

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...

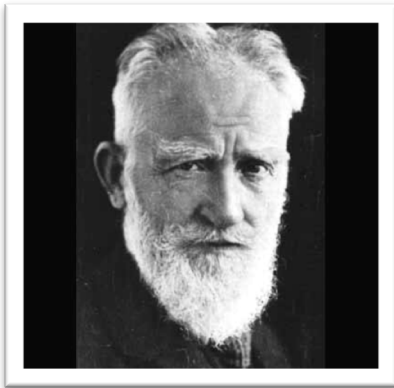
The fundamental nature of illness is not medical; it is personal.

(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

Patients n=118	%
Not being kept alive on a ventilator when there's no meaningful hope of recovery	55%
Relief of physical symptoms	47%
An adequate plan of care & health services after discharge	40%

Needs assessment: according to Patients and Caregivers...

Advanced COPD Care: Top 3 opportunities for Improvement

CAREGIVERS N=37		PATIENTS N=37
Know which doctor is the main doctor in charge of your family member's care	Need to fix 	That you not be a physical or emotional burden on your family
Family member has relief of physical symptoms		An adequate plan of care & health services available to look after me at home after discharge
An adequate plan of care & health services available to look after him/her at home after discharge		To have trust & confidence in the doctors looking after you

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)

INSPIRED decedent data


2016 Update of Rocker, Verma; Clin Invest Med 2014

	INSPIRED 2011-2015	Non- INSPIRED 2011-2013	NS database 2009-2011
Decedents	n=84	n=96	n=129
LOS Days Median (IQ Range)	#2.0 (0-11)	7.0 (4-15)	
ICU/IMCU use n (%)	6 (7%)*	20 (21%)	
Available PDs n(%)	63/86 (74%) completion rate* (July 2014-Sept 2015)	10, 10%	
Home Deaths n(%)	32/84 (38%)*	pending	11/129 (8.3%)

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

HRM ER, admission data, length of stay

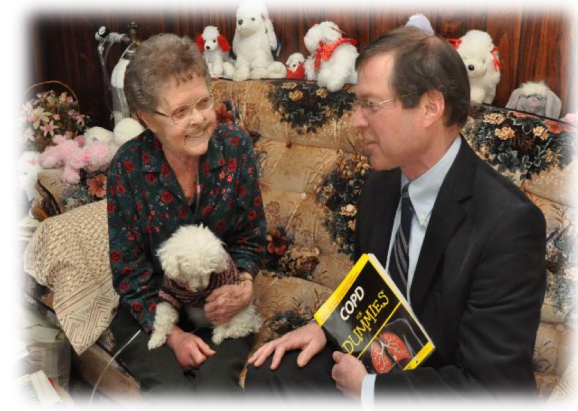
6 month pre/post data (June 2015)

	Pre-INSPIRED N=178	Post-INSPIRED N=178		
	6 /12	6/12	 6 /12 (n, % reduction)	Cost Aversion
ER visits	365	154	-211 (58%)	
Admissions	210	79	-131 (62%)	
Bed Days	2044	813	-1231 (60%)	\$1,230,000 @\$1000/day

Cost aversion at 6 months \approx 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

Information provided by:

INSPIRED COPD Outreach Program

Division of Respiriology- 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."

Local INSPIRED Audit: (N=89)

- high FiO₂ (too often)
- demanded corrective action

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.

Rocker. Harms of over-oxygenation...CMAJ 2017