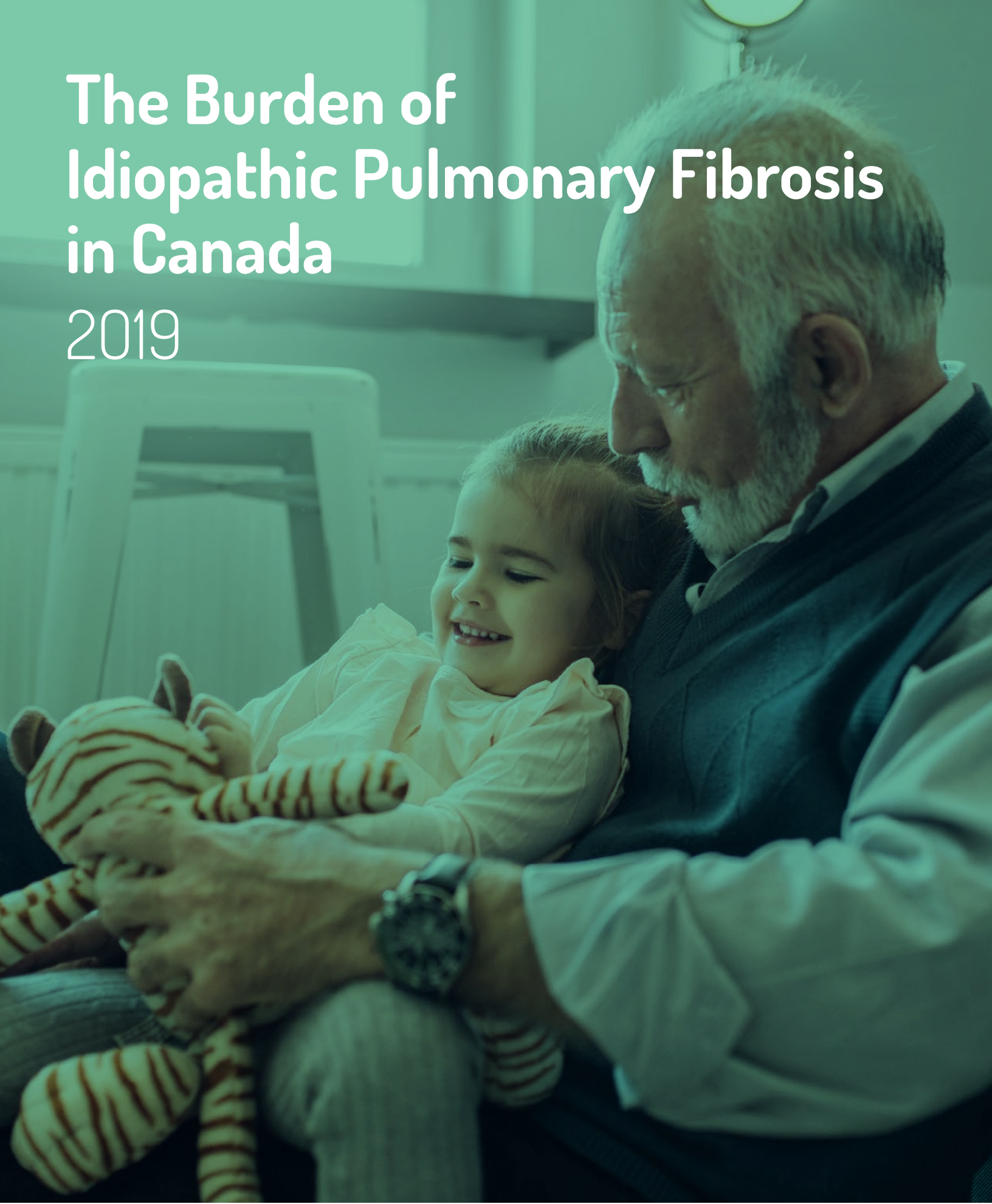


The Burden of Idiopathic Pulmonary Fibrosis in Canada

2019



fightipf.ca
SUPPORTING PATIENTS WITH
IDIOPATHIC PULMONARY FIBROSIS



Canadian
Pulmonary
Fibrosis
Foundation

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Table of Contents

| | |
|--|---------|
| Foreword from The Canadian Pulmonary Fibrosis Foundation | 4 |
| Overview | 5 |
| Introduction | 6 - 8 |
| IPF in Canada | 9 |
| Economic burden of IPF | 10 - 11 |
| Key challenges | 12 - 17 |
| Provincial snapshot | 18 - 20 |
| Calls to action | 21 - 23 |
| Conclusion | 24 |
| References | 25 - 27 |



Foreword from The Canadian Pulmonary Fibrosis Foundation

In 2007 Robert Davidson heard four words from his respirologist that changed his life and the lives of his family members forever: "You have pulmonary fibrosis." (*Breathing should never be hard work*, by Robert Davidson)

More than 14,000 Canadians currently live with this incurable lung disease,¹ equal to about the number of men diagnosed with lung cancer every year in Canada.² Several thousand among those living with pulmonary fibrosis (PF) will die from it each year.³

It was the lack of a support network for patients, as well as limited unbiased and accurate information that led Robert Davidson to found the Canadian Pulmonary Fibrosis Foundation (CPFF) in 2009. With lung transplant as the only treatment option at the time, Robert received a new set of lungs and led the organization's efforts for continued education, research and support so others could have a hopeful future. Robert lived for another 10 years advocating

for the Canadian pulmonary fibrosis community. In the end, Robert suffered additional health complications resulting from his condition and he passed away on May 1, 2019.

PF patients deal with life-altering symptoms that eventually leave them gasping for every breath, as their care partners watch helplessly.⁴ In addition to the financial challenges associated with the disease,⁵ patients and their families often face the burdens of depression, stress and isolation.⁶ Gaps in the education of patients, caregivers and health care professionals, along with limited or inconsistent health care access and social support, often give rise to these burdens.

Provincial health care systems are already burdened by hospital stays. For example, in Ontario, hospitals and long-term care homes are facing capacity pressures that are due to increase.⁷ Direct costs for IPF patients average slightly under \$13,000 per year after diagnosis, with an additional one-time

diagnostic cost of slightly more than \$15,000.⁸

However, there are ways to alleviate the burdens of PF. This report contains credible, evidence-based information on the current state of the prevalence, economic impact, diagnosis and treatment of idiopathic pulmonary fibrosis (IPF) – pulmonary fibrosis of unknown cause - the issues facing patients, their families and the health care professionals who treat them. More importantly, it offers workable solutions to help alleviate some of the burdens they face.

