

The INSPIRED COPD outreach program™

An INSPIRED palliative approach to care

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in Canada and the leading cause of adult emergency department visits and hospitalizations for chronic illness.¹ While COPD cannot be cured, individuals with advanced COPD benefit from an integrated palliative approach to care. This High Impact Practice showcases how the INSPIRED Program was enhanced to provide social supports and advance care planning throughout an individual's illness trajectory.

BACKGROUND

Individuals living with advanced COPD follow a chronic disease trajectory; that includes long periods of slowly declining health punctuated by frequent and repeated cycles of emergency visits, hospital admission and discharge home. The traditional approach of intensive episodic care fails both patients and families. Advanced COPD is a very physically, socially, and emotionally isolating illness. Patients and families may gradually become cut off from friends, family and even the healthcare system as symptoms worsen.²

Despite the high morbidity and mortality associated with advanced COPD, many patients and their families do not receive a palliative approach to care due to lack of communication, understanding and sharing of patients' wishes and preferences for care and death. Families are often hastily prepared for the possibility of death, only to have their loved ones rally and survive. Eventually, death does occur and may be perceived as sudden and unexpected by relatives. Throughout this rollercoaster experience, patients and their families receive little emotional and social support.³

Faced with this evidence in 2010, a team at the Queen Elizabeth Health Sciences Centre in Halifax developed and introduced the INSPIRED (Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease) COPD Outreach Program™. Through a series of qualitative and mixed methods approaches, the development team came to understand the extent of the physical, psychosocial and existential distress experienced by both patients living with advanced COPD and their families. The INSPIRED model embraces a palliative

approach to care and provides strategies to facilitate conversations about a patient's wishes, supports for individual care preferences and family caregiver needs and discussions about places of care and location of death.

DEVELOPMENT

In 2010, a respirologist (Dr. Graeme Rocker), a respiratory therapist (Joanne Michaud-Young) and a spiritual care practitioner and advance care planning facilitator (Dr. Catherine Simpson) at the QEII Health Sciences Centre in Halifax designed, implemented and tested a home care program for patients discharged from hospital after a flare-up of advanced COPD. The impetus for this initiative was based in part on research published in 2008 that ranked the top needs of patients who had been admitted with COPD exacerbation.^{2,4} These findings identified "having an adequate plan of care and health services to look after me at home after discharge" as a top priority. This critical need underpinned the design of the program.

Program Goal and Objectives

The goal was to provide support to enable patients and families to better manage their advanced COPD at home, decrease their sense of isolation and distress, and reduce their dependency on the emergency department and inpatient health care services. The target population included those living with advanced COPD (MRC dyspnea scale 4-5), who were able and motivated to self-manage and who were not living in long-term care. The focus of the program was to improve patients and their families' health-related quality of life and/or their satisfaction with care.

Specific objectives included:

- improving support across care transitions: hospital/ED-to-home/ EHS transfers;
- improving/supporting self-management and care planning;
- identifying needs and arranging for appropriate supports;
- improving end-of-life care/support as disease worsens; and
- · reducing dependency on acute care facilities.

The pilot program provided individualized, coordinated, and proactive care for patients with advanced COPD, including inhome self-management education, a personalized written action plan, psychosocial/spiritual support, phone access, and monthly phone follow-up. Care was provided through home visits and calls by a team composed of a respiratory therapist who also acted as a coordinator and patient navigator, a spiritual care practitioner and a respirologist. The team also coordinated with existing primary care services and programs.

Integrating a Palliative Approach to Care

To ensure a palliative approach to care in a system that lacks the capacity to support management of advanced COPD in the community, a strong education component was incorporated into the program. During the pilot stage and through two visits by a certified respiratory educator (CRE), self-management support and education was provided with liaison/referral to allied health. Individualized action plans for both acute exacerbations and, where necessary, for dyspnea crises were also created. Following the educational visits, a spiritual care provider (with advance care planning facilitation skills) provided psychosocial and spiritual support, discussed advance care planning (ACP) and guided completion of personal directives.

