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What is This?
Reducing emergency room utilization in end-stage COPD – feasible or fantasy?

Robert Horton

Abstract
The emergency room (ER) is a common point of care transition for patients with end-stage chronic obstructive pulmonary disease. Many of these patients present to the ER because of dyspnea, anxiety and caregiver burden that is precipitated by fragmented and reactive systems of care that fail to meet their needs. This article uses an illustrative case report to outline the challenges patients and caregivers face and presents the core elements of care required to improve quality of care and decrease reliance on the ER.

Keywords
COPD, emergency room, palliative care, dyspnea, supportive care

Introduction
Fred was a 78-year-old veteran living with end-stage chronic obstructive pulmonary disease (COPD). He lived with his wife three blocks away from the university teaching hospital. At baseline, he was confined to his bed or chair by dyspnea, required assistance with bathing and dressing, and was tethered to an oxygen tank. He was aware of the advanced progressive nature of his illness and had no desire for intubation/ventilation. He would become markedly more dyspneic with minimal exertion, and this was often associated with significant panic and anxiety. At times, he could abort his dyspnea crisis by using his rescue inhaler, resting and calming himself; but with increasing frequency, things would only be resolved by a frantic call to 911 by his wife, an ensuing trip to the emergency room (ER), followed by a flurry of medical students, residents, x-rays, blood gases, aerosols, steroids and antibiotics. He would often settle overnight in the ER and return home, prescriptions in hand, with a presumptive diagnosis of acute exacerbation of COPD (AECOPD) only to repeat the entire process a few days or weeks later.

As an attending physician with a home hospice program, I often receive referrals from the ER for patients with “end-stage” COPD. The typical patient is much like Fred, housebound due to severe dyspnea, dependent on caregivers for one or more activities of daily living (ADLs) and orphaned by a primary care practice that does not see him at home. He presents repeatedly to the ER because of a dyspnea crisis, with patient or caregiver anxiety and/or failure of his support system. The usual diagnosis written on the ER sheet is AECOPD, though the true precipitators of such presentations are more complex. The consult for these mislabeled “frequent flyers” is usually signed by an ER resident at the behest of ER nursing staff. “Please see this elderly man with end-stage COPD for ongoing support and symptom management” (subtext, “this man has been in our ER more than five times in the past month, please do something to keep this from happening”).

I am often disheartened by the unspoken expectations behind such requests. In my experience, keeping such patients out of the ER is fraught with difficulty and in some situations; success would meet the benchmark for beatification. The care of patients with end-stage COPD has been noted to be fragmented, episodic and reactive, with difficulty defining boundaries between care provided by primary care physicians, specialist physicians and hospice services.

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Most patients who are housebound have significant primary care needs but lack access to primary care services and physician visits at home. In the United States, AECOPD results in over 1.5 million ER visits annually. Many patients with end-stage disease and comfort-focused goals of care would prefer to avoid the ER but without access to a reliable alternative to ER care, that is, care that proactively addresses precipitating factors and manages crisis symptoms in the home, orphaned housebound patients are often habituated to relying on the ER. They are caught in a dyspnea–anxiety cycle culminating in reactively focused care through a revolving door of ER presentation, hospital admission and subsequent discharge back to a system that initially failed to meet their needs.

The ER is a common point of care transition for patients with end-stage disease. A recent retrospective evaluation of ER utilization in the last months of life for 4158 patients over age 65 who died while enrolled in a longitudinal health and retirement study revealed that more than half of patients visited the ER in the 30 days before death, with almost 1 in 10 visiting the ER on the last day of life. More than 40% made multiple visits the last 6 months of life. Of those who visited the ER in their last 30 days, 77% were hospitalized and more than 2/3 of those (68%) subsequently died in hospital. Most patients were elderly (average age 83), suffered a high burden of chronic illness, including cancer (31%) and lung disease (25%) and were dependent on caregivers for three or more ADLs. In contrast, patients who enrolled in hospice programs rarely visited the ER in the last month of life.

Much has been written about the need for alternative models of care to address the needs of patients and caregivers who are living with advanced COPD. If we aim to keep patients like Fred out of the ER, we must embrace models that provide a timely and accessible alternative system of care that is focused on meeting the needs of patients and their caregivers. Patients and families have prioritized these needs which include not being kept alive on life support when there is little hope for meaningful recovery, obtaining adequate symptom relief, having adequate access to care and health services after discharge, having trust and confidence in attending physicians and minimizing the burden placed on caregivers.

Given that patients and caregivers have repeatedly given voice to their unmet needs, it is incumbent upon us to build comprehensive, integrated programs of care that can deliver. Though implementation of disease-specific self-management strategies has shown some efficacy at reducing ER utilization and hospital admissions, augmentation of usual care by à la carte addition of these programs in the absence of a comprehensive integrated approach that includes robust physician support, a detailed care plan that explicitly outlines the goals of care and establishes a plan to deal with crisis symptoms in the home falls short of the kind of care that patients and families deserve.

