The INSPIRED COPD Outreach Program™

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Road to acute care in advanced COPD...

- Arrive at ED in crisis
- Prolonged length of stay

Discharged back to a broken system; off the radar until the next crisis...

Poor knowledge of disease; little or no support
Fear of being a burden to others
Symptoms worsen (denial, panic) - *no plan in place*
Dyspnea: not just a physical symptom

Impacts all aspects of life...

- Psychological
- Social
- Existential/spiritual

... magnified by contextual factors

- Vulnerable population
- Stigma
- End-of-life issues

Demands a more holistic approach to care...
Guiding principle...

The fundamental nature of illness is not medical; it is personal.

(Ira Byock, The Best Care Possible, 2012)
Gaps in COPD Care

- Communication
- Continuity
- Comprehensiveness

The single biggest problem in communication is the illusion that it has taken place.

George Bernard Shaw (1856-1950)
What patients have told us...
Advanced COPD: Most important elements of end of life care

<table>
<thead>
<tr>
<th>Patients n=118</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not being kept alive on a ventilator when there’s no meaningful hope of recovery</td>
<td>55%</td>
</tr>
<tr>
<td>Relief of physical symptoms</td>
<td>47%</td>
</tr>
<tr>
<td>An adequate plan of care &amp; health services after discharge</td>
<td>40%</td>
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</table>

**Needs assessment: according to Patients and Caregivers...**

Advanced COPD Care: Top 3 opportunities for Improvement

<table>
<thead>
<tr>
<th>CAREGIVERS N=37</th>
<th>PATIENTS N=37</th>
</tr>
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<tbody>
<tr>
<td>Know which doctor is the main doctor in charge of your family member’s care</td>
<td>Need to fix</td>
</tr>
<tr>
<td>Family member has relief of physical symptoms</td>
<td>That you not be a physical or emotional burden on your family</td>
</tr>
<tr>
<td>An adequate plan of care &amp; health services available to look after me at home after discharge</td>
<td>An adequate plan of care &amp; health services available to look after him/her at home after discharge</td>
</tr>
<tr>
<td>To have trust &amp; confidence in the doctors looking after you</td>
<td></td>
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Young, Allan, Simpson, Heyland & Rocker (2008)
INSPIRED COPD Outreach Program™
Implementing a Novel and Supportive Program of Individualized care for patients and families living with Respiratory Disease

- After in patient consent - contact 72 hours after discharge
- Four home visits: Self-management support: home-based education based on need (patient and family focused)
- Help line (business hours) - reach someone familiar
- Written action plans (per CTS*) for COPD exacerbations
  - In-home psychosocial/spiritual needs assessment and support, and advance care planning
- Follow up call monthly x 3 (initially) - now prn

*Canadian Thoracic Society
Program Objectives**

Improve patients’/families’ health-related quality of life &/or satisfaction with care:

- Improve support across care transitions: hospital/ED-to-home/EHS transfers
- Improve/support self-management & care planning
- Identify needs & arrange for appropriate supports
- Improve end-of-life care/support as disease worsens
- Reduce dependency on acute care facilities

** For those living with advanced COPD (MRC 4-5), able and motivated to self-manage, and not living in long-term care
Advance Care Planning (ACP)

- Assessment of *psychosocial/existential distress*
  - *support* as necessary

- Assessment of *coping*
  - *referrals* as needed

- **ACP** if/when the patient is ready
  - family member(s)/SDM included
  - PD completed if desired
    - uploaded to EMR; copies dispersed

- **Follow-up as needed**
  - no formal discharge from INSP

When people are given time with a compassionate listener, what is most important to them will surface in the conversation.
ACP as Collaborative Care

Key is *therapeutic relationship* *(partnering)*

- patient’s & caregiver’s “story” - the illness experience
- identifying fears/hopes *(negotiating ambiguity)*, needs *(being a resource)*

**ACP if/when patient is ready:**

- Shaped in accordance with fears/hopes/needs
- Collaborative, responsive care-planning *through to EOL*
- Support for PD completion; uploading PDs to EMR to improve timely access
- Documenting “goals of care” where appropriate
  - EHS “special patient program” *(SPP)*
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<tr>
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<tbody>
<tr>
<td>Decedents</td>
<td>n=84</td>
<td>n=96</td>
<td>n=129</td>
</tr>
<tr>
<td>LOS Days Median (IQ Range)</td>
<td>#2.0 (0-11)</td>
<td>7.0 (4-15)</td>
<td></td>
</tr>
<tr>
<td>ICU/IMCU use n (%)</td>
<td>6 (7%)*</td>
<td>20 (21%)</td>
<td></td>
</tr>
<tr>
<td>Available PDs n(%)</td>
<td>63/86 (74%)</td>
<td>10, 10%</td>
<td></td>
</tr>
<tr>
<td>Home Deaths n(%)</td>
<td>32/84 (38%)*</td>
<td>pending</td>
<td>11/129 (8.3%)</td>
</tr>
</tbody>
</table>

# p=0.001 (Mann Whitney U test); *p<0.0001 (Fishers exact test); PD : Personal Directive

Blackman et al CHEST 2016
# HRM ER, admission data, length of stay

6 month pre/post data (June 2015)

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<tr>
<th></th>
<th>Pre-INSPIRED</th>
<th>Post-INSPIRED</th>
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<tbody>
<tr>
<td></td>
<td>N=178</td>
<td>N=178</td>
</tr>
<tr>
<td></td>
<td>6 /12</td>
<td>6/12</td>
</tr>
<tr>
<td></td>
<td>(n, % reduction)</td>
<td>6 /12</td>
</tr>
<tr>
<td>ER visits</td>
<td>365</td>
<td>154</td>
</tr>
<tr>
<td>Admissions</td>
<td>210</td>
<td>79</td>
</tr>
<tr>
<td>Bed Days</td>
<td>2044</td>
<td>813</td>
</tr>
<tr>
<td></td>
<td>-211 (58%)</td>
<td>-131 (62%)</td>
</tr>
<tr>
<td></td>
<td>-1231 (60%)</td>
<td>$1,230,000</td>
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<tr>
<td></td>
<td></td>
<td>@$1000/day</td>
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Cost aversion at 6 months ≈ 2-3x annual program costs
What have we learned since 2010...

- **Relationships are central**
- **Respect for experience and uniqueness of patients and families**
- **Reciprocity - everyone benefits when we learn from each other**

“There were times when panic was setting in... It was a tremendous relief to know that I wasn't alone and that there was someone who cared that I could turn to... You handled Mum with such dignity and respect that I can never thank you enough!”

Daughters comments in a card after her mother’s death
Safe Use of Oxygen en route to Hospital for Patients with COPD

OXYGEN ALERT CARD

Name: ___________________________

I am at risk of type II respiratory failure with a raised CO₂ level.

Please use my ______% Venturi mask to achieve an oxygen saturation of _____ % to _____ % during exacerbations.

Local INSPIRED Audit: (N=89)
- high FiO₂ (too often)
- demanded corrective action

Information provided by:
INSPIRED COPD Outreach Program
Division of Respirology- QEII Health Sciences Center

Introduction
It is common for people who live with chronic obstructive pulmonary disease (COPD) to have trips by ambulance to the Emergency Department. The purpose of this brochure is to make any ambulance trip you have as safe as possible.

Why am I being given this card and mask?

Some COPD patients live with higher than normal levels of gas called “carbon dioxide” (CO₂) in their blood, a condition referred to as being a “CO₂ retainer.”

Rocker. Harms of over-oxygenation…CMAJ 2017