End of life care in chronic obstructive pulmonary disease: in search of a good death

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Abstract: Chronic obstructive pulmonary disease (COPD) is an incurable, progressive illness that is the fourth commonest cause of death worldwide. Death tends to occur after a prolonged functional decline associated with uncontrolled symptoms, emotional distress and social isolation. There is increasing evidence that the end of life needs of those with advanced COPD are not being met by existing services. Many barriers hinder the provision of good end of life care in COPD, including the inherent difficulties in determining prognosis. This review provides an evidence-based approach to overcoming these barriers, summarising current evidence and highlighting areas for future research. Topics include end of life needs, symptom control, advance care planning, and service development to improve the quality of end of life care.

Keywords: chronic obstructive pulmonary disease (MeSH), palliative care (MeSH), dyspnoea (MeSH), advance care planning (MeSH)

Introduction

Provision of good quality end of life care has become a healthcare priority over the last decade. Medical advances and demographic trends mean that the proportion of people living with serious chronic conditions into old age is increasing rapidly. In the USA in 1997, the Institute of Medicine report ‘Approaching Death: Improving Care at the End of Life’ concluded that “the timing appears right to press for a vigorous societal commitment to improve care at the end of life” (Field and Cassel 1997).

End of life care aims to optimise the quality of life of patients with advanced, incurable disease (Figure 1). Its principles are the same as those of palliative care, which developed in the UK in the 1960s in response to the needs of terminally ill cancer patients. With increasing recognition that those with incurable non-malignant disease also have extensive palliative care needs, specialist palliative care services are attempting to provide needs-based rather than diagnosis-based care (Addington-Hall 1998). In practice, limited resources mean that only those with the most complex needs receive specialist palliative care input. In the UK, approximately 20% of those that die have contact with specialist palliative care services, of which over 90% have malignant disease (NCPC 2006).

Care for those approaching the end of life therefore cannot be, and indeed should not be, simply the domain of palliative care specialists. All healthcare professionals should be able to provide good quality generalist palliative care for their patients (NHS Executive 1996). The relative neglect of end of life care until recently may be due, in part, to death being viewed as a failure in medical care, rather than inevitable (Middlewood et al 2001). It is a duty and privilege to be able to provide compassionate and effective care from diagnosis to death.

The challenge for providers of generalist palliative care is particularly great when caring for those with advanced chronic obstructive pulmonary disease (COPD). COPD is the fourth leading cause of mortality worldwide, and compared to chronic

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End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support. End of life care is underpinned by:

- An active and compassionate approach to care that ensures respect for and dignity of the patient and family
- Partnership in care between patient, family and health and social care professionals
- Regular and systematic assessment of patient/carer needs incorporating patient consent at all times
- Anticipation and management of deterioration in the patient's state of health and well-being
- Advance care planning in accordance with patient preferences
- Patient choice about place of care and death
- Sensitivity to personal, cultural, and spiritual beliefs and practices
- Effective coordination of care across all teams and providers of care

Generalist palliative care is a vital and routine part of clinical practice that aims to promote physical and psychological health, regardless of diagnosis or prognosis.

Figure 1 Definitions (NHS Executive 1996; Department of Health 2007).

cardiovascular and cerebrovascular disease, mortality from COPD continues to rise (NIH 2003; WHO 2003). Its sufferers have extensive end of life needs. Death tends to occur after a prolonged functional decline associated with a heavy symptom load, emotional distress and social isolation. The quality of life of COPD patients appears to be at least as poor, and indeed may be worse than that of patients with lung cancer (Gore et al 2000; Edmonds et al 2001). There is a growing body of evidence that existing service provision is unable to meet these needs (Heffner et al 1996; Claessens et al 2000; Jones et al 2004; Elkington et al 2005; Au et al 2006). The emphasis appears to be on reactive crisis intervention at the time of acute exacerbations, rather than continual supportive care (Skilbeck et al 1998).

Over the last few years, there have been increasing calls for improvements in end of life care for those with advanced COPD (Claessens et al 2000; Gore et al 2000; Edmonds et al 2001; Elkington et al 2001; Guthrie et al 2001; O'Donnell et al 2003; Healthcare Commission 2006; Varkey 2006). In a recent statement, the American College of Chest Physicians support the position that good quality palliative and end of life care should become an integral part of cardiopulmonary medicine (Selecky et al 2005). Barriers to the provision of good quality palliative care have been identified (Varkey 2006). Some steps have been made to overcome these barriers and develop services. End of life programmes and other political initiatives are in the process of being developed in many countries (Byock et al 2006; NHS 2006).

The aim of this review is to provide readers with an appraisal of recent developments in end of life care for COPD patients. An evidence-based approach will be given to overcoming many of the barriers that currently hinder the practice of good quality EOL care. This review is aimed at respiratory specialists, who have a key role in improving the quality of generalist palliative care received by patients with COPD.

The review is based on a detailed search of work published since 1980 in the databases Medline and Embase using Medical Subject Heading (MeSH) terms that included Pulmonary disease chronic obstructive, Palliative care, Needs assessment, Anxiety, Depression, Pain, Fatigue, Communication, Advance directives, Terminal Care, and the textwords Dyspnoea and Breathlessness. The search was extended by hand-searching recent journals and reference lists, and using internet search engines to help identify other pertinent literature.

End of life needs in COPD

Unmet palliative care needs

Over the last decade, several studies have attempted to identify the palliative care needs of patients with advanced COPD

(Claessens et al 2000; Edmonds et al 2001; Seamark et al 2004; Elkington et al 2005). Despite heterogeneity in terms of study populations and outcome measures, the consistent conclusion of all these studies is that patients with advanced COPD experience a poor quality of life.

Skilbeck et al (1998) interviewed 63 patients who had been admitted to hospital with an exacerbation of COPD in the last six months. On a numerical rating scale of 0–100, with 0 meaning poor and 100 meaning excellent, the mean quality of life score was 33. Poor quality of life correlated particularly strongly with a low level of social functioning. In a large retrospective analysis of a prospective cohort in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), out of 416 patients who died within one year of an index hospitalisation, 75% described their quality of life as fair or poor (Lynn et al 2000).

Gore et al (2000) studied 50 patients with an FEV <0.75l and at least one previous admission with hypercapnic respiratory failure, and also found evidence of a low quality of life. Interestingly, the study also included 50 patients with inoperable non-small cell lung cancer and found, using a generic quality of life measure, a significantly worse quality of life in the COPD patients than in those with cancer. These data should, however, be interpreted with a degree of caution as the two study populations were atypical in sex distribution and disease severity (Hill and Muers 2000).

There are many factors contributing to the poor quality of life suffered by patient with COPD. The symptom burden is considerable. Studies based on post-bereavement interviews show that over 90% of patients are breathless in the last year of life, and in nearly half of these the breathlessness is unrelieved by treatment (Edmonds et al 2001). Skilbeck et al (1998) found that 95% of a cohort of patients that had been admitted with an exacerbation of COPD in the preceding 6 months were experiencing severe breathlessness, defined as ‘very much’ on a four point intensity scale ranging from ‘not at all’ to ‘very much.’ Other symptoms were strikingly prevalent, including pain (68%), fatigue (68%) and insomnia (55%). Psychological morbidity is also high in COPD. Gore et al (2000) found that 90% of patients had clinically relevant anxiety or depression. Overall, there can be no doubt that the physical and psychological symptom burden from advanced COPD is at least as severe as that from other incurable diseases. Indeed, in a recent systematic review, Solano et al (2006) found that breathlessness, fatigue and anxiety occur more commonly in COPD than in advanced cancer, heart disease or renal disease (Table 1).