Referral to hospice may be seen by some as the most efficient way of addressing unmet needs in end-stage COPD. Hospice programs are welcomed and valued by patients and caregivers as a means of helping to address gaps in care and can offer expertise in symptom management and patient/family-centered care, home-based care and advanced care planning; but to date, there is little evidence that hospice programs in isolation impact utilization of acute care services in the setting of COPD. Many hospice programs evolved out of providing intensively focused care to terminally ill cancer patients who typically experience a rapid decline from good health to death and thus may have difficulty adapting their service model, skill set and limited resources to address the chronic and sustained needs of a population of patients with significant symptom burden, who though at risk of dying, often have an unpredictable disease trajectory and fluctuating goals of care. As hospice palliative care services refine and adapt their programs to address the needs of those with chronic non-cancer illness, it is recognized that the needs of this population cannot be addressed by hospice in isolation. Primary care and specialist respirology services, though often less frequently involved in provision of home-based care, management of refractory symptoms and transitioning to end-of-life care, have valuable skills and resources to optimize treatment of underlying disease, treat acute complications, provide education about disease self-management and monitor and encourage compliance with prescribed treatment regimens.

The ideal care framework for advanced COPD combines the strongest elements of each discipline; systematically identifying patients with COPD who are at risk of poor outcomes and implementing an individualized and flexible approach that provides collaborative multidisciplinary care and implements interventions that address the need for education about disease progression and prognosis, emotional...
and practical support for caregivers, treatments that integrate chronic disease management strategies with palliation of progressive symptoms, counseling about advanced care planning and end-of-life decision making, and assistance with practical interventions aimed meeting patient and family goals as illness progresses and death nears.

The impact of dyspnea crisis in end-stage COPD has until recently received little attention. Dyspnea crisis has been defined by a working group of the American Thoracic Society as a sustained and severe resting discomfort in patients with advanced—often life-limiting—that over whelms the patient and caregiver’s ability to achieve symptom relief. Dyspnea crisis is one of many factors that lead to intensive utilization of the ER near the end of life. Any care plan that aims to reduce reliance on the ER must have a specific individualized action plan to deal with it. Other key components necessary to meet this goal are outlined in Figure 1.

The patient-centered medical home (PCMH) appears to be the most promising framework on which to develop an integrated approach to the care of patients with end-stage COPD. This comprehensive, multidisciplinary team-based approach to care builds upon Wagner’s Chronic Care Model (CCM) and seeks to transform care of chronic illness from a reactive approach to one of anticipatory planned care that encourages patients and their caregivers to work actively with the health care team through a system of care that emphasizes proactive management through delivery system redesign, optimization of clinical information systems, decision support for clinicians and promotion of patient self-management. Programs that deliver two or more of the key components of the CCM in the setting of COPD have been shown to reduce hospitalization and ER utilization.

Fromer has stated that “chronic care for COPD must reach beyond the primary care practice into patients lives in the community on one hand, and into practices’ linkages with specialty, ER and inpatient care on the other.” One example of an innovative program that embodies this philosophy is the INSPIRED program in Halifax, NS, Canada. An acronym for Implementing a Novel and Supportive Program of Individualized Care for Patients and Families Living with Respiratory Disease, INSPIRED, brings together a multiprofessional team of health care workers to address the needs of patients and families who are living with advanced COPD. Eligible patients are identified during hospital admission and enrolled in a structured program upon discharge that provides dedicated case management by a skilled respiratory therapist who acts as a care coordinator across care transitions. The care coordinator has robust support from a respirologist with interest and expertise in community-based care in advanced COPD. Patients are enrolled during their hospital admission and followed longitudinally in their homes after discharge. Emphasis is placed on providing home-based education and support around disease self-management and advanced care planning, help with navigating the local health care system and gaining access to services that support patients at home, improving communication with other health care providers, providing individualized action plans for AECOPD and dyspnea crisis and providing access to after-hours advice and home-based follow-up assessment and treatments to deal with changes in symptoms. INSPIRED has forged strong links with local primary care teams, home-based nursing services and hospice programs to improve the integration of care for patients living with advanced COPD in the community. Preliminary analysis of the program at 6 months for an initial cohort of 46 patients who completed the program revealed that INSPIRED is associated with a 74% reduction in ER visits and an 80% reduction in hospital admissions (Graeme Rocker, personal communication, August 10, 2012).
Patient selection is a crucial determinant to the success of any intervention that aims to improve outcomes in the setting of advanced COPD. It is important that we effectively target interventions to those patients in whom avoidance of the ER is most appropriate and most likely to succeed. There are many patients with advanced COPD who are well served by emergent care, thus we need to ensure that such care is not uniformly discouraged.

