COMMENTARY

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‘INSPIRED’ COPD Outreach Program™: Doing the Right Things Right

Abstract

The well-documented gaps between needed and provided care for patients and families living with chronic obstructive pulmonary disease (COPD) mandate changes to clinical practice. The multifaceted evidence-based INSPIRED COPD Outreach Program™ was first implemented in Halifax, Nova Scotia, Canada in 2010 (INSPIRED = Implementing a Novel and Supportive Program of Individualized care for patients and families living with Respiratory Disease) and undergoes ongoing evaluation. By enhancing patient confidence to manage their illness more effectively in their homes and communities, there has been a sustained and substantial reduction in facility-based care in comparison with patient care experience pre-INSPIRED. Sustaining and spreading a program recently designated a leading practice by Accreditation Canada, and especially modifying the program as new evidence emerges, requires integrating and modeling at the ‘bedside’ both evidence-based medicine (‘doing the right things’) and quality improvement (‘doing them right’). In Canada, where COPD care gaps are common, a new pan-Canadian INSPIRED-based quality improvement program is supporting multidisciplinary healthcare teams to bridge the chasm between evidence and practice by working together to ‘do the right things right’ in COPD care.

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Advanced chronic obstructive pulmonary disease (COPD) condemns patients and their families to an increasing cycle of repeated and more frequent hospital admissions. Usually this is in a context of an acute exacerbation, which patients have described as 'near-death experiences' [1]. A typical scenario may entail a patient missing the early warning signs of an impending infection and not having access to an 'action plan' that provides a course of antibiotics and corticosteroids according to agreed-upon changes in sputum production and dyspnea. When anxiety coupled with worsening dyspnea exceeds the ability of a patient and caregiver to cope at home, the patient arrives at the local emergency department (ED) in a worse physiological state than necessary. This may lead to hospitalization, possible use of non-invasive ventilation and even intubation or mechanical ventilation if hypercapnia and acute respiratory acidosis do not resolve in the ED. After a potentially lengthy hospital stay, the same patient is discharged home, often without plans for continued support, an early follow up appointment, or strategies to avoid similar events in the future. At home, and in the absence of such support, this cycle inevitably repeats itself and the ED revolving door spins again.

This scenario plays out for COPD patients at hospitals across Canada with few exceptions: COPD remains the primary reason for an admission to a Canadian acute care facility [2]. A nation-wide report card on COPD gave most Canadian provinces poor or failing grades for COPD care [3]. Healthcare systems fail, in part, because the traditional biomedical approach to COPD falls short of addressing the broader needs of those whose lives are so dramatically impacted by the disease. Beyond the substantial physical burdens of advancing COPD (worsening breathlessness and fatigue), patients and their family caregivers live with extensive unmet psychosocial and spiritual needs (anxiety, depression and existential distress) as well as poor quality of life and social isolation [4-9]. These psychosocial factors coupled with worsening dyspnea perpetuate the systemic revolving-door dependency seen most days in Canadian EDs.

The burden for patients living with advancing COPD is profound [10], as is the burden on the healthcare system. In Ontario, Canada's most populous province, the 12% of the population with a physician-made diagnosis of COPD accounts for 24% of hospital admissions, and a quarter of people aged 35 years and older are predicted to develop COPD [11]. According to recent estimates, Canada spends in excess of \$750-million on hospital admissions for COPD (excluding costs of routine care) [12]. With COPD set to become the third leading cause of death worldwide by 2020 [13] and given the obvious shortcomings of the current healthcare system

[14], the need to develop and implement more patient- and family-centred models of care is indisputable [7, 15].

Current COPD Care: Best Practices - The INSPIRED Approach

Gaps in COPD care across Canada are not necessarily the result of a failure to establish best evidence; more often than not, they represent failures in widespread adoption and implementation of existing evidence. At the Queen Elizabeth II Health Sciences Centre (QEII HSC) in Halifax, Nova Scotia in 2010, existing evidence-based practice was adopted and adapted to become the INSPIRED COPD Outreach Program™. INSPIRED, which is an acronym for "Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease" has been a core-funded program at the QEII HSC since 2012. The elements of the program have been described in detail in an earlier manuscript [16] and the key underlying concepts are summarized in Table 1. Patient sample and recent results are shown in Figure 1 and Tables 2-4.

