Fibrosing interstitial lung diseases:

Evidence to support multidisciplinary / integrated care

Policy Brief

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Working document prepared in support of policy discussions related to PF-ILD in Canada.

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BACKGROUND

Individuals diagnosed with fibrosing interstitial lung diseases (f-ILDs) are faced with debilitating symptoms such as dyspnea, coughing, limited physical activity, and pronounced fatigue. More importantly, they are also faced with a new life-threatening diagnosis of a chronic, incurable, progressive condition.

This diagnosis together with these symptoms creates an understandable amount of psychological distress and suffering by patients and caregivers with a corresponding decrement in health-related quality of life. The negative psychosocial impact of the diagnosis and symptoms becomes more evident as the disease progresses.

Given the complexity of the f-ILDs and the physical, mental, social and emotional burden that it is associated with them, patients require multidisciplinary care to address the many domains of care that are required. These could include, and are not limited to:

- Patient care navigators and multidisciplinary team coordinator
- Physicians with specialties in pulmonology / respiratory care, radiology, rheumatology, gastroenterology, sleep dysfunction, thoracic surgery, and general practice.
- Nurses with specialized training in f-ILDs, oxygen, palliation, pulmonary care and associated medical specialty areas.
- Occupational therapists who can facilitate activities in daily life, including energy saving strategies and aids to daily living
- Physiotherapists who can assess physical ability and facilitate pulmonary rehabilitation with specific exercises
- Pharmacists who provide advice on drug dosage regimens and strategies for improving compliance and tolerance of drugs.
- Dietician to provide nutritional support for weight changes or help with side effects from drug therapy.
- Psychologists to determine the psychological impact of disease and treatment and provide support for services such as palliative care or connecting to others with the disease.

In many ways, the care model for f-ILDs can be considered similar to that of cancer, where nurse navigators and multidisciplinary care are increasingly viewed as appropriate service delivery model given the complexity of these diseases and the premature morbidity and mortality associated with them.[1]

One such model of care, developed by the Royal Brompton Hospital in the UK for both progressive and non-progressive ILD patients, is depicted in **Figure 1**. An assessment of depression and anxiety conducted in patients attending this centre demonstrated reductions in anxiety scores among patients, with an increase in depression, independent of disease severity.[2]

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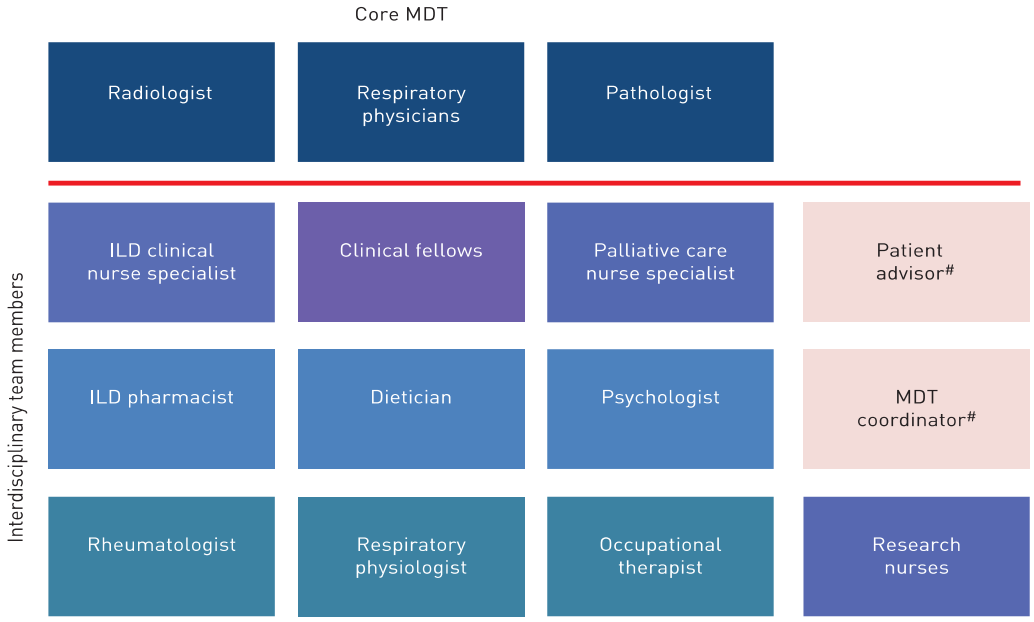
[1] Erin Walkinshaw, "Patient Navigators Becoming the Norm in Canada," *CMAJ : Canadian Medical Association Journal* 183, no. 15 (October 18, 2011): e1109–10, https://doi.org/10.1503/cmaj.109-3974.

[2] Wim A. Wuyts, Fedro A. Peccatori, and Anne-Marie Russell, "Patient-Centred Management in Idiopathic Pulmonary Fibrosis: Similar Themes in Three Communication Models," *European Respiratory Review: An Official Journal of the European Respiratory Society* 23, no. 132 (June 2014): 231–38, https://doi.org/10.1183/09059180.00001614.