Table 1 Symptom prevalence in advanced COPD (Solano et al 2006)

Symptom	Prevalence
Breathlessness	60%–88%
Fatigue	68%–80%
Anxiety	51%–75%
Pain	34%–77%
Depression	37%–71%
Insomnia	55%–65%
Anorexia	35%–67%
Constipation	27%–44%

Qualitative studies have an important role in identifying unmet social, education and communication needs. Patients in the late stages of COPD are often housebound, but receive little support from community services (Gore et al 2000; Elkington et al 2004, 2005). They experience a high degree of social isolation (Skilbeck et al 1998; Elofsson and Ohlén 2004). Care-givers also suffer and have great demands placed on them (Guthrie et al 2001; Jones et al 2004; Seamark et al 2004). There is evidence that patients with COPD have greater information needs than in those with other advanced disease, such as cancer (Curtis et al 2002). Patients’ information requirements are not matched by what they receive. Heffner et al (1996) found that amongst 105 patients enrolled in a pulmonary rehabilitation programme, although 99% wished to discuss end of life issues such as prognosis and advance directives, less than 20% had such discussions.

Patients with COPD tend to experience significant morbidity for longer than patients with lung cancer. In addition, studies of existing services show they are more likely to be admitted to admitted to acute hospital, in particular to intensive care units, they are less likely to know that they are dying, and they are less likely to receive medication for symptom control (Lynn et al 2000; Edmonds et al 2001; McKinley et al 2004; Au et al 2006). This occurs despite the fact that most COPD patients prefer treatment focussed on comfort rather than on prolonging life, and COPD patients are equally as likely as lung cancer patients to prefer not to be intubated or receive cardiopulmonary resuscitation (Claessens et al 2000).

Barriers to good end of life care in COPD

Why, then, are there such considerable unmet palliative care needs in patients with advanced COPD? In order to answer this question and focus future service development appropriately, it is important to establish the causes of the current suboptimal quality of care at the end of life.

Arguably the greatest challenge to provision of EOL care in COPD is the unpredictable disease trajectory (Figure 2). The disease trajectory in COPD is typically that of a slow decline, punctuated by dramatic exacerbations that often end in unexpected death (Lunney et al 2003; Murray et al 2005). This contrasts with that of cancer, where there is often maintenance of good function until a short period of relatively predictable decline in the last weeks or months of life. COPD is particularly unpredictable as it progresses at a highly variable rate. Exacerbations causing respiratory failure occur suddenly and unpredictably, and the outcome of those exacerbations is often determined by last-minute decisions regarding life support.

This disease trajectory has two important implications. First, it causes significant prognostication difficulties. Only dementia has been found to have a more uncertain prognosis than COPD (Hansen-Flaschen 2004). How can good EOL care be provided when it is not clear that the end of life is approaching? Until recently there has been little evidence-based information available to help determine the prognosis in advanced COPD. Commonly used prognostic criteria, including measures of air-flow limitation such as FEV_1, degree of hypoxia, complications such as cor-pulmonale and recent hospitalisation requiring ventilation, have all been found to be unreliable (Fox et al 1999; Domingo-Salvany et al 2002; Nishimura et al 2002; Coventry et al 2005).

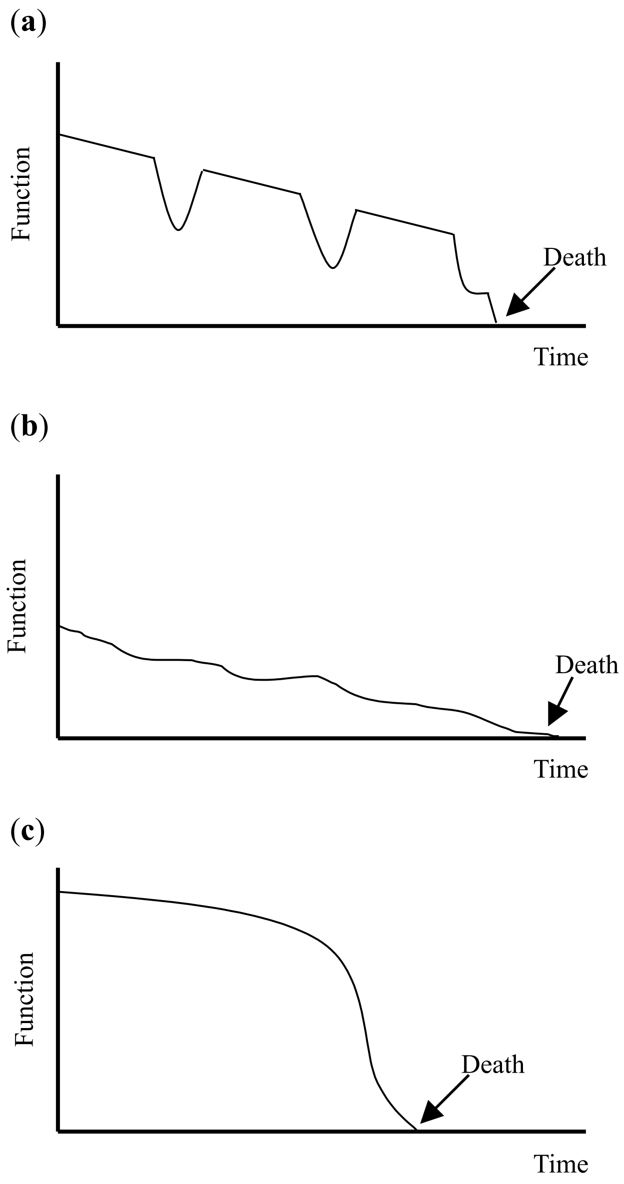

Figure 2 Typical disease trajectories for progressive chronic illness. (**a**)Long-term limitation with intermittent acute episodes eg COPD. (**b**) Prolonged dwindling eg dementia. (**c**) Short period of decline eg cancer. (Adapted from Murray et al with permission from BMJ Publishing Group Ltd.).

Second, unexpected death at the time of an acute exacerbation generates significant communication challenges. It is usually only possible to discover patients' end of life preferences if these have been established in advance. Such advance care planning is often inadequate, making it harder to conform to patients' wishes and provide appropriate EOL care.

Another important barrier to end of life care is that misconceptions about both COPD and palliative care abound. It is sobering that patients and caregivers generally fail to appreciate that COPD is a life-threatening disease that results in an inexorable decline in health status and function (Lynn et al 2000). Good EOL care is impossible without recognition that death may occur prematurely. The appreciation amongst patients that COPD is often a self-inflicted disease lead some to believe that they are not eligible or deserving of measures to improve quality of life. The practice of palliative care is also misunderstood. In our death-denying culture, embarking on a palliative approach can be misconstrued as evidence of failure or 'giving up' (Croft 2005). Patients and professionals often still expect a dichotomous model of care moving from disease modification to palliation, when this has long been superseded by a mixed model of care combining both approaches.