Summary of Key Results:

Compared to six months pre-INSPIRED for n=131 patients who completed the full program and survived for at least 6 months afterwards there were:

- 60% fewer ED visits (from 282 to 113)
- 63% fewer hospital admissions (154 to 57) and the number of patients admitted twice or more in six months decreased from 27 to 5
- 62% fewer days in hospital (1573 to 596 days), where the 977 fewer bed days equated to an estimated indirect cost 'saving' of \$977,000 (more than three times the annual INSPIRED operating costs). These costs are based on an inpatient admission at \$1000 per day(12) and QEII HSC operating costs for part-time team members (including registered respiratory therapists, a spiritual care practitioner and a coordinator/evaluator).

For the same cohort, these reductions continued for an additional subset of 93 patients in a 12-month pre-post comparison: compared to 12 months pre-INSPIRED, 52% fewer ED visits, 55% fewer hospital admissions and 61% fewer hospital days were observed (Table 2)

Interviews with 18 patients post-INSPIRED showed patients felt less anxious, more confident of their ability to manage their symptoms and more willing to discuss goals of care, including advance care planning (ACP) (Table 3)

Highly significant improvements occurred in the Care Transition Measure© pre-post ($n=27$, $p<0.001$), a measure of self-efficacy (data not shown); pre-post INSPIRED changes in quality of life (Chronic Respiratory Questionnaire), anxiety/depression (Hospital Anxiety and Depression Scale) and hope (Herth Hope Index) did not reach significance

For patients who died after enrollment in our program, there was significantly lower length of stay during the final admission and greater availability of personal directives (PDs) to clinical teams versus patients who died from COPD outside of our program (Table 4)

In 2014, the program was recognized as a leading practice by Accreditation Canada. The issue at stake now is how to scale up and spread the concepts of this program (and other evidence-based practices in COPD care) to foster similar positive outcomes for patients, their families and the healthcare system more widely.

Limitations

A 'before and after intervention' design does not control for temporal confounding. The most powerful predictor of future behavior for patients with COPD is past behavior, and many investigators apply the 30-day readmission rate as a standard for COPD care. It was felt that a longer follow up period more realistically reflects the real situation for these patients. Moreover, Table 3 shows the increasing facility usage as the index admission approaches. Were the normal trends to apply to our patients, the substantial fall in patient reliance on facility-based care after our program would not have been

TABLE 1. INSPIRED COPD Outreach Program: components and key elements

- ✓ Hospital-to-home care, early discharge, transition support
- ✓ Self-management support: in-home education based on need (patient- and family-focused)
- ✓ Written action plans (as per Canadian Thoracic Society guidelines) for COPD exacerbations
- ✓ Individualized action plans for "Dyspnea Crises"
- ✓ In-home psychosocial and spiritual needs assessment and support
- ✓ In-home goals of care discussion (GCD) including advance care planning facilitation (personal directives, GCD/Allow Natural Death/Do Not Resuscitate orders)
- ✓ Needs-based follow-up via telephone and home visits
- ✓ Holistic care needs assessment and liaison with appropriate care teams/resources
- ✓ Contact telephone number, reliable coverage
- ✓ Non-abandonment

observed (i.e., the opposite would have been seen) and the significance of this reduction was supported by sentiments expressed by patients during post-INSPIRED patient interviews.

Working Towards Making Best Practice Common Practice

Adoption of new and more effective healthcare practices occurs at a snail's pace in clinical practice, taking on average 17 years according to a widely referenced Institute of Medicine report [17]. Despite attention garnered from professional journals and medical conferences, new knowledge remains inconsistently applied [17] and clinicians face a number of barriers that may undermine best practice adoption and implementation [18, 19]. Clinician adherence to clinical guidelines often relies on system-level improvements such as acquisition of new

FIGURE 1. Flowchart of eligible patients for undertaking analysis of the INSPIRED COPD Outreach Program

resources, facilities and enhanced staff support [20, 21]. There's no 'magic bullet' when it comes to improving clinical practice [22] and the same holds true for healthcare quality improvement [23]. What is lacking is a coherent strategy to spread awareness of new, more effective practice, as well as mechanisms by which to improve the quality of the healthcare system at-large; in other words, a strategy for 'doing the right things right.' [24]

'Doing the right things right' is an approach to closing the 'know-do' and 'evidence-practice' gap that links evidence-based medicine (EBM) and clinical quality improvement (QI) [24]. Glasziou, Ogrinc and Goodman (2011) summarize EBM as "doing the right things", essentially actions informed by the best-available evidence from the clinical knowledge base, whereas QI is "doing things right" or making sure that intended actions are carried out thoroughly, efficiently and reliably.