Care plans that emphasize avoidance of the ER are most appropriate for patients who:

- are at the end stage of disease with symptoms unresponsive further disease modifying therapy;
- are housebound due to dyspnea, frailty or multiple comorbidities;
- have clearly defined goals of care that are focused on treatments aimed at maintaining comfort, quality of life and with a preference for treatments to be administered at home; and
- do not wish to be intubated in the event of progressive respiratory failure or to have attempted resuscitation in the event of sudden death.

Even with the best available supports and a detailed plan, avoiding the ER may be impossible for some patients who are overwhelmed by panic and conditioned by years of reliance on the ER when in crisis. In a recent evaluation of home-based palliative care for patients with advanced COPD, we found that despite access to medical support that included after-hours physician response, some patients continued to turn repeatedly to the ER to deal with any escalation in symptoms.3

Recently, Nova Scotia Emergency Health Services developed a ground-breaking extended care paramedic (ECP) program that provides on-site physician-directed paramedic-based emergency and nonemergency care at the bedside as an alternative to reflex transfer to the ER for nursing home patients with urgent medical issues and conservative goals of care. A team of Advanced Care Paramedics with specialized training tailored to the needs of nursing home patients, including geriatric assessment and management and other skills such as suturing, attend to urgent and non-urgent care of patients at the bedside. The program also includes response to appropriate nonemergency calls as well as regularly scheduled visits for patients with chronic health conditions. The ECP program was developed as a core element of an overall “care by design” quality improvement initiative aimed at revitalizing and optimizing care delivery to residents of long-term care facilities. Interim analysis of the first 599 calls revealed that 73% of patients were managed on-site without the need for transfer to the ER.22 This innovative approach to urgent care targeted to a vulnerable patient population is an example of systemic change that if widely implemented could lead to success in the setting of end-stage COPD.

Revisiting Fred, he and his wife were subsequently enrolled in a palliative care program that had strong linkage to his local specialist respirology service and offered coordinated case management, robust home support, caregiver respite, regular home visits by frontline nurses, hospice nurses and physicians. Goals of care were clearly identified and documented on an in-home medical chart. He received home-based education for self-management of his dyspnea crisis by a skilled respiratory therapist, periodic follow-up in his home by his attending respirologist and an individualized action plan for dyspnea crisis that utilized sublingual fentanyl in addition to his usual medications (Appendix A). Over the subsequent 14 months, he was seen at home on multiple occasions by different members of a broad multidisciplinary team. With the addition of a flexible support network and individualized treatment plan, he was able to avoid the ER in the last year of his life and in his final 2 weeks, was admitted directly from home to a hospital-based palliative care unit in order to manage symptoms of terminal delirium and dyspnea. Fred’s case might be considered to be a rare victory in comparison to the majority of patients for whom, at the end, the only option seems to be ‘a rush to the ER’.23 Developing new models of care to meet the needs of this population has its challenges, and we have just begun to identify the best practices that meet their needs. COPD will become the third leading overall cause of death from illness in the next decade. We need to meet this challenge and must be mindful that there is much we can and have to do in order to improve the care that we provide.
Appendix A

**Action Plan for Shortness of Breath (dyspnea)**

Created for: [Patient Name +/- ID number]
Date: [Insert date plan was created]

A good morning routine to minimize shortness of breath first thing in the morning:

- Take 5 breaths from your incentive spirometer (slowly open airways). Use 4 times daily as needed
- Huffing/cough to clear your airway. Do your pursed-lip breathing if this helps
- Use your blue puffer, gray inhaler, and purple puffer as directed (don’t forget to use your aerosphere and rinse after your purple puffer). Your blue puffer may be used as often as every four hours as needed
- Take your long-acting opioid medication [insert name, dose] as directed

When more short of breath than usual:

- With a slight increase in your shortness of breath at rest (not a result of infection or “crisis”), you can use an extra [insert dose] of your opioid syrup every 1–2 hours as needed for ‘breakthrough’ dyspnea between your regular doses
- For predictable shortness of breath with activity (i.e. getting up, dressed, bathed), time these activities ½ hour after your puffers and opioid dosing

For “crisis” shortness of breath (not due to infection) comes on suddenly, catches you by surprise:

- Use your hand-held fan and do pursed-lip breathing. Try recovery positions
- Use 2 puffs of your blue puffer (with aerosphere) or try your nebule instead
- Adjust oxygen flow from ___ to ___ litres/min for 10–15 mins only then re-adjust back to ___
- Take your anti-anxiety medication [insert name, dose], 1 tablet under the tongue
- If not settling, use Fentanyl, 12.5 µg from pre-prepared syringe. Let liquid dissolve under the tongue. Repeat in 10 mins if still not settling and call 911

*For flare ups of COPD* with increased sputum volume and mucky colour, use antibiotics and prednisone as per your COPD action plan.

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