



# Palliative care for people with COPD: effective but underused

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**Despite its effectiveness palliative care is underused in the majority of patients with COPD**  
<http://ow.ly/d0YH30hPKeu>

**Cite this article as:** Halpin DMG. Palliative care for people with COPD: effective but underused. *Eur Respir J* 2018; 51: 1702645 [<https://doi.org/10.1183/13993003.02645-2017>].

Nearly 100 000 men and over 65 000 women die from chronic obstructive pulmonary disease (COPD) in Europe each year [1]; more die from one of its comorbidities but face the challenges of living and dying with severe COPD during their last years and months. Globally, COPD is the third most common cause of death worldwide and the Global Burden of Disease project estimated that, in 2015, COPD caused 3.2 million deaths, an increase of 11.6% compared with 1990 [2].

For the people that die of, or with, COPD, their final months are often characterised by a progressive decline in health status, increasing symptoms and increased reliance on family and carers to perform simply daily activities such as washing and dressing. Despite this burden of disease, the vast majority of patients with advanced COPD are not offered palliative care, an approach that centres on the management of symptoms, maintaining quality of life and good communication. The underuse of palliative care was first reported nearly 20 years ago [3] and, since then, national and international guidelines have tried to encourage its adoption. The importance and benefits of palliative care were emphasised in the National Institute for Health and Care Excellence (NICE) COPD guideline in the UK published in 2004 [4] and in the American Thoracic Society/European Respiratory Society position paper published the same year [5]. In the UK, the Department of Health also introduced an “End of Life Care Strategy” in 2008 which was a comprehensive framework aimed at promoting high quality care across the country for all adults approaching the end of life [6]. Against this background, it is particularly disappointing that the study by Bloom *et al.* [7], published in this issue of the *European Respiratory Journal*, shows that between 2004 and 2015 only one in five people dying from COPD in the UK were recorded as having received any palliative care. Just under half of those that did get palliative care only received it during the last 6 months of their life and one third only in their last month of life. There was a progressive increase in the use of palliative care over the decade, indicating that awareness and use of palliative care in COPD is changing, but it is clear that palliative care is still much more likely to be used in people with cancer as in the study people with COPD and lung cancer were 40% more likely to be offered palliative care than those with COPD alone. A strength of the study is the large number of patients included from the Clinical Practice Research Datalink which covers 674 UK primary care practices, with representative demographics; however, the analysis does depend on practitioners having specifically documented the use of palliative care using one of a number of codes in the electronic patient record. The authors note that practices are financially incentivised to record palliative care approaches, and suggest that this means under-recording, rather than

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Received: Dec 19 2017 | Accepted after revision: Jan 03 2018

Conflict of interest: None declared.

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underuse, is unlikely. In practice the clinicians may have used palliative care approaches for their patients but regarded these as part of standard care and not coded them separately, but even if this is the case, the extent of under-recording is likely to be small and the study still confirms that most people dying of COPD do not receive palliative care.

Palliative care has much to offer for people living with advanced COPD and includes more than just terminal care. It involves close attention to the emotional, spiritual and practical needs and goals of patients and of the people who are close to them, including determining their views on future care through advance directives [8]. Palliative care is not only relevant for people with advanced COPD, it is important for people with other non-malignant respiratory diseases including interstitial lung disease and bronchiectasis [9, 10]. Both palliative care and rehabilitation have the same aims, and some regard rehabilitation as a palliative approach, but most would see rehabilitation as a powerful component of active restorative care, with palliative care focusing on improving symptoms and quality of life when active approaches are not succeeding.

Even when receiving optimal medical therapy many patients with COPD continue to experience distressing breathlessness and fatigue and often suffer from insomnia, panic, anxiety and depression. Palliative approaches to these symptoms are effective [11] and their use should not be restricted to end of life situations. It is entirely logical to introduce palliative care alongside therapies aimed at correcting the underlying pathophysiological abnormalities and reducing the risk of exacerbations.

Opiates and fans blowing air onto the face can relieve breathlessness [12], oxygen may offer some benefit even if the patient is not hypoxaemic (peripheral capillary oxygen saturation >92%) [13] and a multidisciplinary integrated palliative and respiratory care approach to breathlessness can be of value [14]. Anxiety and depression can be reduced by pharmacotherapy [4] as well as cognitive behavioural therapy and mind–body interventions (*e.g.* mindfulness-based therapy, yoga and relaxation) [15]. Mind–body interventions can also improve physical outcomes such as breathlessness and fatigue.