CPFF strongly believes that the implementation of the report's recommendations will substantially alleviate the current burdens of IPF. Along with research into new treatments, and ultimately a cure, they will deliver a better quality of life, as well as hope to those living with the disease and their families.

Overview

IPF is a chronic, debilitating condition that affects people around the world.⁵ Although it is relatively rare, more research and development, as well as disease education, is needed. Moreover, the health and economic burden of this disease is still being established. In order to mobilize policy changes and leverage

research and funding efforts around IPF, the community needs more information.

This report aims to provide an overview of the burden of IPF both from the patients and support partners' standpoint on the impacts to their health, and also a quantification of the

economic burden that results from diagnostic delays and treatment challenges. It also highlights important disparities in treatment across Canada, which may affect the quality of care that patients receive simply based on where they live.



Introduction

IPF is a chronic, irreversible lung condition that causes scarring (fibrosis) of the lungs for unknown reasons. As the disease progresses, the scarring typically worsens and makes it more challenging to breathe. IPF primarily affects adults, and is most commonly diagnosed in males ages 50 years and older. However, it is seen across gender and the age spectrum.⁵

IPF is a form of interstitial lung disease (ILD). ILD refers to diseases that primarily affect the tissue and space around the alveoli (air sacs), called the interstitium, involving a spectrum of disease from inflammation to repair and scarring.⁹

The incidence of IPF is estimated at three to nine cases per every 100,000 people in Europe and North America, and is increasing worldwide.¹⁰ Comparatively, the incidence of lung cancer in Europe is estimated at 30.5 cases per 100,000.¹¹ Unfortunately, little progress has been made in improving the poor three-to-five year median survival rate associated with IPF. As IPF is common in people over 65¹⁴, due to an aging population and increase in the prevalence and incidence of IPF, the overall mortality rate has increased in the past 20 years.¹²

The burden of IPF extends beyond treatment and survival. Poor prognosis, uncertainty of disease course and symptom burden severely impact quality

of life for patients and their support partners.¹³ Depression is also highly prevalent in patients with ILD, and anxiety symptoms and depression are associated with impaired health status.¹⁴ Furthermore, depression is tied to increased financial burden due to the disease, as many patients can no longer work full-time leading to increased financial strain on both patients and their families.⁵

A qualitative study assessing the perceptions, experiences and needs of patients with IPF found that three main themes emerged within the patient journey: patients struggle to get a diagnosis, loss of previous life before diagnosis of disease, and living with IPF.¹⁵ These commonalities underscore the unmet need of earlier access to specialists and improved education around this condition.

Studies also demonstrate a significant emotional toll on IPF patient support partners, characterized by disbelief and devastation, anger at the situation, helplessness and fear. Symptoms of IPF – specifically breathlessness – are particularly distressing to support partners and can lead to limitations in shared activities, loss of companionship and increased feelings of responsibility and helplessness due to an inability to control their loved ones' breathlessness.¹⁶ At end of life, this suffering is magnified due to lack of palliative care support.¹⁷



“

The burden of IPF extends beyond treatment and survival.

Symptoms

IPF is characterized by two main symptoms: breathlessness (also known as shortness of breath or dyspnea) and chronic cough. As the disease progresses, the symptoms worsen. For example, over time breathlessness may prevent regular daily activities and even occur at rest. Many patients also experience cough as a significant symptom and coughing fits may be debilitating. Other symptoms may include chest pain, weight loss or a rounding of the fingertips known as “clubbing.” In some cases, symptoms and signs of IPF may not even get noticed until the disease has caused severe damage to the lungs.^{18,19}

Acute exacerbation of IPF – defined as a sudden worsening of the disease – is associated with a mortality rate of 30 to 85 per cent, with mean survival of three to 13 days.²⁰ Acute exacerbations of IPF are often the primary cause of death in patients with IPF.²¹

IPF can also lead to other health problems, including lung infections, blood clots in the lungs or a collapsed lung. As the disease progresses, other potentially life-threatening conditions may develop such as respiratory failure, pulmonary hypertension or heart failure.¹⁹

Treatment Options

Currently IPF has no cure. Existing treatments aim to slow progression of the disease, but they may not necessarily improve IPF symptoms.⁴

Currently, there are two anti-fibrotic medicines authorized for sale by Health Canada for the treatment of IPF. In 2012, pirfenidone was authorized for the treatment of IPF in adult patients, followed by nintedanib in 2015.²² These medications have been shown in clinical trials to help reduce inflammation and fibrosis, which in turn may slow the progression of IPF in patients with a wide range of lung function impairment.²³ However, not all IPF patients can take these medications due to their side effects and often need to work with their doctor to determine the correct treatment path.⁴ Clinical research studies on potential new treatments are currently underway.

Disease management may also include supplemental oxygen and pulmonary rehabilitation. Some patients may qualify for a lung transplant. Lung transplantation is the only therapy proven to extend survival in IPF.²² In Canada, IPF is the leading cause of both single and bilateral lung transplantation, accounting for 46.1 per cent and 26.4 per cent of transplant recipients, respectively.²⁴

I've made the decision not to go on the transplant list. I don't want to put myself or my family through all the pain and grief of a transplant plus the associated costs are exorbitantly expensive.

- Peter

However, the availability of a lung transplant is limited due to low supply, and survival for

IPF patients who undergo a lung transplant is shown to be lower relative to other disease categories.²⁵ In addition, in one study, nearly eight out of 10 people with IPF were not eligible for lung transplant (many because of age), and of those, only 16 per cent survived to receive a transplant, based on guidelines.²⁶

As IPF progresses, palliative care services become more important and focus on relieving symptoms and improving comfort and quality of life. It is now recommended as a routine part of IPF care. Palliative care is provided by a multidisciplinary team including doctors, nurses, religious leaders, social workers, psychologists and other health care professionals, and can be offered in a home or inpatient setting. Importantly, palliative care differs from hospice care. While hospice and palliative care do have overlapping goals, palliative care is a treatment option at any point in treatment, not just at the end of life.²⁷

The goal of hospice or end of life care – typically reserved for people with less than six months to live – is to help patients who are dying have peace, comfort and dignity. It may involve treatments to control breathlessness, pain or other symptoms, and can be provided at a hospice center but also at a hospital, nursing facilities or at home.²⁷ Some studies have shown that ILD patients have poorer access to specialist end-of-life care services than patients with lung cancer, signifying an important need for this condition.²⁸

IPF in Canada

IPF affects people worldwide. A recent study using national administrative data from 2007-2011 found the prevalence of IPF in Canada to be higher than many other developed countries, identifying 14,259 prevalent cases (41.8 per 100,000)

across Canada.¹ This is roughly equivalent to the number of men diagnosed with lung cancer in 2017 in Canada.²

