Palliative care for respiratory disease: An education model of care

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Abstract
That palliative care improves quality of life for seriously ill patients and their families is well known – but how can healthcare providers ensure that the palliative needs of all patients are being assessed and addressed? A growing number of curricula in core palliative care practices have been developed to ensure that clinicians from all specialties and disciplines have the necessary training to manage pain and symptoms and discuss care goals with patients and families. Through broad-based training in core palliative care skills, combined with referral to specialty palliative care for high-need patients, providers can improve quality of life for their patients with respiratory disease.

Keywords
Palliative care, pain management, symptom management, goals of care, palliative care training, primary palliative care

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The case for primary palliative care
As teams on the front lines of healthcare delivery know only too well, serious respiratory illness impacts more than just lung function. All facets of a patient’s life can suffer – including ability to perform activities of daily living, social relationships, mental health and family finances – when a patient is diagnosed with serious illness. Consider the fictionalized case of Javier, a 75-year-old retired firefighter.

Javier quit smoking after he was diagnosed with Chronic Obstructive Pulmonary Disease (COPD) 8 years ago. He lives at home with his wife Selena, and their son and two grandchildren live nearby. Javier had loved to play cards with friends and attend his grandchildren’s football games, but as his COPD worsened he has become more and more fatigued. After several hospitalizations – including one on which he was placed on a ventilator – Javier is now afraid to leave the house for fear that his dyspnoea will be triggered by the exertion. He sleeps fitfully, is losing weight, and has withdrawn even from Selena, who is herself exhausted with the task of caring for Javier and anxious over their future.

Despite being on an optimal COPD treatment regimen, as Javier’s disease worsens, he is in and out of the hospital more frequently, calling 911 whenever he gets so anxious that he can’t catch his breath. On one of these hospitalizations he is diagnosed with pneumonia. Javier ultimately dies, intubated and in the ICU, after a difficult and prolonged hospitalization. Selena experiences prolonged terrible grief and guilt because she insisted on calling the ambulance over Javier’s repeated objections, and because when he died in the middle of the night he was alone at the hospital.

While it is not possible to protect patients from all consequences of a serious illness, clinicians can and should work to relieve suffering for patients and their families in addition to providing disease treatment.

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Javier’s case study is taken from an online course built to provide clinicians with core palliative care skills necessary to improve quality of life for seriously ill patients. In recognition of widespread gaps in undergraduate- and graduate-level medical and nursing education in the management of common and distressing symptoms and communication needs of the seriously ill, a growing number of programmes are becoming available to train clinicians in core palliative care practices.

The role of palliative care for the seriously ill

Also known as palliative medicine, palliative care is specialized medical care for people living with serious illnesses. It is focused on providing patients with relief from the symptoms and stress of a serious illness, and the goal is to improve quality of life for both the patient and the family. Palliative care is provided by an interdisciplinary team of specialists who work with a patient’s other clinicians to provide an extra layer of support. Eligibility for palliative care is based on need (and not prognosis). It is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment.

A large and growing body of evidence testifies to palliative care outcomes that include improved patient satisfaction with care, decreased symptom burden and in some cases better survival.1–3 As a result, palliative care has also been shown to create cost savings for health systems due to decreased hospital utilization.4–6

In response to these data and to myriad patient, family and clinician testimonials of the benefits of palliative care, provider organizations including hospitals, home-visiting programmes, clinics and long-term care facilities are increasingly embedding specialty-trained palliative care clinicians into their clinical staff. In the United States in 2015, 4.8% of all hospital admissions (on average) received palliative care services, and more than 90% of large (more than 300 bed) hospitals nationwide reported having palliative care services.7

While the services of these specialty palliative care programmes are appropriate for patients whose needs are most complex, the ever-growing number of seriously ill patients warrants a three-tiered approach as can be seen in Table 1.

| Low palliative need | Medium palliative need | High palliative need |
|---------------------|------------------------|---------------------|
| Usual care with treating clinicians trained in effective communication and symptom management. Specialty palliative care consult(s) as needed | Treating clinicians regularly collaborate with specialty palliative care team, especially for intractable symptoms or complex family communications | Ongoing and active management by specialty palliative care team. The degree of palliative care team responsibility depends on patient need and treating clinician preference |

In recognition of the value of palliative care for all seriously ill patients, many provider organizations have begun to train clinicians from all specialties – including primary care, pulmonology, oncology, cardiology and others – in core palliative care skills.

