

Palliative care for people with COPD

Summary

Patients with advanced COPD may have worse quality of life, greater limitation of activity, and more anxiety and depression than patients with lung cancer, yet access to palliative care services is rare. Primary care clinicians can contribute by identifying those who would benefit from a palliative care approach.¹

The physical, social and spiritual burden

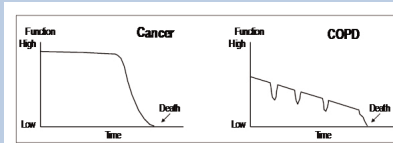
As lung function deteriorates the burden of COPD increases.²⁻⁵ Predominant symptoms are disabling shortness of breath and depression, but cough, fatigue, pain, confusion, anorexia, and thirst are commonly described. This morbidity is reflected in severe impairment of quality of life and activities of daily living. Exacerbations result in frequent admissions and high use of primary care services. Social isolation is common and the burden on carers is high. Many patients with a life threatening illness are stimulated by their experience to consider the meaning and purpose of life. Distress due to unmet spiritual needs increases anxiety, panic attacks and the unscheduled use of medical services.⁶

Illness trajectories

Only two-thirds of patients discharged after an admission with respiratory failure survive two years.

In contrast to cancer where the terminal phase is relatively clearly defined, COPD illustrates the organ failure trajectory at the end of life, where gradual decline over a number of years is punctuated by acute, often severe exacerbations, any one of which may, or may not, prove fatal.⁷ [Figure 1] This uncertain disease progression may be compounded by a tendency for doctors who are familiar with patients to over-estimate survival.⁸ Death, therefore, may occur suddenly

Figure 1: Comparison of the patterns of physical decline for people with cancer and COPD (organ failure).⁶ Reproduced with permission from the RAND Corporation, Santa Monica, CA.



before clinicians have perceived the patient to be "terminal", thereby missing the opportunity to address important issues.

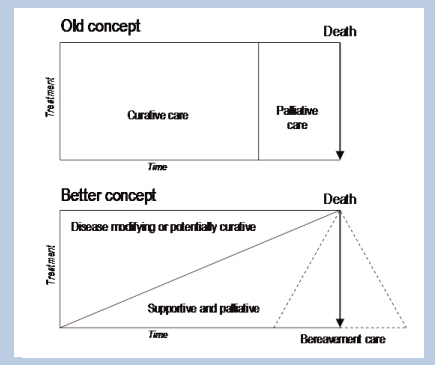
Identifying people who would benefit from a palliative care approach

Prognosis in COPD is difficult, but recognised indicators of a poor outcome are:⁹

- Hospital admissions: only two-thirds of patients discharged after an admission with respiratory failure survive two years.
- Severe disease: an FEV₁ of 30% predicted or less; on long-term oxygen therapy.
- Depression, poor quality of life, being housebound due to COPD
- Co-morbidity (especially heart failure).
- Low body mass index.

General Practitioners (GPs) and nurses may be able to identify those who would benefit from a palliative care approach by considering the question "Would I be surprised if my patient were to die in the next twelve months?"¹⁰ Awareness of the importance of palliative care for patients with advanced COPD will enable practices to identify those who might benefit from inclusion in a "supportive and palliative care register", with a view to facilitating the provision of multidisciplinary care.

Figure 2: Transition from curative care to palliative care.⁶ Reproduced with permission from the RAND Corporation, Santa Monica, CA.



Discussion about end-of-life care

Despite recognising the importance of discussing end-of-life care, many clinicians find it difficult to raise such sensitive issues. Some useful questions include:

- If things got worse, where would you like to be cared for?
- What's the most important issue in your life right now?
- What helps you keep going?
- What is your greatest problem?
- You seem cheerful at present, but do you ever feel down?

Beginning discussions early in the disease course, being open to opportunities to discuss prognosis, and explaining the uncertain trajectory, are amongst the strategies identified by GPs as having 'worked' for them.¹¹

It is important to appreciate that the transition from curative to palliative care may not be clear-cut for people with COPD.² [Figure 2] For example, a decision to accept a palliative care approach to symptom control, does not necessarily preclude a decision to admit a patient to hospital in the event of an exacerbation, or the acceptance of assisted ventilation for an episode of respiratory failure. Other patients may

Figure 3. Palliative prescribing for patients with end-stage COPD¹²

Symptom	Medication
Dyspnoea	Opiates, titrating the dose to achieve relief of dyspnoea. Oxygen may have a small effect on dyspnoea. Cool air, e.g. from a fan, sometimes increases comfort
Cough	Opiates
Excess secretions	Anticholinergics (but take care to avoid the discomfort of a dry mouth)
Anxiety	Benzodiazepines Note: high doses of β -agonists can aggravate anxiety
Confusion	Oxygen may reduce confusion due to hypoxia. Haloperidol may ease confusion and restlessness

within the primary care team (including the out-of-hours services) should be ensured by using an appropriate 'handover form'. The Gold Standards Framework has been developed for the care of people with advanced illnesses.¹⁴ It highlights seven key tasks widely used in providing co-ordinated care for people with cancer, which can be adapted for people with advanced COPD [Figure 4].

