Providing timely end-of-life care to patients who have COPD

Key points

1. People with chronic obstructive pulmonary disease often have unmet palliative care needs
2. Patients need timely referral and access to specialist palliative care services
3. Health professionals need clear criteria to detect patients approaching the end of life
4. Joint working between respiratory and specialist palliative care services can improve outcomes for patients and their families/carers
5. Collaboration between respiratory and palliative care teams can result in up-skilling of staff

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Abstract
Identifying patients with chronic obstructive pulmonary disease who need specialist palliative care is a challenge because of the unpredictable nature of the disease. This article outlines how respiratory and palliative care teams in an acute trust worked together with community respiratory nurses to help patients with COPD approaching the end of life and their carers to access specialist palliative care services, benefit from advance care planning and avoid hospital admissions.

Citation
Mulligan J, Heeks A (2017) Providing timely end-of-life care to patients who have COPD. Nursing Times; 113: 1, 45-47.

The palliative care needs of people living and dying with chronic obstructive pulmonary disease remain largely unmet. To address this, we created, in 2010, an integrated COPD–palliative care multidisciplinary care model in East London. In our experience, integrating respiratory and specialist palliative care services can be done relatively easily and cost-effectively, provided there is plenty of enthusiasm and the workings of a good partnership.

COPD and end-of-life care
People are living longer and dying at an older age from chronic, progressive diseases such as COPD. In England, COPD is the fifth leading cause of mortality among all causes of death, with 23,000 deaths a year (Department of Health, 2011). It is the second most common reason for emergency admissions to hospitals; 15% of those admitted die within three months of admission and around 25% die within a year (DH, 2011).

The quality of life of patients is at least as poor, and maybe worse, than that of lung cancer patients. According to Solano et al (2006), breathlessness, fatigue and anxiety occur more commonly in COPD than in advanced cancer, heart disease or renal disease. Still, people with cancer are more likely to receive timely referrals to specialist palliative care. In 2013/14, only 13% of people accessing inpatient palliative care services in England, Wales and Northern Ireland had a non-cancer diagnosis (National Council for Palliative Care, 2014).

Many barriers hinder the provision of good end-of-life care in COPD, some of which are listed in Box 1. There is some evidence that advance care planning (ACP) increases the satisfaction and sense of...
control of patients, and reduces their fears, anxieties and emotional distress (Spathis and Booth, 2008). This is an area where specialist palliative care nurses can play a direct and valuable role.

Uncertain prognosis
Different life-limiting illnesses follow different progressions: in cancer, a sudden onset of disability often marks the beginning of the terminal phase; in COPD, which is a progressive disease, it can be difficult to pinpoint when people enter the dying phase. This creates uncertainty regarding the prognosis and a potential conflict between treatment aims, with both active treatment and palliative care interventions co-existing.

How can good end-of-life care be provided when it is not clear that the end of life is approaching? To help identify adult patients nearing the end of life as early as possible, the team behind the Gold Standards Framework (GSF) has been producing prognostic indicator guidance since 2006. The fourth edition (GSF Centre, 2011) offers practical guidance for a variety of settings and proposes three types of indicators:

- The surprise question: would you be surprised if this patient was to die in the next six to 12 months?
- General indicators of decline: deterioration, increasing need, patient's choice of no further active care;
- Specific clinical indicators related to certain conditions, COPD being one of several conditions grouped under 'organ failure' and characterised by 'erratic decline'.

Spathis and Booth (2008) contend that ACP cannot take place unless it has been acknowledged that COPD is a progressive and irreversible disease with a limited prognosis. If patients are to express their end-of-life care wishes, and eventually be cared for and die in their preferred place, then the possibility of death and dying must be identified, accepted and discussed well ahead of time.

Innovative palliative care
The degree of integration between mainstream healthcare services and specialist palliative care varies across the country. The End of Life Care Strategy (DH, 2008) identified COPD as one of the conditions for which further evidence is needed as to how ACP can be achieved in practice.

Although there is a lack of evidence on which models of care work best, Gardiner et al (2012) have identified several factors that foster a good working relationship between the generalists who care for most people at the end of life, such as GPs or district nurses, and specialist palliative care services:

- Good communication between care providers;
- Well defined rules and responsibilities;
- Opportunities for shared learning;
- Appropriate and timely access to specialist palliative care services;
- Care coordination.