Resource limitations are a significant impediment to the delivery of effective EOL care (Traue and Ross 2005). Even for cancer patients, the historical focus of palliative care, palliative care provision is not uniform, and patients' needs are not always being met. Improving the palliation of COPD has significant implications for funding, manpower and education. Palliative care specialists are not always well informed about the management of non-malignant disease and respiratory specialists require training in the skills of palliation.

Finally, it is increasingly recognised that a lack of research evidence on end of life care is hindering service development (Field and Cassel 1997). Research in this vulnerable patient group is beset by significant ethical and methodological challenges (Lawton 2001; Addington-Hall 2002; Kendall et al 2007). These include difficulties in gaining informed consent, poor recruitment rates and high attrition rates.

Clearly, the route to improving the quality of EOL provision for COPD patients lies in overcoming these barriers. Challenges caused by the unpredictable disease trajectory can be overcome with improved HCP prognostication and communication skills. Resource limitations can be compensated for by careful evidence-based service development, using existing resources to provide cost-effective interventions. Generalist palliative care education, advance care planning and service development must each be improved in order to enhance the quality of EOL care received by those with COPD. The remainder of this review will provide an evidence-based analysis of aspects of each of these important topics.

Key points

- The end of life needs of patients with COPD are at least as great as, if not greater than, those suffering from advanced lung cancer.
- Patients experience a prolonged deterioration with low quality of life, uncontrolled symptoms, psychological morbidity, social isolation, and unmet communication and information needs.
- Prognostication difficulties, resource limitations and inadequate research evidence to support service development are the principle barriers to the provision of good end of life care.

Symptom control at the end of life

In landmark research, Steinhauser et al (2000a, 2000b) used qualitative methods to generate descriptors of the components of end of life care considered most important by patients, carers and healthcare professionals, and subsequently tested these for generalizability in a national survey. The greatest concern of patients and carers was to avoid dying in distress with uncontrolled symptoms.

Why do patients with advanced COPD suffer from uncontrolled symptoms? Healthcare professionals may be hesitant about proactively managing symptoms, in part, due to concerns about adverse effects of pharmacological interventions, such as respiratory depression from opioids or anxiolytics. There may be an element of therapeutic nihilism, believing that symptoms such as fatigue cannot be ameliorated. Good generalist palliative care education, providing an evidence-based approach to symptom management, is the key.

Dyspnea

Dyspnea is an almost universal symptom in advanced COPD, and it is one of the most significant contributors to the poor quality of life experienced by these patients (Lynn et al 1997; Skilbeck et al 1998; Edmonds et al 2001). The "neuromechanical dissociation theory" suggests that dyspnea is a consequence of mismatch between central respiratory motor activity and incoming afferent information from receptors in the airways, lungs and chest wall (Schwartzstein et al 1989). It can therefore be a consequence either of increased ventilatory demand, or impairment of the mechanical process of ventilation. Cognitive, emotional and behavioral factors contribute to the central perception of dyspnea.

The multidimensional pathophysiology of dyspnea gives scope to a wide range of potential palliative interventions. Interventions that reduce ventilatory demand include oxygen therapy and exercise training (Swinburn et al 1984). Impairment of ventilation may be helped by breathing techniques that improve respiratory muscle function, and oxygen therapy which can reduce dynamic hyperinflation (Somfay et al 2001). The central perception of dyspnea can be modified by pharmacological interventions such as opioids and anxiolytics, and by non-pharmacological measures such as education, psychological support and behavioral interventions. Which of these approaches are of use in the last weeks and months of life?

Oxygen therapy

The use of long-term oxygen therapy (LTOT), involving continuous use of oxygen for 15 or more hours each day is well established in severely hypoxic patients with COPD (PaO_2 less than 7.3 kPa), as two landmark trials have shown that oxygen for 15 or more hours per day improves survival (NOTT group 1980; MRC Working Party 1981). As well as giving benefit in terms of survival, LTOT appears to enhance quality of life in severely hypoxic patients. Eaton et al (2004) have examined the effect of LTOT on health-related quality of life (HRQL) and found significantly improvements in HRQL and dyspnoea scores at 2 months and 6 months relative to a comparison group that did not qualify for LTOT. The two patient groups were well matched in all variables other than the greater degree of hypoxia in the LTOT group.

We have previously systematically reviewed the role of short-burst oxygen therapy (SBOT) in palliating breathlessness in patients with COPD (Booth et al 2004). From examination of all studies included in the original review and three studies published subsequently (Lewis et al 2003; Nandi et al 2003; Stevenson and Calverley 2004), it is clear that there are little data to support the use of SBOT at rest, including before or after exercise. SBOT during exercise does, however, appear to be of greater value. Out of nineteen controlled single assessment studies that recorded dyspnoea scores at 'isotime,' all but one revealed significant relief of dyspnoea when exercising with oxygen.

It cannot, of course, be assumed that acute responders who gain benefit from oxygen in experimental conditions will also benefit when oxygen is used over a longer time period at home. Just four controlled studies have examined the effect of SBOT on breathlessness when used at home during activities of daily living. Two studies, both included in our original review, examined quality of life in patients randomized to receive either home oxygen or air over a 12 week period. Eaton et al (2002), using a study population with significant exercise desaturation and providing light oxygen cylinders, did find an improvement in quality of life in patients who had been receiving oxygen. Interestingly, 41% of patients who had had a response to oxygen declined to use it after the study, citing poor acceptability or tolerability. McDonald et al (1995) recruited patients who desaturated less on exercise and supplied heavier oxygen cylinders; they found no improvement in quality of life. In a more recent study, Eaton et al (2006) randomized 78 patients discharged after an acute exacerbation to cylinder oxygen, cylinder air or usual care. There were no significant differences between the groups in quality of life, breathlessness or acute healthcare utilization. Nonoyama et al (2007), in an interesting study incorporating multiple N-of-1 RCTs for each of 27 patients, also found no evidence to support the use of long-term ambulatory oxygen therapy for patients who do not qualify for LTOT.

Importantly, no studies have been able to find factors that can predict which patients are likely to experience symptom relief from supplemental oxygen. Furthermore, Eaton et al (2002) found that an acute response to oxygen did not predict those that would benefit when using longer-term oxygen. Response to oxygen does not correlate with the extent of dyspnea at rest, level of hypoxemia at rest, degree of desaturation on exercise, or any tests of lung function. The response to oxygen is extremely variable between individuals, although more reproducible on an individual level (Waterhouse and Howard 1983). The only way to select the patients who will benefit from oxygen therapy is to undertake an individual clinical assessment. At its most rigorous, the undertaking an N-of-1 RCT has been described and recommended (Bruera et al 1992; Uronis et al 2006).

The burdens of oxygen therapy are considerable (Spathis et al 2006). A degree of psychological dependence is inevitable, and some patients become acutely anxious during even a short interruption in oxygen supply. Cumbersome, heavy equipment may restrict movement and activities within the home and limit excursions outside. Use of an oxygen mask may impair communication between a patient and family. Some patients feel a sense of social stigma and embarrassment, which may further hinder interaction and lead to isolation. Other issues include its combustibility, its considerable cost being, and the uncomfortable drying of airways including the nasal mucosa.