Further Information on Palliative Care in COPD

End of Life Care for COPD Patients. Mervyn M Dean. *Prim Care Respir J* 2008;**17**(1):46-50. DOI:10.3132/pcrj.2008.00007

References

1. Department of Health. National Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England. London: DoH 2010
2. Habraken JM, Willems DL, de Kort SJ, Bindels PJE. Health care needs in end-stage COPD: A structured literature review. *Pat Ed Counsel* 2007;**68**:121-30.
3. Seamark DA, Seamark CJ, Halpin D. Palliative care in chronic obstructive pulmonary disease: a review for clinicians. *J R Soc Med* 2007;**100**:225-33.
4. Lynn J, Ely EW, Zhong Z, McNiff KL, Dawson NV, Connors A, *et al*. Living and dying with chronic obstructive pulmonary disease. *J Am Geriatrics Soc* 2000;**48**:S91-S100.
5. 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**:1000-06.
6. Grant E, Murray SA, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: perspectives from patients with advanced cancer and non-malignant disease. A qualitative study. *Pall Supp Care* 2004;**2**:371-8.
7. Lynn J, Adamson DM. Living well at the end of life. Adapting health care to serious chronic illness in old age. 2003 RAND Santa Monica.
8. Christakis NA, Lamont EB. Extent and determinants of error in doctor's prognosis in terminally ill patients: prospective cohort study. *BMJ* 2000;**320**:469-72.
9. Coventry PA, Grande GE, Richards DA, *et al*. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. *Age and Ageing* 2005;**34**:218-27.
10. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness. We need to move from prognostic paralysis to active total care. *BMJ* 2005;**330**:611-12.
11. Halliwell J, Mulcahy P, Buetow S, Bray Y, Coster G, Osman L. GP discussion of prognosis with patients with severe chronic obstructive pulmonary disease: a qualitative study. *Br J Gen Pract* 2004;**54**:904-08.
12. Joint Formulary Committee. Prescribing in palliative care. British National Formulary. 58 ed. London: British Medical Association and Royal Pharmaceutical Society of Great Britain: 2009. Available from <http://www.bnf.org>
13. Jennings AL, Davies AN, Higgins JPT, Anzueto-Cabrera J, Broadley KE. Opioids for the palliation of breathlessness in terminal illness. Cochrane Database of Systematic Reviews 2001, Issue 3. Art. No.: CD002066. DOI: 10.1002/14651858.CD002066.
14. NHS End-of-Life Care programme. The Gold Standards Framework. A programme for community palliative care. Available from <http://www.goldstandardsframework.nhs.uk>

decide that they do not want another admission, and they will only accept treatment that can be provided at home. It is important therefore, that these preferences are documented and shared with appropriate colleagues (including drafting an Advance Care Plan and providing the Out-of-Hours services with relevant information).

Alleviating distressing symptoms

Figure 3 summarises the options for palliative prescribing for COPD.¹² Opiates have an important role in relieving the distressing symptoms of dyspnoea and cough, and there is evidence that concerns about the risks of suppressing respiration are unfounded if appropriate doses are used.¹³

Ensuring physical, social and spiritual support for patients and their carers

As well as wanting information and control of symptoms, patients with progressive illnesses appreciate continuity of care. Personal continuity by a named doctor or nurse is ideal, and sharing information

Social needs

Difficulty with activities of daily living may be eased by the provision of appliances such as walking aids, stair lifts, and bath aids. Advice on benefits and support with domestic care may be needed. Social isolation is a major problem: a wheelchair and a disabled parking permit may prevent the COPD patient becoming housebound and day-care may provide a break for both the patient and the carer.

Conclusion

Primary healthcare professionals have an important role in the provision of palliative care for their patients with COPD.¹ Recognising the end-of-life illness trajectory of people with organ failure should facilitate the key step of identifying patients with advanced disease who are 'at risk of dying'. The aim is then to help patients with COPD plan for, hope for and expect a good death: a death where they wish, with the people they want, and with minimal physical, psychological and spiritual distress.

Figure 4 Seven key tasks / standards for co-ordinated care, widely used in cancer care, with suggested adaptations for patients with advanced COPD.

C1 Communication:	Establish a register of patients with advanced COPD, and discuss advance care planning
C2 Co-ordinator:	Appoint a key person for each patient
C3 Control of symptoms:	Regularly re-assess physical, social, psychological and spiritual needs
C4 Continuity out-of-hours:	Ensure Out-of-Hours service have appropriate information
C5 Continued learning:	Ensure that the development needs of the practice team are met.
C6 Carer support:	Ensure practical, emotional, and bereavement support is available for family and carer(s)
C7 Care in the final days:	Discuss, document and respect end-of-life preferences

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