However, the prevalence of IPF varies by province. The highest rates were seen in Quebec, while

lower rates are estimated in the western provinces of British Columbia, Alberta, Saskatchewan and Manitoba. This may be due to greater data capture of cases in areas with greater access to hospital-based care.¹

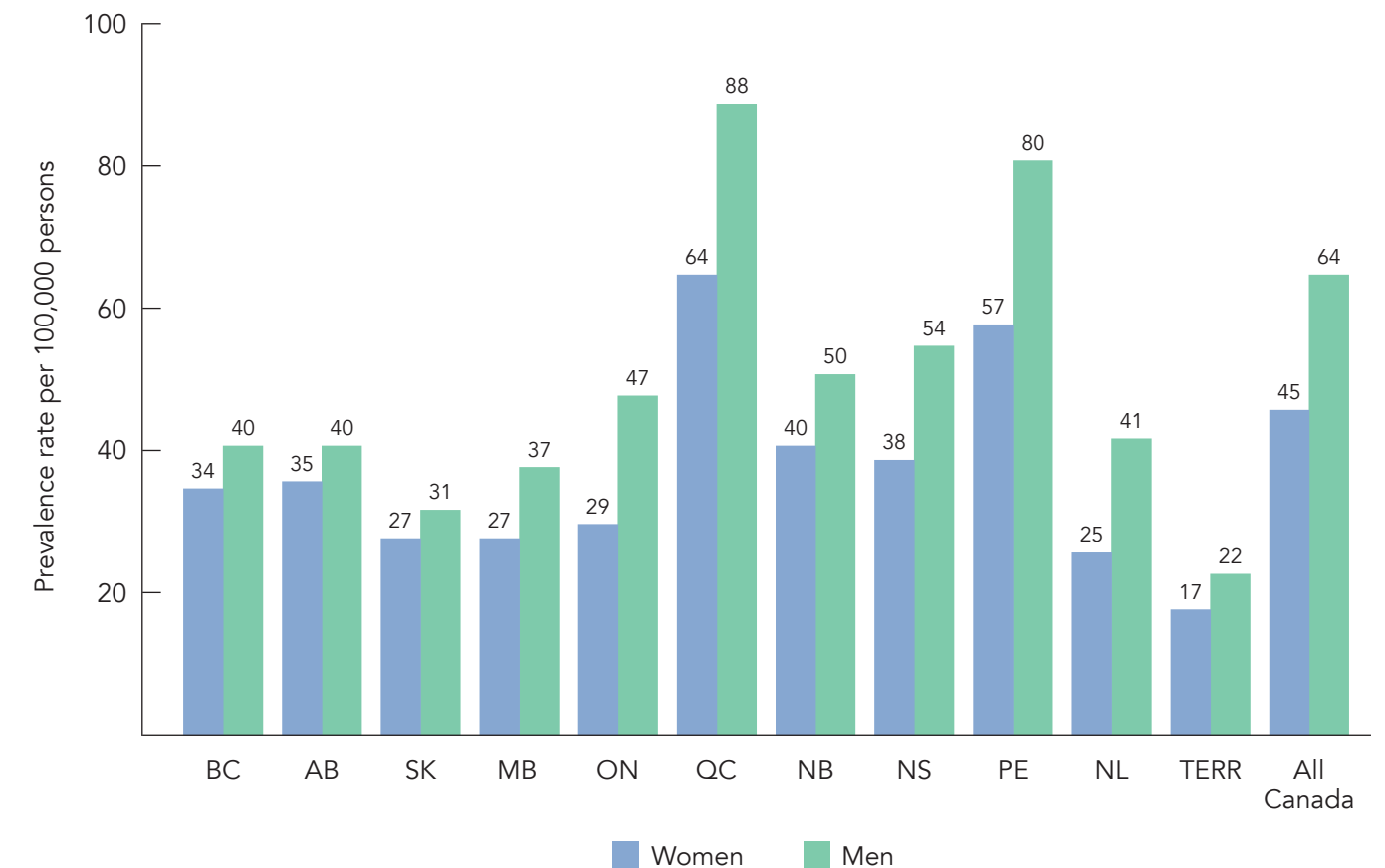


FIGURE 2 Prevalence rates of idiopathic pulmonary fibrosis by the narrow definition, per 100,000 persons aged ≥50 years, by province and sex, in 2011. BC: British Columbia; AB: Alberta; SK: Saskatchewan; MB: Manitoba; ON: Ontario; QC: Quebec; NB: New Brunswick; NS: Nova Scotia; PE: Prince Edward Island; NL: Newfoundland and Labrador; TERR: territories.

Hopkins et al. Eur Respir J 2016¹

Economic Burden of IPF

The economic burden of IPF has not been well-characterized, but data suggest that health care costs are high and likely to increase in the future. A retrospective study of a United States database found that between 2001 and 2008, the total direct cost for patients with IPF was \$26,000 USD per person-year.¹² In addition, a study found that in the U.S. Medicare beneficiaries aged 65 years and older, IPF patients had an 82 per cent higher risk of hospitalization and 72 per cent higher total

