DESKTOP HELPER IPCRG OPINION 4

Palliative care for people with COPD

SUMMARY

Patients with advanced chronic obstructive pulmonary disease (COPD) have worse quality of life, greater limitation of activity, more anxiety and depression than patients with lung cancer, yet access to palliative care services is rare. An approach, such as is used in other end stage diseases, especially malignancy, is valid, with emphasis on quality rather than quantity of life. Primary care clinicians can contribute by identifying those with very severe or end-stage COPD who would benefit from a palliative care approach, discussing prognosis and enabling decisions about end-oflife care, alleviating distressing symptoms, and ensuring physical, social and spiritual support for patients and their carers. Many COPD patients die during an exacerbation, and it is important to develop management strategies before a crisis occurs. There will be different palliative management strategies in different countries, depending on the health delivery system, cultural backgrounds and on individual beliefs.

END-STAGE COPD

End-stage COPD is a progressive incurable illness. Immediate prognosis is difficult and unpredictable as, even in end-stage disease, patients may experience exacerbations and then recover. There are many symptoms to manage and often co-morbidities exist, until ultimately, respiratory function is severely compromised.

ETHICAL ISSUES AND PALLIATIVE CARE

The aim of palliative care is to provide the best possible quality of life in what

SYMPTOMS OF END-STAGE COPD

- Extreme shortness of breath
- Cough with mucous production
- Weight loss (often extreme)
- Depression
- Fatigue
- Pain
- Anorexia
- Thirst
- Confusion

SIGNS AND OBJECTIVE FINDINGS INCLUDE

- FEV₁ < 30% Predicted
- Central cyanosis
- O₂ saturation <92%
- Marked hyperinflation
- Right heart failure (cor pulmonale)
- Cachexia

remains. The success is often assessed by measures of quality of life. This is an individual issue and must be discussed on an individual basis. Long term 'survivors' may be long term 'sufferers', and this needs to be discussed openly with the patient, and their individual needs respected. Issues such as treatment of exacerbations, control of symptoms, intubation and mechanical ventilation should be addressed. It is important to appreciate that the transition from curative to palliative care may not be clear-cut for people with COPD. For example, a decision to accept a palliative care approach to symptom control, does not necessarily preclude a decision to admit to hospital in the event of an exacerbation, or the acceptance of assisted ventilation for an episode of respiratory failure.

Other patients may decide that they do not want another admission, and they will only accept treatment that can be provided at home. It is important 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).

EXACERBATIONS

Exacerbations result in frequent hospital admissions and considerable 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. It is important that patients understand the diagnosis and disease process, treatment, prognosis, and care planning which must be matched with patient beliefs and requests. Understanding the fear that patients have of suffocating in a terminal event can go a long way in planning strategies to ensure control of endstage symptoms.

DISEASE OUTCOME

In contrast to cancer, where the terminal phase is relatively clearly defined, COPD causes gradual decline over a number of years, punctuated by acute, often severe exacerbations, any one of which may, or may not, prove fatal. [see figure 1.] Death, therefore, may occur suddenly before clinicians have perceived the patient to be "terminal" so missing the opportunity to address important issues.



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IDENTIFYING PEOPLE WHO WOULD BENEFIT FROM A PALLIATIVE CARE APPROACH

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

- Hospital admissions: only twothirds of patients discharged after an admission with respiratory failure survive two years.
- Severe disease: FEV₁ of 30% 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

Awareness of the importance of palliative care for patients with advanced COPD will enable primary care teams 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.

ALLEVIATING DISTRESSING SYMPTOMS

Figure 1 summarises the options for palliative prescribing for COPD. As well as standard regular bronchodilatation with β-2-agonists and/or anticholinergics (preferably inhaled), theophylline, and if beneficial, steroids, opiates have an important role in relieving the distressing symptoms of dyspnoea and cough. There is evidence that concerns about the risks of suppressing respiration are unfounded if appropriate doses are used. In some countries home remedies may be used, if there is no evidence of potential harm.

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 and someone who listens to them and values them as a person. Personal continuity by a named doctor or nurse is ideal, and continuity of information within the primary care team (including the out-

of-hours services) should be ensured by using an appropriate 'handover form'. It is imperative that all health professionals in the team deliver the same message! Appropriate training needs to be provided to improve the knowledge about COPD in palliative care support teams.

SOCIAL NEEDS

Difficulty with activities of daily living may be eased by the provision of appliances to assist with walking, bathing and climbing stairs. Financial hardship should be addressed, and support with domestic care may be needed. The extended family and friends can be crucial in supporting the family through their terminal phases. Social isolation is a major problem: a wheelchair and, if available, 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. 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.

FURTHER READING

- NHS End-of-Life Care programme. The Gold Standards Framework. A programme for community palliative care. Available from http://www. goldstandardsframework.nhs.uk/ non_cancer.php
- UK Prognostic indicators for noncancer www.goldstandards framework.nhs.uk/content/ gp_contract/Prognostic %20Indicators%20Guidance %20Paper%20v%2025.pdf
- 3. Liverpool Care Pathway for Dying Patients http://www.mcpcil.org.uk /liverpool_care_pathway/ non-cancer/lcp_non-cancer _briefing_paper_2007
- Jennings AL, Davies AN, Higgins JPT, Broadley K. Opioids for the palliation of breathlessness in terminal illness. The Cochrane Database of Systematic Reviews 2001, Issue 3. Art. No.: CD002066. DOI: 10.1002/14651858.CD002066.
- Global Initiative for Obstructive Lung Disease. Global Strategy for Diagnosis, Management and Prevention of COPD Updated 2007 Available http://www.goldcopd.com

Further reading available on the website: http://www.theipcrg.org/resources/resources copd.php •

FIGURE 1

Symptom	Advice	Suggested prescription
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	Initial dose: morphine 5mg 4 hourly under review due to new evidence
Cough	Opiates	Morphine 5mg 4 hourly under review due to new evidence
Excess secretions	Anticholinergics (but take care to avoid the discomfort of a dry mouth)	400–600mcg sub- cutaneously 4–6 hourly
Anxiety	Benzodiazepines. Note: high doses of ß-agonists can aggravate anxiety	Diazepam 5–10mg daily
Confusion	Oxygen may reduce confusion due to hypoxia. Chlorpromazine or haloperidol may ease confusion and restlessness	Chlorpromazine 25–50mg 8 hourly. Haloperidol 1–3mg 8 hourly
Nausea	May occur due to opioids, steroids or illness	Haloperidol 1-3 mg sub- cutaneously prn