Developing our integrated model
A community-based 'early discharge' service for COPD patients cared for by the community respiratory team was put in place in 2009. It quickly became clear that those with very severe COPD did not fit into this 'early discharge' model. A profile of patients at high risk of dying within a year emerged: these patients had complex needs, uncontrolled symptoms and poor quality of life; they experienced frequent emergency admissions to hospital; and they had to cope with the possibility of imminent death with little opportunity to discuss end-of-life care or participate in decisions. To accommodate these patients, the model was changed from an 'early discharge' to a 'supported discharge' model.

The first step towards developing supported discharge was to set up, in 2009, a steering group at the Margaret Centre (an NHS specialist palliative care unit run by Barts Health Trust) in order to drive service improvements. A COPD–palliative care multidisciplinary team (MDT) was then established in 2010.

How patients are selected
As there are no nationally agreed criteria for access to specialist palliative care, we have developed our own criteria to help us identify patients nearing the end of their lives and trigger their referral to specialist palliative care. These criteria, listed in Box 2, were established using the GSF prognostic indicator guidance (GSF Centre, 2011) and expert opinion from the MDT. They feature as an easy-to-complete tick box list on the referral form. A negative answer to the surprise question about whether the patient is likely to die in the next six to 12 months prompts further questions such as ‘Is the patient likely to be aware of this?’ and ‘Who would be best placed to initiate discussions on the end of life?’.

We have also mapped patients’ journey locally across primary and secondary care, so that we can get the right patients in the right service at the right time. This is either the supported discharge team or the respiratory service with input from specialist palliative care.

How the MDT works
The MDT members include a specialist palliative care consultant, a palliative care nurse specialist, an occupational therapist, a social worker, a complementary therapist, a counsellor, community and hospital-based respiratory nurse specialists, and community matrons. The MDT meets monthly for an hour and discusses four patients on average at each meeting. Patients can be referred to the MDT by any team member of any
Box 3. Case study: David Jones and his wife*

David Jones was 72 years old when he died from severe chronic obstructive pulmonary disease. In the two years before his referral to our COPD–palliative care multidisciplinary team (MDT), Mr Jones frequently attended A&E and was regularly admitted to hospital for exacerbations. During one admission to a general medical ward, he was referred to the ‘supported discharge’ community team. He agreed to be assessed and reviewed at home – where he lived with his wife Beth as his sole carer – the day after discharge.

During that first home visit, Mr Jones made it clear he did not want to be admitted to hospital again, nor did he want to be resuscitated. His wife found this extremely upsetting and said she felt unable to cope. Mr Jones’ disease was debilitating for both of them, and the only time she got a break from caring for her husband was when he was admitted to hospital.

On assessment, Mr Jones was found to have a chronic productive cough, breathlessness, fatigue and pain. His scores for anxiety and depression were high. Furthermore, he had financial concerns that were worrying both him and his wife. The lead community respiratory nurse referred Mr Jones to the COPD–palliative care MDT for symptom control and advance care planning. Within two weeks, he was seen as an outpatient by the palliative care consultant, who prescribed antidepressants and anti-anxiety medication.

Mr Jones and his wife were also put in touch with the Margaret Centre so that they could access all the specialist palliative care services available. They started attending a weekly support group, and appreciated not only having a cup of tea and chatting with other patients and carers, but also the breathing and relaxation exercises. Both accessed various complementary therapies and enjoyed these sessions.

The palliative care social worker arranged support regarding benefits and continuing care funding for home care. The palliative care occupational therapist reassessed the couple’s home and adapted it to make life at home more manageable.

Mr Jones was entitled to four weeks of specialist palliative respite care per year, which meant his wife could plan holidays to visit family. With support from the Margaret Centre, Mr Jones formalised his preferences for care, expressing the wish to die either at home or at the centre.

Once Mr Jones had been referred to the COPD–palliative care MDT, he did not need to be admitted to the acute hospital again. The community respiratory service maintained contact via home visits and telephone calls for 10 months. During a planned respite admission to the Margaret Centre, he suddenly deteriorated and died peacefully a few days later with his wife at his side, in an environment that was familiar to both of them. After her husband had died, Mrs Jones was visited at home by the community respiratory team and was offered bereavement counselling.

Mr and Mrs Jones are a fictitious couple whose story is typical of patients with COPD cared for at the Margaret Centre.