive coping methods they learned to embrace throughout their illness experiences may be what encourages these particular individuals to explore different countries and partake in new activities, regardless of the burdens of planning intricately, packing medications and making accommodations for the accompanying oxygen devices.

Coping positively is evident in the lives of some of these participants, who have tried their hardest not to let their illness dissolve their social lives. These particular participants have fought to keep some sense of normalcy in their lives by continuing to engage in social activities with their friends and colleagues, which could be attributed to what Eaton et al. (2014) would call their “positive inclinations”. In the same way, positive inclinations could be the explanation for why several of these participants are so close to their families and significant others. Strong familial bonds could be a result of the positive attitudes these participants, and their family members, have maintained throughout the participants’ illnesses. Likewise, positive inclinations could be the reason

why so many of these Pulmonary Hypertension patients have been proactive in taking action to support one another, speak out about their illnesses and advocating for matters which affect their well-being. Their positive attitudes, according to Eaton et al. (2014), are the driving force behind their actions to improve the quality of life for themselves and other Pulmonary Hypertension patients.

Developing a positive attitude after recovering from the shock of receiving a rare, chronic and potentially terminal illness has, without a question, aided these participants in coping with their illness. These participants were able to bounce back from their original feelings when they were first diagnosed. The participants' responses to the question "If there was one word you could describe to represent your experience with Pulmonary Hypertension, what would it be?" further emphasize their overall positivity and adaptability in having Pulmonary Hypertension. The words used by these participants to describe their experiences with the disease are: "relentless"; "rollercoaster"; "enlightening"; "adventure"; "thankful"; "rollercoaster"; "eye-opening"; and "tired". The majority of these one-word descriptions reflect the newfound appreciation for life that Martz and Livneh (2007) discuss in their study of chronically ill patients coping with illness. Most of these words chosen to describe these participants' illness experiences do not refer to the negative, gruesome effects that a disease like Pulmonary Hypertension often have on the patients and their loved ones. The devastation, sadness and depression which initially consumed some of these participants once they had been diagnosed with Pulmonary Hypertension, turned into resiliency, adaptability and positive coping due to their positive attitudes.

It is somewhat surprising, especially because of the overwhelming positivity among these Pulmonary Hypertension patients, that religiosity has not played a greater role in influencing their positive attitudes. In contrast to the research that indicates the role of religion in helping people to cope with illness done by Koenig et al. (2001) and Moberg (1965), only two of the eight Pulmonary Hypertension patients in this study have said that they turn to religion to help cope with their illness. Why might this be?

We can turn to Rafferty, Billig and Mosack (2014) to help in trying to understand why so few participants in this research have relied on religion to cope with having Pulmonary Hypertension. Rafferty et al. (2014) offer an alternative approach to understanding religion and its role in illness. They used a mixed-methods approach, administering surveys and analysing conversations among their participants, to understand how religion and/or spirituality (which they refer to as R/S) impacts the psychological well-being of Americans who are living with chronic illness. Rafferty et al. (2014) found that in their research, “[a] few individuals discussed how their illness caused them to question or doubt their R/S beliefs...one must remember that not all R/S coping practices are positive” (p. 1881). This could be a possible explanation for why religion and spirituality are not very significant in the coping mechanisms used by these Pulmonary Hypertension patients. Perhaps their illness experiences have caused some of these participants to doubt their religions and spiritualities, causing them to turn away from it. Perhaps some of these participants feel that religion and spirituality has failed them, since they ended up ill. On the other hand, the lack of religiosity among these specific Pulmonary Hypertension patients could just be because they were not religious to begin with.

Rational thought is an extremely common manner by which people today understand occurrences such as illness. According to Johnstone (2007):

[i]nstead of more or less “explaining” much that happens -- death of loved ones, floods, plane crashes, drought, war –as ‘God’s will’, more and more people are seeking explanations in the laws of physical science and in the social scientific “laws” of human interaction, or perhaps simply as the result of chance or pure accident. (p. 408).

This suggests that more people today are moving away from a religious way of explaining and understanding tragedies, to a more scientific way of understanding these tragedies. The participants in this study could simply be people who fall under this category, by choosing to make sense of their illness and cope with it rationally and medically as opposed to religiously. Though all of these patients demonstrate resilience and exceptional ability in coping with having Pulmonary Hypertension, religion and spirituality are not coping mechanisms for most of these patients.