Primary palliative care education

Primary palliative care education equips clinicians from all care settings and specialties with the skills needed to improve quality of life for seriously ill patients and their families. These include pain and symptom management to ease suffering and reduce crises that lead to hospitalization, communication skills to enable conversations about diagnosis, prognosis and care planning, coordination and communication across settings and over time, and methods for assessing and addressing burden on family caregivers.

Widespread training in fundamental palliative care skills allows for a coordinated approach to meeting patient needs. A patient such as Javier may see his pulmonologist for ongoing disease treatment and monitoring, and his pulmonary team is equipped to

Figure 1. Palliative care along the disease trajectory.
address his palliative care needs as they develop or change over time – including referral for consult by the specialist palliative care team should the need arise. Through this model, patients receive supportive care from the primary treating team with whom they have a trusting long-term relationship. For patients with respiratory disease, such care may include dyspnoea treatment using proven self-care models such as INSPIRED-COPD, and interventions including handheld fans, low-dose opioids, conversations about what matters most to patients and families as the disease progresses, and regular assessment of caregiver stress to identify and secure any needed clinical or social support services (food delivery, transportation, respite care, etc.).

**Primary palliative care training programmes**

Health systems are increasingly investing in palliative care training for their frontline clinical teams, whether they are working in the hospital, in long-term care facilities, in the office or clinic or in patient’s homes. Clinicians and organizations who undertake widespread primary palliative care education now have access to a variety of mid-career training opportunities. These programmes exist in a number of formats and on a spectrum of intensity, ranging from one-time online continuing education activities to year-long graduate-level certificate programmes. Specialist-level palliative care is by definition a team-based approach to care, combining the expertise of physicians, nurses, social workers and chaplains to provide comprehensive support for the complex needs of seriously ill patients and their families. As such, similarly, primary palliative care education is appropriate for primary care and specialist clinicians from all disciplines.

Javier’s story is borrowed from one such interdisciplinary training programme. The US-based Center to Advance Palliative Care (CAPC), an organization that provides technical assistance and training to expand access to palliative care services, has developed an online curriculum for primary palliative care education. Clinicians who take CAPC courses have access to training in symptom management – including in-depth instruction in safe and appropriate use of opioids for seriously ill patients – as well as communication skills, care coordination and family caregiver support. Curriculum users may also choose courses in palliative care techniques for specific patient populations, including patients with chronic obstructive pulmonary disease (COPD), dementia and heart failure.

Launched in 2015, CAPC’s online curriculum was developed to adhere to the principles of accessibility, interdisciplinary and cross-specialty relevance and peer-reviewed quality content. To remove training barriers for busy clinicians, courses were developed such that they can be taken on a computer, tablet or mobile phone and provide continuing education credits required by physicians, nurses, social workers, case managers, and licensed professional counselors to maintain licensure. Each course was co-developed by an interdisciplinary team of experts, to ensure that the training reflects the role of each member of the care team in supporting patients’ palliative care needs. Course users who complete an entire unit of training (e.g. symptom management) receive a certificate of CAPC Designation to attest to their investment in improving their care of the seriously ill. Clinicians may cite their CAPC Designation on their résumé, or employers may require that specific clinician groups receive Designation as part of a standard onboarding or maintenance of privileges process.

Each CAPC course uses a story such as Javier’s to illustrate the impact that palliative care principles and practices can have upon quality of life for patients and families. Because CAPC courses are self-study (a necessity for scaleable, low-cost training), case studies are interspersed with interactive quiz questions in order to apply and reinforce didactic content. To date, the curriculum has been used to train nearly 20,000 clinicians from all 50 US states and from countries around the world. The average CAPC course user has taken 6.2 courses, each between 30 and 70 minutes in length, indicating that clinicians find value in the course content and continue to pursue more training after their first exposure.

**Clinician satisfaction**

This engagement with the CAPC curriculum suggests that despite time pressures and competing priorities, palliative care concepts resonate with clinicians – which should come as no surprise. Palliative care principles speak directly to the motivating force that leads clinicians to healthcare in the first place. Empowering patients to live life as fully as possible is the *raison d’être* of the healthcare professional, and the knowledge that a seriously ill patient is suffering can occasion feelings of helplessness and moral distress on the part of clinicians.
Fundamental to the palliative approach to care is the principle that there are always methods for relief of suffering for patients, whether that means best disease treatment, management of symptoms refractory to treatment or empowering patient decision-making through conversations about priorities for continuing care (and most likely all three). Indeed, palliative care has been shown to improve quantitative quality of life measures for patients and caregivers and to reduce depression and anxiety. Palliative care is as appropriate for patients upon diagnosis of a serious illness as it is for the patient at the end of life, which is of particular significance for patients with chronic respiratory diseases who may live with serious illness over years or even decades.