Overall, therefore, there is little evidence to support the use of oxygen in palliating dyspnea. Although single assessment studies appear to show benefit from oxygen during exercise, these findings are not reproduced when oxygen is used longer-term during activities of daily living. Despite this lack of evidence of benefit, breathless patients approaching the end of life are often commenced on oxygen. Abernethy et al (2005) found in an email survey that 58% of surveyed palliative care and respiratory physicians believe that patients benefit from palliative oxygen. Given the negative aspects of oxygen therapy, it is likely that during end of life care, the burdens of oxygen therapy may well outweigh the benefits in a significant proportion of patients.

Withdrawal of oxygen therapy is, of course, not easy. It can cause distress, feelings of abandonment and fear that life may be shortened. Through careful and sensitive communication, patients may be helped to understand the lack of evidence for benefit from SOBT, the inevitable development of psychological dependence, the burdens of oxygen therapy and the lack of selection criteria to determine who may benefit. With individual clinical assessment, the few individuals who may benefit from SBOT can be identified.

Non-pharmacological approaches

There is good evidence that exercise is one of the most successful non-pharmacological approaches to managing breathlessness. Reconditioning is central to the benefit provided by pulmonary rehabilitation programs (Lacasse et al 2006). In the end of life phase capacity for exercise reduces, and the four most common approaches are use of a fan, energy conserving measures, breathing techniques and relaxation strategies.

The flow of cool air through the nose, mouth or over the cheek can reduce the perception of dyspnea (Schwartzstein et al 1987; Liss and Grant 1988). It is believed that stimulation of nasal or pharyngeal mucosal receptors or facial receptors in the region of the trigeminal nerve leads to afferent information being projected to the sensory cortex where it alters the central perception of dyspnea. There is extensive anecdotal evidence that patients find benefit from use of a fan, or from standing by an open window. Even with end-stage disease, patients find a small hand-held fan easy to use. It is a cheap piece of equipment that, unlike use of oxygen does not draw untoward attention to its user, and has no adverse effects. Interestingly, Booth et al (1996), in a study of cancer patients who were breathless at rest, found that both cylinder air and cylinder oxygen improve breathlessness, without there being a statistically significant difference between them. It may be that some of the benefit that patients perceive from oxygen may simply be due to it being a flow of cool gas. There is, to date, only a small amount of research evidence examining the use of a fan (Booth et al 2006); further studies are known to be underway.

Energy conservation techniques reduce dyspnea by reducing demand for ventilation. Strategies include pacing activities, avoiding unnecessary activities, and rest periods or ‘breathing stations’ during prolonged tasks (Carrieri and Janson 1986). A variety of recommendations have been published that help patients to complete activities of daily living with less effort (Carrieri-Kohlman and Stulbarg 2002). Possible techniques include sitting where possible, avoiding bending by arranging equipment closely and sliding or pushing items instead of lifting. There are no controlled studies evaluating such techniques; observational studies have described patient experiences (Brown et al 1986).

Breathing techniques improve the mechanical efficiency of respiration. They also lower the demand for ventilation by reducing dynamic hyperinflation, which in turn increases tidal volume and improves carbon dioxide elimination (Belman et al 1996; O’Donnell et al 2001). The aim of these techniques is to reduce respiratory rate and prolong expiration, while using a gently leaning forward posture that improves the mechanical efficiency of the diaphragm. Several studies confirm the benefit of pursed-lips breathing on dyspnea (Tiep et al 1986; Breslin 1992). Several step-by-step exercises to alter breathing rhythm have been published (Gallo-Silver and Pollack 2000). Counting during the respiratory cycle has been advocated, such as a count of 4 during inhalation, of 7 during exhalation and a count to 2 before recommencing inhalation. Such breathing patterns need practice until they become unconscious and automatic. It is hard to learn such techniques close to the end of life, and is therefore important to teach patients early.

Relaxation techniques and training in anxiety reduction are particularly important with advanced disease. Anxiety increases breathlessness, which in turn contributes to the anxiety, leading to a deteriorating vicious circle (Bailey 2004). Various methods have been described, and techniques should be tailored and adapted for each individual. Methods include progressive muscular relaxation with systematic tensing and relaxing of all muscle groups, visualization and guided imagery, self-hypnosis and distraction by music (Walker 2004; Carrieri-Kohlman 2006). Renfroe (1988) found that taught relaxation techniques in ten COPD patients reduced anxiety more than in a control group that were told to relax without specific instructions. However, benefits were not maintained after the study, a finding confirmed in other studies (Gift et al 1992). Again this supports the view that such techniques should be continually practiced and should be taught well before the end of life phase in order to be of use when need arises.

Pharmacological approaches

The use of pharmacological measures to palliate breathlessness is important in the final weeks and months of life, in conjunction with continued use of the non-pharmacological techniques described above. Their use is, however, often hindered by controversy, mainly in relation to safety concerns. A recent and commendable review in this journal has examined this topic in detail with reference to COPD patients (Uronis et al 2006). Therefore, only a summary of the most relevant evidence will be given here, with focus on issues of safety.

There is consistent evidence that opioids reduce the sensation of breathlessness. Jennings et al (2002) undertook a meta-analysis of all data prior to 2000 and found a highly statistically significant effect of oral and parenteral opioids on breathlessness and a trend towards improved exercise tolerance. There was no evidence of benefit from nebulized opioids. Thirteen of the eighteen included studies involved patients with COPD. There was more nausea, vomiting, dizziness, drowsiness and constipation in patients taking opioids compare to placebo. No deaths in any of the studies were attributed to opioids. Out of four studies that measured arterial blood gas tensions, in one study there was a statistically significant rise in pCO_2 in patients on dihydrocodeine. However, in no instance did the Pa_{CO2} rise above 5.3kPa, or the Pa_{O2} fall significantly. Amongst the nine studies that measured oxygen saturation, none reported a significant change in patients on opioids.

Abernethy et al (2003) have subsequently undertaken a good quality, adequately powered, randomized, double-blind, crossover study of oral morphine (20mg/24hrs) in a study population where 32 of 38 patients had dyspnea caused by COPD. Dyspnea improved by 15%–22%. Despite all patients being opioid-naïve, the only adverse effect significantly more prevalent in those taking morphine was constipation.

There is no evidence to date that the doses of opioids used to palliate breathlessness causes clinically detectable respiratory depression or increased mortality (Mazzocato et al 1999; Jennings et al 2002). Why, then, is this beneficial therapy so commonly withheld on grounds of safety? The answer lies in the form of a deep societal misconception. The idea that opioids may kill when used for symptom control entered UK society in 1957 when Dr Bodkin Adams used the doctrine of double effect (DDE) as defense when accused of murdering an elderly lady from whose will he was to benefit. Since then this defense has been reused to the extent that unintended death from opioids used for symptom control has now become the classic example of DDE in clinical practice (George and Regnard 2007). This misconception seems to be entrenched, even in the face of lack of evidence. Interestingly, when opioids are given after withdrawing ventilator support in intensive care patients they not only do not hasten death, but may even enable breathing to continue longer after ventilator withdrawal (Chan et al 2004).