TABLE 2. Six- and 12-months results pre/post-INSPIRED for ED visits, hospital admissions and length of stay (LOS) (n=93)*

	Pre-INSPIRED			I N S P I R E D	Post-INSPIRED				
	12 months total	6-12 months	0-6 months		0-6 months	6-12 months	0-12 months total	% change 6 months	% change 12 months
ED visits	266	71	195		54	73	127	-72%	-52%
Admissions	136	21	115		24	37	61	-79%	-55%
LOS (days)	1333	202	1131		235	284	519	-79%	-61%

*To provide a homogeneous group for this analysis we excluded patients who did not see the spiritual care practitioner, did not have an ED visit or admission in the year prior to INSPIRED, those who died, or went to a nursing home or long-term care facility within 6-months of starting INSPIRED, and those who live outside the catchment.

TABLE 3. How INSPIRED helps: top five patient-reported reasons, with illustrative quotes, post-INSPIRED

1. Action plan and prescriptions on-hand or on-order
2. Accessible education, information and resources
3. Improved outcomes relevant to patient and family, for example, less breathlessness, more stamina, recognition and management of COPD, use of medications
4. Someone to call for guidance and support; and not feeling so alone and abandoned
5. Feeling cared for by caring, reliable, knowledgeable staff using effective communication

"I used to feel so alone with my illness. Now people check on me and I know there's someone I can call if I'm having a problem. I would feel so isolated, frustrated and apprehensive without this support."

INSPIRED patient

"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!"

INSPIRED family caregiver

TABLE 4. 2011-2013 Results for INSPIRED (n=20) and non-INSPIRED (n=96) decedents' ICU/IMCU use and hospital length of stay (LOS) as well as availability to clinical teams of personal directives (PDs) and palliative care involvement

	INSPIRED	non-INSPIRED
Decedents	n=20*	n=96
LOS median (interquartile range)	2.5 (0-6) [†]	7.0 (4-15)
ICU/IMCU use, n (%)	4 (20%)	20 (21%)
ICU/IMCU LOS (mean)	3	8.9
Available PDs, n (%)	11 (55%) [‡]	10 (10%)
Palliative care involved, n (%)	13 (65%)	38 (40%)

*INSPIRED patients who died at home = 6/20 (30%)

[†] p = 0.001 (Mann Whitney U test)

[‡] p < 0.0001 (Fishers exact test)

FIGURE 2. Combining evidence-based medicine and quality improvement to 'do the right things right' [24]

bly. In combination, EBM and QI provide the basis for 'doing the right things right' (Figure 2) [24].

The Need: A Fundamental Shift in Care

In the face of modern realities and fiscal pressures, we are continuing to move toward the impending and inevitable failure and potential collapse of our current healthcare model. Three certainties stand out as especially problematic: 1) the increasing incidence of chronic disease; 2) the absurdity of a continued reliance on models of care that were designed to help patients manage acute illness but not chronic disease; and, 3) a growing need to focus on effective QI concurrently with EBM implementation.

1) Rates of chronic disease are increasing:

- In 2010, chronic diseases accounted for 89% of all deaths in Canada [25].
- In 2011, more than half (56%) of all Canadians aged 12 years or older reported living with at least one chronic condition [26].
- By 2020, chronic disease will account for 60% of all diseases globally [27].
- Accounting for indirect factors beyond healthcare, e.g., loss of workforce productivity, chronic disease in Canada is estimated to cost a total of \$190-billion annually [28] - almost as much as the country's entire 2013 annual healthcare costs [29].

- A small proportion (5%) of patients with complex needs often account for as much as two-thirds of healthcare use and costs [30, 31] Healthcare use in Canada is highly hospital-based and the care experience for patients and families is often reported as suboptimal [32].

2) Current models of care were not designed to help patients manage chronic disease:

- The physician- and hospital-centric model of healthcare in Canada, designed to treat acute illness over brief periods of time, is inevitably flawed by its inability to prevent disease or help patients more effectively manage chronic conditions.
- Without an adequate alternative, many patients with longer-term care needs find themselves stranded within a hospital's walls—too sick to be discharged but not acutely ill enough to continue to benefit from the interventions a hospital can offer.
- Care provided within hospitals is vastly more expensive than care delivered in the community or on an outpatient basis. At best, chronically ill patients in hospitals are blocking access for those with acute care needs; at worst, these chronically ill patients are receiving a level of care that is inconsistent with their wishes and needs, while being unnecessarily exposed to additional health risks.

3) There is a growing need to focus on effective QI concurrently with EBM implementation:

Effective linkages between EBM and QI could help to achieve essential shifts in care, including:

- narrowing the gap between best practice and common practice;
- reliance on home-based care over facility-based care;
- movement from provider-, disease- and encounter-driven care to patient-centred and relationship-based approaches; and,
- focusing on value over a preoccupation with volume.

