End-of-life care in patients with chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease is the fourth leading cause of death worldwide, with World Health Organization (2008) projections suggesting it will be the third leading cause of death by 2030.

Patients with chronic obstructive pulmonary disease have a high symptom burden with dyspnoea commonly being the most disabling. At the end of life patients often express the wish to be pain free and breath comfortably, with many fearing suffocation (Reinke et al, 2013). Anxiety and depression also feature (Sorenson, 2013). National Institute of Health and Clinical Excellence (2010) guidelines advocate the use of opioids, benzodiazepines, tricyclic antidepressants, tranquilisers and oxygen to palliate breathlessness. The guidelines also state that patients should have full access to palliative care and hospice care. Hospice day care is particularly useful to limit social isolation. Many patients perceive day hospice as a key social tool, allowing them to discuss and compare their experiences with other patients with chronic obstructive pulmonary disease while being able to access specialist palliative care (Hayle et al, 2013).

Use of oxygen therapy has been widely debated – this can reverse hypoxaemia but not necessarily dyspnoea. Giving oxygen can improve saturations with no significant improvement in dyspnoea when oxygen is used *vs* air. Simply the sensation of having air blowing across the face can improve the feeling of dyspnoea (BMJ Best Practice, 2014). There is mounting evidence for a lack of effect of short burst oxygen therapy for post exercise dyspnoea in patients with chronic obstructive pulmonary disease. Despite this, oxygen is still often provided for palliation of dyspnoea at a reported cost of £18 million/year (O'Driscoll et al, 2011).

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The lack of palliative involvement in chronic obstructive pulmonary disease

Palliative medicine offers a holistic approach and provides symptom control and end of life care, as well as emotional, spiritual and social support, for patients with advanced illness. The World Health Organization (2002) has advised that palliative care should be available to anyone affected by a life-threatening illness and that this should be initiated early on in the disease trajectory. This is reiterated by the American Thoracic Society, who emphasize that palliative care should be available throughout all stages of disease (Lanken et al, 2008).

In the UK, National Institute of Health and Clinical Excellence (2010) guidelines advocate that multidisciplinary palliative care teams should be involved in treating patients with advanced chronic obstructive pulmonary disease, but the challenge is deciding the appropriate time to involve palliative care even when a person has 'advanced chronic obstructive pulmonary disease'. Palliative care services should ideally be introduced early on and continue along the disease course with regular open communication to ensure holistic assessment and treatment of the patient's changing needs. There is a positive correlation between early integration and high quality of palliative care (Dalgaard et al, 2014).

The symptom burden in chronic obstructive pulmonary disease is very similar to cancer, reporting pain, insomnia, fatigue and low mood, and patients with chronic obstructive pulmonary disease particularly experience dyspnoea. However, only a very small proportion of patients with chronic obstructive pulmonary disease receive palliative input compared to the majority of cancer patients who get excellent palliative and social support. Beernaert et al (2013) found that patients with chronic obstructive pulmonary disease (20%) were less likely than heart failure patients (34%), those with severe dementia (37%) and certainly those with cancer (60%) to be referred to palliative care. Patients with chronic obstructive pulmonary disease are also more likely than patients with cancer to be treated aggressively with life-sustaining treatments at the expense of effective symptom control (Sorenson, 2013).

The lack of palliative referrals for patients with chronic obstructive pulmonary disease and late timing may be partly the result of a poor appreciation by patients and their caregivers that the disease is life threatening or suitable for palliative care. Patients and clinicians may also hold the preconception that palliative care services are purely for the terminally ill, signifying 'giving up', and do not think it is appropriate to involve palliative care until very late in the disease.

In the study by Beernaert et al (2013), half of all patients referred to palliative care services died within 10–20 days of referral, which is considerably later than when most cancer referrals are made and limits the palliative input. A large barrier to referral is the difficulty in prognostication. The disease course in chronic obstructive pulmonary disease is unpredictable, so clinicians may be unsure when to refer.

Prognostication

Determining when to initiate end of life communications and palliative care is often largely dependent on prognosis. The disease course in cancer is predictable with a rapid decline and terminal phase immediately preceding death (*Figure 1*). In chronic obstructive pulmonary disease, i.e. organ system failure, the terminal phase is less recognizable and death is far less predictable (*Figure 2*). Clinicians thus face the difficult task of trying to ascertain when it is most appropriate to start discussing end of life and referring to palliative services (Beernaert et al, 2013). There is also a lot of uncertainty among patients about the course of their illness and there is an expectation from many that their doctor will give them a clear message when their disease has become life threatening so they can plan for their death and final arrangements (Lowey et al, 2013). This emphasizes the responsibility that the clinician has to initiate timely end of life conversations.