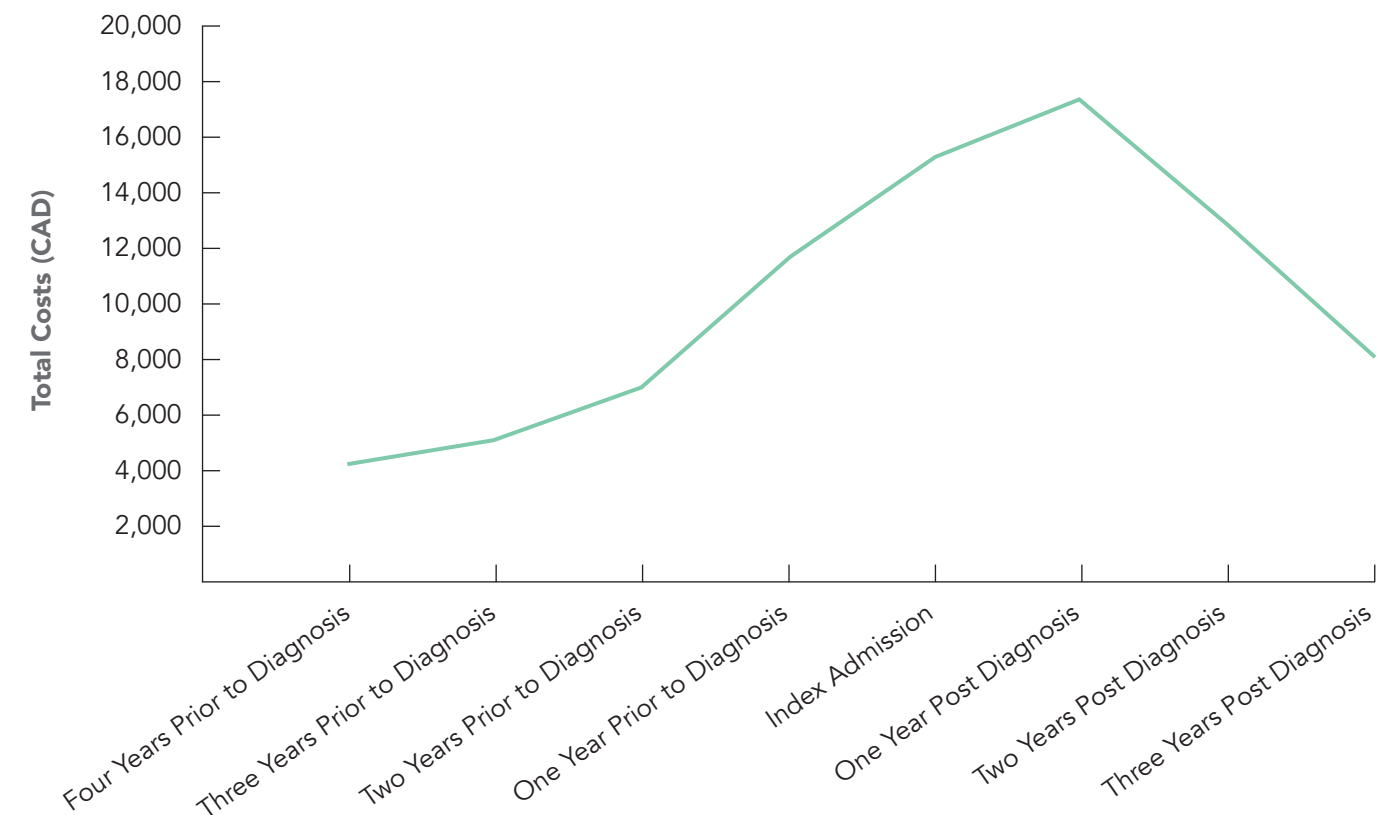
medical costs compared with a matched control population.²⁹ This represents a significant financial burden not just for patients, but for their families and care partners. More studies are needed to better quantify the economic impact of IPF.

A multi-year study based in Quebec found that the annual health care costs for patients with IPF begin to increase prior to diagnosis, reflective of the declining health status that eventually leads to the diagnostic

workup establishing IPF. In Quebec, the average annual cost per patient two years prior to IPF diagnosis was \$7,049 CAD. For the year prior to diagnosis, it rose by 65 per cent to \$11,664 CAD. The average annual cost per patient was \$17,398 CAD the year after diagnosis, excluding the cost of the original diagnosis (index admission) of \$15,281 CAD. The average cost remained above \$12,000 CAD for the second year post-diagnosis.⁸



Mean Annual Costs for Incident IPF Cases (Broad Definition of IPF)



Tarride et al. Clinicoecon Outcomes Res 2018.⁸

Taken together, this demonstrates the need for improved therapeutic strategies that reduce rates of IPF hospitalization and thereby costs.

Of note, when compared to other Canadian burden of illness studies, the direct cost of IPF is comparable to or higher than

asthma, chronic obstructive pulmonary disease (COPD) and lung cancer in Canada. For example, the first year cost of lung cancer in Ontario was estimated at \$30,550 CAD in 2009, similar to the \$25,725 CAD cost of care for IPF (including the original diagnosis) in the first year. Moreover, data from

Alberta suggests that 69 per cent of the total cost of lung cancer medical care occurs within the first three months of diagnosis, while costs for IPF remain high up to two years after diagnosis or until death.⁸ End of life care is also a major component of the economic burden of IPF, since most patients die in hospital.³⁰

Key Challenges

Diagnostic Challenges

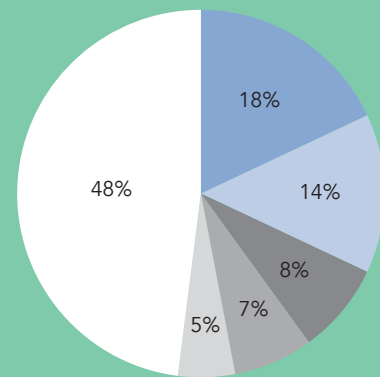
IPF is one of many ILDs that can have overlapping symptoms and features. In addition, the most common symptoms of IPF – dry cough and dyspnea – may be wrongly attributed to smoking behaviour or aging. Because IPF is relatively rare, a swift and accurate diagnosis requires an experienced respirologist and integration of clinical, radiographic (X-ray imaging such as high-resolution computed tomography (HRCT)) and histopathologic (lung biopsy) findings.³¹

“ I was a long-time smoker so I was short of breath. I thought that's what was causing it, and I put any shortness of breath down to that rather than to anything else.

– Suzan

One study found that patients with IPF may be symptomatic for more than five years before diagnosis.³² According to another study, initial diagnosis was frequently incorrect for pulmonary fibrosis patients³⁷ and they reported at least a one-year delay between the onset of breathing problems to diagnosis of pulmonary fibrosis. Frequent misdiagnoses included bronchitis, asthma and COPD. More than one-third of patients reported seeing three or more

Initial Incorrect Diagnoses for IPF



- Bronchitis
- Asthma
- COPD
- Emphysema
- Heart Disease
- Other

Collard et al. Res Med 2007³³



physicians before establishing an accurate diagnosis.³³

In addition, results from a recent survey found that although physicians are the main source of trusted information for patients with IPF, many patients still do not feel that they receive enough information about their disease from them. This disconnect in communication may only serve to exacerbate the distress and confusion around an IPF diagnosis and subsequent steps in treatment.³⁴

“ I changed respirologists part way through [the process of being treated] because I wasn't getting the information I wanted.

– Suzan

The Canadian Thoracic Society published a position statement in 2017 providing evidence-based clinical guidance related to IPF diagnosis.³⁵ In September 2018, four major respiratory societies – the American Thoracic Society (ATS), European Respiratory Society (ERS), Japanese Respiratory Society (JRS) and the Latin American Thoracic Society (ALAT) – published new international guidelines to aid physicians in the diagnosis of IPF. These clinical guidelines seek to help treating physicians make swift and accurate diagnoses through refinement of diagnostic criteria based on high-resolution computed tomography (HRCT).³⁶

Treatment Access Challenges

Even once someone is diagnosed with IPF, it may be difficult to access high quality treatment and care. In addition, the availability of these resources can differ across provinces. Below we highlight several challenges to treatment access, as well as disparities between them at the national level, that may currently be barriers to improving outcomes.