Public and healthcare professional suspicion of opioids will continue until there is good evidence for lack of harm, not simply lack of evidence of harm. A safety study using parenteral opioids for pain in cancer patients has been recently published, showing no evidence for respiratory depression (Estfan et al 2007). A large safety study in COPD patients is urgently needed as, to date, no studies have been sufficiently powered to detect rare but serious adverse effects (Currow et al 2003). In the meantime a pragmatic approach is needed. Opioids should be started at a low dose and titrated up carefully, with appropriate monitoring (Mashford et al 2001; National Institute of Clinical Excellence 2004; Selecky et al 2005). Education of healthcare professionals would facilitate the appropriate use of morphine; for example, it would help prescribers to know that 1.25mg oral morphine four hourly is equivalent to just 75mg codeine over 24 hours (Twycross et al 1999). Clear protocols need to be developed so that patients are not denied this potentially important treatment.

There is almost no evidence to support the use of any other non-specific pharmacological agents in the palliation of dyspnea. Other than opioids, the most commonly used drugs are anxiolytics. Only one controlled study has examined the effect of benzodiazepines on breathlessness in COPD; there was no significant benefit from alprazolam, and of concern, there was a trend for deterioration in blood gases in the active arm (Man et al 1986). The anxiolytic, buspirone is of potential interest as it is a respiratory stimulant. However, two RCTs exploring its role in moderate to severe COPD have failed to find evidence of significant benefit (Argyropoulou et al 1993; Singh et al 1993).

Fatigue

Fatigue is an important and common symptom in COPD. It is a subjective and multidimensional symptom that 'incorporates total body feelings ranging from tiredness to exhaustion, creating an unrelenting overall condition which interferes with individuals' ability to function' (Ream and Richardson 1997). Its prevalence varies from 45-80% in COPD, with the variation due to inconsistent definitions of fatigue and study heterogeneity in parameters such as study population and methods of symptom assessment (Lynn et al 1997; Skilbeck et al 1998; Theander and Unosson 2004). Overall, however, there is consistent evidence that fatigue is the second most prevalent symptom in COPD after breathlessness. There is also little doubt that it has a profoundly negative impact on quality of life (Small and Lamb 1999; Theander and Unosson 2004; Katsura et al 2005).

Fatigue in other chronic, progressive diseases, such as cancer and multiple sclerosis has been the subject of increasing interest in recent years with extensive research into its prevalence, etiology and management (Vogelzang et al 1997; Ahlberg et al 2003; NCCN 2005). This is in marked contrast to the situation in COPD. Despite its significant prevalence and negative impact on quality of life, the topic of fatigue in COPD has been relatively neglected.

There have, to date, been very few studies investigating interventions that may help COPD-related fatigue. The only intervention that has been found to give any benefit is pulmonary rehabilitation. A recently updated meta-analysis of 31 RCTs found that rehabilitation, defined as exercise training for at least four weeks with or without education and/or psychological support, lead to a clinically significant reduction in fatigue, as well as improving dyspnea, emotional function and patients' sense of control (Lacasse et al 2006).

Exercise and reconditioning are rarely feasible options in very advanced disease. The key to improving fatigue in end of care is to improve as much as is possible the underlying causes of the symptom. Fatigue is inextricably linked to three other common symptoms in COPD, dyspnea, depression and insomnia (Woo 2000; Reishtein 2005). Although there is no research evidence to support this, it is intuitively likely that managing these symptoms may improve fatigue. In particular, non-pharmacological measures such as energy conservation and relaxation techniques may have an important role (Theander and Unosson 2004).

Future research examining fatigue in COPD is urgently needed. It is important that the profile of this hitherto neglected symptom is raised. There is some evidence that central nervous system stimulants, such as methylphenidate and modafinil, may have a role in ameliorating fatigue related to cancer and chronic neurological conditions (Rammohan et al 2002; Bruera et al 2006). It may be worth investigating the role of such drugs in advanced COPD where exercise and rehabilitation are no longer an option.

Pain

Pain is another common but neglected symptom in COPD. Several studies have examined the prevalence of pain in advanced COPD. Edmonds et al (2001) conducted post-bereavement structured interviews of the carers of lung cancer and COPD patients and found a prevalence of 'very distressing' pain of 56% in both disease groups, despite anecdotal evidence that cancer patients suffer more pain than those dying of other conditions. The SUPPORT study found that 21% of patients admitted to hospital with acute exacerbation of COPD had severe pain, a value not dissimilar to the 28% of lung cancer patients with severe pain (Claessens et al 2000). Skilbeck et al (1998) found that 68% of COPD patients with a recent hospital admission for an exacerbation had pain. Despite the wide range of documented prevalence caused by considerable study heterogeneity, there can be no doubt that pain is a significant problem in patients with advanced COPD.

Surprisingly, there have been no studies investigating the management of pain in COPD. Pain is usually felt in the chest, and may have a musculoskeletal or pleuropulmonary origin (Leach 2005). Causes of pain in COPD include subcostal pain due to diaphragmatic and intercostal muscle fatigue, rib fractures relating to coughing and/or corticosteroid-induced osteoporosis, and pleural inflammation caused by infection.

Why is pain such a problem in COPD? In a large retrospective cohort study, Au et al (2006) found that patients who died within six months from COPD were significantly less likely to be given strong opioids for symptom control than patients with lung cancer. A strong possibility is that analgesics are withheld because of concerns about adverse effects, in particular respiratory depression and bronchospasm due to opioids and NSAIDs respectively. The presence of pain should be taken as seriously in COPD as in any other condition. The World Health Organization guidelines for the use of analgesic drugs (Figure 3) provide a useful framework for all chronic pain not just for cancer pain (WHO 1996; Leach 2005).

As discussed above, there is no evidence that clinically significant respiratory depression occurs with use of opioids for symptom control. Care should of course be taken, commencing on low doses with judicious upward titration. NSAIDs are often avoided in COPD because of the perceived risk of precipitating bronchospasm. McKeever et al (2005) in a recently published study that analyzed data from over 13,000 individuals from the Third National Health and Nutrition Examination Survey in the USA, found a significant dose-response relationship between paracetamol and the prevalence of COPD, which was not found with aspirin and ibuprofen. Furthermore, paracetamol use was inversely associated with FEV_1, whereas regular

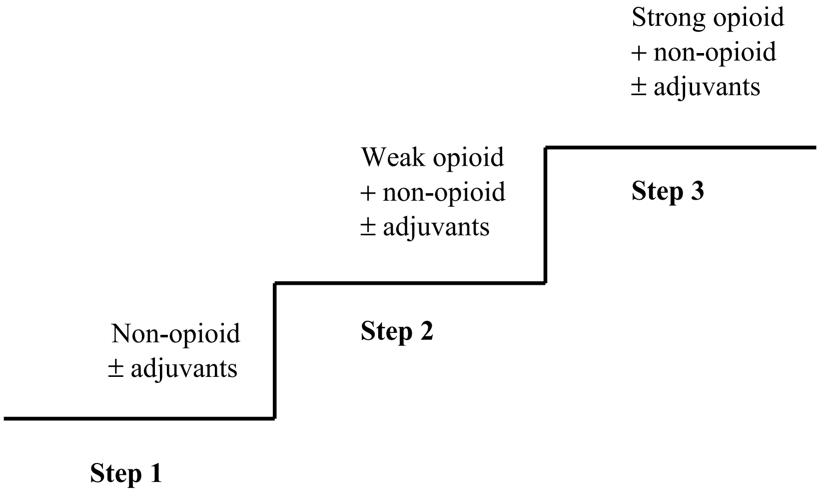

Figure 3 World Health Organisation three step analgesic ladder (WHO 1996). Non opioids include paracetamol and NSAIDs; weak opioids include codeine (approx. 1/10th potency of oral morphine) and tramadol (approx. 1/5th potency of oral morphine); strong opioids include morphine, oxycodone and fentanyl; adjuvants are additional drugs that can be used as part of pain management, such as secondary analgesics (eg. gabapentin for neuropathic pain) and drugs to control analgesic adverse effects.