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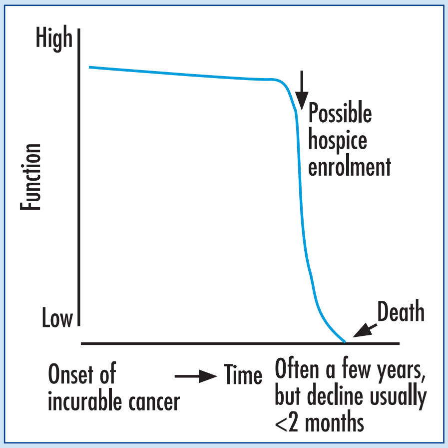

Figure 1. Cancer trajectory: diagnosis to death. From BMJ Best Practice (2014).

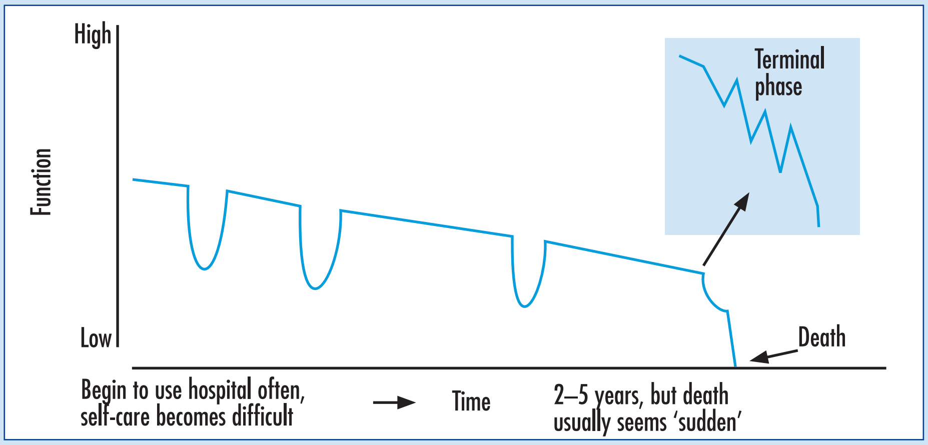

Figure 2. Organ system failure trajectory for patients with chronic obstructive pulmonary disease. From BMJ Best Practice (2014).

The most used severity marker in chronic obstructive pulmonary disease is forced expiratory volume in 1 second (FEV1). This does not change significantly once the patient has very severe disease (FEV1<35%). The modified BODE (body mass index, airflow obstruction, dyspnoea and exercise capacity) score has been reported to be predictive of death although no time frame is given by the score and it is not routinely measured (Benzo et al, 2013).

Benzo and colleagues (2013) analysed data from patients with severe chronic obstructive pulmonary disease to determine whether mortality could be predicted by key variables. They reported that the risk of dying in the next 12 months was significantly and independently increased by a change in some of these parameters, as shown in *Table 1*. These can act as triggers to initiating palliative input. The predictors used are not always readily available in the acute inpatient setting but may be more appropriate for the outpatient or GP setting.

Mannino et al (2013) have developed a score to assess chronic obstructive pulmonary disease severity using a four-point system, incorporating both symptoms and exacerbation history in line with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines. The scale classifies patients from very mild (score of 1.00) to very severe (score of 4.00) as shown in *Table 2*. A mean composite score can be calculated from the individual scores which is directly correlated to the mortality (*Table 3*). The mean score can be calculated based on any number of the components given and can be easily applied in the acute setting. It can also be used to help guide clinicians regarding the initiation of end of life discussions.

The DECAF (dyspnoea, eosinopenia, consolidation, acidaemia, atrial fibrillation) score (*Table 4*) is a good predictor of inpatient mortality for an acute exacerbation of chronic obstructive pulmonary disease and for patients with pneumonia is a significantly better predictor of inpatient mortality than the CURB 65 score (confusion, urea, respiratory rate, blood pressure, age over 65). Steer et al (2012) found that

Table 1. Predictors of death

Decrease in gait speed by 0.14 m/s or 6-minute walk by 50 m or change towards perceiving a very sedentary state
Decrease in maximal inspiratory pressure greater than 11 cmH$_2$O
Feeling upset or downhearted*
Decrease in room air resting partial pressure of oxygen greater than 5 mmHg
Increase in room air resting partial pressure of carbon dioxide greater than 3 mmHg

*as measured by the Quality of Well-Being questionnaire. From Benzo et al (2013)

Table 2. Overall severity or progression score is the mean of the scores for the available data