ILD Centres

- ILD centres have dedicated ILD respirologists, in-house multidisciplinary teams and dedicated ILD nurses and educators.

- There are 16 ILD clinics in Canada.³⁷
- ILD centres are referral-based, and not all provinces have equal access to such specialty clinics.³⁸ In addition, not all ILD centres have adequate staffing and funding.

“Keep working with the doctors. I think a lot of the issues in the medical community is that it is still kind of an unknown disease. Especially in those smaller centers, where maybe the doctor has never seen this.”

- Darren

Respirologist Availability

- Respirologists are trained in the subspecialty of internal medicine focused on the diagnosis and treatment of diseases of the respiratory system. In Canada, certification in adult respiratory medicine takes approximately five years.³⁹ However, a survey of Canadian respirology fellows found that exposure and training in advanced diagnostic and therapeutic procedures was minimal.⁴⁰
- The number of respirologists available per 100,000 people differs by province. In some provinces there may be three respirologists per every 100,000 people, while in others there may be fewer than one.³⁹

Home Oxygen Eligibility

- Home oxygen has demonstrated the ability to prolong life in certain respiratory conditions and improve quality of life, and oxygen therapy has been widely accepted for the management of many other chronic cardiorespiratory conditions. It may also be prescribed to alleviate dyspnea (breathlessness) in a palliative care setting.^{41,42}
- Current prescriptions for long-term oxygen therapy in ILD patients are based on studies of patients with COPD and may not accurately reflect the needs of IPF patients.⁴³
- Eligibility and access to supplemental oxygen, including palliative home oxygen therapy differs by province, with each regulatory

agency establishing policy for its local population.⁴³

Access to Pulmonary Rehabilitation

“I did pulmonary rehab and it really helped. But because I've already done it, and there's such a waiting list, I haven't gone back.”

- Anna

- Pulmonary rehabilitation is an important part of managing chronic lung diseases, such as IPF. Pulmonary rehabilitation programs may include exercise training, education and psychosocial support. Pulmonary rehabilitation can reduce dyspnea, optimize functional status and reduce health care costs.⁴⁴
- The number of pulmonary

rehabilitation centers differs by province. In addition, barriers to access remain, including lack of designated staff, limited effectiveness of the referral system and travel distance for patients.⁴⁴

- Furthermore, studies show that people with ILD have specific educational needs that may not be met in current pulmonary rehabilitation program formats, such as information about end of life planning.⁴⁵

“The doctor suggested I go again recently, and I said to the doctor I don't really feel I can do it. Or have the energy. And then my husband would have to drive me, and it's just sheer distance.”

- Barbara

Total Number of Respirologists and Number/100,000 By Province, 2017

| Province/Territory | Physicians | Phys/100k pop'n |
|-----------------------|------------|-----------------|
| Newfoundland/Labrador | 6 | 1.1 |
| Prince Edward Island | 2 | 1.3 |
| Nova Scotia | 9 | 0.9 |
| New Brunswick | 7 | 0.9 |
| Quebec | 251 | 3.0 |
| Ontario | 290 | 2.1 |
| Manitoba | 15 | 1.1 |
| Saskatchewan | 24 | 2.1 |
| Alberta | 111 | 2.6 |
| British Columbia | 80 | 1.7 |
| Territories | 0 | 0.0 |
| Canada | 795 | 2.2 |

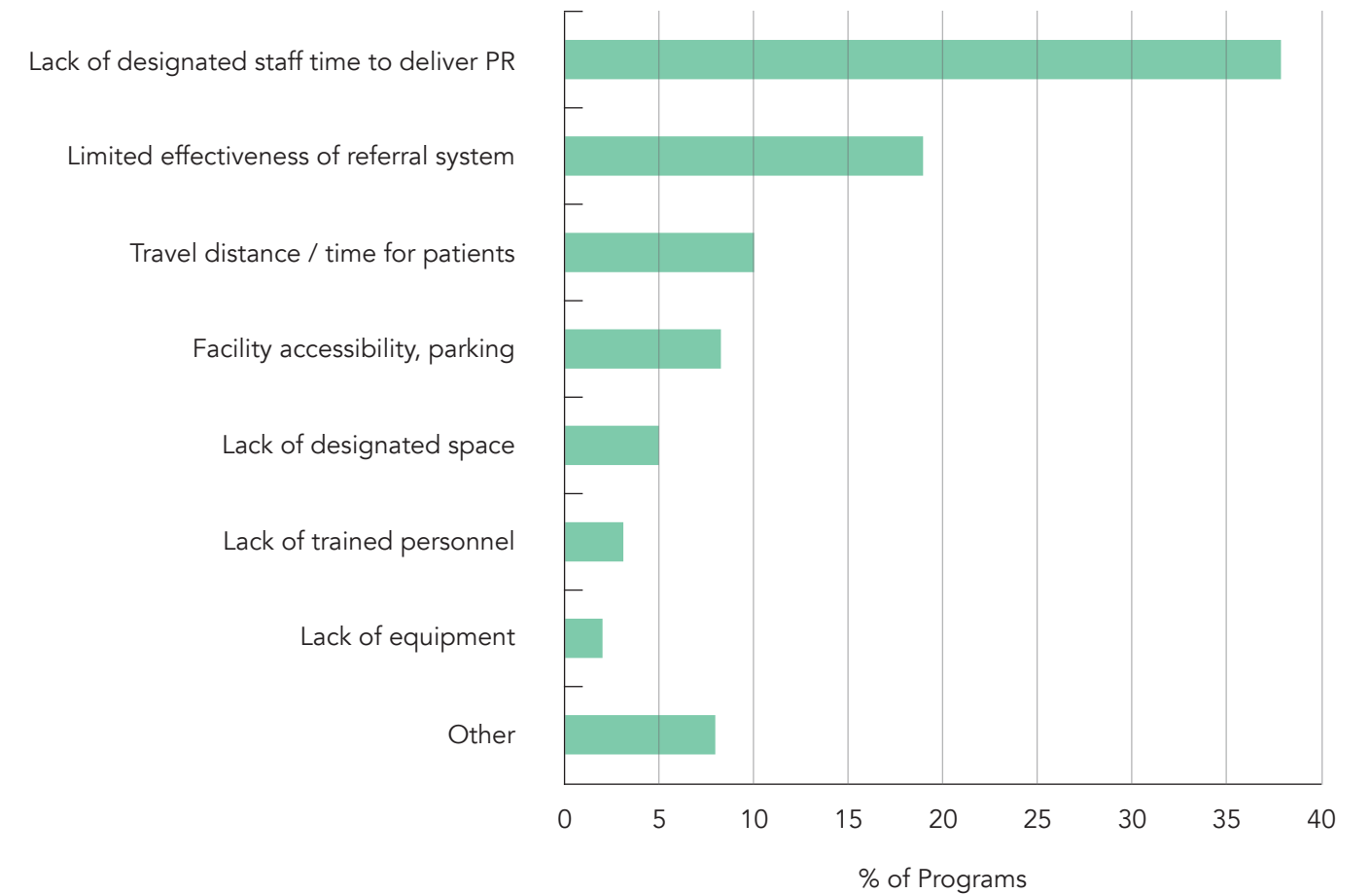
Respirology Profile, March 2018, Canadian Medical Association³⁹