The shaping of lives outside of the doctor's office and the need to more fully understand the broader experience of people living with chronic illness (as captured by two salient quotes in Table 5) underpinned our earlier program of research that informed the INSPIRED COPD Outreach Program. The next section describes how we will scale up and spread this patient-centred approach on a pan-Canadian basis.

TABLE 5. Thoughts on the need for more person-centered health-care

Saskatoon-based health policy expert, Steven Lewis has argued:

Healthcare does not face the grim prospect of collapse due to the loss of customers. It can and does keep the customers it fails, because there is no other place to go. Most of the failures are not catastrophic. They are, rather, the failures of disrespect, inconvenience, poor communication and fragmentation. Put most simply, the system has been designed for the providers more than for the users of services, and it shows.¹

Raymond J. Baxter of Kaiser Permanente expressed a similar sentiment:

[W]e are all starting to realize the limits of what clinical medicine, even prevention-focused medicine can do. We can give information to people, we can prompt them... but we still see that what shapes peoples' lives is outside of the doctor's office.²

¹ Lewis, S. (2009). "Patient-Centered Care: An Introduction to What It Is and How to Achieve It. A Discussion Paper for the Saskatchewan Ministry of Health. http://www.southeastlin.on.ca/uploadedFiles/Public_Community/Board_of_Directors/Board_Committee/Collaborative_Governance_and_Community_Engagement/Ppatient-Centred-Care%20Steven%20Lewis%202009.pdf"

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² Baxter, R.J. as quoted by Kaiser Permanente. (2013). "Forum for Healthy Behavior Change: Connecting Health Care to Healthy Choices." Available from: http://kpihp.org/wp-content/uploads/2013/10/hbc_report/#total-health-framework

The Approach: A Pan-Canadian QI Program for Spreading the INSPIRED approach to COPD Care

Quality Improvement Collaboratives (QICs) are increasingly relied upon as an "efficient approach to improving provider practices and patient outcomes through the dissemination of evidence-based practices." [33] With collaborative assistance

from the Canadian Foundation for Healthcare Improvement (CFHI) – a pan-Canadian, federally funded, not-for-profit organization dedicated to accelerating healthcare improvement – CFHI has launched a 12-month QIC focused on helping multidisciplinary healthcare teams from across Canada. The QIC has the following aims:

- improve patient and family caregiver education, self-management and self-efficacy, particularly for patients with advanced COPD;
- improve continuity of care across the hospital-to-home transition;
- enhance home-based care;
- facilitate effective advance care planning; and,
- reduce reliance on costly hospital-based care; including ED visits, hospital admissions and lengths of stay [16].

CFHI, with support from its industry sponsor, Boehringer Ingelheim (Canada) Ltd., is supporting a number of teams to assess underlying healthcare problems using evidence, design innovative solutions, implement the changes required and evaluate the differences they make. These collaborations will involve faculty who are skilled in EBM and QI and who will focus on a range of evidence-based practices including and beyond INSPIRED. One example of such collaboration is the "Living Well with COPD" program [34, 35]. Conceived and developed by the Montreal Chest Institute, a part of the McGill University Health Centre, it is an example of a self-management program. It has resulted in a positive impact on the health of patients and has been associated with a significant reduction in the frequency of hospitalizations and ED visits. Another example is the "LiveWell Chronic Disease Management (CDM) Program," [36] which is offered to individuals and their families living with a chronic disease such as COPD, heart disease, sleep apnea, asthma, arthritis and other chronic conditions. Based in the Saskatoon Health Region, the LiveWell CDM Program follows best evidence guidelines and includes education, exercise and self-management support. The program works closely with the patient and family physician to optimize management and improve the quality of life for patients and their families: assist patients to take control of their COPD, manage their symptoms and decrease complications, help avoid ED visits and hospital admissions, and design and implement a plan of action for each patient.

Incorporating EBM and QI curricula, the INSPIRED QIC builds on the key elements that were identified in a recent systematic review [33]. According to the review, the most commonly used components of QICs are: multidisciplinary teams, in-person learning, between-session 'plan-do-study-act' (PDSA) cycles and data collection for QI. The review defined

TABLE 6. Principles, supports and key quality domains for the 12-month *INSPIRED Approaches to COPD: Improving Care and Creating Value Collaborative*Principles

- 'All teach, all learn' adult-learning style approach
- All aiming to spread and sustain
- By working together, we can 'leapfrog' common barriers and make best practices common ("If you want to go fast, go alone; if you want to go far, go together")
- Committed to a "just-in-time" (responsive and developmental) design and delivery
- Self-reflective, iterative design recognizing that the benefits we aim to achieve should be greater than or equal to the burden of getting there
- Incorporate patient and family caregiver perspectives as well as case-based examples in all content delivery