Model component	Mild (1)	Moderate (2)	Severe (3)	Very severe (4)
FEV1 % predicted	<80%	>50% to 80%	>30% to 50%	≤30%
Symptoms*	0	1	2	3 or more
Exacerbations per year	0	1	2	3 or more
Comorbidity index	0	1	2	≥3
Quality of life (standardized score)	≥1	0 to <1	-1 to <0	<-1
St George's Respiratory Questionnaire	≤30	>30 to 47	>47 to 64	>64
Body mass index (kg/m^2)	>20 to <25	≥25	…	≤20

*cough, sputum production, wheezing or dyspnoea. FEV1 = forced expiratory volume in 1 second. From Mannino et al (2013)

Table 3. The relationship of the mean composite score to patient mortality

Year 1 mean composite score	% dead at end of follow up
1–1.25	9.5
1.25–1.75	10.5
1.76–2.25	12.6
2.26–2.75	15.9
≥2.76	29.7

From Mannino et al (2013)

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DECAF was an effective predictor of inpatient mortality which stratifies patients to low, intermediate and high risk of mortality within 30 days (*Table 5*). This scoring system has the benefit of having only five variables, which are usually known on admission. It also has the benefit of a clear time frame of giving a mortality prediction within 30 days. This is very helpful for stratifying patients for salvage strategies or for palliation. For the intermediate group it allows the clinician to pursue salvage strategies while potentially initiating end of life discussions and palliative services.

Advanced care planning and care coordination

Advanced care plans promote patient dignity and autonomy and can avoid unwanted treatments. Patients who complete advanced care plans spend fewer days in hospital in the last year of life and family members have lower levels of anxiety and depression (BMJ Best Practice, 2014). Advanced care plans are infrequently made by patients with chronic obstructive pulmonary disease. Health-care professionals do not always regard making an advanced care plan as their responsibility and many find such discussions difficult and feel ill equipped to deal with them. Some physicians have expressed concern that discussing end of life could psychologically harm the patient, yet evidence shows that these discussions do not increase emotional distress or psychiatric problems (Wright et al, 2008). The UK NHS End of Life Care strategy (Department of Health, 2008) calls for open discussions between health-care professionals and patients to ensure well-planned end of life care. Patient knowledge and what is to be expected is a prerequisite for a 'good death' (Momen et al, 2012). Effective communication skills and training in breaking bad news are advised to enable these sensitive discussions to take place (Dalgaard et al, 2014).

Table 4. DECAF scoring

DECAF		Score
Dyspnoea	*eMRCD 5a	1
	*eMRCD 5b	2
Eosinopenia ($<0.05 \times 10^9$/litre)		1
Consolidation		1
Acidaemia (pH <7.3)		1
Atrial fibrillation		1
Total		6

*eMRCD – extended MRC dyspnoea scale, 5a – those who can dress independently, 5b – those who cannot dress independently.
From Steer et al (2012)

Table 5. Mortality prediction using the DECAF score

DECAF score	30-day mortality %
0	1.5
1	3.8
2	11.9
3	27.2
4	45.6
5	70
6	Not available

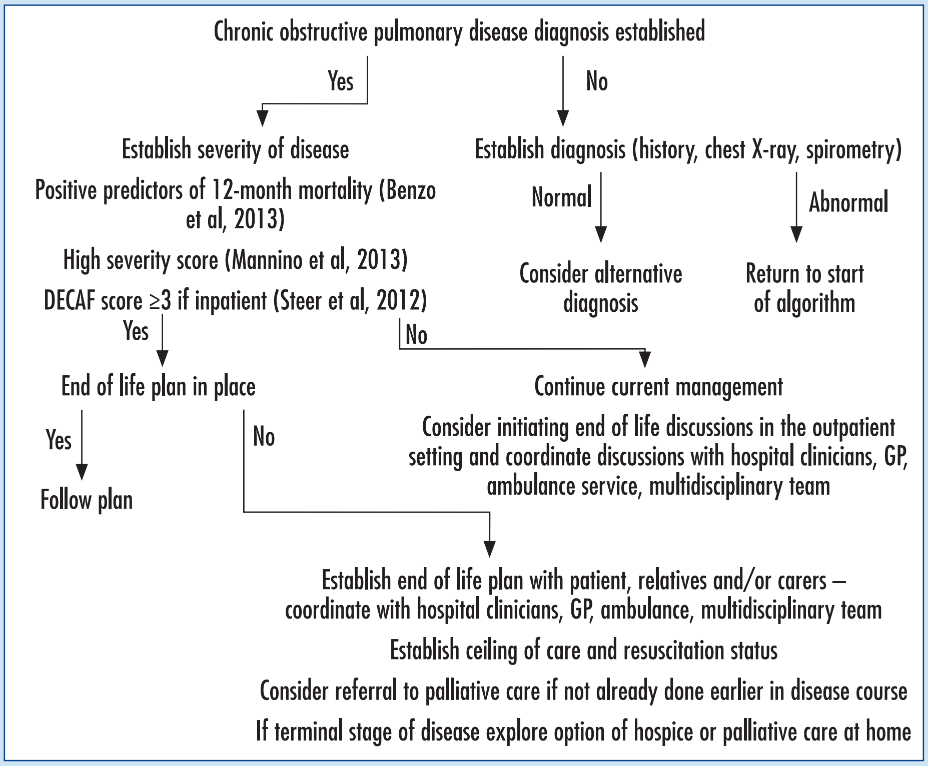
Score 0–1 = low risk; score 2 = intermediate; score 3 = high risk.
From Steer et al (2012)

