

Ask the expert

When to refer patients with advanced COPD to palliative care services

According to the World Health Organization, the health burden from COPD will increase in the coming decades, due to continued exposure to risk factors, population growth and ageing. It will become the third leading cause of death by 2030 [1]. Globally, there were 3.1 million deaths from the disease in 2015, but in addition, COPD deaths may be underreported. It is common for a comorbidity such as cor pulmonale to be reported as the main cause of death, rather than COPD [2]. More than 90% deaths occur in low- and middle-income families [3]. The causal relationship between COPD and smoking has long been established and accepted. In addition, socioeconomic status affects lung function and respiratory function independently, and its impact is second only to smoking [4]. Therefore, in areas of relative socioeconomic disadvantage, not only will more patients present with COPD, but these patients will have poorer outcomes than patients in higher socioeconomic groups.

Most patients with advanced COPD have severe, unremitting breathlessness, yet many patients do not have good access to palliative care, particularly in the developing world. Even in regions where access is good, patients are underreferred, often because of difficulties in prognostication and physicians' reluctance to talk about end-of-life care [5]. COPD patients receive less community support than lung cancer patients; in West Australia, 68% of lung cancer patients received palliative care, as opposed to 8% of non-cancer patients [6]. This trend is replicated in other parts of the world.

A study by BEERNAERT *et al.* [7] in the Netherlands showed that after reviewing 2405 deaths, only 20% of patients with COPD were referred to palliative care services *versus* 60% of cancer patients ($p < 0.001$). There was only a median of 10 days between referral and death. Between 2004 and 2015 only one in five people in the UK dying from COPD was recorded as having received any palliative care [8]. Despite nearly 90% of COPD patients having a Health Anxiety and Depression Scale score strongly suggestive of clinical depression and anxiety, only 4% of these patients were receiving pharmacological treatment [9].

Individuals with COPD may be stigmatised due to the association of COPD with smoking and the perceived "self-inflicted" nature of their condition [10]. Education remains a significant risk factor for COPD as smoking and pack-years are higher among individuals with less than a high school education [11].

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual [12].

If breathless remains a significant issue despite treating all reversible causes, this should prompt a clinician to refer to a palliative care outpatient service, which leads to the question, what is breathlessness? Traditionally, breathlessness has been measured and documented quantitatively,

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COPD is a significant health issue around the world. It is ultimately a fatal disease. Patients are under-referred to palliative care. Palliative care can improve breathlessness and provide other psychosocial interventions that can improve quality of life. <https://bit.ly/2VQ8FrR>



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such as using oxygen saturation or arterial blood gases, rather than incorporating the many qualitative measures in the assessment of breathlessness. Breathlessness can be any symptom that describes an unpleasant sensation of being unable to breathe: air hunger, running out of breath, chest tightness or a feeling of suffocation. The most common descriptors of breathlessness in advanced COPD are not being able to get enough air, feeling out of breath and breathing taking a lot of effort [13]. Men often describe it in terms of the reduction in their physical capabilities, especially if their occupation requires a level of physical fitness.

Simply put, if a clinician believes a patient could die in the next 6 months, they should refer to palliative care outpatient services. If they are symptomatically breathless despite optimal management, they should also be referred. Clinicians are poor at predicting survival in COPD and should ask themselves this question in addition to using prognostication tools [14].

In the case of a patient with COPD, the last months or years usually necessitates several admissions to hospital with the interval between each admission becoming shorter. This pattern should prompt a referral to palliative care; if they are well enough, to an outpatient service, or a community service if housebound. Many clinicians avoid conversations about dying, which can be hugely disadvantageous for patients. It means that the opportunity to discuss potential options for managing patients at home are missed (increasing the probability that a patient will represent to an acute facility), with important psychosocial issues such as anxiety, depression and carer stress being inadequately addressed.

National COPD guidelines should encourage early palliative care referrals. The Australian and New Zealand COPD guidelines (2019) refer to palliative care, but in their key recommendations state that the evidence for palliative care is weak (as it is categorised under optimising function) [15]. The guidelines suggest “the patient may enter their terminal phase and the goals of care may change rapidly to palliation with treatment limitations or palliation alone with withdrawal of active therapy”. This suggests a patient’s goal may change at a single point in time that is well defined, as opposed to a shifting paradigm, which is a more realistic portrayal of advancing COPD.

There are excellent models of care that are deserving of special attention in managing advanced COPD. SMALLWOOD *et al.* [16] developed a long-term, multidisciplinary, integrated service for patients with advanced lung disease (ALD) in Victoria, Australia. The clinic, set within an acute hospital, was staffed by a respiratory specialist, a palliative care specialist, a psychologist, an outreach nursing service and a telephone support line. It involved 171 patients and 83% these had severe COPD. An 8-week pulmonary rehabilitation course was undertaken by 69% of the

group prior to attending the ALD clinic. In addition to the rehabilitation, all patients received education on self-management of their breathlessness and were prescribed opioids if required. There was a strong emphasis on managing psychological issues that exacerbate breathlessness. There was a 52% reduction in respiratory emergency presentations ($p=0.007$) and an advanced care directive was written by 39% (only three had previously written one). Results from the ALD clinic revealed that 75% of patients died outside of an acute hospital, either in a dedicated palliative care bed or at home, supported by a community palliative care service. This contrasts with the current statistics of 72% of Australians with COPD dying in an acute hospital [17].