Supports

- Webinars – delivered monthly with a 90-day follow up post-collaborative
- Teleconferences – scheduled 'office hours' with faculty-coaches as well as affinity calls on topics of shared interest
- Webinar exercises, e.g., live polls and chats – undertaken regularly to capture trends; e.g., in readiness for EBM implementation and QI maturity
- Worksheets and progress updates – take-home exercises (e.g., measurement framework, stakeholder mapping, driver diagrams, PDSA cycles, implementation barriers and facilitators) and project charters
- E-surveys - to understand participant satisfaction with collaborative components and gains in participant learning/knowledge and skills/capacities over time
- Optional self-study, readings and resources – as needed to allow additional learning
- Online learning platform – to facilitate knowledge management and discussions (via discussion boards)
- Coaching – regularly scheduled 'office hours' with faculty-coaches via teleconference as well as opportunities for in-person support
- In-person workshop – one two-day workshop at the collaborative mid-point
- Regional site visits – a series of site visits where teams/organizations are convened geographically (e.g., Atlantic, Central/Quebec-Ontario, West) to facilitate whole-of-system discussions on spread, scale up and policy implications

Quality Improvement Domains & Indicators

- Patient- and family-centred care; e.g., patient and family carer experience, development of an individualized action plan, confidence in symptom management and completing a personal directive (as part of advance care planning) if the patient desires
- Coordination; e.g., % of patients contacted within 48-72 hours post-discharge to arrange the first home visit with a COPD educator, patient self-efficacy over the hospital to home transition (Care Transitions Measure™)
- Efficiency; e.g., frequency of ED visits, hospital admissions, acute inpatient length of stay (including in intensive or intermediate care unit)
- Appropriateness; e.g., use of standard order sets and care pathways, consistent use of best practice (Canadian Thoracic Society) guidelines

QICs as "organized, structured group learning initiatives" involving:

- a focus on improving specific provider practices or patient outcomes;
- training from experts in a particular EBM practice and/or the QI methods;
- a model for improvement, with measurable targets, data collection and feedback;
- multidisciplinary teams representing different levels of the organization and involved in active improvement processes in which they implement "small tests of change" or engaged in PDSA activities; and.
- structured activities and opportunities for learning and cross-site communication (e.g., in-person learning sessions, phone calls, email listservs) [33].

The "INSPIRED Approaches to COPD: Improving Care and Creating Value" program will distinguish itself from existing QICs by incorporating a highly interactive and comprehensive suite of supports (Table 6) to teams (19 in total from the 10 provinces), while also tracking shared progress toward common improvement aims in patient- and family-centred care, coordination, efficiency and effectiveness. The CFHI Improvement Model™ is the framework that provides the primary guidance for the INSPIRED collaborative design and delivery. Complementary frameworks, including the 'Doing the Right Things Right' framework [24] and Wagner's Chronic Care Model [37] provide additional direction.

The INSPIRED program will help develop a 'learning laboratory' focused on shared clinical teams' experiences of implementing EBM to improve care and outcomes for patients

and families living with COPD, while also improving teams' skills and capability to do QI. The program relies on experts who can comment on how EBM and QI are applied in actual clinical settings. The program will address organization- and provider-level implementation barriers (e.g., provider concerns, leadership support, logistics, structural challenges, etc.), foster local ownership of the implementation, evaluation and improvement processes, re-enforce a culture of continuous learning and create a supportive clinical network to facilitate team-to-team sharing and learning from successes and challenges.

Conclusion

In Canada, where COPD care gaps are common, a new pan-Canadian quality improvement program is enabling multidisciplinary healthcare teams to bridge the chasm between evidence and practice by working towards 'doing the right things right' in COPD care. Focusing on the successful INSPIRED COPD Outreach Program™, the INSPIRED collaborative will be an exemplar of how to accelerate the pace of healthcare improvement by encouraging effective practice to be adopted as common practice. By integrating a focus on team-based improvements and organizational support of the complementary disciplines of EBM and QI, we should achieve the aim of 'doing the right things right.'

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Pilot phase of INSPIRED:

Hybrid-funding including an arms-length contribution from GlaxoSmithKline. After 2012, INSPIRED became a core program and is now sustained by funding from Capital Health in Halifax. The INSPIRED collaborative is delivered by the Canadian Foundation for Healthcare Improvement with additional funding support from Boehringer Ingelheim (Canada) Ltd.

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