Post-pilot, the team expanded (in 2018) to include a nurse practitioner (CRE trained), palliative care consultant (family physician) and social worker to further support the palliative

approach to care embedded in INSPIRED. Recognizing increasing frailty and difficulty for patients to physically access primary health care, the role of a CRE credentialled nurse practitioner in providing medication, action plans and follow up has proven to be both cost effective and patient centred.

A therapeutic partnership relationship is created with patients and their families through a holistic approach to care and embedding an advanced care facilitator in the team. Health care team members gain an understanding of the importance of providing opportunities for patients and their families to share their stories, including their emotional journey with the illness. During these conversations, patients and family caregivers can identify their fears, hopes and needs. If and when a patient is ready, a written advance care plan and personal directive is created and included as a core part of the treatment plan and uploaded to the medical record. A copy of the written assessment and treatment plan is sent to the patient's primary care physician to ensure continuity and coordination of care.

The advance care planning process is a continuous, multi-step process of communication and actions that includes:

- assessment of psychosocial/existential distress and arrangement support as necessary;
- assessment of coping and coordination of referrals and information as needed;
- discussion of end-of-life goals and preferences;
- facilitation of a written ACP;
- facilitation of personal directives;
- communication of personal directives (e.g., uploaded to EMR and copies distributed); and
- understanding and inclusion of end-of-life goals and preferences into treatment plans (follow-up as needed—no formal discharge from program).

Elements of the INSPIRED COPD outreach program™

In Hospital

- → obtain consent
- → optimize treatments
- → link with staff
- → develop and review action plan
- → plan for early follow up after discharge (~72 hours)



In Community

- → provide self-management support with in-home education based on needs of patient and family
- → make home visits (4) every 2 weeks
- write action plans for COPD exacerbations and individualized action plans for dyspnea crises
- → conduct in-home psychological/spiritual needs assessment and support
- → discuss in-home goals of care (ACP facilitation)
- → follow up via visits and telephone hotline
- → ensure non-abandonment



IMPLEMENTATION

The program was introduced in Halifax, Nova Scotia in 2010-11 as an evidence-and community-based holistic approach to addressing gaps in advanced COPD care. Since its inception the model and implementation strategies have evolved to meet different jurisdictional contexts and the local needs of individual patients and providers.

Education and Training

The crucial strategy behind the successful implementation of the program is having local teams take ownership of their specific needs for training and engagement. For example, CRE credentialling is now required for all respiratory therapists involved in the NS Health Authority (NSHA) Central Zone program and where the program is being implemented as part of provincial scale-up plans.

Through a dedicated and related educational fund, additional training has been provided without cost to individuals seeking and needing CRE credentialling, including a nurse practitioner involved with the program. INSPIRED also provides educational sessions within primary care/community health teams and for the pulmonary rehabilitation program.

Through support for education, the spiritual care provider in Halifax Central Zone has attended the Canadian Association for Spiritual Care conference for focused education on how to offer effective psycho-spiritual support. Patients and families in the community benefit from the ACP expertise through community outreach education on ACP and personal directives. Supporting ACP education and training is an essential component of INSPIRED and underpins the high rates of completion of personal directives by patients so care can be provided that is consistent with their goals and wishes.

Resources

Financial resources to support team members in new roles depends on team composition and whether they have other responsibilities. Funds are needed for educational programs (e.g., CRE courses and exams, Advance Care Planning Facilitation). Where no new money is available, some organizations may need to re-allocate existing personnel to offset new cost constraints.

Based on the success of the INSPIRED program, the CHFI Collaborative Initiative provided start-up funding of \$50,000 to 19 participating teams from across 10 provinces to spread this program. To sustain this spread, there will be a need for executive support in local health organizations to advance proposals for provincial health funding. The demonstrated success of this program so far will help to build the business case for implementation in other communities.

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OUTCOMES

Since its inception, the program has improved the experience of individuals living with advanced COPD and reduced dependence on hospital-based services through reduced admissions and emergency department visits.