Clinicians with an adequate grounding in core palliative care principles and practices are equipped to identify and address palliative care needs – throughout the disease trajectory and in parallel with disease-directed treatment – and to improve quality of life for the duration of the illness. In this sense, palliative care training can be seen as a tool for empowering not only patients and families, but also the clinicians who devote their lives to helping them.

**Putting primary palliative care skills to work**

For hospitals, clinician groups and other provider organizations that integrate palliative care needs assessments and interventions as the standard of quality care for the seriously ill, clinician training is a necessary first step. Additional steps can and should be taken by organizations to systematize and routinize the use of palliative care clinical practices. These include developing a process for identifying patients who have palliative care needs, risk stratification, embedding palliative care assessment into clinician workflows, matching services to the needs identified on assessment, enabling consistent and standardized documentation of the domains of palliative care (e.g. symptom burden, depression, cognition, functional status, family caregiver burden and needs, etc.) in the electronic health record (EHR) and developing protocols for referral to specialty palliative care when needed.

The impact of these systems change measures can be illustrated using the example of advance care planning. In order for clinicians to achieve the skills and comfort level required to have conversations with seriously ill patients about their values and their care priorities, appropriate communication skills training is needed. However, if a conversation occurs and the clinician has no standardized way to document the patient’s priorities in the EHR, or to call up the documentation at the next patient visit, the information in the care plan cannot be used. If symptom assessment is not part of the routine checklist for patient encounters, it may be forgotten, resulting in a hospitalization for a dyspnoea crisis that could have been averted. Investment in systems change, including EHR support and workflow re-engineering, is therefore critical to embedding palliative care philosophy and practices in the clinical culture of an organization.

**Before and after: The impact of primary palliative care**

Once palliative care training and implementation have occurred, how does the experience of the patient and family – and of their clinicians – change? For a patient like Javier who has a progressive and ultimately fatal condition such as COPD – and who is receiving standard of care disease treatment – what more can clinicians do? Had Javier received primary palliative care from his pulmonologist, his experience could have been different.

Although she knew the conversation might be difficult, Javier’s physician also knew the importance of future planning and initiated a discussion. She learned that while they understood that COPD is eventually fatal and that Javier would get worse over time, Javier and Selena had anxiety about what their lives would be like as the disease progressed. They were both terrified that Javier would suffocate to death at home. She talked with them about what they could anticipate in terms of symptom burden, especially the likelihood of recurrent dyspnoea crises, and what supports could help them manage these episodes at home. Javier told her that he hates being in the hospital and hopes never to come back again – so if she can help them manage when he becomes more short of breath, then he would be much happier to stay home instead of panicking and calling 911.

Javier’s pulmonology team has had training in the INSPIRED COPD model, which creates a checklist of actions patients and families can take at home when dyspnea worsens. After counseling Javier and Selena on the risks and benefits (and especially on the importance of taking his laxative every day to prevent constipation), Javier’s physician prescribes a handheld fan and very low-dose opioids to use as needed to manage his dyspnea and minimize the risk of exacerbations. Javier is instructed to take a dose before venturing outside the house or doing something that predictably makes him short of breath, such as taking a shower.
He is able resume visits with his grandchildren and even makes it to a few football games. His card game moves to Javier’s home and happens once a week.

After several months of stability and good quality of life, Javier develops an upper respiratory infection after a visit from his grandkids and becomes very dyspneic. The very low dose of morphine Javier has been taking is not enough to relieve his distress, so Selena calls his doctor. Based on his clear decision not to return to the hospital as long as he can remain comfortable at home, his physician titrates his morphine and instructs Selena to give it to Javier on a scheduled, instead of an as-needed, basis until he becomes comfortable in bed. She calls the hospice team in to help Selena and Javier manage at home. Over the next few weeks, there is time for his friends and family to visit and express their love and gratitude to Javier. Their priest visits the home and gives the sacrament of the sick, a ritual of great importance to Selena. Javier dies peacefully at home with his family at his side. Selena is proud that she was able to take care of Javier at home as he wanted, that he didn’t suffer, and that ‘we were all together with him when he died’.

Training in core palliative care skills provides a framework for all clinicians to use to support all facets of life for seriously ill patients and their families. In so doing, palliative care skills and knowledge reconnect clinicians to the roots of the healing profession. Given the demonstrated impact that palliative care has on patient outcomes and patient and family experience, palliative care competency should be considered fundamental to the practice of medicine and all healthcare. Until such time as palliative care skills are embedded in undergraduate and graduate training curricula, mid-career palliative care education is not only feasible, but also a critically important undertaking.

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