

End-of-life care in chronic obstructive pulmonary disease

By learning which of our patients have the highest risk of death, we can properly time end-of-life discussions and develop a patient-centred approach to the end of life.

ABSTRACT: End-of-life care is a poorly understood and often neglected aspect of the management of patients with chronic obstructive pulmonary disease (COPD). Knowing what to say to patients and when to say it allows physicians to help patients and their families cope with COPD. Younger patients with mild or preclinical COPD should be counseled to stop smoking. For them, diseases other than COPD pose the greatest risk. Older patients with more severe COPD are more likely to die of a COPD-related illness, and need counseling more specific to COPD. Almost all COPD patients who require some form of mechanical ventilation can be successfully weaned from ventilation, but most have a poor post-ICU prognosis. However, half do survive for longer than 1 year after ventilation is introduced. All patients with COPD require reassurance that they will receive competent and compassionate care throughout their illness.

Patients with chronic obstructive pulmonary disease (COPD) face many hurdles during their illness. Having the diagnosis made in the first place can be a challenge because access to spirometry may be difficult. Once diagnosed, access to medication, rehabilitation, and community support is often limited. The day-to-day struggle of coping with advanced COPD makes planning for end-of-life care a low priority. Physicians and caregivers can help patients with COPD who are approaching the end of life by knowing the answers to a number of questions, including: What do patients of COPD die of? At what stage should physicians and other caregivers start the end-of-life discussion? Is it possible to place patients in prognostic categories that predict a high risk of death? Which patients should be offered mechanical ventilation for acute exacerbations of COPD? What specific measures can be taken to palliate the symptoms associated with near-death COPD?

Causes of death

Studies show the causes of death in COPD patients vary with disease severity and length of follow-up. The Lung Health Study¹ followed smokers

with airflow limitation who “did not consider themselves ill” after a smoking cessation intervention. These patients had mild to moderate COPD and were followed for 14.5 years. Of 5887 patients, 731 died. The most frequent causes of death were lung cancer (33%), cardiovascular disease (22%), and cancer in organs other than the lung (21%). Only 57 patients (7.8%) died of respiratory disease other than lung cancer. Incidentally, and importantly, the study showed a mortality benefit from smoking cessation. These data suggest that detailed end-of-life discussions with newly diagnosed COPD patients would be premature and irrelevant, but a stop-smoking intervention at this early stage of COPD would save lives.

Respiratory failure is the most likely cause of death among patients with more advanced COPD. The BODE index combines four easily obtained patient variables (body mass index, airflow obstruction, dyspnea, and exercise tolerance) and has been validated as a prognostic tool in

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COPD.² A trial of the index followed 625 patients over a 5-year period during which 162 (26%) died. Survivors averaged an FEV₁ of 43% of predicted and nonsurvivors averaged 28% of predicted. (Normal values would be above 80% of predicted.) The leading cause of death was respiratory failure (61%), with myocardial infarction (14%) and lung cancer (12%) causing a minority of deaths. These COPD patients are more representative of those seen by caregivers in clinics and hospitals. End-of-life discussions would be highly relevant for these patients with their more advanced airflow limitation.

As ill as members of the BODE cohort were, only 26% died during the 5-year trial. Most patients survived

Other high-risk groups of COPD patients include those who survive acute exacerbations of COPD (AECOPD) and survivors of invasive mechanical ventilation (IMV). In-hospital mortality from AECOPD can be as high as 11%, and 1-year mortality is in the range of 50%.³ With the advent of noninvasive mechanical ventilation (NIMV) for primary treatment of AECOPD and for bridging from IMV, the in-hospital mortality rates for COPD patients can be surprisingly low. One retrospective study looked at a highly selected cohort of tracheostomized COPD patients who were referred to a regional weaning unit after having been acutely ventilated for respiratory failure. The study reported a 95.5% successful weaning

the severity of the underlying disease rather than the need for ventilation. Thus, patients need not “get stuck” on the ventilator, as our weaning techniques continue to improve. However, the long-term prognosis for these patients is poor, and end-of-life discussions would be appropriate for all survivors of mechanical ventilation for COPD.

Symptom management

What do patients want from their physicians during the end-of-life phase of COPD? They want to feel that they are being cared for by an expert in the field of COPD who is a good communicator, is accessible, and will provide continuity of care.⁵ An aid to preparing for a meeting with patients and relatives is provided in the Canadian Thoracic Society (CTS) COPD management recommendations,⁶ which are also available online.⁷

Methods of end-of-life symptom management are well outlined in the CTS document^{6,7} and in a recent update.⁸ A comprehensive review of the palliative care of terminal COPD patients by Warren and colleagues is also worth considering.⁹

Caregivers are urged to listen to the patient's concerns, provide emotional support, and seek to relieve symptoms. In addition to usual COPD care, treatment of dyspnea with narcotics is often appropriate. These can be nebulized, taken orally or rectally, or given parenterally, with doses titrated to relieve dyspnea. Sustained-release morphine has been shown to relieve chronic dyspnea refractory to other treatments.¹⁰ An earlier trial showed no benefit for less severely ill patients who were still able to perform a 6-minute walk test.¹¹ Benzodiazepines can alleviate much of the anxiety often associated with severe dyspnea.

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for several years. However, the trial still validated the prognostic value of the BODE index by identifying a group of patients with COPD at very high risk of death. Patients with the highest BODE index scores had a 5-year mortality of 80%, with about half of these patients surviving less than 44 months. It is clear that this is the cohort of COPD patients most appropriate for an end-of-life discussion.

rate and a 92.5% survival to discharge.⁴ Long-term survival for those weaned from IMV approximated the poor survival expected of the worst BODE index cohort. One conclusion from these data is that patients with COPD who require mechanical ventilation may have a prognosis similar to patients who do not require mechanical ventilation. That is, the long-term prognosis in COPD is determined by

Nonpharmacological measures are also effective, including a fan directed at the face, music therapy, and giving the patient some measure of control over his or her surroundings. Involvement of the palliative care team, where available, can help in the overall management of the dying COPD patient. The role, if any, of non-invasive ventilation in the palliative care setting remains to be determined. Patients should be reassured that most symptoms at the end of life can be adequately palliated.

Conclusions

We can now identify those patients at increased risk of death from COPD-related respiratory illness. We have data to support providing invasive mechanical ventilation since very few patients will fail to wean. Physicians caring for patients with COPD should identify those patients at increased risk of death from respiratory failure and seek to develop a patient-centred approach to the end of life. Patients should be reassured that the best supportive care can effectively palliate symptoms, especially dyspnea and anxiety.

Patients with COPD bear the burden of this disease for many years. By using appropriately timed patient education about end-of-life issues, caregivers can assure patients that they will be cared for in an effective and compassionate manner at the end of those years.

Competing interests

None declared.

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