Evaluation of Halifax Pilot

In 2014, the outcomes of the pilot program were published, showing reductions of 50–70% in facility reliance and a total cost aversion over 6 months of \$1.23 million. This amounted to 2-3 times the program costs. The mixed methods evaluation process indicated highly positive patient and family feedback and new confidence in self-management and sustained optimism. Some of the quantitative results are outlined below.

Indicator	Results	Period
ER visits	↓ 58%	12 mo.
Hospital admissions	↓ 62%	12 mo.
Bed days	↓60%	12 mo.
Home deaths	38% compared with Nova Scotia average of 8.3%	Over 4 yr.
Personal directives completed	74% completion rate	Over 1 yr.

Enhancements to Indicators

When the INSPIRED program was spread through the CHFI Collaborative Initiative, there was an opportunity for the teams to develop consensus on broad, evidence-based indicators that were flexible enough to be relevant for local contexts. These included:

- · patient and family centredness;
- coordination;
- · efficiency; and
- · appropriateness.

In 2016, CFHI conducted a formal evaluation of the 19 participating teams using a mixed-methods summative approach relying on collated quantitative data, team documents, and surveys sent to core members. Results showed the INSPIRED Quality Improvement Collaborative enabled teams across Canada to adapt and implement a new COPD care model for high users of health care with rapid improvements to work practices, cultural change and skill sets, and at a relatively low cost. More details of this study can be found at the CFHI website: www.cfhi-fcass.ca/WhatWeDo/inspired-approaches-to-copd-scale.

SUCCESS FACTORS

The INSPIRED COPD Outreach Program™ and its adaptation within a pan-Canadian quality improvement collaborative proved to be feasible, effective and created significant efficiencies. This innovative program has shown that addressing unmet needs of patients and families in a more holistic and community-based model with an integrated palliative approach to care can help to reduce reliance on acute care services and increase patients' quality of life. This approach clearly results in better care, improved system outcomes and value for money. Implementation of this program requires strong leadership and commitment, but can quickly show cost-effectiveness. INSPIRED offers an evidence-based, relatively resource-light approach.

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

FUTURE OPPORTUNITIES

The INSPIRED COPD Outreach Program™ continues to be funded locally in the NSHA Central Zone and business plans for extended funding have been submitted to the provincial health authority. The team is continuing to partner with existing stakeholders such as the Emergency Heath Services Special Patient Program, the Provincial Palliative Care Program, and the Nova Scotia Green Sleeve—a provincial palliative care initiative to consistently inform health care providers where patients' goals and wishes can be found. They are exploring the potential for collaboration with, for example, 811 and other community-based outreach. Expanding access to diagnostic spirometry in rural areas and exploring the potential of an expansion from a COPD-based service to a broader symptom-based service (for breathlessness) are currently underway.

Various jurisdictions across Canada have secured long-term program funding for the INSPIRED COPD Outreach Program Given the opportunities for cost aversion with this program, there is a strong likelihood that this program will be supported in the future through provincial and territorial health departments.

The program has received international attention with interest from Australia, the United States, New Zealand and Europe. The Center to Advance Palliative Care is advocating for an INSPIRED approach to COPD in the United States.

RESOURCES

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- 3. Landers A, Wiseman R, Pitama S, Beckert L. Severe COPD and the transition to a palliative approach, Breathe. 2017 Dec; 13(4):310-316.
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The CHCA would like to extend a special thank you to following contributors:

Graeme Rocker, MA, MHSc, DM, FRCP, FRCPC, Respirologist, QEII Health Sciences Centre-Provincial Medical Director of the "INSPIRED COPD Outreach Program", QEII Health Sciences Centre and Professor of Medicine, Dalhousie University

Catherine Simpson, MA, MDiv, PhD, INSPIRED co-founder and advance care planning facilitator, Halifax, Nova Scotia



The Canadian Home Care Association (CHCA) is dedicated to ensuring the availability of accessible, responsive home care to enable people to safely stay in their homes with dignity, independence and quality of life. Our vision is an integrated health and social care system that provides seamless patient- and family-centred care that is accessible, accountable, evidence-informed, integrated and sustainable.