## **Limitations**

Time is a factor which has limited this research. It was feasible and realistic to conduct in-depth interviews with only eight Pulmonary Hypertension patients. As a result, this research is in no way generalizable to all Pulmonary Hypertension patients. The themes and commonalities found among these eight participants are not necessarily indicative of themes and common experiences that all Pulmonary Hypertension patients share with each other. Because this research was constricted by time, perhaps future research could examine the illness experiences of more Pulmonary Hypertension patients with open-ended interviews, to allow for a broader depth and breadth of knowledge in this under-researched area.

Another limitation to this research is the fact that all of these participants were recruited by me through networking with The Pulmonary Hypertension Association of Canada. This deliberate choice is because I am affiliated with The Pulmonary Hypertension Association of Canada, and have networked with some of these participants in the past. The participants who I did not know before conducting these interviews had networked with others I did know, which resulted in snowball sampling. All of the participants, therefore, are somehow affiliated with this organization, which may be a factor which has contributed to some of the similarities in these participants' illness experiences with regards to important areas such as positivity, activism and awareness. Further research could possibly recruit participants through a variety of different networks, for instance, recruiting patients from hospitals or online support groups.



## Conclusion

Despite the aforementioned limitations, it is evident that through this study, much has been discovered about the illness experiences of people with Pulmonary Hypertension. It is clear through many of these participants' experiences that there is much more to a person than meets the eye -- invisible illnesses can affect anyone. Many of these participants appear to be healthy on the outside, despite the reality that they are chronically and seriously ill. Because of its invisible and rare nature, Pulmonary Hypertension is a disease that is severely under-researched, both medically and sociologically. It is important that Pulmonary Hypertension, like all other rare chronic illnesses, receives the same attention and concern as the more common illnesses do. We are all human, and all deserve equality in not only healthcare but with respect to compassion, too. While gathering quantitative data about how Pulmonary Hypertension has affected the people living with it is important, it is also equally as important to understand how the patients themselves qualitatively describe their unique experiences with Pulmonary Hypertension. This allows for greater understanding of Pulmonary Hypertension and its effects, and could lead to improved awareness of and advocacy for Pulmonary Hypertension, which is important to all of the participants in this research and reverts back to the premise of the transformative framework.

*The Diagnosis Experience, Day-to-Day Life and Resilience and Coping* are the three broad themes which the experiences noted by these participants fit in to. These themes accurately describe the process of receiving a correct diagnosis, how the participants' lives have changed as a result of their illness, and how they have adjusted

their lives so they are able to cope positively with having a rare, chronic and sometimes terminal illness.

*The Diagnosis Experience* explores the downplaying of Pulmonary Hypertension symptoms, often by the patients themselves, and the trial-and-error nature of trying to receive a correct diagnosis. In the case of several of these participants, correct diagnoses were delayed due to the dismissal of symptoms and conditions which were being experienced. Receiving a life expectancy was also a gruesome, yet common, aspect in being diagnosed with Pulmonary Hypertension for these participants. Many of their lives were given an expiration date due to the severity of their conditions.

The second theme, *Day-to-Day Life*, consists of the changes these participants have experienced in their daily lives because of their illness. Loss was a major area of change -- energy, independence and work are the three main areas where these participants have lost control in their lives. Personal relationships also underwent changes in the lives of most of these participants, specifically with extended family members, friends and spouses. A third factor, and perhaps the most important, is the invisibility of Pulmonary Hypertension, which many of the participants noted has affected their day-to-day lives. Several of the participants in this research have been judged, criticized and ridiculed for taking necessary precautions they need to take, simply because they do not look like they are sick.

Finally, *Resilience and Coping* is the third theme. This theme pertains to how exactly these participants have coped with and simultaneously fought against Pulmonary Hypertension. The walking tests used to measure the condition of Pulmonary Hypertension patients have demonstrated the resilient attitudes these participants have,

and the determination they possess to maintain their current state of health. The topic of travel also displayed the will-power these Pulmonary Hypertension patients possess to continue doing what they love to do, as long as they can do it for. Lastly, to these Pulmonary Hypertension patients, it is very important to generate awareness, support, research and advocacy for Pulmonary Hypertension and its patients. The initiative these participants have taken to improve their quality of life shows their true strength and willingness to fight against this dreadful disease.