Figure 1: The Brompton multidisciplinary model of care for interstitial lung disease



Exploring the evidence base

While current National and International guidelines for the diagnosis and management of ILD have taken a strong position on the need for multidisciplinary discussion among care specialists, as a means of improving the accuracy of diagnosis[3], they have not recommended any specific approaches for the organization of care across disciplines, including the use of care navigation or multidisciplinary specialized centres. This may be in part due to the health care system-specific nature of care organization but may also be due to an emerging evidence base. As stated by Ferrara[4]:

> *"There is, however, no clear definition of multidisciplinary care of IPF, and it is unclear which professions should be involved in the care of this group of patients. Furthermore, the possibility to build a multidisciplinary team is strictly dependent on local resources, so great variability can be expected across the same healthcare system and especially among different countries and cultures/continents"*

[3] Ganesh Raghu et al., "Diagnosis of Idiopathic Pulmonary Fibrosis. An Official ATS/ERS/JRS/ALAT Clinical Practice Guideline," *American Journal of Respiratory and Critical Care Medicine* 198, no. 5 (September 2018): e44–68, https://doi.org/10.1164/rccm.201807-1255st; Deborah Assayag et al., "Comprehensive Management of Fibrotic Interstitial Lung Diseases: A Canadian Thoracic Society Position Statement," *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine* 2, no. 4 (October 2, 2018): 234–43, https://doi.org/10.1080/24745332.2018.1503456; Kerri A. Johannson et al., "Evaluation of Patients with Fibrotic Interstitial Lung Disease: A Canadian Thoracic Society Position Statement," *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine* 1, no. 3 (July 3, 2017): 133–41, https://doi.org/10.1080/24745332.2017.1359056.

[4] Giovanni Ferrara et al., "Best Supportive Care for Idiopathic Pulmonary Fibrosis: Current Gaps and Future Directions," *European Respiratory Review* 27, no. 147 (March 31, 2018): 170076, https://doi.org/10.1183/16000617.0076-2017.

There are however, emerging pieces of evidence that describe improvements to the quality of life of patients[5], management of disease[6], reductions in emergency room visits[7], physician visits[8], physician workload[9], and improvements in palliative and end-of-life care[10] when a multidisciplinary service with care navigation is employed.

In Canada, there are currently 16 dedicated ILD centres each with different levels of funding, and different approaches to organization of care. Multidisciplinary approaches to management have also been employed in other countries, including Sweden, Australia, New Zealand although the extent to which multidisciplinary management has been adopted globally is difficult to ascertain as not all centres have published evaluations. Some centres have conducted some preliminary cost impact analyses[11] although no formal cost-effective analyses could be identified.

Policy Options and Next Steps for Canada

There appears to be further opportunities to identify optimal approaches to organizing care efficiently across Canada using a more consistent multidisciplinary approach. As such, logical next steps might be to understand different models of multidisciplinary care, their potential impact on patients and care delivery and the cost impact to health systems. This might be accomplished by the following steps:

1. Identify the minimal standards / components for integrated care of PF-ILD in Canada.
2. Conduct a horizon scan of current international and national approaches to integrated care and multidisciplinary management models of care that are applicable to ILD.
3. Conduct a formal cost-effectiveness analyses of these approaches to organizing care, from a Canadian health care payer perspective.

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[5] Wuyts, Peccatori, and Russell, "Patient-Centred Management in Idiopathic Pulmonary Fibrosis"; Nathan Hambly et al., "A Cross-Sectional Evaluation of the Idiopathic Pulmonary Fibrosis Patient Satisfaction and Quality of Life with a Care Coordinator," *Journal of Thoracic Disease* 11, no. 12 (December 2019): 5547–56, https://doi.org/10.21037/jtd.2019.11.41.

[6] Helen E. Jo et al., "Clinical Impact of the Interstitial Lung Disease Multidisciplinary Service," *Respirology (Carlton, Vic.)* 21, no. 8 (2016): 1438–44, https://doi.org/10.1111/resp.12850; S. S. Lok, "Interstitial Lung Disease Clinics for the Management of Idiopathic Pulmonary Fibrosis: A Potential Advantage to Patients. Greater Manchester Lung Fibrosis Consortium," *The Journal of Heart and Lung Transplantation: The Official Publication of the International Society for Heart Transplantation* 18, no. 9 (September 1999): 884–90, https://doi.org/10.1016/s1053-2498(99)00050-9; Gin Tsen Chai et al., "Impact of an Interstitial Lung Disease Service in the Diagnosis and Management of Interstitial Lung Disease in Singapore," *Singapore Medical Journal*, July 11, 2019, https://doi.org/10.11622/smedj.2019069.

[7] Meena Kalluri et al., "Beyond Idiopathic Pulmonary Fibrosis Diagnosis: Multidisciplinary Care With an Early Integrated Palliative Approach Is Associated With a Decrease in Acute Care Utilization and Hospital Deaths," *Journal of Pain and Symptom Management* 55, no. 2 (2018): 420–26, https://doi.org/10.1016/j.jpainsymman.2017.10.016.

[8] Chai et al., "Impact of an Interstitial Lung Disease Service in the Diagnosis and Management of Interstitial Lung Disease in Singapore."

[9] Hambly et al., "A Cross-Sectional Evaluation of the Idiopathic Pulmonary Fibrosis Patient Satisfaction and Quality of Life with a Care Coordinator."

[10] Kalluri et al., "Beyond Idiopathic Pulmonary Fibrosis Diagnosis."

[11] Hambly et al., "A Cross-Sectional Evaluation of the Idiopathic Pulmonary Fibrosis Patient Satisfaction and Quality of Life with a Care Coordinator."