Identified Pulmonary Rehabilitation Programs in Canada, 2015



Camp et al. Canadian Medical Journal, 2015.⁴⁴



Camp et al. Canadian Medical Journal, 2015.⁴⁴

Patient & Support Partner Resources

- IPF patient support groups and programs are important to help patients and their loved ones understand and live with the disease.⁴⁶ For example, a recent study showed that a short multidisciplinary empowerment program

improved quality of life for patients with IPF and their partners.⁴⁷

- Support partners rely on patient organizations to facilitate support groups, but the availability of such groups

also differs by province.

- Information available on the internet for patients is frequently inaccurate and outdated, leaving patients with few means of learning about their condition.⁴⁸

Provincial Snapshot*

In Canada, the provinces and territories hold responsibility for delivering health care services. Despite the fact that medical

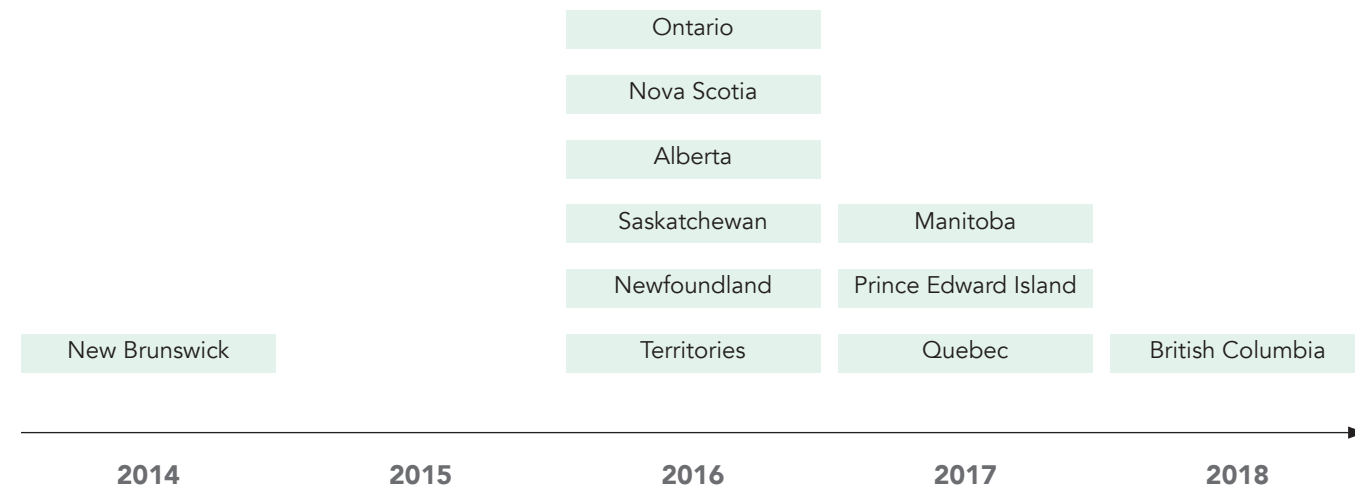
insurance is generally universal, significant differences can exist in treatment across the country. Additionally, these variations can

place a substantial burden on patients and their families as they seek access to quality care.