Most notable from this research are the positive attitudes and positive coping that each participant emulated during their interviews. All eight of these participants have experienced changes in their understandings of self, their social roles and social interactions. Despite these hardships in identity and interaction, all eight participants have found ways to turn the negativity of illness into positivity and hope. These attitudes closely align with previously mentioned theories of positive attitudes and positive coping in illness, where it is understood that positive attitudes contribute to the patient's capacity in coping with illness positively, and in obtaining an overall appreciation for life. It is important that Pulmonary Hypertension continue to be explored in academia. If more Pulmonary Hypertension illness experiences are acknowledged in scholarly studies, then perhaps greater interest in understanding Pulmonary Hypertension among the general public and healthcare professionals will occur.

## *Appendix A: Interview Questions*

1. What type of Pulmonary Hypertension do you have?
2. Tell me about your health before you were correctly diagnosed with Pulmonary Hypertension...How long were you experiencing Pulmonary Hypertension symptoms before you were correctly diagnosed?
3. Tell me about the process of having tried to figure out your diagnosis.
4. Many people with Pulmonary Hypertension experiences what has been called 'doctor shopping' (visiting doctor after doctor, unable to receive an accurate diagnosis). What was your experience with finding a doctor that lead to an accurate diagnosis of Pulmonary Hypertension?
5. How did you feel once you were correctly diagnosed with Pulmonary Hypertension?
6. How did your life change once you were correctly diagnosed?
7. What was the most difficult part in being diagnosed with Pulmonary Hypertension?
8. Tell me about your experience with the assessment tests.
9. How has Pulmonary Hypertension restricted the possibilities for vacation, travel, etc...
10. How has your social life changed since being diagnosed with Pulmonary Hypertension?
11. How has your daily routine changed since being diagnosed with Pulmonary Hypertension?
12. How has your ability to work been compromised by Pulmonary Hypertension?
13. How has Pulmonary Hypertension affected your relationships with your loved ones?
14. Has religion or spirituality played a role in your ability to cope with Pulmonary Hypertension?
15. Do you think you have been offered and referred to enough social services (ex: support groups, therapists) to help you cope with Pulmonary Hypertension?
16. Do you participate in a Pulmonary Hypertension support group? Why or why not?
17. Are you involved with The Pulmonary Hypertension Association of Canada? If so, what is your involvement? Why is being involved with an association like this important to you?
18. What do you wish the general public could know about Pulmonary Hypertension?
19. What do you hope can be achieved for Pulmonary Hypertension patients through advocacy and awareness initiatives?
20. If there was one word you could describe to represent your experience with Pulmonary Hypertension, what would it be?

*Appendix B: Recruitment Letter*

**Understanding Pulmonary Hypertension through the Eyes of the Patients**

Principal Investigator: Renae Mohammed, Department of Sociology, Wilfrid Laurier University

Advisor: Dr. Dana Sawchuk, Department of Sociology, Wilfrid Laurier University

Dear \_\_\_\_\_,

My name is Renae Mohammed, and I am a Master of Arts candidate in the Department of Sociology at Wilfrid Laurier University, in Waterloo, Ontario, Canada. My primary interest in sociology is the sociology of health and illness. Currently, I am undertaking a study focusing on Pulmonary Hypertension and people's experiences with the disease, in addition to the challenges which accompany Pulmonary Hypertension. This study will fulfil, in part, my requirements to receive my Master of Arts in Sociology.

I am seeking eight participants who have been diagnosed with Pulmonary Hypertension. Participants will be interviewed by me in person. I will be traveling to participants to make this possible. The interview process will last approximately one hour.

If you think you may be interested in participating in this study, or if you have any questions about the research, please contact me at [moha6400@mylaurier.ca](mailto:moha6400@mylaurier.ca) or at (905)-767-3996. Interviews will commence in May of 2016. If you know of any other Pulmonary Hypertension patient who may be interested in participating in this study, I invite you to forward this message to him or her. Any response by you now in no way obligates you to participate in the study. If you indicate an interest in the study, I will send you an information letter which will explain the research project, your rights and my responsibilities in detail.