While the ability to use palliative approaches should be part of the skill set of all clinicians managing people with COPD [16], some patients will benefit from referral to specialist palliative care teams, whose multidisciplinary approach can improve a patient's quality of life [17]. Referral needs to be discussed sensitively with patients, with an emphasis on the positive aspects of specialist palliative care input, such as help with symptom control, and family support. There is evidence of the underuse of specialist palliative care services, and referral is sometimes linked more to life expectancy than to the patient's symptom needs. For example, in Belgium, patients with COPD were less likely to be referred to palliative care services than those with other chronic diseases such as heart failure, and patients with COPD who were not referred were more likely to receive inappropriate treatment with a curative or life-prolonging goal rather than a palliative or comfort goal than patients with other conditions who were not referred [18].

Palliative care also involves honest discussion of prognosis and issues such as advance directives about the patient's wishes regarding admission to hospital, ventilation and resuscitation in the event of cardiorespiratory arrest. Surprisingly, many patients do not understand that in most cases COPD is a progressive life limiting condition [19]. Patients who are aware of the prognosis often have concerns regarding the manner of their death with an overriding fear of dying of breathlessness or suffocation, yet they rarely discuss these fears with clinicians [19], and clinicians are poor at eliciting patient's concerns [20]. Sometimes patients and their families have unrealistic views on the prognosis and the likely effectiveness of interventions such as ventilation, but these views must be respected. There is also evidence of cultural differences in acceptance of advance directives, both between cultural groups within countries and between countries themselves, but overall their use is increasing [9].

Concerns have been expressed that patients may change their minds about not wanting life-prolonging therapies when they became necessary; however, when this has been studied, in general there appears to be consistency between end of life decisions and preferences stated in advanced directives [21], but of course patients are free to change their mind about accepting or rejecting treatment if they wish. There is evidence that advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety and depression in surviving relatives [22], as well as reducing the costs of care [23]. It is important that the details of advance directives are regularly reviewed with patients to ensure that their instructions reflect their current wishes.

Although often uncomfortable for clinicians, open communication regarding death is important to alleviate patients' fears and to allow them to make decisions regarding the management of their care at the end of life. Patients with COPD find it particularly difficult to make decisions in advance about ceilings of care [24] and even when they have had prior experience of interventions such as noninvasive ventilation

they trust their doctor to make the right decision about its use in future in preference to making their own decision [25]. Nevertheless it is important that they are given the opportunity to discuss such issues.

Patients with COPD appreciate continuity of care and reassurance provided by their primary healthcare team [26, 27] and general practitioners acknowledge that they are in a key position to deliver and coordinate palliative and end of life care for patients with COPD; however, most find it hard to initiate these discussions, partly because of perceived time constraints but also because they have difficulty identifying when they are appropriate, given the difficulty in predicting prognosis in COPD compared to cancer [28, 29]. Clinicians often feel uncomfortable raising end of life issues and deliberately avoid doing so. There are, however, practical strategies that can be used to facilitate these discussions: raising the implications of the diagnosis; using uncertainty to ease discussion; building relationship with patients; being caring and respectful; beginning discussion early in disease course; identifying and using opportunities such as an exacerbation or hospitalisation to discuss prognosis; and working as a team. Patients with advanced disease are often receptive to the dual agenda: “Hope for and expect the best, and prepare for the worst” [30].

The progressive decline in activities of daily life and social isolation for patients with end-stage COPD are reflected by changes in the roles and responsibilities of spouses and families. They frequently take on multiple new roles as the illness progresses, including nursing the patient and taking over all household tasks [26, 31]. This can put a considerable strain on them and they also need the psychosocial support that palliative care offers, as well as bereavement counselling after the patient’s death [32].

The Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Lung Disease (GOLD) report now recommends “that all clinicians managing patients with COPD should be aware of the effectiveness of palliative approaches to symptom control and use them in their practice” [12]. Although palliative care is about more than just end of life care, clinicians managing patients with advanced respiratory disease would do well to reflect on the words of Dame Cicely Saunders, founder of the modern hospice movement in the UK: “How people die remains in the memory of those who live on” [33].

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