ibuprofen use was associated with a non-linear improvement in FEV_1. It is hypothesized that regular paracetamol use depletes levels of the antioxidant, glutathione, in lung tissue, leading increased lung tissue damage. Ibuprofen may improve lung function through its anti-inflammatory effect. Even in asthma, ibuprofen does not appear to cause harm in population terms (Lesko 2003). In a large study, children with asthma were randomly assigned to receive paracetamol or ibuprofen for a febrile illness (Lesko et al 2002). Those on ibuprofen had significantly less asthma morbidity. These interesting findings are consistent with those of several other studies and deserve further investigation (Konstan et al 1995; Shaheen et al 2000; Shaheen et al 2002).

Overall, existing evidence suggests that paracetamol and NSAIDs should be used with equal care in COPD patients, but that for use in pain at the end of life, benefit from both ibuprofen and paracetamol is likely to outweigh any harm. Ibuprofen may be particularly useful because of its effectiveness for pain of musculoskeletal or pleural origin. A pragmatic approach in COPD may be to use ibuprofen in preference to other NSAIDs, avoid its use individuals with a previous adverse reaction to NSAIDs, and monitor carefully when commencing NSAID-naïve individuals on these drugs. In those that cannot tolerate or gain little benefit from systemic analgesics, intercostal nerve blocks or a thoracic epidural may have a role (Luchette et al 1994).

Anxiety and depression

Advanced COPD is associated with considerable psychological morbidity. Depressive symptoms are not surprising given the associated poor quality of life, limited functioning and social isolation (Skilbeck et al 1998). Anxiety is well known to be both caused by and exacerbated by dyspnea (Bailey 2004). Prevalence data is again highly variable due to inconsistent definitions, heterogenous study populations, and the difficulty in separating symptoms of an affective disorder, such as anorexia, weight loss and sleep disturbance, from that of the disease itself. Overall the majority of studies in patients with moderate to severe COPD give prevalence rates of anxiety and depression each between 20% and 50%, with up to 90% of patients experiencing either or both disorders (Claessens et al 2000; Gore et al 2000; Brenes 2003; Kunik et al 2005; Norwood 2006).

Both affective disorders have a significant negative impact on outcomes in COPD, in particular by reducing perceived quality of life (Aydin and Ulusahin 2001; Felker et al 2001). Comorbid anxiety increases dyspnea and is a significant predictor of the frequency of hospital admission for acute exacerbations of COPD (Gift and Cahill 1990; Yohannes et al 2000; Gudmundsson et al 2005) and both disorders have been linked with poorer outcomes during exacerbations (Dahlén and Janson 2002).

Despite the high prevalence of depression and anxiety, there is evidence that only approximately a third of patients with such disorders are being treated (Kunik et al 2005). This is unfortunate particularly given that, unlike other symptoms of advanced COPD, there is some evidence that simple interventions can provide significant benefit.

Antidepressants have been studied in a number of randomized controlled trials. Both tricyclic antidepressants and selective serotonin reuptake inhibitors (SSRIs) have been found to improve anxiety and depression in patients with COPD. Borson et al (1992) compared the efficacy of nortriptyline with placebo in 30 patients with comorbid depression, of whom 86% had anxiety symptoms, and found that both symptoms of depression and anxiety were improved. Several RCTs have shown benefit from paroxetine and sertraline in both disorders (Papp et al 1995; Smoller et al 1998; Lacasse et al 2004). However, positive outcomes have not always reached statistical significance, and the quality of evidence is limited by small study sizes (Eiser et al 2005).

Pulmonary rehabilitation has been shown to improve anxiety and depression, though this intervention become less feasible in very advanced disease (Paz et al 2007). Two other non-pharmacological approaches that have been studied in those with COPD are cognitive behavioral therapy (CBT) and progressive muscular relaxation (PMR). Evidence in favor of CBT is mixed and PMR may be the most useful non-pharmacological intervention in advanced disease (Renfroe 1988; Lisansky and Clough 1996; Kunik et al 2001). These exercises need to be practiced, and patients will derive most benefit if these techniques are taught early, preferably before the end of life phase.

Key points

- There is little evidence to support the commencement of oxygen therapy to palliate dyspnea in those patients who do not qualify for LTOT. Individual clinical assessments can identify those who may benefit from oxygen.
- Although there is no evidence that judicious use of opioids for dyspnea leads to clinically significant respiratory depression, there is an urgent need for adequately powered safety studies in COPD patients.
- Benefit from both ibuprofen and paracetamol for pain is likely to outweigh harm. There is increasing evidence that, in population terms, ibuprofen may improve lung function, whereas paracetamol may worsen it; further research is needed.

Communication issues in advanced COPD

Inadequate communication is one of the greatest barriers to the provision of good end of life care (Curtis et al 2005). Participants in a large qualitative study identified six major components of a ‘good death,’ of which five depend heavily on the quality of communication between patients and healthcare professionals (Steinhauser et al 2000b) (Table 2). Clear decision-making about treatment preferences empowers patients and leads to a sense of control. Patients often wish to prepare for death by knowing what to expect during the course of their illness and planning for events that would follow their deaths. Completion is a process of individual life review, resolving conflicts, spending time with family and friends and saying goodbye.

Table 2 Major components of a good death (Steinhauser et al 2000)

Pain and symptom management
Clear decision making
Preparation for death
Completion
Contributing to others
Affirmation of the whole person

Advance care planning, acknowledging the approach of the end of life and discussing the issues that relate to it, is a vital component of end of life care. There is evidence that clinicians’ estimates of patient preferences are influenced by their estimates of patients’ quality of life (Uhlmann and Pearlman 1991). Not only are healthcare professionals a poor judge of patients’ quality of life (Wilson et al 2000), but Stapleton et al (2005) have shown that that patients preferences are, in fact, not determined by their quality of life anyway. It is, therefore, impossible for healthcare professionals to predict patients’ preferences without advance care planning discussions.

Advance care planning

There is good evidence that patients benefit from advance care planning. In COPD patients, advance care planning increases patient satisfaction and sense of control, and reduces fear, anxiety and emotional distress (Smucker et al 1993; Heaven and Maguire 1997; Tierney et al 2001; Curtis et al 2004). The vast majority of COPD patients believe advance care planning is important, and wish to undertake these discussions (Heffner et al 1996; Guthrie et al 2001; Curtis et al 2002). Heffner et al surveyed 105 participants in pulmonary rehabilitation programs and found that over 98% wanted to take part in advance care planning. Surprisingly, given the overwhelming desire to discuss these issues, only 19% had had the opportunity to undertake it. Unmet information needs in COPD patients have been confirmed in subsequent studies (Gore et al 2000). Curtis et al (2004) examined patients’ perceptions of communication quality, and found that patients rated physicians poorly in the areas of discussing prognosis, the process of dying and spirituality. Over half of complaints received by the Healthcare

Commission (2007) in the UK relate to end of life care, and the majority of these involve communication issues.