Studies suggest that the majority of patients would like to discuss their anticipated experiences with their clinician so that they feel prepared for their future care and treatments (Sorenson, 2013). Individual preferences for end of life care can vary widely, but if the medical team is unaware of these specifics it is difficult for them to be achieved and can lead to unmet needs and discordant care. Open communication prevents assumptions by professional caregivers which may be inconsistent with the wishes of the patient. However, health-care professionals need to be sensitive to those patients who do not wish to have discussions regarding end of life. It has been reported that at times, around half of patients do not wish to have further information because of its potentially distressing nature. Patients not wishing to discuss advanced care plans are often those who think they have excellent prognosis and report a good quality of life. They often do not want to be actively involved in decision making (Momen et al, 2012).

It can be difficult in the inpatient setting to make adequate advanced care plans as a result of time constraints and because the patient is acutely unwell. It is preferable to complete them in the outpatient or GP setting. However, there will inevitably be situations in which an advanced care plan has to be made in hospital (*Figure 3*). Making an advanced care plan is also an opportunity to help educate the patient and caregivers about the progression of the disease and the practical interventions such as oxygen, pulmonary rehabilitation and opioids that can improve quality of life.

Common factors which patients consider important for a 'good death' include

Figure 3. When to initiate advance care planning and palliative care.



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control of pain and other symptoms, avoiding prolongation of dying, having a sense of control, trusting health-care providers, strengthening relationships and relieving family burdens (Steinhauser et al, 2000). Although there are common preferences among these patients, there is also a large degree of heterogeneity: one study found 43% wished to have the means to end their own life but 47% said this was not important (Reinke et al, 2013).

Janssen et al (2013) examined patient preferences for death and found 51.5% preferred to die at home, 29.6% in hospital, 10.2% in a care home or hospice and 8.7% did not know. After 1 year follow up 61.2% of people changed their mind about place of death and only 39% died in their preferred site. Although most patients with chronic obstructive pulmonary disease prefer to be able to die at home, there is a clear need to regularly assess patients' changing wishes. Currently, respiratory disease has the lowest proportion of people dying in their own home compared to national overall figures of 19% (National End of Life Care Intelligence Network, 2011).

Advanced care planning includes decisions regarding cardiopulmonary resuscitation and mechanical ventilation as many want to avoid such interventions (Reinke et al, 2013) but importantly it takes into account an understanding of the variability of patients' wishes based on their values and enables clarification of patient goals and ceilings of care.

Coordination of care between hospital physicians, palliative teams, the GP, ambulance services and other providers involved in the patient's care is essential to ensure that the patient's continuing needs are met both in and out of hospital. It is particularly important when patients want to avoid admission, as this requires the ambulance to not default to bringing the patient to accident and emergency and for GP and community teams to be able to adequately care for the patient at home or in an alternative environment of his/her choice, e.g. hospice. Transitioning between health-care teams and settings, e.g. from day hospice to inpatient care, can be a source of anxiety to patients.

Good handover practice can ensure that patients feel relaxed and confident with the care arrangements (Hayle et al, 2013). A free DVD (Effective Care - Effective Communication: Living and Dying with COPD), supported by a Department of Health grant, comprises patients' and carers' stories as well as evidence-based practice for enhancing end of life communication in chronic obstructive pulmonary disease. This can be accessed for free from Department of Health respiratory leads. **BJHM**

Conflict of interest: none.

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KEY POINTS

- Patients with chronic obstructive pulmonary disease have a significant symptom burden towards the end of life with considerable palliative care needs.
- Dyspnoea is often the most disabling symptom for which opioids are recommended although there is little evidence to support the use of short burst oxygen therapy.
- There is a poor referral rate to palliative care for patients with chronic obstructive pulmonary disease.
- Prognostication is very difficult but can be guided by predictive factors and severity scales.
- Timely advance care planning facilitates higher quality and more appropriate care for patients at the end of life, including giving them the opportunity to die in an environment of their choice.
- Care coordination between medical professionals is essential to ensure the patient's needs and wishes are properly met.

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