There are other noteworthy models of care worldwide; The Breathlessness Support Service in London, UK, and the Cambridge Breathless Intervention Service, Cambridge, UK [18]. They also offer a multidisciplinary service but unlike the Australian model, do not offer a long-term shared care approach. Given the complexity of the patients and the potential for a relatively longer prognosis for COPD patients, a shared care model is preferable.

Summary

All national COPD guidelines should recommend early palliative care.

Patients should be referred to palliative care as soon as the patient has intractable breathlessness and/or is presenting more frequently to emergency departments with acute exacerbations. Breathlessness is a subjective symptom and self-reporting is an essential tool in addition to quantitative measurements. Respiratory physicians need to be comfortable talking about end-of-life issues and introducing the concept of palliative care, as referral is beneficial not only in terms of symptom control but also in terms of the psychosocial support that is offered to patients and families. They should ask themselves “could my patient die in the next 6 months?”. Palliative care is effective but frequently only made available in the terminal phase. Respiratory specialists need to be comfortable and proficient at using low-dose opioids for the management of breathlessness, in the full knowledge they are safe and effective, and do not adversely affect respiratory function [19].

Services need to develop strategies most suited to the demographics of their region. Health areas with high levels of socioeconomic disadvantage will have a higher prevalence of COPD and this must be factored in when developing the model of service. A shared care model with respiratory and palliative care specialists working together has shown to be effective in improving symptom control and enhancing patient choices at the end of life.

Clinicians need to acknowledge the social stigma that patients may experience with a

diagnosis of COPD. Many patients who need our care are those that were exposed to aggressive and unethical cigarette advertising over several decades, and we have a duty to provide the best available treatment, which includes early palliative care.

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Conflict of interest

R. Strutt has nothing to disclose.

References

1. GBD 2015 Chronic Respiratory Disease Collaborators. Global, regional, and national deaths, prevalence, disability-adjusted life years, and years lived with disability for chronic obstructive pulmonary disease and asthma, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet Respir Med* 2017; 5: 691–706.
2. Mannino DM, Brown C, Giovino GA. Obstructive lung disease deaths in the United States from 1979 through 1993. An analysis using multiple-cause mortality data. *Am J Respir Crit Care Med* 1997; 156: 814–818.
3. World Health Organization. Chronic obstructive pulmonary disease (COPD); Fact sheet; March 2015. www.who.int/mediacentre/factsheets/fs315/en/
4. Prescott E, Vestbo J. Socioeconomic status and chronic obstructive pulmonary disease. *Thorax* 1999; 54: 737–741.
5. Vermeylen JH, Szmuiłowicz E, Kalhan R. Palliative care in COPD: an unmet area for quality improvement. *Int J Chron Obstruct Pulmon Dis* 2015; 10: 1543–1551.
6. Rosenwax LK, McNamara BA. Who receives specialist palliative care in Western Australia – and who misses out. *Palliat Med* 2006; 20: 439–445.
7. Beernaert K, Cohen J, Deliëns L, *et al.* Referral to palliative care in COPD and other chronic diseases: a population-based study. *Respir Med* 2013; 107: 1731–1739.
8. Bloom CI, Slaich B, Morales DR, *et al.* Low uptake of palliative care for COPD patients within primary care in the UK. *Eur Respir J* 2018; 51: 1701879.
9. Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000; 55: 1000–1006.
10. Johnson JL, Campbell AC, Bowers M, *et al.* Understanding the social consequences of chronic obstructive pulmonary disease: the effects of stigma and gender. *Proc Am Thorac Soc* 2007; 4: 680–682.
11. Gilman SE, Martin LT, Abrams DB, *et al.* Educational attainment and cigarette smoking: a causal association? *Int J Epidemiol* 2008; 37: 615–624.
12. World Health Organization. WHO definition of palliative care. www.who.int/cancer/palliative/definition/en
13. Chowienczyk S, Javadzadeh S, Booth S, *et al.* Association of descriptors of breathlessness with diagnosis, self-reported severity of breathlessness and self-reported distress due to breathlessness in patients with advanced chronic obstructive pulmonary disease or cancer. *Thorax* 2015; 70: A228.
14. Jones M, Greening N, Free R, *et al.* P262 Can we improve upon clinician prediction of survival in advanced COPD using clinically measurable prognostic factors? *Thorax* 2019; 74: A233.
15. Yang IA, Brown JL, George J, *et al.* The COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease 2019. Version 2.60, December 2019. Milton, The Lung Foundation Australia, 2019.
16. Smallwood N, Thompson M, Warrender-Sparkes M, *et al.* Integrated respiratory and palliative care may improve outcomes in advanced lung disease. *ERJ Open Res* 2018; 4: 00102–2017.
17. Philip J, Lowe A, Gold M, *et al.* Palliative care for patients with chronic obstructive pulmonary disease: exploring the landscape. *Intern Med J* 2012; 42: 1053–1057.
18. Booth S, Moffat C, Burkin J. The Cambridge BIS Manual – Building a Breathlessness Intervention Service. Cambridge, Cambridge University Hospitals NHS Foundation Trust, 2012.
19. Smallwood N, Le B, Currow D, *et al.* Management of refractory breathlessness with morphine in patients with chronic obstructive pulmonary disease. *Intern Med J* 2015; 45: 898–904.