Health care professionals have insight into this discrepancy between need and receipt of advance care planning. Elkington et al (2001) found in a questionnaire survey of UK General Practitioners (GPs) that the majority of GPs felt that discussions of prognosis are necessary and that they have an important role in facilitating these, but a minority actually undertook such discussions. Half of the GPs surveyed believed that patients who wished to discuss prognosis did not get the chance to do this.

Why, then, is advance care planning inadequate? Several barriers to communication about end of life issues have been identified (Curtis et al 2000; Knauft et al 2005; Davison and Simpson 2006) (Table 3). There is a general consensus in the literature that the greatest impediment to good advance care planning is the difficulty of prognostication in COPD, and the consequent difficulty in timing such discussions (Curtis et al 2005). This should not, however, be such a significant concern. There is evidence that patients need information much earlier than is perceived by physicians (Heffner et al 1996; Sullivan et al 1996; Pfeifer et al 2003; Davison and Simpson 2006). With sensitive communication it is unlikely that these discussions will occur too early.

Another significant barrier is that healthcare professionals are reluctant to engage in end of life discussions because of fear of destroying patients' hope and also patients' trust in them (Selecky et al 2005). Although understandable, such concerns are unfounded. Indeed, there is evidence that the converse is true. Patients' ability to hope appears to be sustained by open communication that relieves fears, empowers, enhances relationships with professionals and family, and allows them to see future possibilities consistent with their values (Davison and Simpson 2006). Fears that are not discussed are often far worse than reality.

Table 3 Barriers to communication about end of life issues in COPD

Healthcare professional barriers
Difficulty in timing discussions because of uncertain prognosis
Lack of time during consultations
Concern about taking away patients' hope
Belief that patients are not ready to discuss end of life issues
Patient barriers
Expectation that healthcare professionals will initiate discussions
Societal taboos with regard to discussing death
Uncertainty about which professionals will be involved during end of life phase
Lack of certainty about the type of care that would be wanted when less well

Strategies to improve communication

The first step in communicating about end of life issues must be to openly acknowledge progressive and irreversible disease with a limited prognosis. Once this has occurred, advance care planning can take place. Issues that should be covered include discussion of patients' preferred place of care and preferred providers of care during the terminal phase. Future treatment preferences during an acute exacerbation should be established, including views about the future use of antibiotics, mechanical ventilation and advanced life support (Hansen-Flaschen 2004).

Healthcare professionals can develop triggers that lead them to initiate advance care planning discussions. It has been suggested that clinicians can target such discussions by asking themselves, "Would I be surprised if this patient died within the next six months?" (Lynn and Goldstein 2003). Severity of dyspnea is a useful marker of poor prognosis. Nishimura et al (2002) found that the level of dyspnea significantly correlated with survival, and that dyspnea severity was more discriminatory that FEV_1 in assessment of prognosis. Admission to hospital with an acute exacerbation of disease could be a trigger for end of life discussions, as there is evidence that over 40% of patients die within one year of an index admission (Lynn et al 2000).

A profile of COPD patients at risk of dying within a year is emerging and includes significant dyspnea, best FEV_1 less than 30% predicted, declining performance status with increasing dependence on others, uninterrupted walking distance limited to a few yards, more than one urgent hospitalization within the last year, left heart or other chronic co-morbid disease, older age and depression (Hansen-Flaschen 2004; Yohannes et al 2006). Interestingly, this profile is very similar to that of COPD patients who chose not to have advanced life support following cardiopulmonary arrest (Pang et al 2004).

Good communication skills are a prerequisite in these sensitive discussions. A well-established technique is to take the dual approach of encouraging and sharing hope whilst also preparing for death, in other words "to hope for the best and prepare for the worst" (Back et al 2003). Open questions can be valuable such as, "Have you any concerns about the future?" and "What are you hoping that we can achieve?" Unhelpful phrases that should be avoided include 'nothing more than can be done,' 'stopping treatment' and 'withdrawing care' (Back et al 2003; Hansen-Flaschen

2004; Braun et al 2007). Patients should be reassured that limiting life-sustaining treatment in no way equates to limiting care (Sulmasy and Lynn 1997). It is important that patients are given specific information about outcomes with different treatment options. For example, detailed information about chances of survival after cardiopulmonary resuscitation has been shown to strongly predict treatment preferences (Fried et al 2002).

Advance directives or 'living wills' are legally binding documents that can be used to record future treatment preferences. Their usefulness is limited because it is rarely feasible to give precise instructions for all potential eventualities. A non-specific statement such as 'no life-sustaining treatment if death is certain' is of no value (Teno et al 1997; Goodman et al 1998). Patients' views may change over time and there is significant concern about the validity of decisions made when a patient is relatively healthy, or decisions made while suffering from depression (Tonelli 1996; Teno et al 1997; Stapleton et al 2005). Experts in end of life care are increasingly calling for professionals to guard against advance care planning being document-based and focused around the completion of an advance directive (Ditto et al 2001; Hansen-Flaschen 2004; Barnes et al 2007). Clinicians working with patients to plan future care can be supported by, but should not be driven by, legal concerns.

Key points

- Advance care planning is of particular importance in COPD patients because of the unpredictable timing of death. Difficulties in determining prognosis should not lead to communication paralysis.
- The obligation is on healthcare professionals to initiate discussions about end of life care, and should take place as early as possible in the disease trajectory.
- Honest and compassionate advance care planning involves a dual approach of optimism and realism, "hoping for the best and preparing for the worst."
- It must be made clear to patients that limiting life-sustaining treatment does not equate to limiting care.

Service development in end of life care

Current healthcare services for patients with COPD tend to be focused on the management of acute exacerbations and prolongation of life (Au et al 2006). Patients, who are often housebound with advanced disease, seem to remain 'socially invisible' until they enter an acute phase, involving either contact with a primary care clinician or admission to an acute hospital (Skilbeck et al 1998). This focus on crisis intervention has led to a fragmented, reactive service rather than a supportive, preventative one (Brumley 2002). This is a major cause of the existing inadequacies in care for patients with advanced COPD.

Principles of service development

The traditional model of care of patients with advanced disease, including COPD, is based on a dichotomy involving an abrupt transition from active, life-sustaining care to palliative care. This model does not work for patients with COPD for several reasons. First, as previously discussed, the timing of death is unpredictable, and it will always be hard to judge when the transition should be made. Second, patients with far advanced disease should not necessarily be denied active interventions such as ventilatory support during an acute exacerbation. Finally, COPD patients often live with a heavy burden of uncontrolled symptoms and psychosocial needs for a relatively long time, compared to patients with other diseases such as cancer; it would be unethical to deny such patients good palliation because they are not yet in the end of life phase.