Thank you,

Renae Mohammed

REB tracking number: 4888

*Appendix C: Informed Consent Statement*

WILFRID LAURIER UNIVERSITY  
INFORMED CONSENT STATEMENT

“Understanding Pulmonary Hypertension through the Eyes of the Patients”

Principal Investigator: Renae Mohammed, Department of Sociology, Wilfrid Laurier University

Advisor: Dr. Dana Sawchuk, Department of Sociology, Wilfrid Laurier University

You are invited to participate in a research study on Pulmonary Hypertension. The purpose of this study is to investigate the experiences of people living with Pulmonary Hypertension, a very rare chronic illness, and to see what challenges this illness poses to its patients. Renae Mohammed is a Master of Arts candidate in the Department of Sociology at Wilfrid Laurier University.

**INFORMATION**

You are invited to participate in an interview about your experience with Pulmonary Hypertension. The interviewer will ask you questions about your history with Pulmonary Hypertension and the effects it has had on various aspects of your life. The interview will be voice-recorded with a tape recorder and will last for approximately one hour. You do not have to answer all of the questions and you can end the interview at any time. After the interview, the voice-recording will be transcribed by the principal investigator. No one else will have access to the data. All information on the tapes will be kept confidential and tapes will be erased two years after completion of this project. Identifying markers such as name, location, etc. can be removed from the transcript if you wish. Approximately eight Pulmonary Hypertension patients will be interviewed in this study. The principal investigator will use your data for research purposes only and may present the findings of the study to The Pulmonary Hypertension Association of Canada as well as in journal articles and conference papers. The final research paper will be kept in the Department of Sociology office at Wilfrid Laurier University.

**RISKS**

There are no costs to you in this research. Some questions during the interview process may cause you to become emotional as questions pertain to having a chronic lung illness. The interview can be stopped at any time and you have the right not to proceed any further. You will also have the option to continue the interview at a later date, if you would like to.

**BENEFITS**

In order for the health of Pulmonary Hypertension patients to be improved, awareness must be generated. Having a qualitative study where the voices of Pulmonary Hypertension patients are heard is a step towards generating awareness and recognition of

Pulmonary Hypertension. This is an opportunity for a small, marginalized population to voice their experiences and struggles of living with such an uncommon, chronic, invisible illness.

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participant's initials

### **CONFIDENTIALITY**

Confidentiality and anonymity of participants are ensured. Only the principal investigator will have access to the voice recordings and transcripts. The tape recordings will be stored securely (locked) in the principal investigator's home office, and will be deleted two years after the completion of the research project. The transcripts of the interviews will be locked up and encrypted on a password protected computer. Transcripts will be shredded and deleted two years after the completion of the research project. Contact information and consent forms from recruitment will be stored separately from collected data. Please indicate to the principal investigator if you would like to be identified and/or quoted in this research. Otherwise, participants will remain anonymous with the use of pseudonyms, to guarantee anonymity with the Pulmonary Hypertension community.

Please check one:

\_\_\_ 1) I do not wish to remain anonymous and you may use my name, as follows:

\_\_\_\_\_ (please enter first name only or full name, as you prefer), in publications and presentations resulting from this research.

\_\_\_ 2) I wish to remain anonymous and agree to be quoted as long as the quotations contain  
no identifying information.

\_\_\_ 3) I wish to remain anonymous and I do not wish to be quoted at all.

### **COMPENSATION**

For participating in this study you will receive a gift card of \$20 to Starbucks in addition to a beverage at the time of the interview, as a thank you for your time and valued information.

### **CONTACT**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study), you may contact the researcher, Renae Mohammed at [moha6400@mylaurier.ca](mailto:moha6400@mylaurier.ca) or (905)-767-3996. You may also contact the advisor, Dr. Dana Sawchuk, at [dsawchuk@wlu.ca](mailto:dsawchuk@wlu.ca) or (519)-884-0710 ext.2306. This

project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or [rbasso@wlu.ca](mailto:rbasso@wlu.ca)

\_\_\_\_\_ participant's initials

### **PARTICIPATION**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed. You have the right to omit any question(s)/procedure(s) you choose.

### **FEEDBACK AND PUBLICATION**

The results of the research will be disseminated in a major research paper which is part of the requirements necessary to complete the Master of Arts in Sociology program. The major research paper will be kept in the Department of Sociology office at Wilfrid Laurier University. It is possible that the research may be disseminated to The Pulmonary Hypertension Association of Canada, in addition to journal articles and conference papers. When the project has been completed, you will be invited to request a copy of the final major research paper. Results should be available no later than December of 2016.

### **CONSENT**

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's signature \_\_\_\_\_ Date \_\_\_\_\_



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