THE PROBLEM

- Most common idiopathic interstitial lung disease (ILD): lead to progressive fibrosis (scarring) of the lungs
- Fatal, incurable and unpredictable disease trajectory: median survival of 2-3 years
- High symptom burden of breathlessness, cough and fatigue lead to poor quality of life, dying and death
- Early integrated palliative care is recommended but there are no practice guidelines for implementation
- Patients/caregivers express frustration at disease-centric care in the clinic & hospitals, with little attention to managing symptoms, improving quality of life or preparing for death & lack of community care support
- Health care professionals express frustration in managing these symptoms

- Only 14% referred to Palliative Care, 71% in their last month.
- Advance care planning occurred in 15-46%
- Unreported and uncontrolled symptoms at end of life lead to high rates of ER visits and hospitalizations, when imminent death is not recognized

- Majority of deaths occur in hospitals or ICU despite patient preferences for a home death.

QUOTES FROM THE MEDICAL LITERATURE:

“…the patient’s relatives didn’t drop their step for the symptoms (…) of his disease…”

“(…) his decision to go to hospital for advanced care planning is one of the things that he and I beat up on, sort of hearts me a bit today…” (Palliative Care Consultant)

QUOTES FROM OUR BEREAVED CAREGIVERS:

“You mean, he just went away? He didn’t suffer or anything?”

“…the scariness away. And, if they hadn’t had that conversation with us, (pause) I don’t know what would have happened. Knowing to get your bank affairs in order. And her being able to plan your funeral would really help.”

“I believe palliative care should be with you from when you’re diagnosed, saying, “You know what, you’re terminal but we’re going to help you live for as long as possible.” When you can enjoy every minute of your life. We don’t know, you could live two years, three years, you could live 6 months or a month. But if you could access somebody and say, “This is the disease I have. What steps can I do to stay in my home, be happy in my home and as my disease progresses, who can I have, whether it’s nursing staff, any access to anything that’s going to make my life at home easier for myself and my caregivers.”

HEALTH CARE UTILIZATION AT END OF LIFE & LOCATION OF DEATH BEFORE/ AFTER 2012

Table 1. Review of consecutive ILP deaths in our ILD clinic from 2009-2016, comparing the incidents of respiratory-related emergency room visits and hospitalizations during the last 6 months of life before (non-MDC) and after (MDC) institution of our collaborative care model in 2012.

<table>
<thead>
<tr>
<th>Location</th>
<th>Non-MDC (n=22)</th>
<th>MDC (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Room</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>21 (95%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>1 (5%)</td>
<td>1 (5%)</td>
<td>0</td>
</tr>
<tr>
<td>2 (10%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3 (15%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6 (27%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11 (50%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>15 (68%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>18 (82%)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2. Review of consecutive ILP deaths in our ILD clinic from 2009-2016, comparing the preferred place of care and death versus actual place of death before (non-MDC) and after (MDC) institution of our collaborative care model in 2012.

<table>
<thead>
<tr>
<th>Preference place of care</th>
<th>Location</th>
<th>Non-MDC (n=22)</th>
<th>MDC (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>21 (95%)</td>
<td>5 (100%)</td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>1 (5%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Not documented</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hospital/CU</td>
<td>0</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>Hospital/Palliative</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hospital/Palliative/CU</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>17 (77%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hospital/CU</td>
<td>5 (23%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hospital/Palliative</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hospital/Palliative/CU</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>12 (55%)</td>
<td>1 (100%)</td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>5 (23%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Not documented</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

In collaboration with Alberta’s SPOR support unit, we are undertaking an economic review of time spent in emergency rooms and hospitalizations.

- Reduced wait time to emergency care
- Hospital stays
- Less ER visits
- Shorter hospital stays

- Reduce the symptom burden
- Reduce the costs of care

Table 3. PRACTICAL TOOLS

- Advance Care Planning
- Breathlessness Assessment Tool
- Conceptual Framework of Dyspnea

QUOTES FROM THE MEDICAL LITERATURE:

“…the patient’s relatives didn’t drop their step for the symptoms (…) of his disease…”

“(…) his decision to go to hospital for advanced care planning is one of the things that he and I beat up on, sort of hearts me a bit today…” (Palliative Care Consultant)

ADVANCED CARE PLANNING

- Advance care planning and palliative care discussion happens in the clinic & hospital setting
- Sometimes, it’s a one-time thing
- It’s not part of the regular practice

- Patients may not understand the disease or not able to express their preferences
- It’s sometimes not enough

- Clear communication between the patient, caregivers and health care professionals

BREATHLESSNESS ASSESSMENT TOOL

- Measures the intensity and distress of breathlessness
- Helps identify patients who may benefit from palliative care

CONCEPTUAL FRAMEWORK OF DYSPNEA

- Represents the patient’s experience of breathlessness
- Includes physical, psychological, social dimensions

UNIQUE MODEL: To our knowledge, no other ILD Clinic in the world incorporates this approach to ILD care.

IMPACT & EARLY SPREAD:

- Alberta’s Renal Strategic Clinical Network has incorporated the breathlessness management strategies into its Conservative Kidney Management
- Edmonton Cardiologists are interested in adapting this model for end-stage heart failure
- The Canadian Pulmonary Fibrosis Foundation has incorporated early integrated palliative care for IFP as a recommendation in its first National Patient Charter, provided funding for a Clinic Nurse Coordinator and advocate for oxygen funding. http://hdp.ca/webcontent/2016/06/IPF-Patient-Charter.pdf

CHALLENGES:

- Incorporation of multiple interdisciplinary care teams & their potential impact on quality of life and quality of death & dying
- Multidisciplinary collaboration with integrated palliative approach in clinics and hospitals
- To provide creative and practical solutions to end of life issues in a Collaborative Care setting
- Patient satisfaction
- End-of-life care planning

MOVING FORWARD:

- Continue to publish our results and patient experiences
- In collaboration with Alberta’s SPOR support unit, we are undertaking an economic analysis of our care model
- Develop clinical practice tools and an evidence base to support their use
- Develop patient and caregiver education material
- Focus on education for primary care teams, allied health care supports, other specialists, palliative care specialists, medical residents & fellows, national and international colleagues.

WHAT DRIVES US – quote from a bereaved caregiver:

"Do you, or the administrators, or anyone who has not experienced this, truly understand how profound a gift this is to the dying and to their families?"

"Take heart in this work, it is meaningful and real and deeply important."