The mixed management model of care is more appropriate for COPD, and involves combining the principles of good end of life care with active treatment (Glare and Virik 2001). Rather than making an abrupt move from disease-modifying therapy and life prolonging interventions to symptom control and death preparation, all these modalities are combined throughout the disease trajectory (Claessens et al 2000; Braun et al 2007). The key to improving healthcare in COPD is to develop services that reflect the principles of the mixed management model by combining the attributes of both aspects of the traditional dichotomous model.

Patient-centered care is central to the philosophy of palliative care. A disease-orientated approach is inextricably linked with perceptions of failure as patients deteriorate, whereas a patient-centered approach aims for success in optimizing patients' quality of life. Patient-centered care includes user involvement, and incorporates the views of patients into service design (Blackler et al 2004). Patients with advanced COPD, often isolated by immobility, require community-based care with continuity of care during hospitalisation (Elkington et al 2005). This can only be achieved with a coordinated, collaborative, multidisciplinary service (Brumley 2002). Service development must reflect the trajectory of advanced COPD, integrating rapid intervention during acute exacerbations with education on self-care and planning for unexpected death (Dy and Lynn 2007).

Practicalities of service development

In the last few years, several national initiatives have aimed to drive forward the quality of provision of end of life care. In the USA, the 'Promoting Excellence in End of Life Care Strategy' was set up in 1999 as a national program to provide $15 million to support research and fund innovative service developments (Byock et al 2006). In 2004, a national 'End of Life Care Programme' was developed in the UK (NHS 2006). £12 million funding over 3 years has been used to disseminate the principles of end of life care for cancer patients to other patient groups, and provide increased patient choice and access to high quality end of life care. As preparation for a forthcoming End of Life Strategy, an ongoing review of end of life services is comparing current service provision with population needs and identifying areas where service improvement is required (Department of Health 2007).

These and other national strategies have lead to a plethora of recent community-based service developments. The PhoenixCare program was a service of home-based palliative care case management for patients with COPD or cardiac failure with a life-expectancy of less than two years (Aiken et al 2006). Services were provided by registered nurse case-managers, in addition to usual active disease treatment provided by managed care organizations. The intervention included education on self-management, preparation for the end of life, and intensive case-management to improve physical and mental functioning. The service was evaluated by randomizing 192 patients into two groups, an intervention group receiving the PhoenixCare program as well as 'usual care,' and a control group. Patients who received the intervention reported significantly lower symptom distress, greater vitality and higher self-rated health than controls. Those with COPD showed stronger responsiveness to the intervention than those with cardiac failure.

Two other studies, in patients with a range of advanced conditions including COPD, have evaluated the impact of mixed management service models, combining multidisciplinary palliative care input with active disease management in the community (Brumley 2002; Edes et al 2006). Although uncontrolled and less rigorous in design, both studies showed significant cost-savings, caused by reduced hospitalization.

The End of Life Programme in the UK has promoted the use of three tools to improve the quality of end of life care, the Liverpool Care Pathway (LCP), the Gold Standards Framework (GSF) and the Preferred Place of Care (PPC) document. These tools aim to increase the quality of palliative care provided by generalists. The LCP is an integrated care pathway that prompts, provides guidance on, and documents appropriate care in the terminal phase, for patients with all advanced diseases in all settings (Ellershaw and Ward 2003). It incorporates advice on the use of drugs to control symptoms in the last few days of life. The GSF is a primary care-based system that improves the quality of care by empowering generalists to provide evidence-based best practice including good communication, symptom control, out-of-hours care and carer support. In the UK, over a third of the population are cared for by general practices that have adopted the framework (Munday and Dale 2007; Thomas and Noble 2007). The PPC document can trigger and facilitate advance care planning conversations. Although there is a growing body of evidence to support the use of these tools, including evidence that healthcare practitioners believe that they improve the quality of care (King et al 2005; Veerbeek et al 2006), there is as yet no rigorous controlled trial evidence that these tools improve patient outcomes (Shah 2005; NHS 2006).

Which healthcare professionals are best place to co-ordinate and provide the necessary end of life care for COPD patients? There is an increasing consensus that respiratory nurse specialists should have a central role in this process (Skilbeck et al 1998; Gore et al 2000; Guthrie et al 2001; Elkington and White 2002; Robinson 2005; Shuttleworth 2005; Mulligan 2006). In the UK, such nurse specialists have responsibility for delivery of care and continuity of care across different settings, including the community. They assess and manage patients' physical, psychosocial and practical needs, and facilitate access to multiprofessional help. Respiratory nurse specialist input appears to increase patient satisfaction, but there is conflicting evidence as to whether they improve quality of life or reduce admission to acute hospital (Skwarska et al 2000; Poole et al 2001; Hermiz et al 2002).

Primary care doctors, such as GPs in the UK, have a significant role in community-based provision of end of life care, and in the recent NHS contract for GPs, incentive payments for COPD management are being used to encourage them to provide this care (Elkington et al 2001, 2005; Lehman 2004; Freeman and Price 2006). Chest physicians also have a vital role. In a recent position statement, the American College of Chest Physicians strongly urges chest physicians to take the lead in focusing on and developing services to provide good quality end of life care (Selecky et al 2005).

As discussed earlier, service development is hindered by an inadequate evidence base. The key to improving end of life care in COPD patients is to undertake good quality research in this patient group, as it cannot be assumed that research outcomes from other study populations are valid in those with COPD (Field and Cassel 1997; Selecky et al 2005). There is increasing evidence that patients facing the end of life actually benefit from taking part in research (Madsen et al 2002; Kendall et al 2007). A recent NIH State-of-the Science conference statement (2004) has outlined future research directions for improving end of life care, with an emphasis on evaluating models of care in terms of patients and family outcomes, and in terms of resource utilization.

Research findings can be used to develop evidence-based education. Incorporating the skills of end of life care into the training all healthcare professionals is a vital step in service development (Hallenbeck 2006). A US national report on the status of medical education in end of life care has revealed that current educational practices are inadequate (Sullivan et al 2003). Palliative care curricula at both undergraduate and postgraduate levels are being developed, incorporating integrated and systematic teaching about end of life care (Simpson et al 1999; Simpson 2000; Wee et al 2001). However, major efforts at an institutional and cultural level are still needed to improve the status and quality of end of life education.

Key points

- Good end of life care does not preclude life-sustaining interventions. The COPD disease trajectory means that a mixed management model is vital.
- Community-based, co-ordinated, multidisciplinary care is needed, with chest physicians and respiratory nurse specialists having a central role in service development and provision.
- End of life care has recently become highly topical, with many national initiatives funding evidence-based developments in services and generalist palliative care education.

Conclusion

COPD is the fourth commonest cause of death worldwide. There is strong evidence that these patients have a particularly poor quality of life in the end of life phase, due to uncontrolled symptoms, psychological morbidity, social isolation and unmet information and communication needs. Traditionally, the palliative care approach has focused on the needs of cancer patients. All patients, however, deserve good quality end of life care, irrespective of diagnosis. Mixed management models where active disease-modifying treatments are combined with palliative care interventions show great promise. Chest physicians and respiratory nurse specialists have a vital role in ensuring that the care of patients dying from COPD improves to the level of the best. As stated by Hansen-Flaschen (2004), "Death is not a failure, but an opportunity to practice a form of professional care that is as old as medicine, and as gratifying as any other services we offer."

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