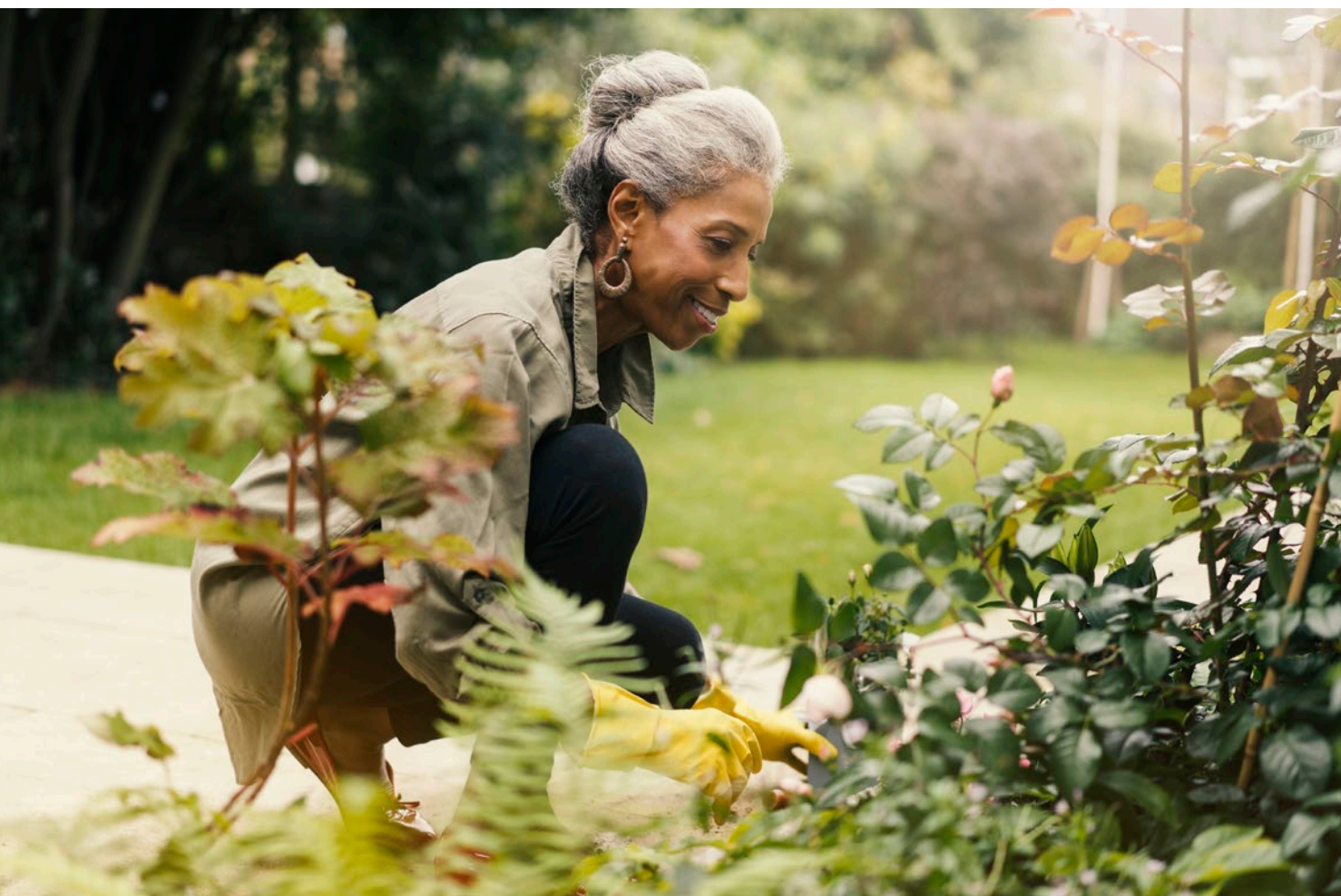
| Province/Territory | # ILD Centres ³⁷ | | # Respiriologists per 100K people ³⁹ | Palliative O2 (oxygen) guidelines ⁴¹ |
|----------------------|-----------------------------|--|---|---|
| Alberta | 3 | <ul style="list-style-type: none"> CALGARY - Calgary South Health Campus Hospital: Dr. Charlene Fell EDMONTON - University of Alberta: Dr. Meena Kalluri, Dr. Giovanni Ferrara | 2.5 | Approved if room air SpO2 < 90% at rest during the day-time for at least 3 consecutive minutes. "Palliative" must be written on the physician's prescription. The maximum authorization is for six months, and will only be extended for one six-month (maximum) period. |
| British Columbia | 2 | <ul style="list-style-type: none"> VANCOUVER - St. Paul's Hospital: Dr. Chris Ryerson, Dr. Pearce Wilcox - Vancouver General Hospital: Dr. Nasreen Khalil | 1.7 | Palliative diagnosis does not ensure home oxygen subsidy. Palliative clients must have hypoxemia according to the same criteria as for resting oxygen, ambulatory oxygen or nocturnal oxygen to be funded. |
| Manitoba | 0 | | 1.0 | Assessment for home oxygen therapy for a palliative care client conforms to the same medical eligibility criteria as those for resting hypoxemia. |
| New Brunswick | 0 | | 0.8 | For end-stage palliative patients, in whom terminal illness affects the respiratory system; SpO2 studies confirm oxygen desaturation with SpO2 < 89% on room air). |
| Newfoundland | 0 | | 1.1 | N/A |
| Nova Scotia | 1 | <ul style="list-style-type: none"> HALIFAX - Dalhousie University – Dr. Paul Hernandez | 0.9 | The home oxygen service does not provide funding assistance for home oxygen therapy when prescribed for psychological support for breathlessness unsupported by evidence of hypoxemia. |
| Ontario | 6 | <ul style="list-style-type: none"> LONDON - London Health Services, Victoria Hospital and Schulich School of Medicine: Dr. Marco Mura HAMILTON - St. Joseph's Hospital: Dr. Martin Kolb, Dr. Gerry Cox, Dr. Nathan Hambly MISSISSAUGA - Mississauga Lung Health Centre: Dr. Noreen Mann TORONTO - Toronto General Hospital: Dr. Shane Shapera, Dr. Jolene Fisher KINGSTON - Hotel Dieu Hospital (Jeanne Mance 4): Dr. Onofre Moran-Mendoza OTTAWA - Ottawa General Hospital: Dr. Nha Voduc | 2.0 | Funded for individuals who are at the end stage of a terminal illness (i.e., life expectancy < 3 months), are receiving end-of-life care and require home oxygen therapy. Funding is provided for a maximum period of 90 days. |
| Prince Edward Island | 0 | | 1.3 | Palliative care with a minimum of two oximetry results showing a % saturation <85% and requiring oxygen therapy for at least 18 h per day. |
| Quebec | 4 | <ul style="list-style-type: none"> MONTREAL - Centre hospitalier de l'Université de Montréal: Dr. Hélène Manganas, Dr. Julie Morisset, Dr. Andréanne Gauthier - McGill University Health Centre: Dr. Deborah Assayag - Hôpital Sacré Coeur: Dr. Marianne Lévesque SHERBROOKE - Centre Hospitalier Universitaire de Sherbrook: Dr. André Cantin QUEBEC CITY - Centre hospitalier de l'Université Laval: Dr. Geneviève Dion, Dr. Steeve Provencher, Dr. Lara Bilodeau | 3.0 | Palliative oxygen may be considered if severe hypoxemia is present (saturation at rest <88%) in a patient with lung cancer or any other cancer with pulmonary involvement, if vital prognosis is estimated to be < 3 months. For non-neoplastic conditions, palliative oxygen may be considered if severe hypoxemia is present (PaO2 ≤55 mmHg, or <60 mmHg in case of right heart failure). |
| Saskatchewan | 1 | <ul style="list-style-type: none"> SASKATOON - Royal University Hospital: Dr. Veronica Marcoux | 2.0 | The time frame for end-stage care may be measured in terms of days or weeks of active dying. Eligibility is according to symptoms and performance status (not saturation). Coverage includes a concentrator and 10 portable oxygen cylinders per month. Funding is for a maximum of four months; only a prescription is required to renew coverage. |
| Territories | 0 | | 0 | N/A |

*accurate as of November 2019

History of Antifibrotic Coverage by Province*



*year first antifibrotic covered



Calls to Action

Improved Education and Awareness of IPF

More education and awareness is needed, not only for the general public but for health care GPs, including general practitioners. This starts with improving medical training programs. GPs should receive training so that they can recognize or at least suspect IPF early enough to refer patients to a specialist. In addition, respirology fellows need sufficient exposure to IPF and other ILDs. This also includes properly resourcing ILD clinics with educated staff who have experience, training and access to resources to help them optimize care. In addition, respirologists should be deployed to help educate GPs on IPF. Finally, GPs should be provided with simple forms to help them answer patient/caregiver questions about IPF.

Joint Treatment Management Strategies

There are guidelines from the major respiratory societies for the management of IPF which also cover treatment aspects. Given the level of experience needed to accurately diagnose and treat IPF, these guidelines are less directive than guidelines known for other disease areas, such as asthma (Global Initiative for Asthma) and COPD (Global Initiative for Chronic Obstructive Lung Disease). With the development of personalized treatments for IPF, it is unlikely that simple and unified guidelines will be available anytime soon, and joint management strategies between community care and academic centers for individual cases will ensure that patients around the country have the opportunity to receive the best possible care, no matter where they are primarily treated.

“ I run everything through my GP first. So, once he found out that I have this, he did not know about it. And he told me, ‘I’ve never had a patient like this before. I’m going to learn all about this.’ And he spent the time learning. He learned on the journey with me, so that’s pretty cool of my doctor.

- Anna

Earlier Integration of Multidisciplinary Palliative Care

Multidisciplinary palliative care approaches should be integrated earlier. The last year of life with ILD is associated with increased acute care utilization and hospital deaths. Despite the fact that clinical care guidelines recommend early integration of palliative care, this is rare. Data show that a multidisciplinary collaborative care model for IPF was associated with reduced health care use in the last year of life and more home deaths.⁴⁹ In addition, conversations around advanced care planning helps support partners to understand and learn about a patient's goals and wishes and to feel more informed and supported.⁵⁰

Expanded Access to Patient and Support Partner Resources

“ I have a strong family support team. It's a very strong team of people who are behind me 100%. I'm lucky that way.

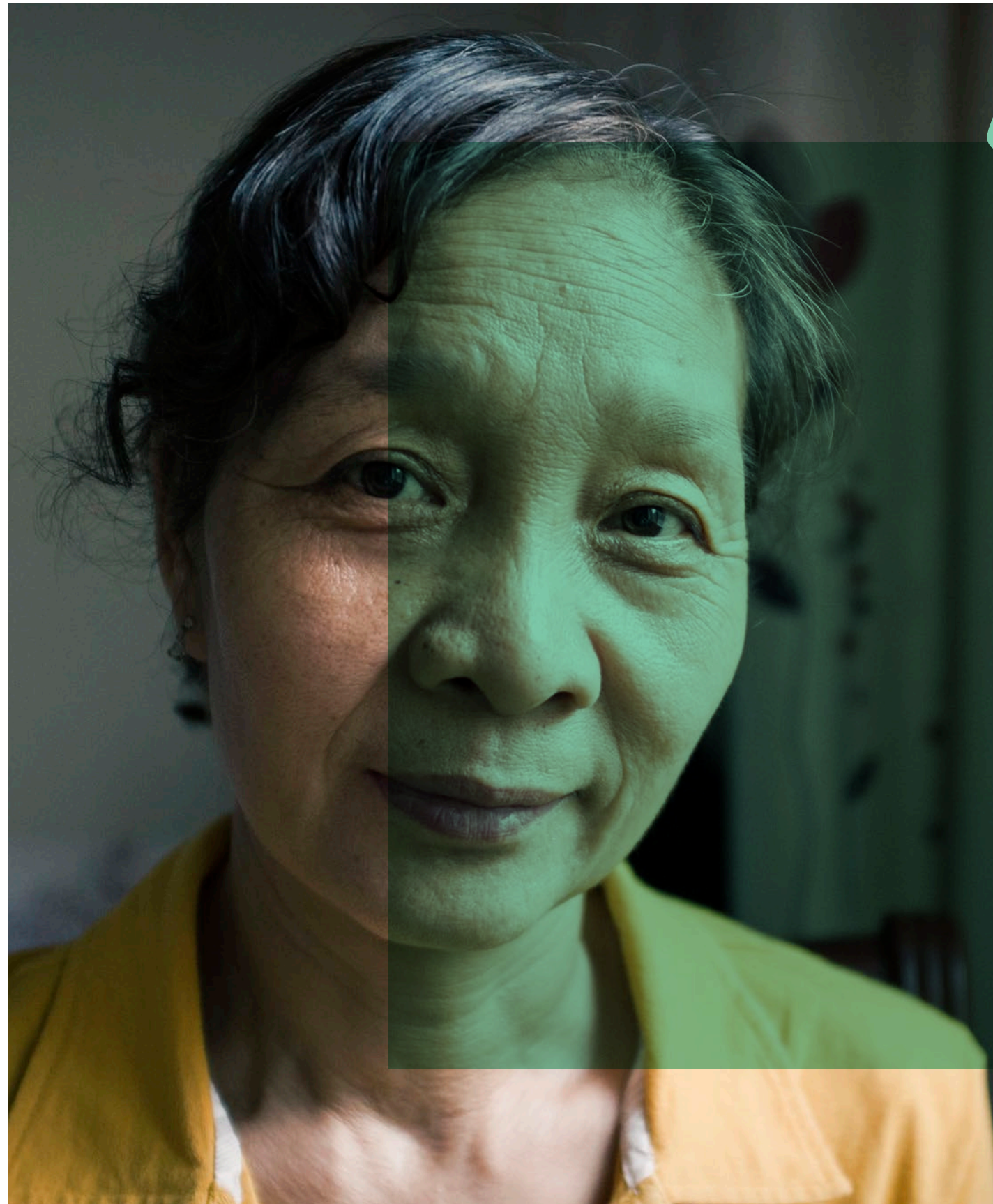
- Anna

Many patients feel alone and unsupported when they receive an IPF diagnosis. Even simply learning about and understanding IPF represents a challenge, especially when existing information may be inaccurate

or outdated. Further, access to patient and support partner peer support groups,⁴⁶ patient empowerment resources,⁴⁷ as well as palliative care, are critical to maintaining quality of life for patients and their loved ones.⁴⁷ Patient forums also provide the opportunity to address patient questions and better understand what additional education and information is needed through research and dialogue. Expanding access to such programs, as well as finding ways to bring these resources outside of the hospital setting or through mobile access, could be a way to lower barriers and broaden availability.

Equality of Care Across Provinces

Quality of care should not be determined by where you live. Some provinces are quicker to adopt policies that benefit patients with IPF, such as funding for anti-fibrotic treatment. To ensure quality of care throughout the country, progressive health care decisions and dedication of resources to IPF treatment need to be established everywhere. In addition, ILD centres need improved funding from the government to be able to attract and retain qualified staff in order to provide the best care. The disparities in care should illuminate the need to efficiently enact evidence-based and patient-centric policies that collectively improve the lives of patients across Canada.



“

Quality of care should not be determined by where you live.

Conclusion

While much progress has been made in the diagnosis and management of IPF, there are still ways to improve patient-centric care of this devastating disease in Canada. Data shows that access to health services differ across the country, which could contribute to variation in care, treatment and ultimately health outcomes. Health care policy decisions should be grounded in research, and our findings demonstrate that there is still an unmet need in improving the lives of people with IPF and other ILDs.

“ ***It's just building that awareness that when you're getting older if you're feeling that you're out of breath – it's not just getting old. You need to go to the doctor because it might be IPF. It might be something completely different, but don't just chalk it up to old age.*** ”

- Darren

Everyone with IPF deserves access to the right treatment and care. This report aims to highlight differences in health care access as well as unmet needs in IPF, in hopes of empowering patients and driving meaningful change in treatment guidelines, standard of care and healthcare policy and regulations.



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